Yarning, Hearing, Understanding, Knowing

A qualitative study of the experiences of Fetal Alcohol Spectrum Disorder assessment and diagnosis for justice-involved youth and their care networks

Sharynne Lee Hamilton BA (Hons)

This thesis is presented for the degree of
Doctor of Philosophy
The University of Western Australia
School of Paediatrics and Child Health
2020

Thesis Declaration

I, Sharynne Lee Hamilton, certify that:

This thesis has been substantially accomplished during enrolment in the degree.

This thesis does not contain material which has been submitted for the award of any other degree or diploma in my name, in any university or other tertiary institution.

No part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of The University of Western Australia and where applicable, any partner institution responsible for the joint-award of this degree.

This thesis does not contain any material previously published or written by another person, except where due reference has been made in the text and, where relevant, in the Declaration that follows.

The work(s) are not in any way a violation or infringement of any copyright, trademark, patent, or other rights whatsoever of any person.

The work described in this thesis was funded by: The National Health and Medical Research Council (grant number APP1072072).

Ethics approval was given by the Western Australian Aboriginal Health Ethics Committee (approval #582) and the University of Western Australia Human Research Ethics Committee (approval #RA/4/1/7116). The former Department of Corrective Services granted research approval (DCS; project ID 335). The former Department for Child Protection and Family Support (DCPFS) also gave approval for the research to include young people in their care (approval #2015/8981).

Third party editorial assistance was provided in preparation of this thesis by Kylie Lowe AE.

This thesis contains published work and/or work prepared for publication, some of which has been co-authored.

Any material published in this thesis or made publicly available by the author/s cannot be considered as either endorsed by the Department of Justice or an expression of the policies or the views of the Department. Any errors of omission or commission are the responsibility of the author.

Signature: [redacted]

Date: 9 June 2020

Abstract

Youth justice systems in Australia experience difficulty managing the behaviours and diverse needs of youth in trouble with the law. Despite the fact that neurodevelopmental challenges have major implications for justice-involved youth, Fetal Alcohol Spectrum Disorder (FASD) and the effects of neurodevelopmental impairments associated with the disorder are not recognised or well understood in this population. Diagnostic assessments for neurodevelopmental disabilities such as FASD in justice-involved youth are necessary and important. However, important consideration must be given to the fact that Aboriginal and Torres Strait Islander[1] youth, well known to have experienced intergenerational trauma, are significantly over-represented in the Australian justice system. Given the varying vulnerabilities of justice-involved youth, therefore, it is imperative to ensure harm is minimised and youth benefit from diagnostic assessments.

A study was undertaken in a youth detention centre in Western Australia to establish the prevalence of FASD among sentenced, detained youth. The study participants shared their experiences in an accompanying qualitative study that makes up the subject matter of this thesis. Due to the high number of Aboriginal participants, the methodologies and interpretation for this qualitative study privilege Indigenous epistemologies and ontologies. Interviews were conducted with young people and their caregivers using 'social yarning' and 'research-topic yarning' data collection methods. Focus groups and interviews were held with non-custodial staff in the detention centre.

Interviews with the young people found that research-topic yarning during and following assessments provided an opportunity for two-way knowledge sharing about the assessments. Yarning provided a space that was flexible, neurodevelopmentally and culturally responsive, and offered an opportunity for the participants to learn more about their neurodevelopmental strengths

---

[1] In this thesis, the term 'Indigenous' is used when referring to global populations, and 'Aboriginal and Torres Strait Islander' is used when referring to Australian populations. No Torres Strait Islander youth participated in the study, so participants are respectfully referred to as 'Aboriginal'. Terminologies used to adhere to journal requirements in publications have not been changed.

and challenges. Research-topic yarning with caregivers showed that there were clear cultural differences in receiving and understanding diagnoses. While the non-Aboriginal participants were more likely to raise institutional concerns relating to the health and education and of their children, diagnostic understandings and engagement with diagnostic resources for Aboriginal participants were embedded in family, community and culture.

Social yarning with young people and their caregivers allowed for an holistic understanding of the challenges that young people with FASD and neurodevelopmental impairments encounter in their daily lives, in their family and community interactions, with their education and in pursuit of different paths to their future. This component of the study found that a consideration of neurodevelopmental disability when exploring recovery options is critical to achieve positive outcomes, particularly when interventions take place within the context of the justice system. Understanding recovery in the context of justice involvement and determining how neurodevelopmental challenges can affect the ability to explore and take up opportunities are important in supporting these youth towards more positive and meaningful futures.

When youth are incarcerated, non-custodial detention centre staff are critical connectors between these youth, their families, the community and the professional sector. However, focus groups conducted with the non-custodial staff showed that they had scant knowledge of, and little access to, training about FASD and the effects of neurodevelopmental impairments. The study found that staff were poorly resourced and that mechanisms for communication between services both within the detention centre and between the centre and the community were poor, thereby compromising the care of youth in detention and limiting opportunities for continuity of care between the detention centre and the community.

This thesis reports a collection of peer-reviewed articles that, as an international first-of-a-kind study, offer a unique contribution to the health and justice scholarship. Clear evidence is presented of the critical need for routine assessments to establish the presence of neurodevelopmental impairments when children and young people come into contact with the law.

However, for assessments to be a worthwhile future investment, great care must be taken to plan and implement a sustainable, routine model for assessments that are culturally responsive and inclusive, and that follow through with genuine pathways that give hope for recovering meaningful lives. It is critical to minimise potential harm from receiving a diagnosis and ensure that support and services are available and accessible to diagnosed individuals and their families.

Table of Contents

Acknowledgments

This research was undertaken on the country of the Noongar Wadjuk people in Perth, Western Australia, and we walked on the country of many communities. I thank my Elders and brothers and sisters on Noongar Boodjar, on the traditional lands of the communities we visited and on my home country of the Ngunnawal people in Canberra. Thank you all for generously giving your time, knowledge and stories of strength, survival and hope. Thank you especially to the Elder co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project; Telethon Kids Institute who provided their collective knowledge, wisdom and guidance for the thesis.

During my candidature, I was supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award, the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341) and the Centre of Research Excellence, Indigenous Health and Alcohol, University of Sydney (NHMRC #APP1117198). The research was funded by the National Health and Medical Research Council (#APP1072072).

My PhD supervisors. I thank you all for your guidance, the generosity of your knowledge and sharing of your skills. Professor Carol Bower, Dr Melissa O’Donnell, Clinical Associate Professor Raewyn Mutch, Associate Professor Sarah Maslen, Associate Professor Tracy Reibel and Professor Valerie Braithwaite, I am honoured to have shared this journey with such a compassionate, inspirational, thoughtful and caring group. Thank you all. I specifically acknowledge the lasting support of two of my supervisors. Sarah, thank you so much for your guidance, your teaching, your time and your passion from those first days as an undergraduate student at the Australian National University through to the end of this PhD. You have taught me so much. And Val, I thank you from the bottom of my heart for taking me on as an intern with the team at RegNet all those years ago. Your love, compassion, heart and hope inspire me, and I will

always be indebted to you for the opportunities I have been afforded to shape a career in research and complete this PhD. Thanks to all my colleagues at RegNet.

I acknowledge the support to begin this PhD journey from the Poche Centre for Indigenous Health, University of Melbourne. For hosting me at the 2016 PhD Familiarisation Program, thank you. I also acknowledge and thank my Student Advisory Panel, Professor Roz Walker, Professor Donna Chung, Dr Brad Farrant, Mara West and my supervisors for their early advice and guidance for developing the thesis. Thanks to Professor Dawn Bessarab for expert advice and guidance on yarning with the young people and their families.

I thank the Banksia Hill FASD study Chief Investigators and Associate Investigators, the members of the Consumer and Community Reference Group and the Steering Group for their support of the study. To everyone in the Banksia project team, thank you. It was a journey that was long and tough and challenging, yet your passion and commitment to build a better system of justice for our kids continues. Thank you all for your support and ongoing contribution to this important area of work. I especially thank Jacinta Freeman, whose professional support in our work at Banksia, and whose support throughout this PhD journey, has been unyielding. Thank you to the staff at Banksia for allowing us to share your world. The job you do is tough, and I admire your passion and care. To the young people and their families who yarned with me and told me your stories, your hopes and dreams. Without you we would have no story to tell. You have already made the future better. Thank you.

Thanks to Professor David Best from the University of Derby, UK for your support and encouragement and the sharing of your intellectual knowledge of recovery and recovery capital. Thank you also to Professor John Braithwaite (RegNet, Australian National University) for facilitating the connection with Professor Best, for your early expert insights into the justice capital ideas and for your enduring support of this work.

From the Telethon Kids Institute, thanks to the Student Learning and Development team and the Kulunga Aboriginal Research Development Unit for your support over the time of this PhD journey. There are far too many to name, so I thank all my colleagues for their support, guidance and encouragement over the last five years. Thanks to my Ngulluk Kulunga Ngulluk Koort colleagues. My thanks especially to Carol Michie, you have been there every step of the way through the best and the worst of it! Thank you my sister.

I thank my co-investigators, and the stakeholders and supporters of the Game Changers football project in Derby, particularly Krissie Dickman from the Department of Local Government, Sport and Cultural Industries in Broome and Dr Deeta Kimba, Tracking Better® program facilitator. From Telethon Kids Kimberley, thanks to John Jacky and Janine McNamara for their support of both the visits related to the Banksia study, and my time in Broome for the Game Changers project. And for the support during my stay in Broome, my jij Jules Owen, Roma Hinder and Juli Coffin. For your cultural advice and guidance, for walks on the beach, swims in the 'pea soup', a yarn anytime and a laugh when times were tough, thank you so much.

Thank you to my brothers and sisters at the University of Sydney, Centre of Research Excellence, Indigenous Health and Alcohol. You are our future leaders, and your passion and commitment for bettering the health and lives of our people is inspirational. Thank you especially to Professor Kate Conigrave and Associate Professor Kylie Lee for your passion, leadership and support.

Thanks to all my family and friends again too many to name. To my longest time and closest friend Lyn Tlach, thank you for sharing and supporting this journey with much love and encouragement. And thank you to Richard Bonney for joining me on this journey as a community connector and for your invaluable cultural advice about 'men's business'. And personally, thank you my brother for your longest-time friendship and support of my work.

My deepest gratitude goes to my children for being who they are. To my Annie, you inspire me. Your tenacity and your endless love, your 'she'll be right mum' messages when things got tough, your exquisite food and your passion for what is human and right. And my Lachie, thank you for teaching me patience and love. Your fight, your compassion and your love inspire me every day.

Finally, my Mum. At a tender young age you were taken away from your family, your home, your community and your culture. You simply weren't black enough. Everything that mattered to you was gone. It destroyed your life. It destroyed our family. This research honours you, your experiences and those of too many of our brothers and sisters. Rest in peace now.

> *... we reflect in particular on the mistreatment of those who were Stolen Generations—this blemished chapter in our nation's history.*
>
> *We today take this first step by acknowledging the past and laying claim to a future that embraces all Australians ...*
>
> *A future where we embrace the possibility of new solutions to enduring problems where old approaches have failed ...*
>
> Excerpt from the Apology to the Stolen Generations. (Rudd, 2008)

Candidature Research Activity

Presentations

- **Hamilton**, **S**. (2019, 10 December). Australia and New Zealand Society of Criminology Conference. *Voices from Youth Detention: Exploring the Potential for Recovery Capital for Youth with Neurodevelopmental Disability*. Perth, WA.

- **Hamilton**, **S**. (2019, 18 November). Centre of Research Excellence, Indigenous Health and Alcohol, University of Sydney. *Indigenous Methodologies*. Sydney, NSW.

- **Hamilton**, **S**. (2018, 3 August). Centre of Research Excellence, Indigenous Health and Alcohol Student Symposium. *Yarning and the Banksia Hill Project.* Sydney, NSW.

- **Hamilton**, **S**. (2018, 7–9 November). National Indigenous Drug and Alcohol Conference (NIDAC). *The Banksia Hill Project.* Adelaide, SA.

- Freeman, J., & **Hamilton**, **S**. (2017, 21–23 August). National Indigenous Colour of Justice Conference. *The Banksia Hill Project: Preliminary Findings*. Brisbane, Qld.

- **Hamilton**, **S**., & J. Freeman. (2017, 12–14 September). Bringing Them Home: Securing the Rights of Our Children: 6th National Secretariat of National Aboriginal and Islander Child Care (SNAICC) Conference. *The Banksia Hill Project: Preliminary Findings*. Canberra, ACT.

- **Hamilton**, **S**., & J. Freeman. (2017, 19 September). Australian National University Innovation Seminar Series, Regulatory Institutions Network (REGNET). *The Banksia Hill Project: Preliminary Findings*. Canberra, ACT.

- **Hamilton**, **S**. on behalf of the Banksia Hill Team. (2017, 14–15 November). 6th Annual NHMRC Symposium on Research Translation with the Lowitja Institute, The Butterfly Effect. Poster Presentation (see Appendix 5). *A Prevalence Study of Fetal Alcohol Spectrum Disorder in Youth Detention in Western Australia.* Brisbane, QLD.

- **Hamilton**, **S**., Freeman, J., & Bonney, R. (2017). *The Banksia Hill Study Community Translation*. Karratha, WA.

- **Hamilton**, **S**., Freeman, J., & Bonney, R. (2017). *The Banksia Hill Study Community Translation*. Broome, WA.

- **Hamilton**, **S**., & Freeman, J. (2017, 2 August). Child Protection Practitioner's Forum, Fiona Stanley Hospital. *The Banksia Hill Project, Findings and Recommendations.* Perth, WA.

- Freeman, J., & **Hamilton**, **S**. (2017, 3 August). Department for Child Protection and Family Support Ministerial Advisory Council. *The Banksia Hill Project, Findings and Recommendations.* Perth, WA.

Submissions

- Banksia Hill Project Team. (2017). *Submission to the Royal Commission into the Protection and Detention of Children in the Northern Territory (RC-NT).*

- Banksia Hill Project Team. (2017). *Submission to the Australian Law Reform in relation to Terms of Reference for: Incarceration Rates of Aboriginal and Torres Strait Islander Peoples*.

Guest Invitations

Keynote Speaker

- *Aboriginal Women Researching for the Mob*. (2018, 10 May). International Women's Day Event; Bidyadanga La Grange Remote Aboriginal Community. Bidyadanga, WA.

- *Our Children Our Heart Our Future*. (2018, 31 October). Restorative Health and Justice Symposium, University of Canberra. Canberra, ACT.

- *Our Science Our Stories*. (2018, 21–22 November). Session Chair: 2nd Australasian FASD Conference. Perth, WA.

Panellist

- *Physical Health and Its Connection to the Complexity of Addressing Harmful Alcohol and Other Drug Use*. (2018, 7–9 November). National Indigenous Drug and Alcohol Conference (NIDAC). Adelaide, SA.

- *Complexities of Alcohol and Other Drug Use, and Aboriginal Social and Emotional Wellbeing in the Justice System*. (2018, 8 November). National Indigenous Drug and Alcohol Conference (NIDAC). Adelaide, SA.

- *University of Sydney: Centre of Research Excellence, Indigenous Health and Alcohol Student Panel*. (2018, 9 November). National Indigenous Drug and Alcohol Conference (NIDAC). Adelaide, SA.

Blogs

- Best, D., & **Hamilton**, **S**. (2020, 18 February). Justice capital: From the darkness into the light. *Power to Persuade*. https://www.powertopersuade.org.au/blog/recovery-capital-in-prisons

- **Hamilton**, **S**. (2018, 9 August). Justice, parents and child protection: A role for a Charter of Rights? *Power to Persuade*. http://www.powertopersuade.org.au/blog/justice-parents-and-child-protection-a-role-for-a-charter-of-rights?rq=hamilton

- **Hamilton**, **S**., Cleland, D., & Braithwaite, V. (2019, 14 March). Stigma by association: Understanding its consequences for Australia’s dysfunctional child protection systems. *Power to Persuade*. http://www.powertopersuade.org.au/blog/child-protection-stigma?rq=hamilton

- **Hamilton**, **S**. (2019, 26 June). From locked up to linked up: Developing the recovery capital assets of justice-involved children and young people. *Power to Persuade*. http://www.powertopersuade.org.au/blog/from-locked-up-to-linked-up-developing-the-recovery-capital-assets-of-justice-involved-children-and-young-people/26/6/2019?rq=hamilton

- **Hamilton**, **S**. (2018, 22 November). Adopting or adapting: Past mistakes vs new possibilities for child protection in Australia. *Power to Persuade*. http://www.powertopersuade.org.au/blog/adopting-or-adapting-nsw-child-protection-policies?rq=hamilton

Media

Podcast

- SciTech. (2019). *Particle Podcast: Tackling FASD in WA* [Audio podcast]. https://particle.scitech.org.au/podcast/particle-podcast-fasd-in-wa/

Upcoming Invitations

- Keynote Speaker: Australasian FASD Conference 2020. *Science & Experience: Facing the Future Together*. Sydney, NSW, 11–12 November 2020.
- Visiting Academic: University of Derby, United Kingdom, 2020/2021.

Professional Memberships

2017–2018	BOAB Health Advisory Committee, Broome.
2015–current	Canberra Restorative Community Network; Restorative City project. Australian National University.
2017–current	FASD Centre for Research Excellence, Telethon Kids Institute.
2017–current	Kimberley/Pilbara Working Group, Telethon Kids Institute.
2017–current	Centre for Research Excellence: Indigenous Health and Alcohol, University of Sydney.
2019–current	Indigenous Advisory Working Group, National Centre for Clinical Research on Emerging Drugs, University of New South Wales.
2019–current	Wisdom Circle (Aboriginal community welfare advisory board), Uniting Care West, Perth.

Awards

- 2019 WA Premier’s Science Award: Shell STEM Aboriginal Student of the Year.
- 2017 Peter and Anne Hector Award, Translational Research in Aboriginal Health.

Other Research Activity

- 2018–2019 Chief Investigator ‘Gamechangers’ evaluation, Derby (see Appendix 8).

Additional Publications

Bower, C., Watkins, R., Mutch, R., Marriott, R., Freeman, J., Kippin, N., Safe, B., Pestell, C., Cheung, C., Shield, H., Tarratt, L., Springall, A., Taylor, J., Walker, N., Argiro, E., Leitao, S., **Hamilton**, **S**., Condon, C., Passmore, H., & Giglia, R. (2018). Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia. *BMJ Open*, 8: e019605. https://doi.org/10.1136/bmjopen-2017-019605

Freeman, J., Condon, C., **Hamilton**, **S**., Mutch, R. C., Bower, C., & Watkins, R. E. (2019). Challenges in accurately assessing prenatal alcohol exposure in a study of fetal alcohol spectrum disorder in a youth detention center. *Alcoholism: Clinical & Experimental Research*. https://doi.org/10.1111/acer.13926

Hamilton, **S**., Cleland, D., & Braithwaite, V. (2019). ‘Why can’t we help protect children too?’ Stigma by association among community workers in child protection and its consequences. *Oxford Community Development Journal*. https://pdfs.semanticscholar.org/f650/9240b8670e4bd6f341669fc547df92bdc92b.pdf

Passmore, H. & **Hamilton, S**. (Forthcoming). Fetal Alcohol Spectrum Disorder and the Criminal Justice System. In G. Lansdell, B. Saunders, & A. Eriksson (Eds), *Neurodisability and the Criminal Justice System: Comparative and Therapeutic Responses*. Edward Elgar Publishing.

Journal articles under review

Hamilton, S. & Maslen, S. (Submitted May 2020). Redressing “unwinnable battles”: Towards institutional justice capital in Australian child protection. *Social Issues*.

Best, D., **Hamilton, S**., Hall, L., & Bartell, L. (Submitted June 2020). Justice capital: A model for reconciling structural and agentic determinants of desistance. *Probation* (Special Issue: Critical Perspectives on Desistance).

Authorship Declaration: Co-Authored Publications

This thesis contains work that has been published and/or prepared for publication, is in agreement with The University of Western Australia Doctor of Philosophy Rules for the content and format of a thesis and is presented as a series of papers.

Journal article: Published 6 November 2019: *Qualitative Health Research*
Hamilton, S., Reibel, T., Maslen, S., Watkins, R., Freeman, J., Passmore, H., Mutch, R., O’Donnell, M., Braithwaite, V., & Bower, C. (2020). Disability ‘in-justice’: The benefits and challenges of ‘yarning’ with young people undergoing diagnostic assessment for Fetal Alcohol Spectrum Disorder in a youth detention centre. *Qualitative Health Research, 30*(2), 314–327. https://doi.org/10.1177/1049732319882910

CHAPTER THREE

Student contribution: First author. Banksia Hill Qualitative Researcher. Study design. Conceptualised framework. Data collection, analysis and writing. Wrote first draft, applied edits and redrafts, finalised final article for submission. Coordinated full article submission process.

Co-author signature		Date
[redacted]	Tracy Reibel	August 2019
[redacted]	Rochelle Watkins	August 2019
[redacted]	Raewyn C. Mutch	August 2019
[redacted]	Jacinta Freeman	August 2019
[redacted]	Hayley Passmore	August 2019
[redacted]	Melissa O’Donnell	August 2019
[redacted]	Sarah Maslen	August 2019
[redacted]	Valerie Braithwaite	August 2019
[redacted]	Carol Bower	August 2019

Student signature: [redacted] August 2019

Journal article: Published 24 June 2020: *Sociology of Health and Illness*

Hamilton, S., Maslen, S., Conigrave, K., Mutch, R., Watkins, R., O’Donnell, M., Freeman, J., & Bower, C. (2020) ‘That thing in his head’: Aboriginal and non-Aboriginal caregiver responses to Fetal Alcohol Spectrum Disorder diagnosis. *Sociology of Health and Illness.* Early view doi: 10.1111/1467-9566.13146

CHAPTER FOUR

Student contribution: First author. Banksia Hill Qualitative Researcher. Conceptualised framework. Data collection, analysis and writing. Wrote first draft, applied edits and redrafts, finalised final article for submission. Coordinated full article submission process.

Co-author signature		Date
[redacted]	Sarah Maslen	February 2020
[redacted]	Kate Conigrave	February 2020
[redacted]	Raewyn C. Mutch	February 2020
[redacted]	Rochelle Watkins	February 2020
[redacted]	Melissa O’Donnell	February 2020
[redacted]	Jacinta Freeman	February 2020
[redacted]	Carol Bower	February 2020

Student signature:	[redacted]	February 2020

Journal article: Published 20 January 2020: *International Journal for Crime, Justice and Social Democracy*

Hamilton, S., Maslen, S., Best, D., Freeman, J., O’Donnell, M., Reibel, T., Mutch, R., & Watkins, R. (2020). Putting ‘justice’ in recovery capital: Yarning about hopes and futures with young people in detention. *International Journal for Crime, Justice and Social Democracy*, 9(2): 20-36. https://doi.org/10.5204/ijcjsd.v9i2.1256

CHAPTER FIVE

Student contribution: First author. Banksia Hill Qualitative Researcher. Conceptualised framework development. Data collection, analysis and writing. Wrote first draft, applied edits and redrafts, finalised final article for submission. Coordinated full article submission process.

Co-author signature	Date	
[redacted]	Sarah Maslen	January 2020
[redacted]	David Best	January 2020
[redacted]	Jacinta Freeman	January 2020
[redacted]	Tracy Reibel	January 2020
[redacted]	Melissa O’Donnell	January 2020
[redacted]	Raewyn C. Mutch	January 2020
[redacted]	Rochelle Watkins	January 2020

Student signature: [redacted] January 2020

Journal article: Published 28 August 2019: *Youth Justice* Hamilton, S. L., Reibel, T., Watkins, R., Mutch, R. C., Kippin, N. R., Freeman, J., Passmore, H. M., Safe, B., O’Donnell, M., & Bower, C. (2019). ‘He has problems; he is not the problem …’ A qualitative study of noncustodial staff providing services for young offenders assessed for Foetal Alcohol Spectrum Disorder in an Australian youth detention centre. *Youth Justice*, *19*(2), 137–157. https://doi.org/10.1177/1473225419869839		
CHAPTER SIX		
Student contribution: First author. Banksia Hill Qualitative Researcher. Conceptualised framework. Data collection, analysis and writing. Wrote first draft, applied edits and redrafts, finalised final article for submission. Coordinated full article submission process.		
Co-author signature		Date
[redacted]	Tracy Reibel	August 2019
[redacted]	Rochelle Watkins	August 2019
[redacted]	Raewyn C. Mutch	August 2019
[redacted]	Natalie Kippin	August 2019
[redacted]	Jacinta Freeman	August 2019
[redacted]	Hayley Passmore	August 2019
[redacted]	Bernadette Safe	August 2019
[redacted]	Melissa O’Donnell	August 2019
[redacted]	Carol Bower	August 2019
Student signature: [redacted]		August 2019

I, Professor Caroline Bower, certify that the student statements regarding their contribution to each of the works listed above are correct.

Coordinating supervisor signature: [redacted] June 2020

List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ALSWA	Aboriginal Legal Service Western Australia
AOD	Alcohol and Other Drug
DOC	Department of Communities
DOJ	Department of Justice
FASD	Fetal Alcohol Spectrum Disorder
ID	Intellectual Disability
NI	Neurodevelopmental Impairments
OICS	Office of the Inspector of Custodial Services
OMS	Offender Management System
PTSD	Post-Traumatic Stress Disorder
PYJ	Positive Youth Justice
WA	Western Australia
WD	Without Disability

Introduction

For children to thrive, it is imperative that they grow up knowing who they are and where they belong, and to know their strengths and challenges (Walker, 2015). For most children this is accomplished in the family home, at school and in the peer and social interactions in which their life learnings are embedded and grow. Some children, though, live in poverty and disadvantage, are socially isolated and have fewer opportunities. Some may live in situations of neglect or abuse, or they may live away from their parents in foster care or relative care (Walker, 2015).

Whatever the situation, when day-to-day life is layered with complexity, these challenges may mean that less attention is paid to the unique needs of children who have less obvious, or 'invisible' (Chudley, 2008) neurodevelopmental disabilities such as Fetal Alcohol Spectrum Disorder (FASD). FASD can result in a range of difficulties across the life course. Some of these difficulties, such as behavioural problems, affect children's social and educational development, and for many, these challenges can put them at risk of future contact with the law (Streissguth et al., 1999). As such, when children begin showing signs that they are struggling at school or are getting into trouble, there may be value in exploring their strengths and challenges through assessments for conditions such as FASD that, undetected, can impede their life chances (Bower et al., 2018; Koren et al., 2004; Steinhausen et al., 1993; Streissguth et al., 2004). Detection of neurodevelopmental difficulties through diagnostic assessment can build awareness for children and their families of the individual abilities and challenges that will support, assist and enable them to grow up to lead meaningful lives.

The youth justice system in Australia is complex and presents significant challenges to policy-makers, personnel and justice-involved youth (Lohmeyer, 2018). Aboriginal and Torres Strait Islander youth are considerably over-represented in the youth justice system in Australia. On an average night around 1,000 youth are detained, with Aboriginal and Torres Strait Islander youth 26 times more likely to be imprisoned than their non-Aboriginal peers (Australian Institute of

Health and Welfare, 2018), despite comprising just 5% of the youth population. In Western Australia (WA), where this research was undertaken, Aboriginal youth make up around 70% of the youth detention population (Department of Justice [DOJ], 2018).

The shortcomings and negative effects of persistent policy failures in the Australian criminal justice system have been repeatedly described in published literature (Arabena & Moodie, 2014; Atkinson, 2002; Cunneen and Tauri, 2019; Dodson & Hunter, 2006; Sherwood, 2013). These policy failures have also been described over decades in reports, most notably the Royal Commission into Aboriginal Deaths in Custody (Commonwealth of Australia, 1991), the Human Rights and Equal Opportunity Commission (1997) inquiry into the forced removal of Aboriginal and Torres Strait Islander children, and most recently, the Royal Commission into the Detention and Protection of Children in the Northern Territory (Australian Government, 2017), which inquired into the mistreatment and abuse of youth at the Don Dale Detention Centre.

Over the last 30 years, few recommendations from these inquiries have been implemented, and approaches to youth crime continue to largely ignore the social determinants of health (Marmot & Wilkinson, 1999; Viner et al., 2012); the relationship between socioeconomic inequalities and offending (Hughes et al., 2020) and systemic and institutional racism and discrimination (Blagg, 2008; Harmes et al., 2019; Wacquant, 2009; Weatherburn & Ramsey, 2016). Further, the effects of crime policies as they are experienced by Indigenous peoples in relation to historical circumstances are largely overlooked (Cunneen & Tauri, 2019; Jordan et al., 2018). There has been little concerted effort to decrease the over-representation of incarcerated Aboriginal and Torres Strait Islander youth in prison and to address the intergenerational harm and trauma which continues to be incurred by individuals and communities from colonising forces and institutions. Moreover, there has been little effort to support self-determination or to embrace community led solutions to crime, despite hundreds of millions of dollars in annual expenditure on youth justice service provision (Productivity Commission, 2018).

There are well-established benefits of assessments and screening justice-involved youth for a variety of conditions (Altschuler & Armstrong, 1994; Bower et al., 2018; Hancock, 2017; Potter, 2014; Wasserman et al., 2003). Yet, it is globally recognised that people involved with criminal justice systems are being incarcerated with untreated complex trauma and resultant mental health problems, and neurodevelopmental disabilities including undiagnosed FASD (Bower et al., 2018; Dias Ware et al., 2013; Garland et al., 2001; Johnson et al., 2004; Teplin et al., 2002; Wasserman et al., 2002, 2005). However, the lack of routine screening and diagnosis for FASD means that justice personnel may be blind to the specific needs of children and young people with neurodevelopmental impairments. Potentially, this lack of screening also contributes both to the extent of the over-representation of Aboriginal and Torres Strait Islander youth in prisons and the persistent inability to develop effective policies that could assist to address this over-representation.

This thesis presents the results of a qualitative study that explores the experiences of youth undergoing assessment for FASD while sentenced to detention in WA’s only youth detention facility, Banksia Hill Detention Centre (Banksia). In addition, it presents the views of participants who represent the young people’s care and professional networks. The thesis will be presented through a lens of recovery and healing, with a focus on the importance of using Indigenous methodologies in research of this nature. The research has been developed as a series of peer-reviewed publications that explore the assessment experiences and views of multiple participants. The publications examine whether there is value in applying routine assessments for FASD and neurodevelopmental impairments for youth who come into contact with the law and, if so, how the qualitative evidence provided in the thesis can inform how assessments are shaped for maximum benefit, particularly for Aboriginal participants.

Thesis Aims

This thesis focuses on the perspectives of young people, their caregivers and non-custodial staff in Banksia regarding assessments and diagnosis for FASD. The research explores the scholarly literature with the aim of understanding how the connections between history, social determinants and having a neurodevelopmental disability may influence involvement with the criminal justice system. The thesis argues that these factors are inextricably linked.

Exploring and reporting on the experiences of undergoing assessment and being diagnosed with FASD or a neurodevelopmental disability while engaged with the criminal justice system presents an opportunity to better understand the complex needs of young people and their families. The primary aims of this thesis are to provide an in-depth understanding of:

1. how diagnostic assessment for FASD is understood by the young people and their caregivers,
2. the value of a diagnostic assessment model for youth that considers neurodevelopmental disability, social circumstances and recovery in the context of justice involvement, and
3. how diagnostic assessment may benefit youth justice service provision.

As the only qualitative study of this nature to have been undertaken in a detention centre internationally, the participants' views and experiences will significantly contribute to understanding the potential for strength-based frameworks that can be used to inform and positively reshape future youth justice service delivery.

Thesis Outline

This thesis presents a case study analysis of the experiences of multiple participants who underwent diagnostic assessment for FASD at Banksia.

Chapter 1 begins by introducing the Banksia FASD prevalence study (referred to in this thesis as 'the prevalence study') and describing the study setting to provide a context for this qualitative research. The chapter then briefly describes the qualitative study, including participant descriptions and the broad methodological approaches undertaken.

Chapter 2 presents an overview of the scholarly work on FASD and its comorbidities and examines the implications of FASD and involvement with the criminal justice system.

Chapter 3 presents the first peer-reviewed article from the qualitative study, published in *Qualitative Health Research*. The article describes the benefits and challenges of yarning with youth who underwent diagnostic assessment in the prevalence study. It provides valuable insights for future qualitative studies involving children and young people with neurodevelopmental disabilities.

Chapter 4 presents the second peer-reviewed article, published in the *Sociology of Health and Illness* journal. This article presents case study vignettes that explore the experiences of caregivers in the study. It examines the unique differences between Aboriginal and non-Aboriginal caregivers of receiving a diagnosis for their child, as well as their understanding and use of diagnostic resources.

Chapter 5 presents the third peer-reviewed article, published in the *International Journal for Crime, Justice and Social Democracy*. Through a lens of ‘recovery’, the article reports the social yarning results with the young people from the study and explores recovery in the context of justice involvement and neurodevelopmental disability.

Chapter 6 presents the fourth and final peer-reviewed article of the thesis, published in *Youth Justice*. The article describes the understandings and challenges of the prevalence study for non-custodial staff working at Banksia in various rehabilitative roles. It explores what is required for these staff to be able to use the prevalence study results for the benefit of the young people in their care.

Chapter 7 discusses the findings of the peer-reviewed articles from the Banksia qualitative study presented in this thesis.

Chapter 8 concludes the thesis and provides a series of recommendations for moving forward.

Chapter 1: Study Setting

1.1 Banksia Hill Detention Centre Fetal Alcohol Spectrum Disorder Study

Between 2015 and 2018, a study was undertaken to determine the extent of FASD in youth detention. A full study protocol is available (Passmore et al., 2016). The study was the first of its kind undertaken in Australia, and the first internationally to include a qualitative component to capture participants' experiences. Located in Perth, WA, Banksia is the only detention centre in the State, and houses approximately 150 offenders at any given time. The population consists of children and young people aged 10-18 who are on remand, awaiting trial or bail determination, or who have been sentenced to detention. Males and females are detained in separate residential units within the facility. Around 75% of the population at the time of the study were Aboriginal (Office of the Inspector of Custodial Services [OICS], 2015). The aims of the prevalence study were four-fold: to estimate the prevalence of FASD among youth sentenced to detention; to develop and evaluate a FASD screening instrument; to design, administer and evaluate a workforce development intervention with custodial staff; and to conduct the qualitative study that this thesis reports on. During the prevalence study, specialist clinicians in the research team undertook comprehensive medical, neuropsychological, motor skills, and speech and language assessments with participating youth (Bower et al., 2018; Freeman et al., 2018; Kippin et al., 2018; Passmore et al., 2016; Safe et al., 2018; Safe, Joosten, & Giglia, 2018). The formal workforce development component of the study involved the production of training resources and a structured training intervention for custodial staff (Passmore et al., 2018). Detailed methods explaining study participation and informed consent can be found in the peer-reviewed article presented in Chapter Three of this thesis (Hamilton, Reibel et al., 2020).

1.1.1 Governance and Consultation

The study was governed by three separate bodies: 1) Consumer and Community Reference Group; 2) Steering Group; and 3) DOJ and Department of Communities (DOC) Reference Group.

The Consumer and Community Reference Group comprised carers of children with FASD, an Aboriginal researcher, an Aboriginal community worker and a foster carer of children with FASD. This group provided crucial advice during the design and implementation of the research, including advice on the development of ethics documents such as consent forms and participant information forms, the development of resources, the dissemination of information and cultural guidance. The Steering Group comprised representatives from consumer and advocacy organisations such as the Aboriginal Legal Service of WA (ALSWA), the OICS, community members and senior administrative staff from Banksia. The group regularly met and provided direction and guidance on the research process. The Reference Group was a high-level managerial group that assisted in navigating the challenges that arose out of conducting research in Banksia. The group comprised the Deputy Commissioner for Youth Justice Services; senior management from the DOJ and DOC; staff from the detention centre, senior administrators, senior managers from health services, psychology and education; an Aboriginal welfare officer; and the chief investigators of the study. This group aimed to safeguard the security requirements for Banksia by advising on adjustments to the research protocols and operational procedures within Banksia in order to implement and maintain efficiency throughout the research process.

Extensive consultation and working relationships with key stakeholders and wide-ranging networks were built in the development of the research, across the research process, and continue to be built during translation of the research. The research was multi-layered and, as a result, consultation occurred across multiple government sectors (DOJ, DOC, Department of Education and Department of Health) and non-government sectors (youth and community support providers and advocates, carers and family members affected by FASD, and leading academics). These relationships were integral to the research process and the translation of research outcomes.

1.1.2 Ethics

Ethics approval was given by the Western Australian Aboriginal Health Ethics Committee (approval #582) and the University of Western Australia Human Research Ethics Committee (approval #RA/4/1/7116). The former Department of Corrective Services granted research approval (DCS; project ID 335). The former Department for Child Protection and Family Support (DCPFS) also gave approval for the research to include young people in their care (approval #2015/8981).

1.1.3 Multidisciplinary Diagnostic Team Meetings

Upon completion of the clinical assessments and the collection and collation of data, a multidisciplinary team of clinicians undertook a comprehensive review of the assessment results and, if relevant, formed a diagnosis for the participant, considering co-morbidities such as Attention Deficit Hyperactivity Disorder (ADHD), intellectual disability and traumatic brain injuries, and other factors such as a history of trauma. The team then prepared an ‘Assessment Results and Recommendations Report’. This report provided comprehensive assessment results, strengths and challenges that the young person may experience, as well as individualised strategies to assist them.

1.1.4 Feedback

Upon completion of the multidisciplinary diagnostic meetings and report preparation, members of the research team met with the young person and their guardian to provide the assessment results, and if applicable, a diagnosis. The results and recommendations were provided in a culturally sensitive and supportive way. When necessary, Aboriginal language services were used for those with English as a second language to support understanding of the assessments and results. In many cases, a professional or community member identified by the young person or their guardian also assisted with this process. Additional information was provided to young people regarding follow-up services in Banksia, and community services were provided to help guardians understand, translate or cope with the content of the reports. The youth and their guardians own their report and were encouraged to share these with relevant health and other service providers to inform future treatment and service delivery appropriate to the strengths and challenges of the young people.

1.1.5 Results

The prevalence study found that of the participating young people, 36% had FASD and 89% had at least one domain of severe neurodevelopmental impairment. For Aboriginal youth in the study, the prevalence rate of FASD was 47% (Bower et al., 2018). These results represent the highest documented prevalence of FASD in a youth justice setting internationally.

1.2 Banksia Hill Detention Centre Qualitative Study

The prevalence study was the first of its kind internationally to use qualitative inquiry methods to explore the lived experience of youth undergoing assessments and diagnosis for FASD and other neurodevelopmental disabilities while incarcerated. This thesis provides a qualitative account of the experiences of the youth who participated in the prevalence study. It provides comprehensive insights into the complexities of living with neurodevelopmental disability and being involved with youth justice services. More broadly, it contributes to scholarly work seeking to address the over-incarceration of Indigenous youth.

The qualitative research was undertaken concurrently with the prevalence study. An overview of the participants' information and data collections methods is provided in Table 1.1. The qualitative researcher and thesis author is an Aboriginal woman, a proud descendant of the Ngunnawal people from the Canberra region, who is strongly committed to ensuring that the voices of the participants are represented accurately and in a culturally respectful way. Given this, and the fact that 71% of the young people in Banksia who participated in the qualitative study were Aboriginal Australians, foremost in the development of the thesis was ensuring rigorous and ethically sound research processes for including Aboriginal perspectives throughout the analysis of the data, in the research translation and in the development of the publications.

Table 1.1

Participant Information and Data Collection Methods

Participants	No.	Data collection method
Young people	38	Social/research yarning
Parents and guardians	17	Social/research yarning
Non-custodial staff:		
Caseworkers	5	Semi-structured focus group
Psychology staff	5	Semi-structured focus group
Education staff	14/18	Two semi-structured focus groups
Medical staff	1	Semi-structured interview
Aboriginal welfare officer	2	Social/research yarning

1.2.1 Ethical Indigenous Research

There is increasing global recognition of the importance of including Indigenous perspectives in research and its impact (Dudgeon, 2008; Tuhiwai Smith, 1999), including its effect on practices that promote cultural regeneration (Alfred, 2009). From an Indigenous perspective, research is linked to colonial practices and oppression (Sherwood, 2013; Tuhiwai Smith, 1999); thus, decolonising methodologies are important and provide alternative ways to think about research processes and practice. Decolonising methodologies aim to ensure that research is conducted in a way that is sympathetic, respectful and ethically sound from the perspective of the participants (Dudgeon, 2008; Sherwood, 2013; Tuhiwai Smith, 1999). Like the Indigenous worldview of relatedness, culturally safe research processes are interrelated, thereby making the researcher accountable for all aspects of the research.

Respectful and ethically sound presentation of this research will follow the framework put forward by Absolon and Willett (2004), which requires the researcher to ‘consider how you represent yourself, your research and the people, events, phenomena you are researching’ (p. 15). Decolonising methodologies in this research included ongoing consultation with Aboriginal Elders in the processes of inquiry, data immersion and translation. These were used to make the assumptions, theories, methods and ethics of this study transparent, and to provide an accurate strength-based interpretation of the data.

1.2.2 Governance

The qualitative study was guided by the committees set up for the prevalence study, as previously described. Specific cultural governance was sought. The thesis author sought expert guidance for yarning with participants from Professor Dawn Bessarab at the University of Western Australia. The Kulunga Aboriginal Research and Development Unit (Telethon Kids Institute) was consulted and provided expert advice throughout the research process, and the Elder co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project (Telethon Kids Institute) provided their collective knowledge and wisdom for guiding the interpretation of the data from the research, and provided direction for this thesis to ensure alignment with community aspirations.

1.3 Methods

Specific methods for each data set collected are described in the four peer-reviewed articles that form Chapters Three, Four, Five and Six of the thesis. This section will describe the broad methodological aspects of qualitative research considered in this research. ‘Qualitative quality’ (Tracy, 2010), or research rigor, was achieved in this research through the application of authenticity, thick description, data triangulation, multi-vocality and member reflections.

1.3.1 Authenticity

Authenticity supports research rigor. Tracy (2010) argues that research authenticity is underpinned by honesty and transparency, which is achieved through critical self-reflection about personal values, biases and weaknesses, and how they affect the methods and research. Self-reflexive researchers think about the types of knowledge that are freely available, as well as knowledge that is veiled or not readily apparent. They interrogate their own thoughts and opinions and discuss these with participants (Tracy, 2010). Honesty and transparency in this research were underpinned by the use of specific Indigenous methodologies for youth, their caregivers and family members. Trust was gained first through an ongoing relationship with the research officer responsible for collecting the data in the prevalence study, and second by using Indigenous data collection methods. Social and research topic yarning (Bessarab & Ng'andu, 2010) was employed as a way to respectfully build trust and govern responsibility (Martin, 2008). Extensive self-reflections were written at the end of each yarning interview, the content of which was clarified with participants. This ensured accurate interpretation of yarning content, and offered an opportunity for corrections, additions or omissions to the participants stories.

1.3.2 Thick Description

Thick description is an in-depth design that explicates culturally situated meanings and tangible detail in a research setting. It requires clarification of knowledge and meaning first by noting who is talking and the content of the discussion, and then by noting who is not talking and what is not being said. This is described by Altheide and Johnson (1994) as 'largely unarticulated, contextual understanding that is often manifested in nods, silences, humour, and naughty nuances' (p. 492). Quality in qualitative research probes and explores issues that are assumed, implicit and have become part of participants' reality. Noticing, analysing and unpacking this knowledge is key to understanding interactions and behaviours, and assisting in the comprehensive delivery of research (Kaplan, 1973). This process requires the researcher to have sensitivity toward, and connection with, the participants. In this research, the thick description aspect of quality was achieved by recording the expressions, postures and demeanours of the participants; using methods specific to Indigenous interests such as story sharing; checking in and reflecting on the data with participants; and deep listening through 'dadirri', an Aboriginal spiritual form of trust and rapport building (Ungunmerr, 1988).

1.3.3 Data Triangulation

Triangulation in qualitative research suggests that the use of various researchers, data sources and methods, and viewing the problem through a variety of theoretical lenses, helps to achieve research credibility. Multiple types of data, researcher viewpoints, theoretical frames and methods of analysis allow different facets of problems to be explored, increases scope, deepens understanding and encourages consistent interpretation, or allows for multiple interpretations. This research used two types of triangulation: investigator and methodological triangulation. Investigator triangulation encompasses the use of more than one researcher or data analyst. Confirmation of data analysis among investigators where there has been no previous collaboration, potentially provides greater credibility to the research interpretations (Thurmond, 2001). Investigator triangulation is an important methodological tool designed to lessen the likelihood of biases that may arise from using a single method (Thurmond, 2001). This research was composed of a team of researchers who collected, independently analysed and regularly discussed the data in order to minimise researcher bias and balance potential weaknesses in data collection and analysis.

Methodological triangulation is employed when more than one method is used for data collection. The use of multiple cases and comparisons across cases allows the researcher to recognise and evaluate relationships (Yin, 2013). In this research, focus groups, interviews and questionnaires, case files and clinical screening sessions captured the vast range of participants' views. A multiple case study approach is particularly appropriate for an investigation into the experiences of young people undergoing assessments for FASD, for understanding FASD and its effects on families and communities and the way these may be experienced differently within individual cases.

1.3.4 Multivocality

Multivocal research includes multiple and diverse voices in a qualitative analysis. Multivocality plays a number of roles, including providing an empathetic understanding and a space for a variety of opinions and voices (Tracy, 2010). Qualitative analysis represents all views, including thoughts and opinions that deviate from the status quo or from those of the researcher. Therefore, credibility is enhanced when the research pays attention to multiple voices and views. This study included the varied voices of the young people, their caregivers and family members and youth justice staff.

1.3.5 Member Reflections

Taking the form of member checks and data validation, member reflections enhance qualitative credibility. Member checks and data validation provides an opportunity for a richer analysis (Bloor, 2001). Member reflections are both a test of research findings and an opportunity for collaboration and elaboration to enhance the ‘thick description’ of the research. In this research, member reflections assisted the researcher to understand whether participants and other key stakeholders found the research comprehensible and meaningful. This research sought regular and ongoing input and feedback during the data collection and interpretation processes, which allowed the researcher to share and discuss the study’s findings with the participants, provide opportunities for questions and feedback, and confirm the interpretation of the analysis.

1.3.6 Data Collection

As this study examined the experiences and understandings of multiple parties involved in FASD screening and diagnosis, a case study methodology was chosen. Case study research varies widely, but it is primarily a method whereby researchers explore a program, event, activity, process or one or more individuals (Creswell, 2012; Yin, 2013). The cases are typically bounded by time, and researchers collect detailed information using a variety of data collection procedures (Stake, 2013). When a multidimensional study of a phenomenon is undertaken, Weick (2007) argues that complex data collection mechanisms are required to see the intricacies and nuances of a problem. A large amount of data has been collected in this study, capturing what Weick (2007) describes as ‘richness’. These data provided a comprehensive set of information that was used for the analysis and interpretation in this thesis. Finally, Kaplan (1973) suggests that it is impossible to understand the life experiences of someone in a ‘total institution’ such as a prison without also being subject to the same constraints as those who are forced, either by circumstance or the law, to be there. Data collection for the young people and youth justice staff was undertaken over two years by the researchers on-site at Banksia.

1.3.7 Data Analysis

Initial analysis of the data and its organisation used Pope, Ziebland and Mays’s (2000) model of five stages of data analysis. The stages comprise: 1) familiarisation; 2) identifying a thematic framework; 3) indexing; 4) charting; and 5) mapping and interpretation. Data were then analysed using thematic network analysis (Attride-Stirling, 2001), which explored the understanding and significance for participants undergoing assessments for FASD. Thematic network analysis groups information into organising principles, which allows linkage of the relationships between themes and defines the processes that may be employed when interpreting and analysing texts (Attride-Stirling, 2001). The process of analysis is a three-stage process: breaking down the text, exploring the text and then integrating the exploration, providing an effective and efficient way to reduce and understand the data (Attride-Stirling, 2001). This methodology was used to analyse all data from the interviews and focus groups. Data were analysed in two ways. First, NVivo 11 PRO, a comprehensive data collection tool, was used to thematically organise the data. Second, the thesis author and another senior qualitative researcher independently thematically analysed the data. Final themes were developed from a constant comparative process.

1.3.8 Identifying and Triangulating Themes

Triangulation of data for theme convergence was undertaken across the views of each group of participants: young people, their caregivers and youth justice staff. Triangulation was conducted over the course of the research by multiple members of the research team and other stakeholders. The qualitative methods described here were used within and alongside Indigenous research methods to provide a framework for the application of interpretative lenses, which maintained a constant culturally mediated effect on what was being heard and read.

Chapter 2: Fetal Alcohol Spectrum Disorder Literature

2.1 Fetal Alcohol Spectrum Disorder Overview

Alcohol is a teratogen, or a substance identified as crossing the placenta and causing structural damage to a developing fetus (Chudley, 2008). FASD describes a range of physical, cognitive, behavioural and neurodevelopmental damages that can result from maternal alcohol consumption during pregnancy (Chudley, 2008). The disorder is a global public health concern, with many countries seeking to understand the prevalence and problems associated with the condition (for problems with executive function, see Fast & Conry, 2004; Moore & Green, 2004; for adaptive functioning, see Spohr et al., 2007; Streissguth et al., 1999; Whaley et al., 2001; for language and communication, see Kippin et al., 2018; Snow et al., 2017; for conduct disorders, see Jirikowic et al., 2008; and for secondary disabilities, see Baer et al., 2003; Lupton et al., 2004; O'Connor et al., 2002; Steinhausen et al., 1993; Streissguth et al., 1999). In Australia, FASD is underdiagnosed and its effects are unrecognised (Bower et al., 2018; Elliott et al., 2008; Payne et al., 2011). A higher rate of FASD has been found among Aboriginal children born in WA (Mutch et al., 2015). In 2016, Australian guidelines for the screening and diagnosis of FASD were released to establish consistency for categorising FASD across the nation (Bower et al., 2017).

A vast array of difficulties can be experienced as a result of FASD, including impairments in executive functioning (Moore & Green, 2004). Executive functions are higher-order cognitive processes involving thoughts and actions that are under conscious control (Clark et al., 2002), such as the ability to plan, pay attention, control inhibition, think flexibly and be able use effective strategies to self-regulate behaviour (Kaemingk & Paquette, 1999; Rasmussen & Bisanz, 2009). Other areas of impaired functioning can manifest in communication and language disorders (Anderson et al., 2016; Kippin et al., 2018; O'Leary et al., 2010; Snow et al., 2012, 2017), poor academic achievement and memory problems (Fast & Conry, 2004). Of the youth diagnosed with FASD in the prevalence study, severe impairments were found in academic functioning (86%), attention (72%), executive functioning (78%), cognition (21%), memory (56%), motor skills (50%) (Bower et al., 2018) and language and communication (69%) Kippin et al., 2018). More than half of the youth diagnosed with FASD had severe impairments in three or four neurodevelopmental domains, and the remainder had severe impairment in five or more domains. Severe impairments in these domains were also noted in this study in youth without a FASD diagnosis, albeit at lower levels of prevalence (Bower et al., 2018).

Another area of impairment for individuals with FASD is adaptive functioning (Spohr et al., 2007), which refers to the personal and social skills (communication, living skills and socialisation) required to live independently (Streissguth et al., 1999). This has been described as one of the most striking shortfalls in children with FASD (Steinhausen et al., 1993). Decreased social skills become more pronounced with age in people affected by FASD (Whaley et al., 2001), and individuals with FASD can have an impaired understanding of verbal commands and substantial trouble meeting social expectations as a result of disruptive and uncooperative behaviours (Jirikowic et al., 2008). Due to the highly structured environment of the detention centre, formal measures for adaptive functioning were not applied. However, given that the youth were in trouble with the law and had been imprisoned, and given the high levels of neurodevelopmental impairment in other domains, it can be assumed that adaptive functioning was also impaired (Bower et al., 2018).

2.2 Fetal Alcohol Spectrum Disorder and Secondary Disabilities

As a consequence of the domains affected by FASD, people diagnosed with the condition are highly likely to have secondary disabilities, which can result in adverse life outcomes (Bower et al., 2018; Koren et al., 2004; Steinhausen et al., 1993; Streissguth et al., 2004). The literature on the co-occurrence of disabilities associated with FASD shows that individuals experience a diverse range of additional challenges to the neurodevelopmental impairments outlined above. Secondary disabilities include emotional, conduct and sleep disorders that are persistent over time (Steinhausen et al., 1993), and decreased social skills which can result in victimisation, bullying and disrupted schooling (Carpenter, 2011; Page, 2001; Peadon et al., 2009). People with FASD more commonly experience homelessness, unemployment, and alcohol and other drug (AOD) use (Lupton et al., 2004), difficulties with self-care and financial management (Spohr et al., 2007) and mental health problems (Baer et al., 2003; Cox et al., 2008; O'Connor et al., 2002).

Conduct disorders are prevalent in people with FASD. Difficulty with attention and impulsive behaviour exposes individuals to unsafe situations in which they are unable to determine the consequences or judge the effect of their behaviour, increasing their risk of trouble with the law (Fast & Conry, 2004, 2009; Fast et al., 1999; Koren et al., 2004; Lynch et al., 2003; Streissguth et al., 2004). Children can be exposed to higher-than-normal levels of family dysfunction and environmental stressors. Many children with FASD live in foster care (Badry & Felske, 2013; Burd & Popova, 2019; Malvaso, Delfabbro, & Day, 2017a, 2017b; Tilbury, 2009) or are adopted (Streissguth et al., 2004). A combination of these factors places individuals with FASD in 'double jeopardy' (Carmichael Olson & Montague, 2011), with multiple adversities placing these children at much higher risk for negative outcomes in their adult lives (Streissguth et al., 2004). Overwhelmingly, the literature shows that impairments from FASD result in serious problems with life adaptation, limited life chances and leads to affected individuals entering the criminal justice system as children and youth.

2.3 Fetal Alcohol Spectrum Disorder and the Criminal Justice System

Globally, FASD is significantly correlated with criminal justice involvement, and individuals with FASD are disproportionately represented in the criminal justice system (Bower et al., 2018; Fast & Conry, 2004; Koren et al., 2004; Lynch et al., 2003; Popova et al., 2011; Streissguth et al., 2004). Studies estimate that there are high numbers of undiagnosed youth and adults in United States and Canadian correctional facilities (Burd et al., 2003, 2004; Malbin, 2004). One study found that 14% of children and 60% of adolescents diagnosed with FASD had been in trouble with the law (Streissguth et al., 2004). Yet criminal courts are mostly unaware of FASD and the complexity of problems for individuals with this diagnosis (Douglas et al., 2012; Fast & Conry, 2004; Moore & Green, 2004; Mutch, 2013; Nevin et al., 2002).

Individuals with FASD who come into contact with the criminal justice system raise serious concerns regarding fairness and equity. When they come into contact with the police or are arrested, they may experience an impaired understanding of why they are in trouble and have poor comprehension of their arrest rights (Roach & Bailey, 2009). Individuals with FASD can be highly suggestible, can have sporadic memory recall and can be easily influenced by suggestion during police interviews. They may have poor concepts of time and the sequence of events and are prone to confabulation (Fast & Conry, 2004). Confabulation, often construed as lying, concerns the unintentional creation of false or inaccurate memory and has critical consequences in the context of criminal justice where accurate recollection plays a major role in retelling of events, eye-witness accounts and confessions, including self-confession (Brown et al., 2019). There is evidence that those with FASD have high rates of self confession and that they are more likely to consent to pressure to plead guilty with very little understanding of the legal or personal consequences (Fast & Conry, 2004, 2009; McLachlan et al., 2014).

A justice-involved individual with FASD may not understand investigative procedures and there are questions about their fitness to stand trial, the potential for diminished responsibility, their capacity to testify, and the reliability of that testimony (Moore and Green, 2004). When individuals with FASD come before the courts, they do not always understand court processes (Roach & Bailey, 2009), and present with language deficiencies and poor communication skills (Kippin et al., 2018; McLachlan et al., 2014; Snow et al., 2012). Often, individuals with FASD are involved in impulsive, petty crime (Lynch et al., 2003; McLachlan et al., 2014). Once criminally involved, they are susceptible to recidivist offending due to their inability to learn from punitive consequences and are more likely to be incarcerated (Fast & Conry, 2004, 2009; McLachlan et al., 2014). When incarcerated, they can be susceptible to bullying and coercion by other inmates (Boland et al., 1998; Fast and Conry, 2004), are less likely to understand and respond appropriately to instructions or orders and be punished, and are managed by custodial and non-custodial workforces who are unaware of their needs (Hamilton, Reibel et al., 2019; Kippin et al., 2018; Passmore, 2018).

Identifying individuals with FASD who come before the law, therefore, is extremely important. A diagnosis of FASD recognises that there is a reason or cause for these behaviours, shifts unrealistic expectations of individuals affected by FASD and encourages a more appropriate service response (Badry & Choate, 2015; Bagley, 2019; Boland et al., 1998). Moreover, recognising that someone is affected by FASD when entering the youth justice system could assist in reducing recidivism or later entry to adult prisons (Boland et al., 1998; Streissguth et al., 1999).

The rates of youth potentially affected by FASD and who come before the courts or are incarcerated across Australia are unknown. Concern has been raised nationally about the potential prevalence of FASD and its contribution to criminal behaviour. An Australian Government report produced by the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs (2011) highlighted concern about subjective evidence it received regarding the potential prevalence of FASD in Aboriginal and Torres Strait Islander youth. The report noted the behavioural challenges of children and young people with FASD and discussed the high rates of Aboriginal and Torres Strait Islander youth ending up in prison in Australia and argued that this was a result of the failure to recognise that FASD is an underlying contributor to criminal behaviour. The Aboriginal Legal Service in WA (ALSWA), where this research was undertaken, also raised concerns about the over-representation of young Aboriginal people in the justice system and the potential links between these youth, undiagnosed and untreated FASD, and offending (ALSWA, 2013). Criminal justice personnel in Australia are recognising that FASD may be an issue for many of the youth and adults with whom they are involved, that FASD exacerbates the likelihood of recidivism, and that support specific to the impairments associated with FASD is required (Bower et al., 2018; Douglas et al., 2012; Flannigan et al., 2018; Mutch et al., 2016).

It is important to note that just as FASD and its co-occurring disabilities pose a significant risk to involvement with the youth justice system, there are many other influential factors. The individual characteristics of youth such as resilience, self-esteem or self-efficacy; social and community aspects such as their interactions with family, peer groups and institutions can all have a significant influence on the paths taken by youth in their lives (Catalano et al., 2011). Socioeconomic inequality, family problems, homelessness, school, alcohol availability and early age AOD use have been identified as some of the causes for increasing criminality in youth (Catalano et al., 2011; Hemphill et al., 2006, 2009; Stiglitz, 2012; Toumbourou et al., 2013, 2015). Importantly, children who experience a confluence of predictive factors such as witnessing and experiencing violence, living in communities where there are high rates of AOD use and living in poverty and disadvantage can experience long-term developmental harm, or ‘toxic stress’ (Garner et al., 2012). The presence of FASD or neurodevelopmental impairments can compound the effects of disadvantage, leading to involvement with the youth justice system. Although scholarly works that explore FASD in both the population and in the criminal justice system provide important scientific evidence of the likely extent of the problem, few studies to date have explored these broader social determinants, FASD and the link to involvement with the criminal justice system.

2.4 Conclusion

Youth with FASD often come from dysfunctional backgrounds and have experienced trauma, mental health issues, substance use disorders and other complex problems such as trouble with the law (Dowse et al., 2014; Hafekost et al., 2017; Indig et al., 2016). Youth with FASD can be misunderstood across their entire engagement with justice services, from the initial attribution of culpability, longitudinally into the courts, they can be victimised in jails and mismanaged in the transition back to the community unless those working with them are aware of the condition and its implications specific to that individual (Streissguth et al., 1999). Youth justice services in Australia do not routinely assess young people for FASD on entry to the justice system, despite strong evidence that early recognition and support for justice-involved individuals with FASD is crucial for just outcomes (Boland et al., 1998; Streissguth et al., 1999). Importantly, it is likely that ascertaining confirmation of maternal alcohol consumption in youth of this age will be difficult (Freeman et al., 2019); thus, this thesis argues that a broad focus on neurodevelopmental impairments rather than FASD would be more equitable for youth when developing routine screening in the youth justice system.

There is an urgent need for greater resources and support for the assessment, diagnosis, treatment of and education of the effects of FASD and neurodevelopmental impairments across criminal justice settings in Australia and more broadly, in human services agencies and the general community (Bower et al., 2018). Further, there is a need to examine effective, evaluated interventions to inform the development of programs that can prevent children with FASD from coming into contact with the law or being incarcerated and assist to direct their lives towards positive and productive futures. To do this, it is critical that we attempt to understand neurodevelopmental challenges within a broad social context. In the chapters that follow, I contribute to this conversation by examining the qualitative study participants' views through a variety of lenses. The experiences and understandings of the young people, their caregivers and non-custodial welfare staff will be understood and translated, prioritising cultural understandings of diagnostic assessment, the social determinants of Indigenous health and through lenses of recovery and healing.

2.4.1 Next Chapter Outline

The next chapter presents the first published article, which reports the research-topic yarning component of this qualitative research with youth in detention. A full description of the data collection and interpretation methods used are detailed in the article. The article has undergone a small amount of reformatting to ensure thesis consistency. The article's references can be found in the comprehensive reference list. The published version of the article can be found in Appendix 1. The citation for the publication is:

Hamilton, S., Reibel, T., Maslen, S., Watkins, R., Freeman, J., Passmore, H., Mutch, R., O'Donnell, M., Braithwaite, V., & Bower, C. (2020). Disability 'in-justice': The benefits and challenges of 'yarning' with young people undergoing diagnostic assessment for Fetal Alcohol

Spectrum Disorder in a youth detention centre. *Qualitative Health Research*, *30*(2), 314–327. https://doi.org/10.1177/1049732319882910

Chapter 3: Disability ‘in-justice’: The benefits and challenges of ‘yarning’ with young people undergoing diagnostic assessment for Fetal Alcohol Spectrum Disorder in a youth detention centre

3.1 Abstract

Undertaking research with young people presents an array of methodological challenges. We report the findings from a qualitative study that took place alongside a FASD prevalence study among detainees in Australia. Of 38 participants, 27 were Aboriginal youth. Interviews were conducted using ‘social yarning’ and ‘research-topic yarning’, an Indigenous research method that allows for data collection in an exploratory, culturally safe way. A complex interplay emerged between social yarning and research-topic yarning, which provided a space to explore responsively with participants their experiences of FASD assessments. Flexibility, including language adaptation and visual descriptions about assessments were utilised to assist participants’ recall and retell their experiences. There were, however, challenges in gathering data on the assessment experiences of some participants. We describe how employing a ‘yarning’ method for collecting data could benefit children and young people undergoing neurodevelopmental assessments in the future.

3.2 Introduction

Methodological challenges abound when researching vulnerable populations such as children and young people, marginalised groups such as Indigenous populations, people with disabilities, or those who are incarcerated, as all these populations are potentially more vulnerable to unequal power relationships (Ogilvie & Lynch, 2001). As such, the effectiveness of interventions and understanding of what works for youth have been found to be enhanced by listening to their experiences (France & Homel, 2006; Lount et al., 2017). In this article, we explore the methodological challenges associated with qualitative research, which focused on FASD assessment experiences for a population of detained, mainly Indigenous youth in Australia. The approach adopted was an Indigenous prescribed ‘yarning’ method, a technique that supports cultural and research integrity while maintaining participant autonomy. The objective was to understand young people's impressions of their participation in a clinical diagnostic assessment process while in detention, and what harms, if any, may be associated with such participation.

Indigenous Australians are among the most intensely scrutinised and researched groups in Australia since British settlement more than 200 years ago. This has occurred at the same time that overall physical health and social and emotional wellbeing is comparatively poor by most measures (Arabena & Moodie, 2014; Bainbridge et al., 2015; Thomas et al., 2014; Tsey et al., 2016). While explanations for this state of affairs is complex, Indigenous scholars have argued for increased adoption of Indigenous ontologies and methodologies that build bridges for both conducting research and sharing benefits of research across Indigenous and non-Indigenous people (Bessarab & Ng'andu, 2010; Moreton-Robertson, 2000; O'Donoghue, 1999; Rigney, 2001; Tuhiwai Smith, 1999). These Indigenous scholars do not discourage non-Indigenous research continuing to attempt to understand and address the health inequalities between Indigenous and non-Indigenous people. Rather, they seek to emphasise the importance of privileging Indigenous epistemologies and ontologies and prioritising cultural safety when Indigenous people are the main focus of research. Similarly, ontological approaches in conventional interviewing techniques are also underpinned by an acknowledgement that participant realities are subjective and diverse, and what people say they experience has the potential to influence future outcomes (Creswell, 2012).

Guiding principles for harm reduction in research have been outlined by the Lowitja Institute (Laycock et al., 2011). According to these principles, research that aims to benefit Indigenous people should be designed to hold at its centre consultation with, and leadership by, Indigenous people. It should also aspire to authentic engagement with communities, and a commitment to deep analysis of the impact of the research and its influences on Indigenous health. Researching incarcerated youth, when the largest proportion of participants is Indigenous, could therefore reasonably be seen as intrusive and upsetting for participants and their communities. Stigmatisation and greater discrimination against Indigenous youth might be feared, and with justification. Minimising potential harm, therefore, is imperative (Bessarab & Ng'andu, 2010; Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Tuhiwai Smith, 1999).

In addition to minimising harm, how we come to acquire knowledge, the concepts we use and the value we attach to things vastly differs between Indigenous and non-Indigenous people in Australia. As such, it is important to keep evolving research techniques for respectful sharing of information and the use of these knowledges (Doyle et al., 2017). The Indigenous voice in research has continually been suppressed and using an Indigenous data collection tool such as yarning is one vehicle through which the knowledges and values important to Indigenous participants can be prioritised in research (Bessarab & Ngandu, 2010).

3.3 Background

Underpinning the critiques that have been offered as to how and why Western approaches to health research do not deliver the best possible outcomes for Indigenous people is the idea that power differentials have engendered suspicion and distrust of research and researchers. Methodologically sound approaches for undertaking qualitative research with vulnerable populations are continually developing, including both conventional interviewing techniques and research techniques specific for Indigenous peoples.

3.3.1 Conventional Qualitative Methods

Conventional qualitative techniques such as structured, semi-structured and unstructured interviewing (Creswell, 2012; Kvale, 1994) can be used to collect data, where the aim is to describe the experiences and views of participants. Interviewing is broadly understood to be about a participant giving information on a particular topic to a researcher. Scholars, though, have long advocated that research should not be done 'to' children, but rather 'with them' (Christensen, 2004), and methodologies have been developed to allow more relational engagements when undertaking qualitative research, particularly with vulnerable groups such as children and youth with cognitive disabilities.

For children with cognitive disabilities, repeated interviewing has been found to have benefits, particularly when each child’s unique characteristics, abilities and challenges are known to the interviewer and the interview format is adapted accordingly (Cederborg et al., 2008). Flexible communication, including periods of silence, using prompts, rephrasing questions and summarising and repeating responses back to participants have been found to be necessary when interviewing individuals with cognitive disabilities (Sigstad & Garrells, 2017). Preparedness to be adaptable when interviewing can assist in meeting the special needs of children and young people with cognitive disabilities (Teachman & Gibson, 2013), and this is particularly important when the research explores challenging topics such as the experience participating in assessments for FASD (Pain, 2012).

Much has also been written on tools to assist in interviewing young people who are vulnerable, disadvantaged or who have difficulty recalling or reporting their experiences, particularly in relation to health assessments and crime interrogation (Driessnack, 2006; Glegg, 2019; Horstman et al., 2008). Other interviewing techniques, such as ‘cognitive interviewing’, use a variety of tools to assist in data collection (Bryan et al., 2019; Meyer et al., 2018). The use of a ‘toolbox’ of interviewing techniques, such as drawing and writing and the use of pictures, have been identified as critical to seeking the views of children who are subject to health assessments or research (Bryan et al., 2019; Lees et al., 2017; Lys et al., 2018). Further, the merits of interviewing children who are able to move around in what is termed by Irwin and Johnson (2005, p. 826) as having a ‘kinetic conversation’ and the use of visual tools have been explored (Davison et al., 2015; Glegg, 2019). These techniques facilitate relationships and provide opportunities for participants to express their thoughts and feelings in a non-threatening and honest way (Driessnack, 2006; Glegg, 2019; Horstman et al., 2008).

Underpinning all these techniques is the concept of ‘do no harm’ to participants. Arguments for research to be done ‘with’ rather than ‘to’ Indigenous populations are also consistently articulated (Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Thomas et al., 2014; Tsey et al., 2016; Tuhiwai Smith, 1999). On the basis of the critiques of conventional interviewing techniques and their use with Indigenous populations, the processes used for information gathering have undergone change in both professional and research contexts. One example that has become particularly popular in the Australian context is ‘yarning’.

3.3.2 Yarning as a Distinct Indigenous Qualitative Method

Yarning has become established as a research method, both in Indigenous Australian and global Indigenous studies (Bessarab & Ng’andu, 2010; Fredericks et al., 2011; Kovach, 2010; Martin et al., 2019; Rigney, 2001; Walker et al., 2014). Having a ‘yarn’ is ‘an Indigenous cultural form of conversation’ (Bessarab & Ng’andu, 2010, p. 37). The essence of a yarn is listening and exchange, with each side being willing to give information and show genuine connection to, empathy with and interest in the other. The suitability of yarning, however, for Indigenous people stems from its everydayness—drawing as it does on long standing cultural practices used by families and communities. Control in a yarning conversation is shared, with more emphasis on connection than on separateness, mutual respect and knowledge exchange (Bessarab & Ng’andu, 2010; Martin et al., 2019; Walker et al., 2014).

Yarning is arguably more flexible than many conventional interviewing approaches, even though overlap and compatibility with some conventional methods is apparent. For example, as with yarning, narrative and conversational interviewing draw on storytelling as a way in which people are encouraged to make sense of their experiences and communicate these through description of what is broadly meaningful to them rather than just retelling events (Emerson, 2018; Mishler, 1995).

When considering the interviewing needs of vulnerable participants such as incarcerated youth, researchers need to scrutinise the relational aspects of the research and the inherent power dynamics with a traumatised or vulnerable population (Kevers et al., 2018). Yarning is a method that respects the ‘stories’ participants ‘want to share’ as opposed to participants being expected to give the researcher what they ‘want to hear’. The yarning approach represents an opportunity for two-way learning and knowledge-sharing that is not dependent on an unequal power relationship in which the researcher maintains control.

Depending on context and purpose, yarning can both orient the social interaction approach and centre the research-topic (Bessarab & Ng'andu, 2010). In this study, social yarning was used at the beginning of conversations with young people to establish a connection not strongly associated with the actual purpose of the yarn. In more conventional interviewing situations, this goal might be stated as establishing rapport. Social yarning goes further in setting the tone for research-topic yarning by encouraging the participant to lead the yarn, with the researcher valuing the participant as a whole person; valuing their story and knowledges and minimise power imbalances between the researcher and participant (Bessarab & Ng'andu, 2010). Ideally, no assumption is made that the researcher is in control. In fact, the role of 'researcher' carries little weight during this early stage of 'summing' each other up. Through social yarning, the intent is deeper, achieved through purposeful exchanges and trust-building, in which the researcher shares information about themselves with the participant, and the level of information exchange is controlled by the participant.

Throughout this process, the continuing responsibility of the researcher is to find shared ground through authentic interest in participant's lives. This might be achieved through sharing information about culture and family, sports, hobbies or interests. The research remains flexible to finding the shared ground, which requires some knowledge about and empathy towards the participant's circumstances. For example, asking a participant 'do you want to have a yarn about the research?' promotes an approach of 'let's explore what we feel, think, see together rather than saying 'this is what I want to know about the research, let's talk'. By conducting a relational exchange in this way and establishing a genuine rapport, yarning becomes a tool of authentic information exchange, which when done well, with respect and by mutual agreement, has the potential to reveal information relevant to the research without necessarily asking direct questions (Bessarab & Ng'andu, 2010; Martin et al., 2019; Walker et al., 2014).

For Indigenous people, storytelling is a traditional form of knowledge sharing and respectful communication. Yarning provides a safe space for Indigenous people to share their feelings, hopes and fears through storytelling. Moving between social and research-topic yarning is therefore a fluid process (Bessarab & Ng'andu, 2010). Even when the research topic is introduced, yarning remains informal and relaxed. Interspersing answers to research questions within stories provides a fuller more meaningful and detailed engagement with the research topic than providing one or two word answers. While this will not guarantee that an Aboriginal person will engage in a yarning process, more often than not, yarning provides participants with an opportunity to assess the potential threat or ulterior motives of the researcher/interviewer through a process of sharing knowledge and building mutual understandings. Yarning then becomes a journey of mutual discovery and learning through storytelling.

In both social yarning and research-topic yarning, deviations from the purpose of the research are tolerated more than is the case in conventional interviewing, operating as a sign of respect for the connection established through the yarn. This is carried through to other forms of yarning. Collaborative yarning expands the opportunity for sharing information through exploring other topics that lead to new understandings (Bessarab & Ng'andu, 2010). Therapeutic yarning occurs when very personal or traumatic information is disclosed by a participant. In such situations the researcher needs to seamlessly switch from data collection to listening and supporting the participant (Bessarab & Ng'andu, 2010). Yarning requires the researcher to have sensitivity towards the participant and deep listening, or 'dadirri', a spiritual form of trust and rapport building (Atkinson, 2002).

Overall, yarning creates relationships and governs the responsibility of both parties to be good listeners and genuine contributors and supporters of the other (Martin, 2008). Yarning as research method was therefore the most culturally safe means of gathering information, for the majority of the research population who were Indigenous youth. Additionally, the language of 'having a yarn' is colloquially well understood to mean 'having a conversation', certainly among most Indigenous people but also in the broader Australian society. Thus, understanding of having a yarn and its suitability was readily extended to the non-Indigenous youth who were involved in this study.

In this analysis, we consider whether the use of yarning is an appropriate research data collection tool for both Indigenous and non-Indigenous youth in detention, particularly those with a neurodevelopmental disability.

3.4 Study Context

FASD is a lifelong, preventable brain injury caused by alcohol exposure during pregnancy (Fast & Conry, 2009; Popova et al., 2011). People with FASD can have a myriad of secondary problems including an increased likelihood that they will come into contact with the law (Fast & Conry, 2004). Streissguth et al. (2004) find that 60% of adolescents and adults with a FASD diagnosis in the US had engagement with the justice system. Those with FASD have difficulty with language and communication (Kippin et al., 2018), understanding and linking consequences to actions, they have memory problems, difficulty with attention and judgement, and are prone to impulsivity and suggestibility (McLachlan et al., 2014).

In Australia, a House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs (2011) report described receiving 'compelling evidence on the issue of Fetal Alcohol Spectrum Disorder and [its] links with offending'. The ALSWA (2013) has also expressed concern that youth with unrecognised FASD are coming before the law in Australia. Despite representing 3% of the population, 27% of prisoners in Australia are Aboriginal or Torres Strait Islander (hereafter respectfully referred to as Aboriginal) (Australian Bureau of Statistics, 2017a) and almost half of all youth in custody are Aboriginal (Australian Bureau of Statistics, 2017b). In WA, Aboriginal youth are 54 times more likely to be incarcerated as non-Aboriginal youth (Australian Institute of Health and Welfare, 2016), and represent 75% of the youth detention population (OICS, 2015). There is a lack of understanding and knowledge of FASD and its implications in youth detention in WA in both the custodial (Passmore et al., 2018) and non-custodial workforce (Hamilton, Reibel et al., 2019).

In response to these concerns, a first-of-its-kind multi-strand research study was undertaken to establish the prevalence of FASD among youth in detention in WA (Bower et al., 2018; Passmore et al., 2016; Passmore et al., 2018). The prevalence study found that 36% of participants had FASD. Additionally, 89% of participants had at least one domain of severe neurodevelopmental impairment, and 21% were impaired in cognition (Bower et al., 2018). It is important to note that, due to the age of the participants, ascertaining maternal alcohol consumption was challenging (Freeman et al., 2019), and as such, the FASD prevalence rate is likely to be underestimated (Bower et al., 2018).

Concurrently with the FASD prevalence study, a qualitative study was undertaken. Participants included the young people who had participated in FASD assessments, non-custodial staff who provide rehabilitative services to them while in detention, and the young people's caregivers, family members and support networks. A core aim of the qualitative study was to determine whether the benefits of young people's participation in the assessment process outweighed potential harms that may have occurred in the course of the prevalence study. This determination would be made based on the cumulative evidence that young people provided during yarning, how they expressed their experiences of participation and what the assessment outcomes meant to them. This article aims to provide insight into the experiences of undergoing assessments for FASD and seeks evidence of how the assessment process might produce possible harm or benefit for those who undertook the testing.

3.5 Methods

3.5.1 Study Setting

Banksia Hill Detention Centre ('Banksia'), the only youth detention facility in WA, houses male and female young offenders aged 10–18 (DOJ, 2018). At the time of the study, Banksia housed approximately 155 youth, and 75% of the population was Aboriginal (OICS, 2015). Of these youth, 95% were male and more than half were aged between 16 and 17 years. Over half (57%) were urban youth and 43% were from regional and remote areas of WA (OICS, 2015).

All youth who had been sentenced to a minimum of two weeks in detention and were aged between 10 and 17 years, 11 months were eligible to participate. Participants were recruited using a face-to-face approach by a research officer based at Banksia, who identified eligible young people from the centre census each week.

3.5.2 Assessments

Clinicians in the research team undertook comprehensive assessments with participating sentenced youth (Kippin et al., 2018; Passmore et al., 2016). Assessments began with a research officer collecting bio-social information from the young person about their life history, schooling, and general health and wellbeing. The participants then undertook clinical assessments: 1) a comprehensive health and medical assessment; 2) a neuropsychology assessment; 3) a speech and language assessment; and 4) a motor skills assessment.

On completion of clinical assessments of the assessment results, a multidisciplinary team of clinicians undertook a comprehensive review of the findings and, if relevant, formed a diagnosis for the participants. An Assessment Results and Recommendations Report was compiled of comprehensive assessment results, including the young person’s strengths and difficulties, and proposed individualised strategies to assist in their future care.

Researchers met with the young person and their parent or guardian to feedback the assessment results. Where relevant, interpreter services were used when English was an additional language. Additional information for follow up services in Banksia for young people, and community services for supporting those who care for the young people to understand, translate or cope with the content of the reports was provided.

3.5.3 Informed Consent

Written assent from the young person, and written consent from their parent or guardian to participate in the prevalence and qualitative studies was undertaken by a research officer. Because of the vulnerability of this population, a child-centred approach to seeking assent was followed (Dell Clark, 2010). The research officer explained the purpose of the study using simple language and pictorial information sheets and assent forms allowing time for the participant to review and ask questions (Bower et al., 2018).

Upon assent, written consent was then sought from their identified parent or guardian. Written assent and consent recognised the capacity of young participants to be involved in informed decision making about research participation, while at the same time respecting the responsibility of their parents as their guardians to provide informed consent for participation (Lambert & Glacken, 2011).

3.5.4 Qualitative Study Participants

The qualitative study began at Banksia 12 months after the prevalence study had commenced. As a result, some earlier prevalence study participants did not have an opportunity to participate as they had been released prior to the qualitative study commencing. Sixty-one participants had been released and seven returned to Banksia. Three of these participants received feedback during this time, following which they undertook a yarning interview. A purposive sampling method was used to identify qualitative study participants from the 99 young people who completed assessments in the prevalence study (Bower et al., 2018). Of these 99 participants, 38 agreed to participate in a yarning interview (see Table 3.1). Most participants (27/38) self-identified as Aboriginal and the remaining 11 non-Aboriginal Australian, three of whom were born overseas. To protect the identity of participants, two descriptors are used in this article: Aboriginal and non-Aboriginal Australian.

At the time of the yarning interviews, the researcher had no knowledge of participants' diagnostic outcomes although was familiar with background information about the participants' circumstances. Subsequent analysis showed that of the qualitative participants, 24% had FASD. Of these participants, 90% had an additional diagnosis (mental health and conduct disorders), which was identified by their parent or guardian or derived from available health, justice or child protection records. Of the participants diagnosed with neurodevelopmental impairments, 26% of participants had one or more additional diagnoses. The remaining 42% of participants did not receive a FASD or neurodevelopmental impairment diagnosis.

3.5.5 Qualitative Study Data Collection

Data were collected primarily using social yarning, progressing to research-topic yarning. The researcher and participant first exchanged information about family, where they lived, their education experiences, and their hopes for the future. The research was undertaken by an Aboriginal woman from Eastern Australia with a background in social work. Yarning therefore involved sharing information about Aboriginal heritage and country, a cultural protocol essential to honest and identifiable engagement between Aboriginal people, and highly relevant to the young people in this study. When opportunity arose, the researcher moved from social yarning to the research-topic yarn. This transition into research-topic yarning occurred at different times, depending on how engaged the young person was in their own story-telling. The research-topic yarning explored assessment experiences, what the participants liked or were challenged by, and discussed specific assessment information.

Table 3.1

Participant Characteristics

		Prevalence study participants (*n*=99) Number (%)	Qualitative study participants (*n*=38) Number (%)
Ethnicity[(a)]	Aboriginal Australian	73 (74)	27 (71)
	Non-Aboriginal Australian	16 (26)	11 (29)
Age	13 years	4 (4)	2 (5)
	14 years	16 (16)	6 (16)
	15 years	23 (23)	11 (29)
	16 years	23 (23)	11 (29)
	17 years	33 (33)	8 (21)
Gender	Male	92 (93)	35 (92)
	Female	7 (7)	3 (8)
Residential Area	Urban	51 (51)	6 (15)
	Regional/Remote	49 (49)	32 (85)
Consenting Adult	Parent	62 (63)	10 (26)
	Guardian	24 (24)	15 (40)
	DOC[(b)]	13 (13)	13 (34)

(a) Includes young people of New Zealand, Asian and African ethnicity

(b) State guardianship: DOC

All but two interviews took place in an outdoors area at Banksia and all yarns were in sight, but not in hearing of custodial officers. Yarns took place in the residential units (n=3 male units, n=3 female units). Two yarns were undertaken with young people attending but not participating in sporting activities and the remainder (n=30) took place during Banksia's school and vocational activities and were undertaken in the education quadrangle. The yarns lasted between 10 minutes and 30 minutes.

Most yarns were undertaken with the researcher and participant seated side by side with a respectful distance between and an intent to maintain a natural and non-threatening engagement. At the same time, the proximity allowed the researcher to observe the participant’s body language, demeanours and other non-verbal cues.

Every effort was made to undertake research-topic yarning as close to the assessments as possible. The yarns typically took place within one week following completion of each young person’s assessment but ranges from the same day as an assessment up to 16 days. Not all the young people in the qualitative study had completed all the clinical assessments. However, all had undertaken, at a minimum, the biosocial interview with a research officer and had completed one clinical assessment. At the time of yarning, only seven participants had received feedback about their assessments. As such, the majority of participants were only in a position to yarn about their assessment experiences.

To minimise potential harm to participants, a voice-recording device was not used during yarning. Brief hand-written notes were taken during the interview, with salient points recorded in writing (verbatim) and double checked with participants for accuracy at the time of the interview. Immediately following the yarn, the researcher comprehensively documented details of the interview, including multiple reflective fieldnotes.

3.5.6 Ethics Approval

Ethics approval was granted by the Western Australian Aboriginal Health Ethics Committee (approval number 582) and University of Western Australia Human Research Ethics Committee (approval number RA/4/1/7116). Research approvals were also gained from the (former) Department of Corrective Services (project ID 335) and the (former) Department for Child Protection and Family Support (approval number 2015/8981).

3.5.7 Data Analysis

These data were analysed using thematic analysis (Attride-Stirling, 2001). The research-topic yarning data were entered into NVivo 11 Pro (2016) by the lead researcher, and multiple reviews and coding were conducted. Study team members as well as clinicians undertaking the assessments regularly met and discussed emerging themes from these data. Two researchers, one senior qualitative researcher independent from the study, separately reviewed these data and identified, compared and finalised key themes.

3.6 Findings

The findings presented here focus on observations identified in the young people's yarning data related to the benefits and challenges of yarning as a data collection method. This analytical perspective focused on participants' experiences with the clinical assessments, what the process meant to them. The analysis is presented under descriptive headings that seek to untangle the nuances of yarning as a research data collection method and demonstrate the fluidity of the approach particular to each individual circumstance. Beginning with a description of how yarning was conducted culturally with Aboriginal participants, and in a 'two-way' conversation with non-Aboriginal participants, we then explore the challenges and strategies used when yarning with participants with a neurodevelopmental disability. The exchange between social yarning and research-topic yarning as an interconnected entity, and the necessity for researcher flexibility is explored. Finally, the prior knowledge of participant disability and social circumstances as a prerequisite knowledge for researchers are then discussed.

3.6.1 Yarning and Language Adaptation

Yarning provided an opportunity for sharing information between the researcher and the participants. An Aboriginal participant who identified English as his first language, and who was diagnosed in the study with FASD, provides a good example. This participant remembered his assessment experience, and said 'the assessments were all good, though there were some silly words'. In yarning about the 'silly words' the researcher explained these to the participant in a way that Aboriginal people commonly communicate. For example, FASD was yarned about between the participant and the researcher as 'that thing in your head' or feeling confused or not understanding became 'when your head feeling silly'. When describing a personal strength identified in the assessment, the researcher described it as ‘solid’ or a ‘deadly thing’, terms that Aboriginal people use to describe something as very good. Towards the end of the yarn, the researcher asked the participant if he understood better the ‘silly words’, and his response was ‘yes, now you said it blackfulla way’.

It was not only Aboriginal young people who required changes in descriptive language during yarning. For one non-Aboriginal participant who did not understand what confusion was, the researcher said, ‘when your head is feeling all mixed up’.

3.6.2 Silences

Using yarning did not necessarily mean participants were able to communicate their thoughts and feelings about the assessments or their experience of these. One Aboriginal participant diagnosed with neurodevelopmental impairment in the study was noted by the researcher as ‘difficult to engage’. The field notes went on to describe:

> a difficult interview. [The participant] continually stood up and sat down during the yarn. He was very hyper-vigilant, continually looking over his shoulder (we had our backs to the wall of a main classroom), and almost startled at every noise. He was fidgety and his legs never stopped … Although he smiled a lot and seemed happy he actually said very little.

Another non-Aboriginal participant was noted by the researcher as ‘not really wanting to [yarn] even though he said he did’. More than once this young person, due to a lack of responses was asked if he would like to return to the class he had been in before the yarn. Even though he said very little, he declined to return to the class. This raises interesting questions about his agreement to participate in the study and whether participation in yarning was a way to escape the daily routine of detention life.

One non-Aboriginal participant with no diagnosis from the study, and no previously noted diagnosis, had completed assessments over three weeks, and the yarning interview took place three days after his final assessment. Although this participant had on the surface a much greater ability of social connection and capacity to comment on and remember his assessment process than some of his peers, yarning was nonetheless difficult for him. For example, he said ‘it is hard to remember specifics about the assessments’, while the field notes recorded he was ‘happy and talked openly … maintained eye contact and was smiling most of the time. He wasn’t fidgety and was able to focus on our conversation’. As such, it was interesting that this participant had no view of his participation in the assessments. Possibly the experience was just not worthy of his attention in the context of incarceration where so much else was going on, and which was possibly more relevant to his wellbeing.

3.6.3 Walking and Yarning: Visual Cues to Promote Yarning

An Aboriginal participant, diagnosed with many impairments including in his communication, was happy to have a yarn about assessments and feedback when invited. When the researcher asked the participant where he would like to sit for the yarn he indicated a brick wall in the education block. He politely invited the researcher to sit, and then proceeded to stand right in front of the researcher, less than a metre away. Although not intentionally threatening, the participant was a tall and solid young person and the researcher was not comfortable. The researcher repeated a request to him to take a seat on the wall; however, he continued to just look at the researcher, smiling. In response, the researcher stood and suggested ‘we walk and yarn’. The flexibility of yarning, which could arguably have been more difficult using traditional qualitative methods, provided an opportunity for this participant to share what he could about his experience in a way that affected neither the researcher nor the participant but gave some choice of the environment in which the yarn took place. In this case, yarning flexibility provided a way to manage this young person’s poor social skills and inability to understand the concept of ‘personal space’.

3.6.4 Using Additional Tools to Facilitate Yarning

It is apparent that in order to effectively contribute their experiences in yarning, many participants needed additional assistance. This section explores the use of additional tools to assist participants to tell their stories.

One of the benefits of yarning over other qualitative research methods, especially in this study, is that it directs the researcher towards considerations such as the appropriate use of language, visual illustrations, and different ways to conduct conversations according to individual participant needs. Therefore, its emphasis is on the researcher's responsibility to ensure that a safe space is created in which to engage with participants.

During research-topic yarning, a non-Aboriginal participant diagnosed with ND and an Intellectual Disability (ID) said 'assessments were all good, nothing special'. In words alone, the research yarn revealed very little. However, in the yarn it became apparent that this participant struggled to understand his diagnosis of ID. The young person was eligible for disability services support but was worried about meeting with personnel from the service. The researcher visually demonstrated what he could not understand. This included using a flowchart created with Post-It notes and drawing a number of pictures to assist the participant's understanding, including visuals on different parts of the brain affected. Working through this process in the context of the yarn had immediate benefits for the young person. It also suggests that such approaches may be valuable in communicating about the research and assessment processes. It is important to note that although fidget tools were mostly useful additions to yarning, they did not help this participant. During the first yarning session, he was given a stress ball to help him focus, but its use was noted by the researcher to provide 'not too much effect'.

Another non-Aboriginal participant had difficulty remembering his strengths and challenges provided in his report feedback. In response, his strengths were written on Post-It notes for him to put in his room. The researcher also showed him a blank copy of one of the pictorial assessment protocols, to which he responded, 'oh yes, I remember'. While browsing through the protocol, the participant went on to say, 'I don't remember anything particularly bad about them', but then shared his feelings about the speech pathology component, saying he 'didn't like the mouth stuff … moving my mouth and tongue around. It felt funny'. Using these tools in the context of the yarn, he was able to reflect on and benefit from his participation in the assessment experience and enhance his understanding of his assessment results.

One non-Aboriginal participant with neurodevelopmental impairment, ADHD and Post-Traumatic Stress Disorder (PTSD) was very conversant during the research yarn; however, his complex problems resulted in displays of some inappropriate behaviours during the yarning. Rather than abandon the yarn, the researcher instead provided fidget tools, such as a stress ball and picture cards, to minimise the potential for his actions, and to assist the young person to maintain his personal space without imposing this on him.

Like conventional qualitative methods, tools assisted the participants to understand and communicate. However, unlike the more linear fashion associated with conventional interviewing, yarning allowed the flexibility to weave between the social and the research-topic.

3.6.5 Transitioning from the Social to the Research Yarn

Social yarning was also an important way to get through to some of the participants whose problems with things like substance use dominated other thoughts. A participant with confirmed ADHD, PTSD and Conduct Disorder was one example. The young person, who had lived in foster care with ‘too many homes to count’, was noted in the yarning fieldnotes as being ‘highly focused on drug use’, with the yarn terminated as the researcher ‘was unable to divert his attention from the topic of drug use’. While, in this case, there was limited data collected on the research topic, the process of yarning was perceived as of benefit to this young person, highlighting that social yarning in particular is about more than ‘data collection’. This participant was noted in this yarn as being ‘so so sad’. During the yarn, the participant said to the researcher ‘you don’t know nuffin miss’, indicating a barrier from the perspective of the young person to sharing their experience. In the context of the yarn, the researcher shared with the young person some similarities in their teenage lives in the hope that the young person could see a future outside of detention and drug use. The participant engaged with this aspect of the yarn, the researcher recording this response from the participant: ‘[name] looked me fair and square in the eye and said “really”?’ This suggests that yarning encouraged a conversational exchange of information through building trust and arousing interest. Further, it indicates that yarning as method, while not completely successful in terms of moving to research-topic yarning, was able to open a space for communication between the research participant and the researcher that would have been even more difficult using conventional qualitative interviewing methods.

Three yarns were ceased during social yarning due to inappropriate conversations about the young people's crimes or drug use and an inability by the researcher to shift the young people to yarning about the assessments. In fieldwork notes, the researcher recorded reasons for ceasing the yarn: 'high levels drug use ceased yarn due to an inability to move the young person away from the topic'; 'no engagement or interest in, and possibly no memory of assessments'. Later analysis of the diagnostic results revealed two of these participants had been diagnosed in the prevalence study, one with FASD and one with neurodevelopmental impairment. The other participant had confirmed diagnosis of ADHD, PTSD and Conduct Disorder. All three youths were Aboriginal.

3.6.6 Yarning Flexibility and Fluidity

For the most part, the focus of the observations have been on research-topic yarning. However, in most cases, social and research-topic yarning were intertwined, at times extending to therapeutic yarning. We have presented these findings to directly illustrate this intertwining, as well as noting the challenges in transitioning from the social into the research yarn, and occasionally, therapeutic contexts.

Yarning was a method that had the required flexibility to allow space for the participants to talk about what was important to them, even if it appeared off topic in the first instance. An Aboriginal participant with no diagnosis advised that they had undertaken the assessments to understand more about what a family member who had been assessed and diagnosed with FASD had experienced. The participant, when asked about their thoughts on the assessments said, 'I have much greater insight into his problems and what he went through'. In this case, moving between social and research-topic yarning allowed increased knowledge for participants about themselves, as well as opening a space to talk about the assessment process.

These examples of difficulties with research-topic yarning should not be interpreted as failures of the method. The participants were still able to provide information about their difficulties and what they needed. Prior to the yarn being stopped, a participant with FASD said: ‘don’t really care about them [the assessments]’. He participated because it seemed ‘better than going to school’. A number of features of FASD and the reason for his difficulties were evident on later analysis of the transcript. First, managing his behaviour and impulsivity was difficult for this young person. Yarning about not liking the consequences, the researcher asked this young person ‘do you think about whether you should not do something so you don’t get into trouble?’ the participant said ‘[laughing] aaaah too late—I would have done it before I thought about whether I should’. While this information was presented within the social yarning component, it provided important information related to the research-topic yarning: that of difficulties with impulsivity, which is important to address for young offenders with FASD.

3.6.7 Researcher ‘Need to Knows’

Much of the feedback presented here emphasises the need for researchers to be armed with information regarding a young person’s neurodevelopmental and social challenges following assessments. One participant, an Aboriginal youth diagnosed in the study with ND, was positive about his experience: ‘it has helped me to understand more about myself’. He then explained he ‘struggled with the story part, I got confused trying to tell the story back, but everything else was ok’. His acknowledgement of his ‘struggle with the story part’ of the assessment suggests that he had some good awareness of his own challenges. It also suggests that, had the researcher known previously that this young person struggled with comprehending and relaying information because of impairments in language, communication and his executive functioning, this young person may have been ‘yarned’ with differently to provide him with a better opportunity to tell his story. This was a predicament in the yarning related to not always being aware of young people’s diagnoses, having limited knowledge of their personal circumstances or their assessment outcomes. Prior knowledge may assist with approaching the yarn in a more tailored way. At the same time, no prior knowledge reduces researcher bias. This therefore emphasises the need for research flexibility and using the fluid nature of yarning to create the best possible circumstances for the yarn to take place.

3.7 Discussion

The findings presented here have focused on the benefits and challenges of yarning as a data collection method, and suggest yarning provided a way to acquire knowledge about research experiences from vulnerable young participants while giving them some control over the interview process (Ogilvie & Lynch, 2001). The findings also suggest that, with or without neurodevelopmental disability, young people may not answer questions for a variety of reasons. They may not be listening, they may not understand, they may not know the answer, or they may not want to give an answer. The findings provide some insight into how youth in detention approach the issue of researchers wanting to know about their capacities and experiences.

The findings also suggest that yarning allows the flexibility to deal with poor listening and understanding, to work out the likelihood of youth not having an answer through not noticing or not remembering and identifying cases where youth may not want to share knowledge. Yarning assisted young people, who were confused or had difficulty understanding aspects of their impairments to better understand their assessments. Yarning also provided flexibility for participants who struggled because of poor social skills, or impairments in memory and attention. As with conventional interviewing methods (Bryan et al., 2019; Meyer et al., 2018; Teachman & Gibson, 2013), this flexibility offered accommodation of specific needs such as walking, descriptive explanations, assistance with focus and for the structure or flow of the interview. The findings suggest that yarning gives scope to be responsive to the many different reasons for not receiving an answer and working out most likely explanations. By employing changes in language such as plain language or ‘blackfulla way’ explanations and drawing or providing visual imagery, yarning assisted participants to understand more about their strengths and challenges. The flexibility of yarning in combination with a variety of tools provided examples for participants to be able to ask for or get what they need in the future. Although the use of fidget tools and other devices can be used to assist young people with sensory challenges with their education (Worthen, 2010), there is no known literature on the use of fidget tools and yarning with youth with neurodevelopmental disability. The way fidget and visual tools were used both to maintain engagement in yarning, and as an educational resource that had benefits both during the research and for the participant's future needs, provides a significant contribution to future qualitative health research methods for young people undergoing clinical assessments in the future.

Although there were many benefits, the yarning method was not a silver bullet. Bessarab and Ng'andu's (2010) description of 'social yarning' as a process that can be used to build participant rapport ahead of 'research-topic yarning' would seem a reasonably straightforward process. In this research, however, there was a necessary back-and-forth movement between social and research-topic yarning in order to maintain rapport, to maintain engagement and to gain information relevant to research-topic yarning. Talking with detained youth, many of whom had a range of complex problems, with or without neurodevelopmental disabilities, is tough. It is therefore no surprise that there were participants who could not provide the information we were seeking about the assessments in the research-topic yarning. Importantly, there is no evidence to suggest that it was more difficult for any particular group, Aboriginal or non-Aboriginal, or those with or without a diagnosis. Moreover, yarning as a method for collecting data with non-Aboriginal participants had resonance with other more conventional qualitative interviewing techniques for children with cognitive disabilities (Sigstad & Garrells, 2017).

Continually yarning and providing feedback following assessments appears to be generally a useful process regardless of neurodevelopmental capability. Further, in order for the researcher to be flexible and responsive to participant needs, diagrams, drawings and printed information can be used to enhance the sharing of knowledge and ensure mutual understanding in accordance with different communication, language, life experiences and preferred learning styles.

This research was undertaken to invite the participants to express their thoughts about their assessment experiences. Difficulties that can be experienced by those with FASD such as an impaired ability to understand and communicate, memory problems and difficulty with attention and judgement (McLachlan et al., 2014) were all found to be present among the participants. It is imperative to consider the views and experiences of participants to minimise the potential for harm, particularly for Aboriginal youth (Bessarab & Ng'andu, 2010; Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Tuhiwai Smith, 1999).

Documenting neurodevelopmental disability through clinical assessments for justice-involved youth has the potential to identify and direct future assessments and interventions that could initiate a process of supported pathways for youth away from crime. Recognising and supporting individuals with FASD or neurodevelopmental impairment in the youth justice system facilitates understandings of these youth and their needs. Undiagnosed neurodevelopmental disabilities means that these youth are being dealt with by a justice system that is blind to their disability, and in so doing, perpetrates a 'disability in-justice'. Knowledge of how those assessed as having a neurodevelopmental disability such as FASD regard their experience with the process of assessment may open new pathways for understanding and assisting these youth in future.

3.8 Limitations

The study was limited by the nature of the sample—a select cohort of detained youth—and was determined by the availability and willingness of participants to be involved in yarning interviews. At times, there were limited opportunities to access the young people, due to factors associated with the operation of the detention centre. This impacted the time between the assessment and the interview, potentially impacting their recollections. It was also limited by being unable to link reactions to testing to different categories of neurodevelopmental impairments due to not have this data at the time of interviewing.

A decision was made by the researcher not to use recording devices with the participants in the detention centre. Discussing the use of a voice recorder with one young person who immediately associated the device with his police interview, the researcher decided it would be less harmful for the participants not to have this means of data recording associated with the yarning aspect of the research. As such yarning was dependent on note taking, with verbatim quotes written during the interviews and detailed reflective field notes prepared immediately following yarning. Additionally, the participants' neurodevelopmental disabilities meant the researcher needed to ask different questions or use different approaches. Both of these factors meant there was variability in the amount of data between participants at times, which resulted in one word or short answers.

The participants had difficult lives and histories and at times the researcher, although externally composed, was disturbed by the trauma experienced by the participants. In one or two cases, this influenced the direction yarning took, and influenced the questions the researcher both chose to ask and how they were asked. In these cases, this may have influenced participant responses in both the social yarning and in moving to research-topic yarning.

3.9 Conclusion

Using a yarning methodology to interview young people assessed for neurodevelopmental disability enables a partnership to develop between researcher and participants in which information can be shared between the two. Researchers can gain insight into how young people make sense of the process of clinical assessment and elements that need further refinement to meet their needs. Yarning with young people opens the possibility for building relationships between researchers and participants in such a way that researchers can give something back reciprocating the 'gift' of participation. This analysis has also revealed that researchers could benefit from being armed with information about a participant's neurodevelopmental strengths and impairments ahead of yarning. Having such insights suggest that the use of additional techniques such as fidget tools, walking while yarning, or through using visual aids such as diagrams or drawing, may provide benefits for participants. The research suggests that there is much value in evolving shared knowledges, which enable improvement in future assessment processes and provide participants with an opportunity to gain valuable information about themselves.

3.9.1 Author's Note

Any material published or made publicly available by the authors cannot be considered as either endorsed by the DOJ or an expression of the policies or the views of the Department. Any errors of omission or commission are the responsibility of the researchers.

3.9.2 Acknowledgment

The authors thank the young people and staff at Banksia Hill Detention Centre. SLH thanks Professor Dawn Bessarab from the University of Western Australia for expert advice on ‘yarning’. SLH is grateful for the valuable contribution from the Elder Co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project, Telethon Kids Institute for sharing their knowledge and wisdom and contribution to the interpretation of the data from this research.

3.9.3 Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

3.9.4 Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This research is funded by the National Health and Medical Research Council (grant number APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341). SLH is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award, the FASD Research Australia Centre of Research Excellence and the Centre of Research Excellence, Indigenous Health and Alcohol, University of Sydney. HMP is supported by an Australian Government Research Training Program Scholarship and the Stan and Jean Perron Award for Postgraduate Excellence.

3.9.5 ORCID iD

Sharynne Hamilton: https://orcid.org/0000-0002-3057-8992

3.9.6 Supplemental Material

Supplemental material for this article is available online at: journals.sagepub.com/home/qhr. https://doi.org/10.1177/1049732319882910

3.9.7 Next Chapter Outline

To supplement the above journal article about the benefits and challenges of yarning with young people, the views of their caregivers will now be presented in an article that reports on yarning interviews. A full description of the data collection and interpretation methods used are detailed in the article. The article has undergone a small amount of reformatting to ensure thesis consistency. The article's references can be found in the comprehensive reference list and the published article can be found in Appendix 2. The citation for the publication is:

Hamilton, S., Maslen, S., Conigrave, K., Mutch, R., Watkins, R., O'Donnell, M., Freeman, J., & Bower, C. (2020). 'That thing in his head': Aboriginal and non-Aboriginal caregiver responses to Fetal Alcohol Spectrum Disorder diagnosis. *Sociology of Health and Illness*. Early View. doi: 10.1111/1467-9566.13146

Chapter 4: ‘That thing in his head’: Aboriginal and non-Aboriginal Australia caregiver responses to neurodevelopmental disability diagnosis

4.1 Abstract

Little is known about the significance of cultural differences to how caregivers receive a diagnosis of neurodevelopmental disability. As part of a FASD prevalence study among sentenced, detained youth, our qualitative study explored the experiences of diagnostic assessment among detained young people and their caregivers. We present findings from the perspectives of caregivers. In conversation with the sociology of diagnosis literature, we present vignettes of three Aboriginal and two non-Aboriginal caregivers’ experiences of the diagnostic assessment process. We found that Aboriginal caregivers conceptualised their children’s diagnosis and ongoing management in the context of their family networks and community. In contrast, non-Aboriginal caregivers focused on how the diagnosis would affect their child and interactions with various institutions including healthcare systems and schools. Caregivers’ engagement with diagnostic reports and resources also followed cultural lines. Reflections on intergenerational drinking were voiced by Aboriginal caregivers, who expressed shame at receiving diagnosis. These findings advance our appreciation of cultural difference in receiving a diagnosis, the examination of which is in its nascent stages. We also suggest ways to mitigate harm from a stigmatising diagnosis and soften the well-established effects of medical dominance over the process of defining a person’s capacity and status.

4.2 Introduction

Diagnosis serves a critical function in organising illness, identifying and providing pathways to treatments, and predicting likely outcomes. Fully appreciating diagnosis requires an appreciation of how diagnoses sit within the wider context of social forces, interactions, and relationships (Blaxter, 2004; Blum, 2015; Jutel, 2009, 2019). As sociological contributions have demonstrated, much of the practice of diagnosis is often taken for granted, with reported professional labels glossing over the ways in which diagnostic work is embodied (Gardner & Williams, 2015; Maslen, 2016), and a product of communication between the doctor and patient (Turowetz & Maynard, 2019) with the potential for clinical uncertainty (Rafalovich, 2005; Rasmussen, 2017). The doing of diagnostic work is also embedded in relations of medical authority and power (Nettleton & Jutel, 2011), giving diagnosticians the ability to define patients' behaviour and control access to health resources (De Swaan, 1989; Whelan, 2007). The extensive literature on medical dominance and patient expertise highlights how patients and caregivers are not passive recipients of a diagnosis. Instead, people receive and understand a diagnosis increasingly within social, cultural, and environmental circumstances, and their lived experience (Blaxter, 2004; Blum, 2015). The diagnostic process can also be a site of resistance (Gill et al., 2010; Zarhin, 2015; Maslen & Lupton, 2019a, 2019b).

The social aspects of diagnosis have long been of interest to sociologists, though relatively little attention has been paid to the ways in which different social groups engage with diagnostic processes. Gendered aspects of diagnosis have received some attention, particularly via analysis of gender-specific conditions. Studies of women's engagements with endometriosis diagnoses have emphasised contestation of medical expertise (Whelan, 2007; Young et al., 2019). The significance of masculinities to men's discourses about mental health diagnoses have also been subject to inquiry (Johnson et al., 2012), demonstrating that men are more reluctant than women to seek a diagnosis for a mental health condition (Zimmerman et al., 2015). Understanding diagnosis in relation to aging has also been examined, particularly in cases such as Alzheimer's and dementia, revealing the importance of listening to both caregivers and patients about their experiences of receiving a diagnosis regardless of cognitive condition (Brossard & Carpentier, 2012; Schrag et al., 2018).

Many of these studies involve examination of social status and stigma of diagnosis, including the potential harm from diagnostic labels (Brown, 2008; Link & Phelan, 2001). In a study of middle-class fathers' experiences of ADHD for their child, fathers described feeling pressure to seek a medical diagnosis for what they felt was a social problem in order to receive support (Olsvold et al., 2019). Middle class fathers were more likely than fathers from a low socioeconomic group to describe shame and guilt about having a child who misbehaved or was uncontrollable (Olsvold et al., 2019). Studies of mothers' parenting children with disabilities have also captured the stigma associated with the difficult work they undertake navigating systems of care and advocating their children's needs (Blum, 2015; Landsman, 2010; Ryan & Runswick Cole, 2008). Cultural aspects of diagnosis have also been highlighted, with scholars demonstrating that racial and ethnic disparities can prevent accessing diagnostic services, prompting calls for culturally relevant community-based diagnostic services and interventions (Magana et al., 2013).

Studies of how different cultural groups respond to diagnoses are in their nascent stages. How health and illness is understood in the context of global Indigenous[1] cultures, particularly where these cultures have endured centuries of colonial oppression, has been the subject of inquiry in a range of scholarly areas, including anthropology, medicine, and post-colonial studies (Wandji, 2019). Comprised mostly of deficit focused, Western-centred assumptions of Indigenous health and illness, these works have been extensively criticised for their lack of regard to Indigenous voices and knowledge systems (Sherwood, 2013). Despite the well-established benefits of privileging Indigenous voices in health and illness research (Bessarab & Ng'andu, 2010; Sherwood, 2013), examination of the potential for shame and stigma to affect access to diagnostic services, or how a diagnosis is received, are largely absent in the context of Indigenous populations (Ayunerak et al., 2014).

This article begins to address this research gap through a comparative analysis of how caregivers from Aboriginal and non-Aboriginal Australian backgrounds respond to receiving a diagnosis of FASD or neurodevelopmental impairments for their child. These caregivers participated in a first-of-its-kind Australian study that was undertaken to establish the prevalence of FASD among youth sentenced to detention in Banksia Hill Detention Centre between 2015 and

2017 (Bower et al., 2018). FASD is a lifelong, preventable brain injury caused by alcohol exposure during pregnancy and those affected can have a myriad of secondary problems including trouble with the law (Fast & Conry, 2004). Individuals with neurodevelopmental impairments (regardless of prenatal alcohol consumption) can have memory and attention problems, difficulty with language and communication, they are suggestible and prone to impulsivity (McLachlan et al., 2014). Of the 99 youth who underwent full assessments in the prevalence study, 74% were Aboriginal and half were from remote or regional WA (Bower et al., 2018). Thirty-six per cent of participants were diagnosed with FASD and 89% were diagnosed with at least one severe neurodevelopmental impairment (Bower et al., 2018). In addition to providing important information about the prevalence of FASD, this study has opened a unique opportunity to explore cultural needs and understandings about receiving a diagnosis and diagnostic resources.

Variation between Indigenous and non-Indigenous peoples is signalled by the broader literature on Indigenous conceptualisations of health. The worldviews of Australian Aboriginal people are diverse and vary across Australian states. In WA, where this study was conducted, scholars have investigated the cultural intersections and different worldviews that affect the health of Aboriginal people (Vicary & Westerman, 2004). Acknowledging the impact of colonisation and the connection between history and the current circumstances of Aboriginal families and communities, Vicary and Westerman (2004) argue that it is critical to appreciate Aboriginal people’s engagement with Western models of diagnosis and treatment in the context of the multiplicity of factors that impact wellness, including employment, overcrowding and inadequate housing, high rates of family violence, crime, AOD use and poverty. Aspects of Aboriginal culture may also be significant to engagements with the diagnostic process. Indigenous cultures share knowledge through the oral transmission of stories and have visual-spatial strengths that assist understanding and learning (Hickey & Wilson, 2017; Hughes et al., 2004; Pewewardy, 2002; Thomas et al., 2019).

We conducted interviews with 17 caregivers of diagnosed youth. The qualitative study is the first of its kind internationally to examine multiple participant experiences, understandings, and perceived implications of assessments and diagnoses for justice-involved youth in detention. We present five vignettes to provide a rich account of the lived reality and experience of receiving a diagnosis. We demonstrate cultural patterning in how caregivers conceptualise their children's diagnosis and ongoing management, with variation in whether diagnosis and care is considered principally in relation to individuals or their communities, and whether Western institutions (legal, healthcare, schools) are seen as sites of support. Shame is also significant in how Aboriginal caregivers receive a diagnosis of FASD in the context of intergenerational drinking.

4.3 Background

There is a paucity of literature exploring the way that caregivers receive a diagnosis for neurodevelopmental disabilities such as FASD. North American studies have found caregivers typically reported high satisfaction with FASD diagnostic processes and outcomes (Astley, 2014). Other studies have captured how receiving a diagnosis can have dual consequences, with birth mothers experiencing grief, guilt and regret, and simultaneously feeling validated and relieved to have answers to their child's difficulties (Sanders & Buck, 2010). Caregivers have also expressed concern about the uncertainty of their child's future in the absence of community support as they age (Murphy et al., 2007).

Two Australian studies (Chamberlain et al., 2017; Doak et al., 2019) have explored FASD diagnostic experiences for caregivers, though neither discussed nor differentiated between Aboriginal and non-Aboriginal Australian caregivers. The studies found the experience of diagnosis was validating (Chamberlain et al., 2017) and a positive for caregivers, and that caregivers gained new knowledge and insight about their children. Caregivers saw benefit in diagnosis from raised awareness of children's problems being attributed to neurodevelopmental impairments, and from recommendations and supports provided during the diagnostic process (Doak et al., 2019). However, a lack of access to long-term services tailored to children's needs left caregivers feeling alone and unsupported (Chamberlain et al., 2017). Factors such as age, socioeconomic status, and geographical proximity to services obstructed benefits from diagnosis (Doak et al., 2019).

The broader literature on caregivers posits that social and biomedical explanations of diagnosis are interwoven narratives, and that network and resource mobilisation can be preferred to medical intervention (Blaxter, 2004; Malacrida, 2004; Riessman, 2008; Ryan & Runswick Cole, 2008). Interwoven narratives can produce collective understandings and connections which can assist caregivers (Blum, 2015; Garro & Yarris, 2009; Malacrida, 2001). With increasing use of digital and internet sources, concerns have been raised by patients and caregivers about privacy and a lack of access to credible information (Petersen et al., 2019).

Caregivers' experiences of shame in response to diagnosis has also been raised in relation to mental health conditions and conduct disorders (Olsvold et al., 2019), and autism and FASD (Corrigan et al., 2017). In each of these cases, shame relates to caregivers' perceptions or awareness of having caused their children's problems and being subjected to messages of parental incompetence. Caregivers can feel shame because they anticipate negative labelling and stigma from a diagnosis, with blame and shame often occurring simultaneously (Francis, 2012). Avoidance of a diagnosis in some cultural groups has also been identified, as diagnosis of disability is shameful (Heneker et al., 2017; Liu, 2005).

This existing scholarship on the sociology of diagnosis and caregiver experience leads us towards a series of research questions:

1. How might understanding of, and engagement with, a diagnosis for FASD or for neurodevelopmental impairments be different for Aboriginal and non-Aboriginal people?
2. In what ways are engagements with diagnostic resources affected by cultural background?
3. Are there observable patterns in how caregivers conceptualise the needs of their children?
4. How do feelings of shame manifest in response to the diagnostic process?

4.4 Methods

4.4.1 Participants

Purposive sampling was used to recruit caregivers. Nineteen caregivers who provided consent for their young person's participation in a FASD prevalence study were approached for an informal 'yarn' to explore their understandings and experiences of the research. Fifteen yarns with 17 participants were conducted, including two dads, two couples, six mothers, and five grandmothers. There were 12 Aboriginal and five non-Aboriginal Australian participants. Six participants were from urban WA, five were from remote areas, and four from regional areas. Participants had previously met with researchers from the multidisciplinary clinical team and, where relevant, had been given their child's diagnosis. All participants were provided with a Multidisciplinary Diagnostic Report (hereafter 'diagnostic report') prepared by the multidisciplinary clinical team. A researcher met with the participants to provide feedback and translation of the diagnostic report (Hamilton, Reibel et al., 2020).

The researchers were aware of the need to minimise the harm that caregivers may have experienced. Some of these interviews were attended by the qualitative researcher in company with the Research Officer because of the rapport that had already been built between them. In two interviews, both researchers were present for the entirety. The remainder were undertaken by the lead qualitative researcher. Remote and regional interviews were set up in community, with the assistance of youth justice personnel who worked with the families.

4.4.2 Data Collection

Data were collected using 'yarning' (Bessarab & Ng'andu, 2010). Having a 'yarn' is embedded in the language of Australian Aboriginal people and is an 'Indigenous cultural form of conversation' (Bessarab & Ng'andu, 2010, p. 37). Yarning creates relationships and governs responsibility and although yarning data can seem superfluous or irrelevant, it often reveals rich, insightful and valuable contexts (Bessarab & Ng'andu, 2010). The qualitative researcher was an Aboriginal woman, making yarning culturally safe and aligned with the cultural values of

Aboriginal people. It was also considered to be appropriate for non-Aboriginal participants in the study (for more details on the yarning method, see Hamilton, Reibel et al., 2020; Hamilton, Maslen et al., 2020). It is important to note that while two Aboriginal fathers participated in this research, there were cultural barriers to how much these participants could share with a female researcher, and so we focus on female caregivers in our analysis.

Six urban and five regional yarns were face-to-face. For remote participants, one interview took place in the detention centre and the remaining five in their community, four face-to-face and one via Skype. Location was chosen by the participants. On average, the yarns took half an hour. All participants were advised that the yarn was confidential and that neither they, nor their family members, would be identifiable. They were advised that they could stop the yarn at any time.

Prior to the yarn, participants were advised that the purpose of yarning was to get thoughts about receiving feedback about the results of their young person's diagnostic assessments and to explore their thoughts on the diagnostic reports. With verbal consent, interviews were voice recorded and transcribed verbatim. Immediately following the yarn, the researcher recorded reflective field notes.

4.4.3 Data Analysis

Data from all participants were analysed using thematic network analysis (Attride-Stirling, 2001), sensitised by an ontological approach that privileges what participants say they experience and how they make sense of these experiences (Creswell, 2012). From such a perspective, participant reality is subjective and diverse.

Two researchers initially reviewed the data and identified key themes, with preliminary analysis undertaken immediately following data collection. Data were entered into NVivo 11 Pro (2016) for coding and themes compared. Study team members regularly met and reviewed themes from the participant data. These reviews helped to ensure consistency in data interpretation through multiple perspectives and iterations. The primary researcher also conducted multiple analysis reviews to compare, confirm, and develop final data interpretations.

Vignettes were chosen to complement the narrative yarning approach taken to data collection. Constructing vignettes offered a comprehensive way to provide a rich account of the lived reality and experience of receiving a diagnosis. It also provided a culturally relevant and safe method (Blodgett et al., 2011) for presenting the unique stories of the participants in this research.

In preparing the vignettes, the data from all 17 participants were re-analysed through an interpretivist lens that acknowledges participant realities are socially constructed and changeable, and agreed within cultures, social setting and relationships (e.g., Denzin & Lincoln, 2003). From this process, five participants were selected based cultural background, depth of available data, children's diagnosis and transcripts reflecting diverse of views of the diagnostic process. This allowed for a rich amount of data that reflects the stories of all participants in the qualitative study. All names are pseudonyms. Small details, such as immaterial but potentially identifying elements of examples, and reference to specific personnel and institutions, demographics and contextual information have been changed to protect participant identities. The vignettes were reviewed by members of the research team to ensure no story was identifiable.

4.5 Vignettes

4.5.1 Phyllis and Peter

Phyllis is an Aboriginal grandmother who lives in a small community in very remote WA. The community is around 400 kilometres from the closest regional centre. Phyllis has many grandchildren, including 16-year-old grandson Peter, who was diagnosed with FASD in the prevalence study. At the time of the interview Peter had been released and was living with Phyllis.

When discussing whether Phyllis was surprised by the diagnosis she said, ‘No, not really. I went to the school a lot because the kids were always in trouble, but school never tried to teach him special ways. Just saw them as naughty. Just put on band aids at school’. For Phyllis, diagnosis provided a way to explain the behaviour and combat the stigma Peter experienced:

> He is not an asshole like plenty of people think. It is because of that thing in his brain [FASD] … I send Peter to tell the other one to come home. Peter has forgotten what he

> is doing by the time he finds his brother, so neither of them get home and then they both end up getting into trouble. I want her [daughter's] other kids assessed you know, because she drank heavily, and they are still quite young, and they are running amok already.

Justice personnel assisted Phyllis with understanding and translating the contents of the diagnostic report. Diagnosis was useful in that it helped get assistance for Peter: 'I gave the report for [social services personnel] and Peter, he's been able to get help for disability. It much easier than for him remembering to go for job thing'. Phyllis liked the visual strategies that were provided as part of the diagnostic report. Relaying a story of how she sends Peter to the shop, she explained:

> He never get that right. I make it clear ORANGE JUICE [participant emphasis], but he always come back with an orange. Next time I drew a picture of a bottle of juice to take with him and he brought back the one; it worked!

The diagnosis also helped Phyllis recognise FASD in another family member: 'I think my son has it [FASD]. He has been in and out of prisons … I drank a lot, but I didn't know you know'.

While there were a number of useful aspects about receiving the diagnosis, it also came with shame and concerns about supporting family members with FASD long term. Phyllis commonly has a dozen or so grandchildren in her care, including Peter's brothers. Particularly in remote Aboriginal communities, this central role of the extended family in care is normal and accepted. 'All the sisters are aunties, all the nans are mums—it blackfulla way', she said. However, she had concerns about how long she would be able to keep caring for her grandchildren given her age. Peter's mum was unable to significantly contribute to care because she continued to drink. Her continued drinking, and drinking in pregnancy, was a source of shame for Phyllis, and yet she recognised the intergenerational mirroring of negative behaviour [drinking in pregnancy]: 'I am so mad with her but then I did it to [drink alcohol during pregnancy] and she was the same'.

4.5.2 Katie and Kieran

Katie is a non-Aboriginal mother who lives in urban WA. Katie is a professional, working full-time and lives with her husband and children. Katie's 15-year-old son, Kieran, was diagnosed with neurodevelopmental impairments in the severe range in the prevalence study. At the time of the interview, Kieran was still incarcerated.

When asked about her thoughts on Kieran's diagnosis, Katie indicated that it confirmed what she already knew about his strengths and weaknesses. She linked the diagnosis to her observations of Kieran's difficulties with schooling:

> When we were told the diagnosis it made sense. About grade 2 it was obvious he had problems with reading and writing and was struggling with learning. We have been to the school so many times. By year 10 he stopped going and he had lots of detentions and suspensions from school. It is good that people are beginning to understand that it is not because he doesn't want to read and write, but because he actually cannot do it.

The diagnostic report, which she had read, while useful, did not provide new information:

> Well it [the diagnostic report] didn't really tell me anything new. It pretty well describes his strengths and challenges. And nothing in the report changes my view of him, because he is still my child. But the report is important because it provides knowledge of Kieran's challenges. The report is really very useful, it mostly helps to recognise and make people aware of his vulnerabilities.

Katie spoke of the usefulness of the diagnosis and diagnostic report in securing access to services: 'I think it was good for him to have the assessments so he can receive proper supports and understanding as to why he thinks way he does and does the things he does'.

This understanding of diagnosis extended to how Katie imagined the diagnosis may have changed Kieran's interactions and outcomes with the legal system:

> I wish he had had the assessments years ago … things might have been very different for him and he may well not be in [name of detention centre]. Kieran didn't understand what was happening when he got arrested. He got confused and didn't understand the seriousness of what was happening. He is essentially a 15-year-old boy with a 7- or 8-year-old mind. He is easily influenced and was just at the wrong time, at the wrong place and with the wrong people. This might have been different if they [police/courts] knew he had impairments in his brain.

The diagnostic report had been shared with a service provider and was also being used to plan for Kieran's release: 'We have drawn up schedules to make sure he does what he needs to do. It will be hard for him so things like Medicare and Disability Services will be supporting him too when he gets out'. When asked if she would share the diagnostic report with these services, Katie said she would 'share it with anyone who would listen'.

4.5.3 Jill and Jasper

Jill is a non-Aboriginal single mum with two children and lives in urban WA. Jill's 16-year-old son, Jasper, was diagnosed with neurodevelopmental impairments in the severe range in the prevalence study. At the time of the interview Jasper was still incarcerated. Like Katie, Jill viewed the diagnosis as a confirmation of her own observations about Jasper's challenges:

> Jasper always hated school. Even in primary school it was too hard for him. He was always on detention or being suspended from school. Why? Because he never got help. I tried and tried to get help, but none was forthcoming. He is a sweet kid who just couldn't stay out of trouble. Actually I don't think he just ever thinks that he might get into trouble. The fact that he can't focus, well this [diagnosis] kind of explains it.

As the diagnostic information was explored in more detail, Jill focused on the lack of support provided through the healthcare system in Jasper's early childhood years:

> Jasper's problems started with childhood anxiety, followed by sexual abuse which caused extreme anxiety and mental health problems for which there is a lack of services and little help, then and now apart from being prescribed drugs which never seemed to work and which he often refused to take no actual help was forthcoming … my pleas for help fell on deaf ears.

When discussing the diagnostic report and strategies and whether they were beneficial, Jill again came back to the amount of assistance she had tried to get:

> Maybe this [report] will help Jasper. We have tried and tried to get help for him. Maybe what you have given us can help him. There is lots of useful information in this report which can be used to help him.

Jill discussed what she thought was useful about the diagnostic report. She was not surprised by the information provided about Jasper’s strengths:

> The strategies are valuable. I am looking forward to trying the strategies when he gets out and work on his strengths. Using pictures and flowcharts makes sense for him. It doesn’t surprise me that he is good at these skills; it will be great to harness that in him.

4.5.4 Suzie and Samuel

Suzie is an Aboriginal mum of two children. She cares for her children full time and lives with her family in a remote town in WA. Suzie’s 16-year-old son was diagnosed with FASD in the study. At the time of the interview he had been released and was living with Suzie.

Suzie felt positive about Samuel’s participation in the assessments because it provided some insights into his behaviour that she was previously unaware of. She had wondered why Samuel had tended to play with much younger children. ‘That “this thing in his head” [FASD] explains this’, she said. However, Suzie had difficulties engaging with the diagnostic report: ‘It [the diagnostic report] was hard cause the ‘whitefulla speakin’, I understand I ask [justice personnel] to tell me. Having it said simple helped me’.

Suzie liked the strategies and ideas around using visual aids detailed in the diagnostic report to assist Samuel to remember things: ‘I stuck picture on the door that said ‘NO GROG’ [alcohol] … he stopped, well at least in the house’. There was a sense of pride and achievement as Suzie spoke of how local community leaders had praised the initiative: ‘They took photo to show other mob round ya know’.

Concern about diagnosis for Suzie was very much embedded in Samuel’s connection to culture and community:

> It doesn’t matter [Samuel’s diagnosis of FASD] it’s just important that he is connected to his mob and knows who he is and where he fits eh. When he out in community they look after him and guide him and he is happy. He never gets into trouble out there and loves to go hunting. Last time went hunting for kangaroo and he got one, cut it all up and then bought it back to the family for sharing. He was proud and I want that for him.

Suzie commented that Samuel was different to many other children in the community, but not due to FASD: ‘He isn’t like other Aboriginal kids. He doesn’t like sport and doesn’t play sport. This is the ‘weirdness’ he has, not that he can’t do school good’. Suzie then asked the researcher: ‘Can he go through lore [traditional customs related to emerging adulthood]?’ The researcher encouraged Suzie to discuss this with community Elders.

4.5.5 Sandra and Seb

Sandra is an Aboriginal mum of five children. Sandra cares for her children full time and lives with her family in a small town in regional WA. Sandra’s 17-year-old son, Seb, was diagnosed with FASD in the prevalence study. At the time of the interview Seb had been released and was living with Sandra. Sandra was visibly upset by her son’s diagnosis. Crying, she said:

> I would rather not have known [Seb had FASD]. I feel shamed and sad and I don’t not really know where to go or who to turn to … I feel ashamed and responsible for Seb’s challenges because of my drinking.

Sandra also described confusion. Being the mother of a number of children, she was unsure why some of her children would be affected and not others: ‘I don’t really understand why Seb has many problems when [name, another child], well she is bright, finished school and works and is a good kid and I drank more with her, a lot more’. Sandra also discussed an older incarcerated child, wanting to know how he could be assessed:

> [Name] has been in trouble since before he could walk, he can’t focus, he doesn’t think about anyone, he is obsessed with fire and he can be really violent which is why he is in there [prison] now. How can he be assessed at [prison name]?

The diagnostic report for Seb came with a number of recommendations for health needs. Reflecting on the recommendations, Sandra said:

> What help he would really get—are there any services to help with kids with FASD? Anyway, do you know what is in [town name]? Nothing. It is a small community we can’t even get proper food and I don’t have enough money for bills let alone this stuff.

4.6 Discussion

In keeping with previous sociologies of diagnosis, our findings capture how diagnoses are understood in the wider context of culture and community, family relationships, and social structures and interactions (Blaxter, 2004; Jutel, 2009; Malacrida, 2004). Our study demonstrates cultural patterns in responses to the diagnostic processes for neurodevelopmental impairments and FASD among Aboriginal and non-Aboriginal caregivers that have not previously been described.

Regardless of cultural background, there was a shared absence of the use of medical terms. Aboriginal participants used the term ‘that thing in his head/brain’ to refer to FASD. Neither of the non-Aboriginal participants used the terms FASD or neurodevelopmental impairments, but they did refer to their child’s ‘problems’. Avoidance of biomedical terminology should not be interpreted as an inability to understand the diagnosis. All participants linked the diagnosis to clinical indicators (Riessman, 2008): Phyllis and Sandra to alcohol consumption during pregnancy, Suzie and Phyllis to poor memory and Phyllis, Jill and Sandra to difficulty with attention, impulsivity, and difficulty understanding and following instruction. All participants also linked the diagnosis to their children’s behavioural problems (McLachlan et al., 2014). With respect to these clinically recognised aspects of neurodevelopmental impairments, diagnosis principally validated or provided explanation for what the caregivers already knew about their children (Chamberlain et al., 2017; Sanders & Buck, 2010). Only Suzie indicated that the diagnosis explained an element of her child’s behaviour that she previously did not appreciate.

The Aboriginal caregivers, Phyllis, Suzie, and Sandra, each demonstrated an understanding of the impact of diagnosis in the context of their families and communities (c.f. Popay et al., 2003). The unfortunate reality is that FASD is experienced for Aboriginal people in the context of intergenerational trauma and the resultant high levels of alcohol use (Fogarty et al., 2018; Vicary & Westerman, 2004). Some communities in WA have very high rates of FASD for justice-involved youth (Blagg et al., 2015). Phyllis and Sandra raised concerns that other family members might also be affected by FASD.

This appreciation of the diagnosis in a community context was not necessarily negative. Despite Suzie's engagement with the diagnostic report and resources, for Suzie, Samuel's diagnosis of FASD did not carry negative connotations because her child's happiness and place in the community were more important than having a diagnosis (Jutel, 2009; Riessman, 2008; Velarde, 2018). Reflective of this, Suzie raised a question about whether Samuel would be able to 'go through Lore', indicating that diagnosis would be problematic only if it affected her child's participation in the community. Suzie also described her perception of what makes Samuel different from his peers in the community: he does not like or play sport. High rates of FASD in communities may mean that, for Suzie, the diagnosis is not what makes Samuel different, but rather his unusual disinterest in sport.

In contrast, the two non-Aboriginal caregivers, Jill and Katie, spoke only about what the diagnosis meant for their children. They did not discuss the potential for diagnoses in other children or family members, or how the diagnosis may affect community participation.

The participants all viewed the strategies provided in their diagnostic report as useful. However there were observable patterns to how they were engaged with. Aboriginal participants, Suzie and Phyllis, were particularly interested in visual strategies, in keeping with previous findings on the dominance of visual cultures among Aboriginal Australians including in respect to healthcare (Hickey & Wilson, 2017; Hughes et al., 2004; Pewewardy, 2002; Thomas et al., 2019). They both reported successfully using visual strategies to assist their children. In Suzie's case, local community leaders identified this potential for this to help others, further evidence of the understanding of diagnosis within a community context (Potter et al., 2018). Jill and Katie did not speak of visual strategies to the same degree, although the two non-Aboriginal young people had not yet been released so their caregivers had not yet had a chance to implement strategies.

Of note, the diagnostic reports were not as easily understood by the Aboriginal participants. Suzie said they were hard to understand because of the 'whitefulla speaking'. Both Phyllis and Suzie received additional assistance to translate and understand the diagnostic report, highlighting the different understandings and worldviews of Aboriginal people (Velarde, 2018; Vicary & Westerman, 2004). This suggest that translating Western medical information into culturally appropriate resources would be useful for Aboriginal caregivers (Magana et al., 2013). In this, it is imperative to pay attention to the colonial history and its complex relationship with many factors that impact on wellbeing for Aboriginal people. Ignoring or glossing over cultural understandings and knowledge can inflict harm in the assessment process (Vicary & Westerman, 2004). Such approaches are also likely to create distrust, disengagement, and deter caregivers and family members from help-seeking.

There was also observable cultural patterning in how caregivers envisioned their children's needs being met following the diagnosis. As reflected in Phyllis's (Aboriginal) and Jill's (non-Aboriginal) accounts, experiences of struggling to access appropriate support for their child prior to a diagnosis were common and crossed cultural lines. Following the diagnosis, the non-Aboriginal caregivers envisioned more institutional assistance. Katie focused on Kieran's potential engagement with services, while Jill came back to the lack of assistance for Jasper, both discussing negotiating multiple systems for assistance (Blum, 2015; Garro & Yarris, 2009; Johnson et al., 2012; Landsman, 2010; Malacrida, 2001; Ryan & Runswick Cole, 2008; Hamilton, Reibel et al., 2020). This perspective is in keeping with sociologies of diagnosis that emphasise how a diagnosis from a practitioner controls access to care (De Swaan, 1989; Whelan, 2007).

However, for Aboriginal participants, receiving a diagnosis did not reorient how they imagined the support needs of their children being met towards institutions such as schools and healthcare system. Rather, they said that the support needs of diagnosed children continued to be met mostly within the community. While Phyllis was concerned about how she would continue to meet the needs of each of her grandchildren, she also said that the responsibility for care resting with nans (where parents were unable) was 'the blackfulla way' (Murphy et al., 2007; Popay et al., 2003). Sandra commented on the lack of access to services, highlighting the underlying social and structural inequalities that affect engagement in interventions, education, and support (Ennis-Cole et al., 2013), and the significant and complex burden of work and responsibility that mothers of children with disabilities assume (Landsman, 2010).

Where there is potential for self-blame by caregivers for their children's conditions, such as in the case of FASD, shame responses to diagnosis are of particular concern (Olsvold et al., 2019; Zimmerman et al., 2015). Sandra's preference to not know that Seb had FASD suggests that she recognised the potential for stigma and messages of parental incompetence from diagnosis and anticipated negative labelling (Francis, 2012). Similarly, Phyllis's discussion of alcohol use during her own pregnancy reflects the intergenerational shame that can be experienced by Aboriginal people at the interface of traditional and contemporary culture (Morgan et al., 1997). Such experiences of shame from receiving a diagnosis has the potential to affect taking up diagnostic support (Long, 2015; McNally & Lathan, 2009).

The vignettes presented in this article underscore the harm from stigma and labelling emphasised in the broader literature, which can often accompany parenting children with disabilities (Blum, 2015; Heneker et al., 2017; Landsman, 2010; Liu, 2005; Ryan & Runswick Cole, 2008). Valuing and understanding more about cultural differences when receiving a diagnosis could serve to mitigate the shame and harm that can be incurred from diagnostic assessments.

4.7 Conclusion

Diagnosis can be a label, or it can be a key that opens the door to understanding and opportunity to access the resources and supports required to manage the constellation of impairments that accompany a diagnosis of a neurodevelopmental disability. This contribution of caregiver experiences to the sociology of diagnosis scholarship provides a unique account of cultural patterning when Aboriginal and non-Aboriginal caregivers receive a diagnosis for their child. Demonstrated preferences for visual strategies among Aboriginal caregivers for transferring knowledge provides valuable information on ways to formulate resources to manage the effects of 'that thing in his head'. Difficulties among Aboriginal caregivers in understanding diagnostic reports and the continuation of support needs being met within communities also highlights differences in experiences and potential unmet needs.

Further exploration of the cultural patterning of receipt of a diagnosis and provision of diagnostic resources could valuably inform future sociology of diagnosis scholarship. For cultural reasons, our article only reports on the experiences of female caregivers. A focus on the distinct experiences of male caregivers warrants further investigation. Moreover, how different cultures receive diagnoses and how diagnoses relate to individual or community understandings of health and wellbeing is currently under-investigated.

The translation and use diagnostic resources within cultural groups also demands attention, with a focus on alternative delivery of diagnoses and care strategies. Increasing access to and use of the internet and social media on mobile devices in remote Aboriginal communities (Rennie et al., 2018) introduces the potential for digital platforms to support provision of culturally relevant resources that build on visual strengths. There are also potential benefits in peer-to-peer knowledge sharing and support (Maslen & Lupton, 2019b). The experiences of shame and how it can be managed in the diagnostic process, particularly in the context of intergenerational trauma, warrants further inquiry.

4.7.1 Footnote

[1] In this article, the term ‘Aboriginal’ is used with respect when referring to Australian Aboriginal and Torres Strait Islander peoples. The term ‘Indigenous’ is used when referring to global populations.

4.7.2 Disclaimer

Any material published or made publicly available by the authors cannot be considered as either endorsed by the DOJ or an expression of the policies or the views of the Department. Any errors of omission or commission are the responsibility of the researchers.

4.7.3 Acknowledgments

The authors thank all the parents and family members who have contributed their knowledge and views of the research. We thank the professionals in the community who provided vital support to the research and to the young people and their families during the research. The authors thank all at Banksia Hill Detention Centre, the study team, the members of the Consumer and Community Reference Group, the Steering Group and the studies Chief Investigators and Associate Investigators. SLH thanks the Elder Co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project, Telethon Kids Institute for sharing their knowledge and wisdom and for their contribution to the interpretation of the data from this research.

4.7.4 Funding

This research is funded by the National Health and Medical Research Council (#APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341). SLH is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award, the FASD Research Australia Centre of Research Excellence and the Centre of Research Excellence, Indigenous Health and Alcohol, University of Sydney (NHMRC #APP1117198). KC is supported by an NHMRC Practitioner Fellowship (APP1117582).

4.7.5 Competing Interests

The authors have no competing interests to declare.

4.7.6 Availability of Data and Materials

For further information, please contact the corresponding author.

4.7.7 Next Chapter Outline

To complement the previous two journal articles presented in this thesis about participating in the prevalence study and the experiences of receiving a diagnosis and diagnostic resources, this chapter presents a published article reporting interviews with the young people using a social yarning method to collect data. This component of the research allows for a more complete understanding of the effect of FASD and neurodevelopmental impairments on the lives of the young people who participated in the prevalence study. Guest blogs related to this article, and which were published with Power to Persuade, can be found in Appendix 6 and Appendix 7. Appendix 8 presents an evaluation of a sport and education initiative conducted during the PhD candidature. These articles both informed and were informed by this qualitative research. The article presented in this chapter has undergone a small amount of reformatting to ensure thesis consistency. The article's references can be found in the comprehensive reference list. The published version of the article can be found in Appendix 3. The citation for the publication is:

Hamilton, S., Maslen, S., Best, D., Freeman, J., O'Donnell, M., Reibel, T., Mutch, R., & Watkins, R. (2020). Putting 'justice' in recovery capital: Yarning about hopes and futures with young people in detention. *International Journal for Crime, Justice and Social Democracy,* 9(2): 20-36.. https://doi.org/10.5204/ijcjsd.v9i2.1256

Chapter 5: Putting ‘justice’ in recovery capital: Yarning about hopes and futures with young people in detention

5.1 Abstract

Aboriginal and Torres Strait Islander young people are over-represented in Australian youth detention centres and the justice system. In contrast to deficit-focused approaches to health and justice research, this article engages with the hopes, relationships and educational experiences of 38 detained youth in WA who participated in a study of screening and diagnosis for FASD. We report on a qualitative study that used a ‘social yarning’ approach. While the participants reported lives marred by substance use, crime, trauma and neurodevelopmental disability, they also spoke of strong connections to country and community, their education experiences and their future goals. In line with new efforts for a ‘positive youth justice’ (PYJ) and extending on models of recovery capital, we argue that we must celebrate success and hope through a process of mapping and building recovery capital in the justice context at an individual and institutional level.

5.2 Introduction

Globally, Indigenous peoples are over-incarcerated (Reitano, 2017; Ulmer & Bradley, 2018). Australia is no exception, with Indigenous peoples comprising 27% of the prison population, which is 13 times the rate of non-Indigenous prisoners (Australian Bureau of Statistics, 2017a). Incarcerated Indigenous youth comprise 59% of all youth in detention, despite only comprising 5% of the population (Australian Institute of Health and Welfare, 2018). In WA, where this research was undertaken, Indigenous youth make up 70% of youth in detention (OICS, 2018).

Various key factors explain the over-representation of incarcerated Indigenous people in settler–colonial countries, including the shift away from traditional life (Bougie & Senecal, 2010; Kaspar, 2014; MacDonald & Steenbeek, 2015) and systemic and institutional racism and discrimination (Blagg, 2008; Harmes et al., 2019; Weatherburn & Ramsey, 2016). In Australia, the fabric of Aboriginal and Torres Strait law and society was disrupted by the intrusion of white settlers, and colonisation was advanced by such policies and practices such as the forced removal of children from their parents, families and communities; compulsory land relinquishment and restricted freedoms through incarceration (De Maio et al., 2005; Memmott et al., 2001). This resulted in a pattern of over-incarceration, which is a situation that increases the likelihood that trauma and colonisation are continued (Blagg, 2008; Rynne & Cassematis, 2015).

It must be acknowledged that, generally, justice-involved youth are traumatised populations with high levels of mental health problems, conduct disorders, self-harm, and AOD use (Indig et al., 2016). The nexus between criminality, mental health problems, AOD problems and crime trajectories is well established internationally (Bennett & Holloway, 2009; Caudy et al., 2018; Hafekost et al., 2017; Indig et al., 2016). This is compounded among Indigenous youth, who have higher levels of neurocognitive disability (Baldry et al., 2015; Dias et al., 2013), intellectual disability (Indig et al., 2011) and FASD (Blagg et al., 2015; Bower et al., 2018) compared with their non-Indigenous peers.

In this article, we report the qualitative findings of a first-of-its-kind Australian study that was undertaken to establish the prevalence of FASD among youth sentenced to detention in Banksia Hill Detention Centre (‘Banksia’) in WA between 2015 and 2017 (Bower et al., 2018; Freeman et al., 2018; Hamilton, Reibel et al., 2019; Hamilton, Reibel et al., 2020; Kippin et al., 2018; Passmore et al., 2016, 2018). The article focuses on specific facets of participants’ recovery capital: happiness and hopes for the future, family relationships, and networks and connections.

FASD, which is a lifelong condition, describes a range of anomalies in brain function caused by maternal alcohol consumption during pregnancy. Individuals with FASD have difficulty with memory, attention, judgement and impulse control (Fast & Conry, 2004) and many have communication and language impairments (Kippin et al., 2018; Snow et al., 2017). FASD limits an individual’s understanding of social expectations (Fast & Conry, 2004) and results in learning difficulties, poor school performance and reduced prospects for employment (McLachlan et al., 2014). Internationally, FASD is significantly correlated with criminal justice involvement and the number of individuals with FASD is disproportionate to the total number of justice-involved people (Fast & Conry, 2004; Streissguth & O'Malley, 2000).

Individuals with FASD who come into contact with the justice system raise serious concerns about fairness and equity. When they come into contact with police, they may experience an impaired understanding of why they are in trouble and have a poor understanding or comprehension of their arrest rights (Roach & Bailey, 2009). They can be highly suggestible, have poor concepts of time and sequence, and have sporadic memory recall (Fast & Conry, 2004). They are more likely to succumb to pressure to plead guilty without an understanding of legal or personal consequences (McLachlan et al., 2014). Finally, they may struggle to understand the effect of their behaviour, potentially leaving them vulnerable to being viewed as lacking remorse or compassion (Roach & Bailey, 2009). Knowing the prevalence and understanding the effects of FASD in youth justice systems is imperative.

Internationally, youth justice systems ascribe to many narratives: 'child protection', 'punishment', 'public interest', 'public safety', 'welfare' and 'rights' (Goldson & Muncie, 2012). 'Punitive justice' models, which give precedence to proportionate punishment, formal sentencing and administration of accountability (Morris & Giller, 1983), and 'correctionalism' models, which seek to control and correct an individual's flaws and weaknesses (Farrington, 2007), are dominant. These models assume children and young people make rational choices, offend with 'free will' and therefore require discipline, control and accountability for their actions. In their discussion on Indigenous youth with FASD in WA, Blagg et al. (2015) highlighted that Western criminal justice systems, and in particular their diversion practices, do not realistically consider that youth with FASD do not 'mature' out of crime or respond to desistance from offending, lessened police interaction or access to desired stability or productivity.

Given Australia's colonial history and the resulting challenges that bring youth into contact with the law, there is a need to explore relational frameworks (Burford et al., 2019; Slade, 2010) that privilege the voices and knowledges of these youth and consider the broader aspects of their lives. PYJ is an approach that argues against the punitive youth justice policies and practices that dominate Western approaches to crime (Cavadino & Dignan, 2006; Cunneen & Rowe, 2014; Dunkel, 2014; Goddard & Myers, 2017; Winterdyck, 2014). Rather than prioritising the prevention of youth crime, the focus of PYJ is on developing six key areas for youth: health, work, education, communities, creative skillsets, and social networks and relationships (Butts et al., 2010).

Consistent with these PYJ principles, this article investigates the potential for a ‘recovery capital’ lens to shift focus to the importance of relationships and networks for justice-involved young people’s recovery and healing. Although this introduction has focused on Indigenous youth and the effects of colonisation, the authors consider a recovery capital approach to be beneficial for all youth involved with the criminal justice system. After outlining recovery capital approaches, we present the study findings and explore how recovery capital can benefit these youth.

5.2.1 Applying Recovery Capital Approaches to Justice-Involved Youth

Recovery capital was originally developed in the context of recovery from severe AOD problems (Granfield & Cloud, 2001). It is a dynamic and interactive strength-based model that attempts to measure the range of internal and external resources that can be used to initiate and sustain recovery (Cloud & Granfield, 2009). Recovery capital has also been applied in the broader context of recovery from mental health issues and trauma, which are adversities that often encompass the lives of justice-involved youth (Hafekost et al., 2017; Indig et al., 2016).

Recovery is conceptualised at three levels: personal, social and community. Personal recovery capital represents an individual’s level of personal skills, abilities and personal resources including self-esteem, self-efficacy, coping mechanisms and resilience (Best & Laudet, 2010; Cloud & Granfield, 2009). It includes individual communication skills, interpersonal and educational/vocational skills, problem-solving capacities, hope, optimism and goals.

Social recovery capital refers to the recovery supports available to individuals (Best & Laudet, 2010; Cloud & Granfield, 2009). The concept of social capital was initially developed by Bourdieu (1985) and scholars have argued the importance of social capital and networks for providing a sense of belonging (Durkheim, 1984) and as a resource rich in trust, mutual obligation and reciprocity (Putnam, 2000). In the context of recovery capital, social capital allows for identification of intimate relationships, family networks and broader social relationships, and constitutes the availability of culturally prescribed pathways that resonate with particular individuals and families, including models for Indigenous peoples (Coyhis & White, 2006). It supports analysis of the willingness and capacity of family members to participate in treatment, access to prosocial activities, and interpersonal connections to others in institutions such as school, work and community organisations.

Community recovery capital refers to the tangible influences on recovery such as having access to safe housing and meaningful opportunities (Brunelle et al., 2005; White & Cloud, 2008). This can be built up through the promotion of community attitudes; policies and resources that support the resolution of problems; active community efforts to reduce stigma associated with addiction and recovery; increased visibility and diversity of peers and positive role models; comprehensive resource provision; and increased local recovery community support institutions (Brunelle et al., 2005). Resources can include specific recovery rehabilitation centres, playgroups, schools, healing initiatives, parenting centres, peer-led self-help groups and sporting clubs (Best, 2014; White & Cloud, 2008).

Within a recovery capital model, recovery is viewed as a staged process that involves destabilising a problem, initiating recovery and stability, and then maintaining recovery (Laudet et al., 2006; White & Cloud, 2008) while acknowledging that individuals possess different aspects of recovery capital and that it can change over time. However, aspects of recovery capital interact with the severity or complexity of problems, which in turn shape the intensity of the support and the length of time for which support may be needed (Laudet et al., 2006). The process of destabilising a problem and initiating recovery possibilities can occur within institutions, whether they be hospitals, rehabilitation centres, psychiatric facilities, prisons or youth detention centres (Best, 2014, 2019; Laudet et al., 2006; White & Cloud, 2008).

Many obstacles can stand in the way of recovery, which is a problem that creates what Cloud and Granfield (2009) refer to as ‘negative recovery capital’. Justice-involved individuals, particularly those with additional problems such as addiction, can be negatively labelled (Dingle et al., 2014), experience stigma and marginalisation (Scott & Gosling, 2016) and thus be excluded from various forms of social and community capital. Moreover, some groups in communities do not have a positive effect on physical or psychological wellbeing, or the recovery process (Best & Savic, 2015; Haslam et al., 2012; Jetten et al., 2014). Belonging to such groups sustains negative values and lifestyles and presents barriers to accessing and utilising resources in the community such as education, jobs and safe housing (Best & Savic, 2015). Therefore, professional interventions need to provide opportunities to build positive social networks, enable access to community resources and reduce the potential for stigma (Best, 2019; McNeill & Maruna, 2007; McNeill & Whyte, 2007; Ward & Maruna, 2007).

Generally, the recovery capital approach has been targeted towards adult populations. Little is known about the benefits of establishing and building on the recovery capital assets possessed by youth (Hennessy, 2017), and the authors found no literature that explored recovery capital models inclusive of Australian justice-involved youth or Australian Indigenous youth. The literature predominantly examines the role of peers in recovery from addiction; however, there are some related concepts that have been developed in the context of adolescents that point to the potential relevance of recovery capital approaches to these social groups. The peer recovery support model, which is closely related to Native American people’s traditional kinship systems and values, has shown improvement in housing stability, employment and health for Native American peoples (Kelley et al., 2017). According to Nash et al. (2017), alternative peer group models have also received attention for youth in recovery, the authors positing that building networks and new friendships can provide different influences, attitudes, values, ideas and ways of doing things that support recovery. Highlighting that there are many gaps in recovery capital for specific populations, Hennessy (2017) identified that aspects of this may further marginalise youth and argued for the need to understand youth's perceptions of what forms of community participation would lead to a healthy and meaningful life.

A recovery capital model constitutes a framework to assess recovery while being cognisant of the AOD use and mental health problems that are well established in the justice-involved youth population in Australia. However, for the case that we address in this article, the recovery capital model does not systematically consider how assessments for recovery capital assets can be applied to justice-involved youth with neurodevelopmental disability. For its success, many of the features of developing recovery capital rely on individuals having the ability to focus, communicate and initiate and maintain positive relationships. For justice-involved youth with neurodevelopmental disability, an enhancement of the recovery capital model is necessary to support effective communication and equitable participation in decision-making about their futures.

5.3 Methods

The findings reported here are part of a broader program of work that sought to assess the prevalence of FASD among detained youth in WA (Bower et al., 2018). A qualitative study was designed to gain an understanding of the participants' perspectives of FASD assessment. To gather these data, the researchers adopted the yarning method (Bessarab & Ng'andu, 2010; Fredericks et al., 2011; Martin, 2008). The essence of a yarn is listening and exchanging, with each side being willing to give information and show genuine connection to, empathy with and interest in the other, drawing on longstanding cultural practices used by Indigenous families and communities. In this research interaction, the researcher is an 'active participant' and 'learner' as opposed to the 'possessor of knowledge'. Yarning can be approached in four ways: social yarning, research-topic yarning, collaborative yarning and therapeutic yarning (Bessarab & Ng'andu, 2010). Our study used both social and research-topic yarning. A yarning methods paper reporting research topic data for this study is published elsewhere (Hamilton, Reibel et al., 2020). As the lead researcher (first author) was an Aboriginal woman from the eastern states of Australia, yarning involved sharing information about traditional heritage and country, which is essential to honest and identifiable engagement in yarning (Bessarab & Ng'andu, 2010). The participants exchanged information with the researcher about their family, where they lived, their school experiences and their hopes for the future. The data we report on in this article are drawn from the social yarning.

5.3.1 Participants

Purposive sampling was used to identify qualitative study participants from the 99 young people who completed the assessments in the prevalence study. Of these participants, 38 agreed to participate in a yarning interview. They self-identified their ethnicity; 27 identified as Aboriginal and 11 as non-Aboriginal Australian. No Torres Strait Islander youth participated in this study. The participants will be referred to as Aboriginal or non-Aboriginal participants.

At the time of the yarning interviews, the researcher had no knowledge of the participants' diagnostic outcomes. Subsequent analysis of the qualitative study found that 24% of the participants had FASD and 34% were diagnosed with neurodevelopmental impairments in the severe range. The remaining 42% of the participants had not received a diagnosis; however, 89% of the prevalence study participants were found to have at least one severe neurodevelopmental impairment, making yarning appropriate to their interviewing needs (Hamilton, Reibel et al., 2020).

5.3.2 Data Collection

All but two interviews took place outdoors at Banksia and all yarns were in sight, but not in hearing, of custodial officers. The length of time of the yarns was between 10 and 30 minutes. A voice-recording device was not used during yarning. So as not to interfere with the yarning process, brief handwritten notes were taken during the interview, with salient points recorded in writing (verbatim) and accuracy double checked with the participants at the time of the interview. Immediately following the yarn, the researcher comprehensively documented the details of the interview in writing, including multiple reflective fieldnotes.

5.3.3 Research Ethics

Ethics approval for both the study was granted by the Western Australian Aboriginal Health Ethics Committee (approval number 582) and the University of Western Australia Human Research

Ethics Committee (approval number RA/4/1/7116). Research approvals were also gained from the (former) Department of Corrective Services (project ID 335) and the (former) Department for Child Protection and Family Support (approval number 2015/8981).

5.3.4 Informed Consent

Assent from the young person and consent from their guardian to participate in the study was obtained by a research officer. Due to the vulnerability of this population, a child-centred approach to seeking assent was followed (Clark, 2011). If a young person expressed interest in being involved in the study, the research officer explained the purpose of the study using simple language and pictorial information sheets and assent forms (Passmore et al., 2016). Upon assent, written consent was then sought from the participant's identified legal guardian. This approach to assent and consent recognised the capacity of young participants to be involved in informed decision-making about research participation while respecting the responsibility of their parents as their guardians to provide informed consent (Lambert & Glacken, 2011).

5.3.5 Data Analysis

Data were analysed using thematic analysis (Attride-Stirling, 2001). We used the methods of interpretive phenomenological analysis to interpret the interview data (Smith et al., 2009). Study team members met regularly and reviewed the themes in the participant data that had been noted by the lead researcher. These reviews helped to ensure consistency in data interpretation over the time of data analysis using diverse perspectives and many iterations. Initially, two researchers manually analysed and coded the data using NVivo Pro Qualitative Data Analysis Software (2016). The lead researcher also conducted multiple analysis reviews over time to confirm and develop final data interpretations. The authors then cross-analysed the data for these aspects of recovery capital.

5.4 Results

The following analysis examines the participants' yarns through the lens of the recovery capital model (i.e., personal, social and community recovery). Diagnosis is indicated for FASD [FASD], neurodevelopmental impairments [NI] and participants without diagnosis [WD]. Most of the young people experienced a confluence of difficulties, such as previously identified mental health and conduct disorders and AOD use (Bower et al., 2018).

5.4.1 Personal Recovery Capital: Happiness and Hope

Overwhelmingly, participants with and without a diagnosis found happiness within their family relationships. When asked by the researcher ‘what makes you happy?’, responses from the non-Aboriginal participants included ‘being home with my family makes me happy’ and ‘I’m happy when I have had a visit with Mum’. The Aboriginal participants also spoke of cultural activity: ‘I’m happy being with family, like getting out on country like and learning about medicines and catching bush meat’; ‘I’m really happy when I go hunting goanna and turtle with my dad’; and ‘I like fishing with Pop’. Four of the participants, two Aboriginal and two non-Aboriginal, had their own children and expressed that their children provided hope, purpose and happiness. One participant said, ‘I can’t wait to get out so I can spend some time with my little daughter’.

5.4.2 Personal Recovery Capital: Futures

Many participants yarned about going back to school or taking trades on their release, particularly those from the urban region. They identified many occupations in which they would like the opportunity to work, including as a plumber, electrician, mechanic, welder, bricklayer and carpenter or builder.

One non-Aboriginal participant [FASD] said, ‘I want to do bricklaying or work in construction’. A non-Aboriginal participant [NI] yarned about wanting to be an electrician. A non-Aboriginal participant [WD] saw opportunities to pursue these aspirations through Banksia: ‘I’m doing a construction certificate here [at Banksia]. It’s good cause I never got opportunities to succeed and I want to do cabinet making and get a carpentry certificate’.

While in Banksia, this participant was proud that they had ‘little wooden things’ for their child. Most of the Aboriginal participants from remote and regional WA wanted to join an Indigenous rangers program, be a station hand or to be involved at some level in community programs and looking after country. One participant [WD] said: ‘I hope to I can go back and live with Mum and Dad and I want to work on my country with the Indigenous Rangers’.

Another participant [NI] said, ‘I want to go and work on a station. I love animals and can’t wait to go home’. Other Aboriginal participants, all from remote or regional communities, said: [WD]: ‘I am hoping to go to an alternative type of schooling. I would like to see a bush school for the young people in my [remote] community’; [FASD]: ‘I want to get a [drivers] licence and work on the mines or on a station’; [FASD]: ‘I want to be a [Indigenous] ranger and look after the country’.

Some of the participants wanted more professional futures. One non-Aboriginal participant [WD] wanted to undertake a business course and run their own business, while others wanted to work with computers or in accountancy, graphic design or music. One non-Aboriginal participant [NI] wanted to join the navy. Another non-Aboriginal participant [WD] said, ‘I would like to be a custodial officer so then I could help kids like me’.

Some of the participants were more interested in having somewhere to live, a relationship and a family of their own. A non-Aboriginal participant [WD] said, ‘I dream of having a big house on the beach with lots of kids and stability’. The participant went on to say, ‘and I really want to travel’.

For a few participants, their goal was just to stay out of trouble and out of Banksia. One non-Aboriginal participant [FASD] said, ‘I just hope I don’t have to come back [to Banksia]’. Another Aboriginal participant [FASD] said:

> I just want to stay off the drugs and keep out of trouble. If I have cravings [for drugs] I will do sport. I plan to do bricklaying. I know where to get help to do bricklaying, but the community doesn’t understand why I get into trouble [alluding to FASD].

While almost all the participants spoke of their hopes and dreams for their futures, a minority were unable to identify positive futures. One non-Aboriginal participant [WD] identified smoking cannabis as their ‘future career aspiration’. Two participants [one FASD one NI] saw their futures as bleak and did not know what they wanted to do. One Aboriginal participant [NI] envisioned his future as being ‘in the big house across the road [pointing to the adult prison]’. An Aboriginal participant [FASD] said, ‘there is nothing to hope for, I’m just going to smoke dope every day’. Finally, a non-Aboriginal participant [NI] said, ‘I have no plans for when I leave Banksia. I’m not sure I can get a job anyway cause I’m a criminal’.

5.4.3 Social Recovery Capital: Relationships and Networks

As noted earlier in the article, most participants described happiness as being embedded in family relationships. While family relationships were a source of identity, happiness and cultural connection, there were complicating factors that could impede the potential for recovery. A few participants talked about their parents’ use of drugs and identified family members as initiating their drug use.

One non-Aboriginal participant [WD] said, ‘I love my mum and dad, but they use all the kinds of drugs’. Another Aboriginal participant [FASD] said, ‘I smoked cigarettes and drink alcohol with my family since I was 14’ and another Aboriginal participant [NI] said: ‘me and my bro [brother] use meth’. One Aboriginal participant [WD] recognised that their family’s AOD use made it difficult for them to deal with their own AOD problem: ‘I smoke and drink with my family, they all do it, so I do too … it’s pretty hard, you know’.

Many participants also spoke of other family members who were incarcerated, particularly male relatives. One Aboriginal participant [FASD] said, ‘I don’t know my dad ‘cause he’s been in the big house [adult prison] forever’, while another Aboriginal participant [NI] said, ‘My dad and brother are inside’. An Aboriginal participant [FASD] said, ‘both my uncles were there [pointing across the road to the adult prison] but one of them hung himself’.

While the common experience of incarceration is devastating for communities, it can also be a source of support while in detention. An Aboriginal participant [WD] said, ‘I’m ok, I’m in here with my cousins and nephews, and uncles’. This could extend to friendship networks, with a non-

Aboriginal participant [NI] commenting: ‘I’m happy being here at Banksia … because I feel safe and have friends here’.

Around a quarter of the participants had been in state child protection care prior to being incarcerated. These participants particularly yarned about instability. A non-Aboriginal participant [WD] said, ‘I have lost count of how many foster homes I have lived in’. Another non-Aboriginal participant [WD] spoke of losing touch with family: ‘I haven’t seen my parents for a few years now’. Another non-Aboriginal participant [WD] yarned about being repeatedly removed from and reunified with their mother and said, ‘I went home a lot, but it never worked out’. Another Aboriginal participant [NI] said, ‘I been away from my family for half my life; I get sad and angry’. This participant echoed the experiences of the other participants when they said, ‘Miss, I just grew myself up’.

5.4.4 Community Recovery Capital: Access to Education Opportunities

Participants yarned about school experiences. Some participants liked school and described achievement. One non-Aboriginal participant [WD] was a ‘gifted’ student prior to their incarceration, while another non-Aboriginal participant had successfully completed school and an apprenticeship. Two Aboriginal participants had attended school on football scholarships. One of these participants went to school interstate but discontinued to return home. He said, ‘I liked it [school], but I missed being with my mob [family]’. Many of the participants liked the social aspects of school, particularly of sport. An Aboriginal participant [FASD] said, ‘I like hangin’ with my bruz [brothers] but not the work; it’s too hard’. Another Aboriginal participant [WD] said that the ‘best part [of school] is playing sport’, while a non-Aboriginal participant [WD] said, ‘I liked the social aspects of school like playing footy and being with my mates’.

For many, the complexity in their lives combined with their neurodevelopmental challenges meant that they were unable to complete their schooling. One Aboriginal participant [NI] said, ‘I didn’t attend school for years’. They went on to say, ‘I am trying to do a course [high school] while I am here [at Banksia]’. Another Aboriginal participant [FASD] said, ‘I went to primary school sometimes but not high school. I didn’t mind school, but I don’t go to school no more’. There were many social problems in this young person’s remote community, and they had experienced significant grief during their early teenage years.

A few participants said that they did not like school. One non-Aboriginal participant [WD] said, ‘I didn’t like school. I was told I was stupid regularly’. Another non-Aboriginal participant [WD] said, ‘I was in trouble all the time’. After describing multiple suspensions, he said, ‘Miss, I hated school’ and then shrugged and said, ‘anyway, school gave up on me’.

Although most participants were between 13 and 15 years of age and still in the early stages of high school, many described irregular attendance and disengagement. One non-Aboriginal participant [WD] said, ‘I done ok in school. I liked school but I’m not going back’. When asked why, they said, ‘I didn’t like the teachers much and I hated having to wear a uniform. I also hate it when they say one thing and then do another. It does my head in when things change’. Another Aboriginal participant [NI] said, ‘it’s not worth going back to school; I will just fail’. Other reasons given for irregular attendance or school disengagement included multiple school changes linked to multiple foster placements.

A few participants were interested in returning to school on their release from Banksia. One Aboriginal participant [WD] from a remote community was keen to return to school if it was different from what they had previously experienced. They described an alternative ‘bush school’:

> Learning in a classroom first for reading and writing maybe, and the rest of the day learning how to survive—like our own first aid—how to eat, ya know, hunting and how to heal like, traditional medicines like. Then the kids might stay in school.

5.5 Discussion

5.5.1 Locating Recovery Capital

While most previous health and justice research have focused on the problems of young people, this research captured how young people in detention yarned about what makes them happy, what they hope for, their families and relationships, and their views about their education and school. Theirs were not only stories of the challenges of their circumstances, but also of their dreams for the future, their networks and their opportunities. The findings highlight the importance of family as a source of support and connection for participants. It was evident that being at home with family, having family members visit and the hope provided by the participants' own children were all centrally important to participants' happiness.

However, the findings also suggest that some families are a source of negative recovery capital (Cloud & Granfield, 2009), as evidenced by the participants' discussions about AOD use and the incarceration of family members. The participant who used AOD with their family because 'they all do it', and the participant who casually pointed to the adult prison as the location of their male relatives and their future, evidence the normalisation of family incarcerations for the Aboriginal participants. Both realities reflect the well-documented shift away from traditional norms and values held by pre-colonial Indigenous cultures (Kelley et al., 2017) and the subsequent trauma (Memmott et al., 2001; Rynne & Cassematis, 2015).

Stability was a problem, particularly for those in the care of the state. Instability affects the capacity of individuals to build a sense of identity and connectedness. The participant who 'grew himself up' highlighted the vulnerability of the family and community structures and the influence that colonising forces have had on families and communities (Memmott et al., 2001). Nevertheless, there was an Aboriginal participant who recognised the potential for combining Western and traditional models in 'bush schools' to keep children and young people engaged with and attending school. These aspects of cultural capital held by the Aboriginal participants, positive or negative, can be supported by increasing social capital and positive social connections (Bougie & Senecal, 2010; White & Cloud, 2008) through positive peer support and role modelling (Nash et al., 2019). This will be important for supporting these youth to shape their pathways to recovery.

The participants yarned about their education as a source of social and sporting opportunities for some and learning for others. Some participants liked school and said they did well. Some participants had attended multiple schools. Some spoke of being told they were 'stupid' and continually getting into trouble. Negative labelling fuels barriers to rehabilitation and should be challenged and rejected at a systemic level as part of establishing sustainable, recovery-oriented systems of change (Dingle et al., 2014). Many participants had ceased attendance or felt that schools had ‘given up’ on them. Assessing what activities may better suit these young people to increase positive community participation could better inform their recovery needs (Hennessy, 2017). For children, schools are the place where peer relationships are built, and opportunities and resources are made available to pursue their goals. The findings show a clear need for services that help cultivate a strong culture and identity, and regular opportunities to participate in prosocial and cultural activities (Hovane et al., 2014).

The findings suggest that participants were not unmotivated in terms of their hopes for productive futures. While a few of the participants saw little in their futures, they still had hopes to be with family or stay out of prison. Many participants had job and study aspirations. Given the neurodevelopmental and other complex difficulties of the participants, the careers they identified such as bricklaying, working on a station, or working for ranger programs were not beyond their capacity with the right assistance and support. Significantly, participants did not yarn about relationships with teachers, officers or social support workers. While some participants saw their incarceration as an opportunity for education and futures (Laudet et al., 2006), there was little evidence of key professional relationships as sources of hope and inspiration. The absence of these relationships suggests that there is a need to consider applying relational, strength-based lenses (Burford et al., 2019; Slade, 2010) for justice-involved youth, which factor in the effects of neurodevelopmental impairments and other complex difficulties that affect relationship building. By doing so, it would be possible to develop appropriate interventions, treatments and service responses based on trust and reciprocity (Putnam, 2000).

5.5.2 A ‘Justice’ Lens for Youth with Neurodevelopmental Disability and Fetal Alcohol Spectrum Disorder

The high prevalence of neurodevelopmental impairments and FASD diagnoses among the participants in this study alerts us to the widespread experience of impairments in this population (Baldry et al., 2015; Bower et al., 2018; Dias et al., 2013; Indig et al., 2011). The prevalence study results (Bower et al., 2018) should encourage a shift in the expectations of young people in the justice system and recognition of the effect of neurodevelopmental impairments have on the behaviour of detained young people. Further, it provides an opportunity to support young people in developing strategies to deal with their impairments and to find different pathways into the future. The relationships that the young people have within their families and networks; their participation in education, employment and prosocial activity for their futures; and their neurodevelopmental strengths and difficulties will all need consideration (Bower et al., 2018; Fast & Conry, 2004; Kippin et al., 2018; McLachlan et al., 2014; Snow et al., 2017).

Youth with neurodevelopmental disabilities can have a range of impairments that result in impulsivity, poor attention, impaired memory and poor communication, and are likely to be disadvantaged at all junctions of the criminal justice process. Their lack of (or different) understandings of social norms and inability to learn from experience exacerbate their involvement in crime (Blagg et al., 2015; Streissguth & O’Malley, 2000), as do mental health problems, AOD problems and trauma (Hafekost et al., 2017; Indig et al., 2016).

Given the increased likelihood that these youth will come into contact with the law, there is a necessity to scaffold support for justice-involved youth differently. Whether young people in contact with the criminal justice system are fit to stand trial, have an ability to understand investigative procedures such as police interviews, can remember and retell their story accurately and can understand more broadly what may be required of them in court or detention is vitally important (Fast & Conry, 2004; Streissguth & O’Malley, 2000). Equally important is that they have their neurodevelopmental challenges considered in their rehabilitative efforts and the planning of their futures. Understanding their recovery capital assets in the justice context and including their neurodevelopmental resources that may help or hinder this process is imperative to achieving a PYJ (Butts et al., 2010). The findings from this qualitative study suggest that it is possible to assess recovery capital assets in this population and to utilise those assets as part of a therapeutic process using neurodevelopmental diagnostic information. However, further research is required to confirm the salient dimensions of recovery capital in the context of justice. Table 5.1 provides a broad conceptualisation of the qualitative data connections with positive and negative justice capital. There is potential for developing an assessment model that measures recovery capital in the justice context and facilitates knowledge about neurodevelopmental disability, disadvantage, trauma and the recovery needs of justice-involved youth. This could also assist in establishing whether applying recovery-focused assessment models as a routine aspect of youth justice service provision can assist in reducing the rising imprisonment rates of Indigenous youth in Australia.

Table 5.1

Positive and Negative Justice Capital: Data Connections

Data connections	Negative justice capital	Positive justice capital
Neurodevelopmental disability	Undiagnosed neurodevelopmental disability FASD, ND	Access to strength-based diagnostic assessments Disability services and support Access to special education support
	No access to legal advocacy services	Legal representation and advocacy
	Unrecognised language need No interpreters	Speaking multiple languages Interpreter services Plain language explanations Destigmatising narrative/optimistic language
	Lack of opportunity engagement with community activities or organisations Social exclusion from community and its assets	Hope and future aspirations Goal setting and skill development Engagement with community (sport and employment)
AOD use	Untreated problematic AOD use	Access to rehabilitation
	Negative peer influences	Positive peer support and mentoring
Trauma and past harm	Removal from family	Family relationships supported through contact visits Strong relationships with family Safe housing
	Negative family influences Social isolation	Relationships based on trust and mutual obligation Peer support and positive mentoring
	Intergenerational trauma Culture denied Disconnection from country Absence of cultural identity, beliefs and values	Recovery and healing services Commitment to culture, community and country Opportunity for cultural activity Strong cultural identity

5.6 Conclusion

Justice-involved youth are well understood to be a traumatised population with high levels of trauma and neurodevelopmental disability. The examination of recovery initiatives is consistent with a move towards PYJ for justice-involved youth, regardless of cultural identity. The views presented in this article of young people in detention provide the opportunity for an improved understanding of recovery capital in the justice context and to consider strength-based, future-focused assessment models for recovery. Most of the young people described backgrounds of adversity, with three-quarters of the participants identifying as Aboriginal and therefore likely to be carrying additional intergenerational trauma. As such, the application of a recovery-focused model of assessment that explores the personal, social and community capital assets possessed by justice-involved youth provides a way to understand and respond to their neurodevelopmental needs, build on their skills and assist them to plan pathways to achieve their goals. A complete appreciation of the challenges and support needs of these young people requires the specific consideration of recovery capital in the justice context and, as such, we advocate developing a broad assessment tool that measures the positive and negative recovery capital assets of justice-involved youth.

5.6.1 Acknowledgments

The authors thank the young people who participated in the study for sharing their stories. We thank all at Banksia Hill Detention Centre. We thank the study team, the members of the Consumer and Community Reference Group, the Steering Group and the Reference Group, and the Chief Investigators and Associate Investigators. Sharynne Hamilton thanks the Elder co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project, Telethon Kids Institute for sharing their knowledge and wisdom and for their contribution to the interpretation of the data from this research.

This research is funded by the National Health and Medical Research Council (#APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341). SLH is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award, the FASD Research Australia Centre of Research Excellence, and the Centre of Research Excellence, Indigenous Health and Alcohol, University of Sydney (NHMRC #APP1117198).

5.6.2 Disclaimer

Any material published or made publicly available by the authors cannot be considered as either endorsed by the DOJ or an expression of the policies or the views of the Department. Any errors of omission or commission are the responsibility of the researchers.

5.6.3 Correspondence

Sharynne Hamilton, PhD Candidate, Telethon Kids Institute, Hospital Ave, Nedlands WA 6001. Email: sharynne.hamilton@telethonkids.org.au.

5.6.4 Next Chapter Outline

To complete presentation of the peer-reviewed articles, and to give perspective to the service delivery element of this research, the following chapter presents the final published article reporting on the data collected with non-custodial rehabilitative staff during individual interviews and focus groups in the detention centre. The article has undergone a small amount of reformatting to ensure thesis consistency. The article's references can be found in the comprehensive reference list. The published version of the article can be found in Appendix 4. The citation for the publication is:

Hamilton, S. L., Reibel, T., Watkins, R., Mutch, R. C., Kippin, N. R., Freeman, J., Passmore, H., Safe, B., O'Donnell, M., & Bower, C. (2019). 'He has problems; he is not the problem …' A qualitative study of noncustodial staff providing services for young offenders assessed for Foetal Alcohol Spectrum Disorder in an Australian youth detention centre. *Youth Justice, 19*(2), 137–157. https://doi.org/10.1177/1473225419869839

Chapter 6: ‘He has problems; he is not the problem …’ A qualitative study of noncustodial staff providing services for young offenders assessment for Fetal Alcohol Spectrum Disorder in an Australian youth detention centre

6.1 Abstract

Little is known about the challenges non-custodial youth detention centre staff face supporting young people with FASD. We undertook qualitative inquiry to identify and describe the perspectives of non-custodial staff detention staff regarding the value of a FASD prevalence study. Data were collected using semi-structured interviews and focus groups and analysed using thematic network analysis. Staff held few concerns about the prevalence study and its impact on participating young people; however, they identified barriers related to study processes, and practices and culture within their workplace, which hindered gaining maximum benefit from the research and its findings.

6.2 Introduction

The United Nations (1985) Standard Minimum Rules for the Administration of Juvenile Justice, Rule 26.1 espouses that ‘the objective of training and treatment of juveniles placed in institutions is to provide care, protection, education and vocational skills, with a view to assisting them to assume socially constructive and productive roles in society’ (p. 14), highlighting the importance of the roles a youth detention centre workforce undertake. Staff are central to nurturing incarcerated young people to move from involvement in criminal activity towards more life-affirming opportunities and goals.

On any given night around Australia, 980 children and young people are in youth detention facilities (Australian Institute of Health and Welfare, 2018). Aboriginal young people are significantly over-represented in these facilities, comprising 54% of incarcerated young people nationally, despite only being 3% of the population (Australian Institute of Health and Welfare, 2018). This article describes a qualitative study undertaken with non-custodial staff as part of a larger study (described in section ‘Methods’) establishing the prevalence of FASD in a youth detention centre. At the time of the study, the detention centre housed approximately 155 male and female young people aged 10–18 (OICS, 2015). Of these young people, 95% were male and more than half were aged between 16 and 17 years, and 75% were Aboriginal young people. Just over half of the young people (57%) lived in urban areas and 43% were from regional and remote regions (OICS, 2015). While in detention, young people are provided with opportunities to attend school, vocational training and other personal development and sporting activities (DOJ, 2017). Staff at the detention centre use the Offender Management System (OMS), an electronic database containing demographic, program and assessment information about the young people, to access and share information. These staff perform a vital role in the care and rehabilitation of young people in detention.

6.3 Previous Literature

Young people involved with justice systems are often living with numerous conditions that can affect their social and emotional wellbeing (Dias et al., 2013). Research has found, for example, that Australian Aboriginal young people have higher levels of neurocognitive disability (Baldry et al., 2012; Dias et al., 2013) and intellectual disability (Indig et al., 2011) compared with non-Aboriginal young people involved with the justice system. Research has also found that many young people have not had diagnosable conditions previously identified. High numbers of young people involved in justice systems, for example, were found to have undiagnosed neurodevelopmental and mental health disorders (Bower et al., 2018; Dias et al., 2013; Garland et al., 2001; Teplin et al., 2002; Wasserman et al., 2002, 2003). Previously unidentified health problems (Kumwenda et al., 2017), cognitive and intellectual disabilities (Leonard, 2016; Sotiri & Simpson, 2006) and language disorders (Anderson et al., 2016; Kippin et al., 2018) have also been found among young people in contact with youth justice. There is also a small but growing body of evidence identifying high prevalence of FASD in Australian justice populations (Bower et al., 2018; Flannigan et al., 2018).

The availability of data about the potential prevalence of FASD among both Aboriginal and non-Aboriginal children and young people in Australia is limited, and the rate of young people living with FASD who come before the courts is unknown. However, due to the high number of Aboriginal young people who end up in prison, FASD has been recognised as a potentially significant underlying contributor to youth crime (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, 2011). It is vitally important for young people with FASD to have their conditions recognised when involved with youth justice. The range of neurocognitive impairments, together with broader psycho-social risks often experienced by those with FASD, can result in young people having limited understanding of judicial processes (Baldry et al., 2015; Flannigan et al., 2018; Frize et al., 2008). Unrecognised neurodevelopmental disabilities such as FASD among young people who encounter the justice system can have serious implications, as it may mean that these young people have not had their health and wellbeing needs met and have received punitive approaches in response to their maladaptive behaviours rather than supportive proactive responses (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, 2011). Developing screening instruments for the recognition of young people with FASD and neurodevelopmental disability when they encounter the law is, therefore, critically important.

Screening for undiagnosed disorders both on entry and throughout involvement with the justice system can be an efficient mechanism for gathering information (Young et al., 2006). This, however, needs to occur at various points of a young person’s contact with the justice system to inform both the identification of risk and the needs of young offenders and promote fairness and consistency in practice. Moreover, there is a need for the ongoing screening and assessment of potential difficulties young people may be experiencing to assist with connections to external services; with screening and assessment critical for detention case management, and for assisting a successful transition from a highly organised detention setting to a more unstructured life in the community (Altschuler & Armstrong, 1994; Hancock, 2017; Potter, 2014; Wasserman et al., 2003). The most effective programmes in youth detention are those which are designed to meet the needs of individuals, based on the assessment of multiple possible contributing factors such as prior service involvement, previous assessments, school reports, and familial and social histories to identify both genetic and social stressors which may impair individual functioning (Murphy et al., 2007).

Qualitative studies have explored the experiences of youth justice staff working with and providing services for detained young people. These have explored themes of race and the over-representation of minority populations (Conley, 1994; Holley & VanVleet, 2008), behaviour management and perceptions of differences in gender (Baines & Alder, 1996), sexual diversity (Feinstein et al., 2000), general practice and work culture (Field, 2007), and injury prevention for detained young people (Reed et al., 2015). Health and mental health services have received attention (Knowles et al., 2012; Kumwenda et al., 2017). The studies found that a lack of comprehensive healthcare histories and the inadequate knowledge of the healthcare needs of young people, and inadequate resources and financing all have negative implications for young people in detention. Only by identifying, and thereby reducing the factors contributing to health problems of young offenders, will it be possible to reduce future harms and increase the likelihood that young people will increase knowledge of their needs and seek assistance (Kumwenda et al., 2017). Youth justice staff views of mental health services provided to justice-involved young people have also received some scholarly attention (Knowles et al., 2012), providing insight into understanding the barriers to youth justice staff screening young offenders for self-harm and mental health issues and highlighting the need to improve the knowledge and responses of these staff to young people presenting with problematic mental health. This body of work also highlights the necessity for the ongoing training of all staff in youth detention settings. A lack of knowledge, inadequate training and the inconsistent sharing of information have been found to inhibit the ability of custodial staff to provide appropriate care for young people with FASD in detention (Passmore et al., 2018).

A recent Royal Commission (Australian Government, 2017), which inquired into allegations of abuse and operational problems at Don Dale Youth Detention Centre in Australia, found numerous failings relating to poor case management practices and poorly skilled, inadequately trained youth justice staff who reported they were unsupported and under-resourced. These failings resulted in appalling abuses of young people, the majority of whom were Aboriginal (Australian Government, 2017). Although not the focus of this article, it must be recognised that the over-representation of Indigenous young people in justice systems globally cannot be separated from the well-understood problems of systemic and institutional racism and discrimination (Blagg, 2008; Harmes et al., 2019; Wacquant, 2009; Weatherburn & Ramsey, 2016). There is a small amount of literature specifically relating to the lack of focus on the employment and advancement of Indigenous staff in Australian prisons, which highlights that too few Aboriginal people have senior positions in these organisations, and as a result, they have little to no ability to contribute to leadership provision, decision-making, representing the views and wishes of the broader Indigenous community or training in cultural competency (Shepherd & Phillips, 2016). Without a concerted effort to build the numbers and capacity of an Indigenous workforce, institutional racism will continue unabated (Shepherd & Phillips, 2016). These authors argue a commitment from the top to bottom levels of organisations is required to facilitate the ‘unbuilding of racism’ in institutions (Shepherd & Phillips, 2016, p. 308).

In their inquiry, the NT Royal Commission (Australian Government, 2017) also found there were inadequate needs assessments of young people being undertaken. The report highlighted the importance of case-managed throughcare planning which can assist in smoother transitions back to communities for young offenders and enable greater consistency in transitional support for their education and rehabilitation.

The views of staff in education services in youth detention have received some qualitative inquiry. One US study explored an ‘Alternative Education Initiative’, which examined the way schools could play a role in curbing offending from the perspective of youth justice staff (Atkins et al., 2005). Ninety-five per cent of participants in that study cited inadequate funding and a lack of resources as the main barriers to providing successful alternative education programmes. An Australian study which explored the education of young people in detention (Strnadova et al., 2017), acknowledged the complex needs and lives of incarcerated young people and highlighted the well-known high levels of disengagement from school for young offenders. Education provided within a youth detention facility can therefore present an opportunity for incarcerated young people to address learning deficits as classes are usually small, and education is mandatory (Tobin & Sprague, 2000). An Australian study of youth detention staff, which explored their views of having a speech–language intervention, found staff valued the speech pathology service, and moreover, the intervention assisted staff to understand more about the young people and provided them with strategies and support to better engage with the young people (Snow et al., 2017). Even though delivering effective interventions can be challenging within a detention centre environment (Goldson, 2005; Lanskey, 2011), these studies suggest that education, health and welfare services in custodial settings play a vital role in improving wellbeing and creating positive futures for young offenders.

Due to the lack of knowledge about FASD in detention facilities and the need for workforce support to assist in the management of young people with FASD and other neurodevelopmental disabilities, a study was undertaken in an Australian youth detention centre (Bower et al., 2018; Passmore et al., 2016). The study established a FASD prevalence of 36%, the highest known estimate in a justice setting worldwide. In addition, 89% of young people were identified with at least one neurodevelopmental impairment in the severe range, including 21% of young people with impairment in cognition (Bower et al., 2018). There are no known published qualitative studies that explore the views and experiences of non-custodial detention centre staff who provide services to young people with FASD or who have been working in a detention centre facility during a FASD prevalence study. To provide understanding of the impact and value of the prevalence study, this qualitative research we report now aimed to capture the perspectives of non-custodial detention centre staff to identify the value of the study and to describe the impact the study had on their services.

6.4 Study Setting

The Banksia Hill FASD study is the first of its kind undertaken in an Australian youth detention centre. The aims of the study were fourfold: to estimate the prevalence of FASD among young people sentenced to detention; to develop and evaluate a FASD screening instrument; to design, administer and evaluate a workforce development intervention with custodial staff; and to conduct a qualitative evaluation of the prevalence study.

Clinicians undertook comprehensive medical, neuropsychological, motor skills, and speech and language assessments with participating young people. Following assessments, multidisciplinary meetings were undertaken with the clinical research team, and an extensive Assessment Results and Recommendations Report containing diagnostic information and individualised recommendations was written for each young person (Passmore et al., 2016). The formal workforce development component of the study involved the production of training resources and a structured training intervention for custodial staff, but the intervention stage had not commenced at the time this study was undertaken (see Passmore et al., 2018).

Upon request by the education staff at the centre, members of the research team who conducted clinical assessments also provided information about FASD to non-custodial staff via a series of professional development sessions, which took place simultaneously to this study. These sessions also included classroom-specific strategies for young people with neurodevelopmental disability and information about age-appropriate resources.

The views of those who participated in two of these professional development sessions are reported here.

6.5 Methods

6.5.1 Participants

A case study research methodology (Yin, 2013) was used to capture the views of noncustodial staff in education, health, psychological, case management and Aboriginal welfare services in the detention centre. Purposive sampling was used to recruit participants. Initial planning for focus groups occurred through email contact with the lead researcher and team leaders for each service. All team leaders agreed to their team's participation in a focus group which was scheduled during existing team meeting times. Although this maximised the opportunity for inclusion, it also meant competing priorities influenced the length of time of the focus groups, which ranged between 20 and 45 minutes. Focus groups were held on-site with the following participants: case managers (n = 6), psychologists (n = 5), educators (n = 18), and a follow-up educator focus group (n = 14) with overlap of some participants in the two groups. Individual meetings were held with staff members from the health service (n = 1) and Aboriginal welfare officers (n = 2).

6.5.2 Data Collection

Focus groups and interviews were used as the methods for data collection. Five topics for discussion were provided to the detention centre staff team leaders from each service, who shared these topics with group members prior to the focus group. The topics were (1) FASD assessments, (2) impacts of the research for staff and for the young people, (3) access to and use of the young people's Assessment Results and Recommendations Reports, (4) participants' thoughts on the value of the strategies generated by the research team and entered into the OMS and (5) any questions, comments, concerns or suggestions the staff have about FASD, cognitive disabilities or the research itself.

At the beginning of the focus groups and interviews, a summary of the topics for discussion was provided to the group. Following explanation that participant responses would remain anonymous, verbal consent was received from all participants. For some meetings, two researchers attended, one facilitating and the other scribing verbatim quotes and noting non-verbal observations.

One researcher paraphrased the content of the focus group back to participants at the time of discussion to acknowledge their input and ensure data validity from participant perspectives. Further, the two researchers met immediately following each focus group meeting and recorded a discussion of their observations for later analysis.

Due to the large number of teaching staff involved in two focus groups, they are referred to as educators. To protect the identity of participants in focus groups and single interviews, they are identified only as 'participants'.

6.5.3 Data Analysis

Two researchers independently reviewed the data to identify key themes, with preliminary analysis undertaken immediately following data collection. The lead researcher entered the data into NVivo 11 Pro (2016). Data were analysed using thematic network analysis (Attride-Stirling, 2001) and triangulated across all focus groups and interviews. Study team members regularly met and reviewed themes noted by the lead researcher from the participant data. These reviews helped to ensure consistency in data interpretation through multiple perspectives and iterations. The lead researcher also conducted multiple analysis reviews at regular time points over a 12-month period to compare, confirm and develop final data interpretations.

6.6 Results

We present our findings according to the following themes: (1) FASD assessments, subtheme (i) impact on service delivery; (2) Assessment Results and Recommendation Reports; and (3) identified barriers to maximising benefit from the prevalence study. Subthemes from Theme 3 included (i) professional development opportunities, (ii) resourcing and staffing and (iii) communication and information access.

6.6.1 Theme 1: Fetal Alcohol Spectrum Disorder Assessments

The first theme relates to the multidisciplinary team assessments conducted with 99 young people in the prevalence study (Bower et al., 2018). Concern for the young people was expressed by some participants. Several participants reported the young people often returned from assessments ‘tired’, ‘exhausted’ and ‘needing quiet time’. One participant said that some of the young people felt they were involved in the research ‘because they are stupid’ or because ‘the courts think they are idiots’. Other participants were concerned about trauma. They said, ‘I hope the [research] team take into account the amount of trauma these young people have been through’.

Overall though, no participants observed any major problems in the young people who were involved in the assessments. One participant, for example, said, ‘everything is going well. We have no concerns about the project’, while another said, ‘the young people aren’t really fussed [about the assessments] that I’m aware of’.

Participants from across the different groups provided positive examples of outcomes for some young people whom they worked with. In one focus group, an educator highlighted a raised awareness for the young people from the assessments about their difficulties when they said:

> the young people often have ‘light bulb’ moments following the assessments … they will impulsively do something and then go ‘oh but I do that because my brain’s a bit different’. It has made them think about why they do things.

Another participant said a young person was identified through the assessments as having an intellectual disability and was subsequently referred to appropriate disability services from which ‘he is now receiving additional support which has made it much easier for working toward better support in all aspects of his life on his release’. Another participant said that ‘having a FASD assessment and subsequent diagnosis has had a positive effect on sentencing and on the court personnel’s understanding of FASD’.

There were a small number of participants who were sceptical about FASD and its relationship with the young people’s criminality. One participant asked, ‘what does it all really mean? [a FASD diagnosis] Is it around lesser sentences?’

Another asked of FASD and crime generally, ‘is it a cop-out?’ Most participants, though, were supportive of assessments for young people in detention. The importance of the assessment and diagnosis and the necessity to develop behavioural management strategies were captured by one educator who said, ‘He has problems, he is not the problem. We must be part of the solutions for him’.

6.6.1.1 Subtheme (i): Impact on Service Delivery

Communication problems and consultation about the research were central to the feedback on the impact of the research for non-custodial staff. One participant said, ‘communication gets lost and people are often not informed about what is going on, particularly when staff are transient and staff changes are significant over time’.

Across all groups, there were comments such as the following: ‘we didn’t have any input into how it [the research] was going to be run and what was required’, and ‘there is a need for courtesy to be given to the … staff [by the research team] about what is expected from the staff on site’.

Participants felt their own service provision had been impacted by the study, and for some it was intrusive on their time. There were educators who expressed frustration when the young people were called out of the classroom for assessments or interviews conducted for the research. One participant said, ‘it was frustrating when young people were removed from programs or recreation times as they are really important for the young people’.

Participants commented, ‘… [we] are extremely unhappy about the lack of consultation by the research team’, ‘communication about the testing should have been more effective’ and ‘communication has been the central problem in the conduct of this project’.

6.6.2 Theme 2: Assessment Results and Recommendations Reports

The second theme refers to participant views on the Assessment Results and Recommendations Reports (report/s). Comprehensive reports were generated for each young person who completed assessments. Most participants had seen a report, and for many, the reports provided clarity about a young person’s behaviour and, as put by one participant, their ‘ways of being’. Participants said that the reports and the research had a positive impact on their own professional practices. One participant said, ‘the reports and the project generally, have positively impacted on our own practices and the way we talk to and work with the young people’.

Another participant said that a report they had read for a young person ‘is very thorough and addresses what problems were found’. Several participants commented on the limitations of acting on the recommendations provided in the reports. One participant said, ‘we are often not sure of whose responsibility it is to organise things recommended in the reports’. Another participant said, ‘various recommendations made in the reports are outside the scope or funding of the service. For example, recommendation for eye testing and glasses’.

The value of the reports external to the detention centre was also raised. One participant suggested, ‘it would be useful if the reports were incorporated into a release plan for Youth Justice Officers. This could provide some continuity of management of the young people in the community’.

Not all staff had access to completed reports, as this was dependent on dissemination from detention centre management. However, staff were provided with prioritised strategies for managing young people via OMS. Across all the groups, participants advised that in the current format ‘TOMS strategies are not useful’. Another participant said, ‘it is often difficult to find things—strategies are often not available for a young person or are hard to find’.

The participants explained that there can be many case notes and that they ‘would not have the time or the willingness to trawl through TOMS to find three strategies which may or may not be useful’. Another participant said, ‘access to TOMS strategies are inconsistently recorded and often difficult to find’. A participant had not seen any of the strategies provided for the OMS system.

Participants also provided solutions. One participant felt that ‘strategies and recommendations should be independently available immediately if effective in addressing concerns about the young person’, while an educator suggested that ‘a simple format could be developed which uses codes/stickers to indicate diagnosis or disability or individual difficulty, but at the same time, maintain the confidentiality and dignity of the young person’.

6.6.3 Theme 3: Identified Barriers to Maximising Benefit from the Study

Participant questions and statements across all the focus groups and interviews illustrated the many barriers to gaining maximum benefit from the research. This theme is related to barriers identified by participants that inhibit their ability to support the needs of young people in their care. Participants across all groups identified essential requirements to realise the full value of the research and assist the young people's rehabilitation.

6.6.3.1 Subtheme (i): Limited Professional Development Opportunities

The most prevalent need identified was for training and information about FASD and neurodevelopmental disability and its effect on young people. Participants had concerns about how to address the implications of a young person's FASD diagnosis and how well equipped they were in their professional roles to address this sensitively with a young person. Participants commented:

> training and information would be useful;
>
> we need training and information sessions—on FASD, ID [Intellectual Disability], and other co-morbidities such as ADHD; training specific to FASD in justice would be good;
>
> more training and information on FASD, and specifically FASD and justice would be useful.

A participant also added, 'We need time off [for training and professional development]'. Educators also provided feedback on the value of the professional development sessions provided by the research staff, saying:

> The professional development sessions [run by the research staff] were fantastic, really beneficial in terms of understanding sensory issues particularly;
>
> Information on motor skills [in relation to handwriting] was very useful;
>
> Information during the professional development session provided by the speech therapist and occupational therapist was very useful.

6.6.3.2 Subtheme (ii): Inadequate Resourcing and Insufficient Staffing

Participants were keen to ensure relevant support which, as put by one participant, ‘reflects the special needs of the young people’ were available for young people with FASD and other disabilities. An educator said, ‘teaching is very difficult because the usual teaching aids are not available to educators [in youth detention]’.

The researchers in an education focus group asked what, from the project and in general, they had not found useful and any gaps they see in relation to delivery of education to children/young people at the detention centre who have been or may be diagnosed with FASD. Specific resource needs were overwhelmingly identified for the education of these young people. A number of times, participants and educators discussed eye testing and the provision of glasses for the young people. One educator said, ‘eye and hearing testing is needed for all—with glasses provided if required’. Another educator said, ‘literacy and numeracy programs need to be developed specific to those with cognitive disabilities because the young people experience shame of not being able to read’. Other needs identified were ‘access to computers and programs’, ‘sensory objects such as headphones, beanbags, weight blankets’, ‘a variety of workstations to provide young people with flexibility’, ‘air-conditioning in the workshops’, ‘reading specialists’ and ‘education assistants’.

An educator talked of sensory resources not being understood within the system in which the teaching is taking place and that resourcing does not reflect the usual classroom experience that teachers would anticipate in an external environment where there was an identified student need ‘… it is hard to justify resources, for example, soft furnishing or headphones to address sensory processing in the security environment … these are not seen as usual in our education environment’.

Concern about the teacher/student ratio and insufficient staffing was raised by several educators. One educator said that ‘the current teacher to student [meaning student to teacher] ratio is 9:1—one over that of a custodial officer who has an 8:1 ratio and this has direct implications on teachers managing the daily classroom environment’.

Participants considered that entry to be a relief teacher involved too much red tape. As a result, they spoke of ‘custodial officers are taking activities groups and teachers are being moved around’. Another educator described this as ‘plugging holes, rather than maintaining consistent teaching practice with a group of young people and this has a destabilising effect’. One participant suggested that ‘reviewing the current 9:1 student/teacher ratio to be consistent with other juvenile justice services around the country would be very beneficial for the young people’.

Participants identified the employment of specific professionals as integral to successful future interventions which may result from the research findings, necessary because as identified by an educator, ‘we are not able to provide quality education. In other settings outside [the detention centre], supports are put in place when children have special learning needs’. One participant said, ‘it would be good to employ an Educational Psychologist to develop individual learning plans which focus on the young people’s identified strengths and weaknesses’. Another said, ‘employing a speech therapist will be integral to successful future interventions which may result from the findings in the study’.

6.6.3.3 Subtheme (iii): Poor Communication and Information Access

Problems with communication and sharing information across services were discussed in all the focus groups. Participants identified the operation of service silos as a major factor impeding access to information about the young people, both internally, within the detention centre and externally, across the community and education sectors. Educators said that they are not provided with the information they need about the young people. They provided examples such as the following: ‘having no knowledge of a young person’s family history or their circumstances’ and ‘[not knowing] whether a young person had a previous diagnosis or is on medications’.

Of significant concern to the educators was their inability to access the young people’s school records: ‘they [school records] do not accompany the young person from either primary or high school to [the detention centre]’.

Identified communication problems extended outside the detention centre. Another educator said, '[the detention centre] and 'the outside' don't communicate well to assist young people with transition to the community to maintain continuity of education'. Similarly, a participant talking about working with the community sector said, 'they either don't communicate or communicate poorly'.

6.7 Discussion

We have presented the voices of non-custodial staff who delivered support and rehabilitative services to young people who participated in a FASD prevalence study at an Australian youth detention centre. Importantly, the study findings suggest that the assessments did not appear to have a detrimental effect on the young people and have positively increased the awareness of staff about the young people's difficulties and some of the reasons for them. Although there were some negative comments regarding the broader impact of assessments on the young people, there were positive individual outcomes identified by the participants. Overall, assessments completed with the young people were deemed by the non-custodial staff to be beneficial.

The project was governed by a leadership team, cross-sector senior government representatives (health, education, child protection and justice) and other representatives over the term of the study to ensure the project was applied smoothly. For many reasons, including the necessity to prioritise security over research requirements (see 'Limitations and Strengths' section), communication across the detention centre about the project was the responsibility of the detention centre management and was largely out of the hands of the research team. Despite the study being a carefully planned and detailed process (Study protocol: Passmore et al., 2016), communication problems, relating both to the research and more broadly in the detention centre featured in participant feedback about the impact of the research for non-custodial staff. The results suggest that future research would benefit from broader consultation with all centre staff throughout the development of the research. Further, regular consultation between the research team and all staff could help overcome challenges or clarify misunderstandings about the research. Moreover, in order to manage security priorities, it is important that future research consider adopting a flexible approach to the time span of the research and to consider the potential for conducting staff interviews in external settings.

Some participants felt that they had not effectively been included in the design of the research and had trouble accessing information provided for them by research staff. Participants expressed concern at having young people taken out of programmes to attend aspects of the research project including interviews and assessments. Participants also raised concern about some young people experiencing fatigue. Much time was invested in minimising harm to young people undergoing assessments in the development phase of the research. Researchers conducting the assessments were flexible. If the young people were tired or appeared to be unable to perform the required assessments, they were offered food drinks and breaks. In some cases, assessments were split into two sessions. These aspects of the results from the interviews and focus groups in this study provide valuable guidance if future studies of this nature are to be undertaken in a youth detention centre.

The perspectives of the non-custodial staff in this study also provide an important contribution to understanding the factors which have an impact on the abilities of the workforce to support and rehabilitate incarcerated young people living with FASD and other neurodevelopmental disability. Participants articulated the benefits they gained from the information provided about the young people in the reports generated in the study. It was evident, however, that recommendations in the reports caused confusion, and there was a lack of understanding of the purpose of the reports. Considering the high level of neurodevelopmental disability identified among the representative sample of 99 young people assessed, and the likelihood that more than one in two will return to detention (DOJ, 2017), these strategies and reports need to be made accessible to all staff to enable better management and smoother transitions back into the community for these young people. This was particularly evident in the comments about staff access to the OMS and access to strategies and reports on the young people. Notably, the OICS (2018) also identified poor information sharing and limited access to important information, including on the OMS. This included information sharing about the young people and resulted in staff not having the information they needed to plan services and interventions conducive to rehabilitation. The research team requested the development of a specific tabulated area on the OMS so as to easily communicate assessment results and individualised management recommendations. This tabulated area on the OMS was not established during the study period. The DOJ initially mandated the mechanism for recording no more than three priority management options into the body of daily OMS recordings and so explains frustration described by the participants.

Effectiveness of programmes for young people in detention is dependent on both early assessments and drawing data from a variety of sources to reliably capture the broad range of issues known to exist in young offenders (Bird et al., 1992; Murphy et al., 2007; Wasserman et al., 2003). A lack of comprehensive social, educational and medical histories has implications for understanding and responding to the complex needs of young people in detention (Knowles et al., 2012) and their care on return to communities (Kumwenda et al., 2017). The results of this study with non-custodial staff suggest that there are significant problems with siloed operations and difficulty with accessing and sharing information across the services. Educators, for example, highlighted their inability to access information, including previous assessment or diagnostic information, family histories and, of significant concern, the young people's school records. Participants identified this as a major factor affecting their ability to provide effective services to the young people.

Not having the resources to undertake their jobs effectively was a major concern identified by participants. For education participants, they identified an inappropriate teacher/student ratio which directly impacts their ability to teach. The OICS (2018) report identified the school at the detention centre as being understaffed for years and described education services as 'one of the biggest casualties of [the detention centres] instability and lack of direction' (p. xi). Due to teacher shortages, OICS (2018) found that it was almost daily practice for classes to be supervised by a custodial officer, saying, ‘this is not a standard that would be accepted in the community, and it should not be accepted at [the detention centre]’ (p. 49). While the teacher/student ratio would be suitable in mainstream education, working with a population where 89% have significant neurodevelopmental impairments makes it incredibly challenging to provide appropriate individual attention when teaching. Provision of resources for young people, such as hearing and eye testing, along with the provision of glasses, was also raised a number of times across educators and participants. Given the already significant challenges experienced by these young people, not having access to hearing testing, eye testing or glasses is likely to further impede any chance of progress, particularly in school. Training and professional development about neurodevelopmental disability and FASD (and having allocated time to attend training) was also a need identified by many participants in this research. As highlighted in the literature (Hancock, 2017; Passmore et al., 2018; Wasserman et al., 2003), ongoing training is essential for staff to better understand the needs of young offenders and to develop skills that can enable staff to design and deliver rehabilitative programmes.

Many of the young people assessed during the prevalence study did not have their disabilities previously recognised despite significant involvement with services such as child protection, youth justice, and health and education services (Bower et al., 2018). This is consistent with international scholarly literature indicating that young people enter the justice system without having a variety of health and cognitive disabilities recognised (Anderson et al., 2016; Dias et al., 2013; Leonard, 2016; Sotiri & Simpson, 2006; Wasserman et al., 2003). It demonstrates that despite high levels of neurodevelopmental disability warranting earlier assessment of these young people, they have slipped through the cracks in multiple systems of care and education over their lives. It is essential to consider assessment for previously unidentified health, mental health and neurodevelopmental problems, both on entry to detention and throughout their incarceration. This could potentially provide a key turning point to enable the rehabilitation of youth in detention.

6.8 Limitations and Strengths

The Banksia Hill FASD study is the first to determine the prevalence rates of FASD among young people in an Australian youth detention centre. Significant work on the design of the study took place with widespread consultation occurring within the detention centre and in the broader community. Conducting research within a youth detention centre poses unexpected challenges and environmental limitations. Over the time the focus groups occurred, the detention centre was experiencing considerable instability and research processes were adapted according to operational and security requirements of the detention centre. There were frequent critical incidents which escalated between 2016 and 2017, creating an unpredictable and unstable environment. Staff assaults, roof ascents by detainees and regular violent incidents commonly occurred (OICS, 2018). The detention centre was frequently attended by the tactical response agency, the Special Operations Group, which resorted numerous times to deploying flash bombs using chemical agents and other distraction devices to restore order at the centre (OICS, 2018). As a result in parallel and preceding the commencement of the research project, human resource grievances and workload issues were chronic points of tension. The challenges faced by non-custodial staff in such a complex setting contributed to the themes which were raised by participants.

A strength of the study was that the research team were present on the campus for more than 2 years. Participants in all components were advised that there was opportunity for follow-up or clarification from the research staff about any aspect of the study, including supporting assessed or diagnosed young people. Detention centre staff and participating young people frequently took advantage of this opportunity.

6.9 Conclusion

Comprehensive assessments for FASD and neurodevelopmental disabilities were viewed by non-custodial staff participants as a necessary and worthwhile part of their service provision. Moreover, the reports were considered to provide a comprehensive understanding of the strengths and difficulties of the young people assessed. However, participants identified barriers to gaining full benefit from the study. Insufficient resources, including training and professional development, and inadequate staffing were key challenges. Further, inconsistent accessibility to information stored across electronic platforms designed to share assessment information and management strategies between rehabilitative services at the detention centre was identified as a potential barrier to utilising this information and providing effective rehabilitation services specific to the special needs of young people with FASD and neurodevelopmental disability. These findings are beneficial for youth detention centre staff working with young people with FASD or neurodevelopmental disability. Further, they are more broadly applicable in youth justice populations. Assessments can provide valuable information for rehabilitative support about the well-known complex health, mental health and support needs of young people in detention. If rehabilitative staff are to provide young people with opportunities for change, then participants in this study provide key insights to inform variations in service delivery which will be required to meet the unique and complex needs of incarcerated young people.

6.9.1 Authors’ Note

Any material published or made publicly available by the authors cannot be considered as either endorsed by the DOJ or an expression of the policies or view of the Department. Any errors of omission or commission are the responsibility of the researchers.

6.9.2 Acknowledgments

The authors thank all at Banksia Hill Detention Centre for their engagement in, and support of, the study. They thank the Banksia Hill study team, the members of the Consumer and Community Reference Group, the Steering Group and the Reference Group, and the Chief Investigators and Associate Investigators for their ongoing contribution to, and support of, the study. The authors thank the (former) Department of Corrective Services and (former) Department for Child Protection and Family Support for their support of the study. The authors acknowledge the staff with these services who have been involved with and continue to support this important work.

6.9.3 Authors' Contributions

SLH: qualitative researcher; literature search; conducted interviews; thematic analysis and data interpretation; wrote the first and final draft. TR: thematic analysis; data interpretation; editing and writing. RW: data interpretation; editing and writing. RCM: Clinical assessor; data interpretation; editing and writing. NRK: Clinical assessor; data interpretation; editing and writing. JF: thematic analysis; data interpretation; editing and writing. HMP: thematic analysis; data interpretation; editing and writing. BS: Clinical assessor; data interpretation; editing and writing. MO: editing and writing. CB: data interpretation; editing and writing. All authors read and had the opportunity to contribute to all drafts of the paper. All authors approved the final paper.

6.9.4 Availability of Data and Materials

For further information about the data, please contact the corresponding author.

6.9.5 Ethical Approval

Ethics approval has been granted by the Western Australian Aboriginal Health Ethics Committee (approval number 582) and University of Western Australia Human Research Ethics Committee (approval number RA/4/1/7116). Research approvals were also gained from the (former) Department of Corrective Services (project ID 335) and the (former) Department for Child Protection and Family Support (approval number 2015/8981).

6.9.6 Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This research is funded by the National Health and Medical Research Council (grant number APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341). SLH is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award and the Centre of Research Excellence: Indigenous Health and Alcohol, University of Sydney. NRK is supported by a FASD Research Australia Centre for Research Excellence Scholarship and Australian Government Research Training Program Scholarship. HMP is supported by an Australian Government Research Training Program Scholarship and the Stan and Jean Perron Award for Postgraduate Excellence.

6.9.7 ORCID iDs

Sharynne Hamilton: https://orcid.org/0000-0002-3057-8992

Jacinta Freeman: https://orcid.org/0000-0001-8784-7295

Chapter 7: Discussion

7.1 Yarning, Hearing Understanding, Knowing

Australia is experiencing unmitigated and ongoing problems related to the governance and management of justice-involved youth (Cleary, 2016) who have a myriad of complex problems relating to cognitive disability (Baldry et al., 2015; Dias et al., 2013; Indig et al., 2011; Indig et al., 2016) and FASD (Bower et al., 2018; Flannigan et al., 2018). These disabilities are often unrecognised and undiagnosed, and children and youth are being managed by a justice system that is blind to their disability (Bower et al., 2018; Dias et al., 2013; Flannigan et al., 2018; Hamilton, Reibel et al., 2020; Wasserman et al., 2002, 2003). As is the case in global research (Badry & Felske, 2013; Burd & Popova, 2019; Streissguth et al., 2004) many of these youth in Australia are also involved with the child protection system (Bower et al., 2018; Hamilton, Maslen, Best et al., 2020; Malvaso, Delfabbro, & Day, 2017a, 2017b; Tilbury, 2009). Every state and territory has reported experiencing significant problems managing the behaviours of youth populations in detention (see Cunneen 2016). By almost every measure, the punitive approaches used in Australia's youth justice systems are failing to serve the purpose of protecting and rehabilitating the youth in their care, as most recently evidenced in the Don Dale Royal Commission (Australian Government, 2017). Australia spent $769.5 million on youth justice services in 2016–2017, including $482.1 million on incarcerating youth (Productivity Commission, 2018). The economic and social costs indicate an urgent imperative for proactive approaches from governments to advance frameworks of positive youth justice (PYJ) (Butts et al., 2010).

Through peer-reviewed publications, this thesis has explored participants' understandings and experiences of diagnostic assessments for FASD. The findings from the yarning interviews with detained youth (Hamilton, Reibel et al., 2020, Hamilton, Maslen, Best et al., 2020) and their caregivers (Hamilton, Maslen, Conigrave et al., 2020), as well as the focus groups with non-custodial youth justice staff (Hamilton, Reibel et al., 2019) who participated in the prevalence study

(Bower et al., 2018), provide valuable information to assist in developing a more proactive and positive approach to youth justice service provision. Difficulties that can be experienced by those with FASD, such as an impaired ability to understand and communicate, memory problems, and trouble with attention and judgement (McLachlan et al., 2014), were all found to be present among the young people who participated in this study. Considering the participants' views and experiences is a critical component of minimising potential harm from assessments and diagnosis. This is particularly important for the Aboriginal participants, who carry the additional burden of intergenerational trauma (Cunneen & Tauri, 2019; Cunneen & Rowe, 2014; Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Tuhiwai Smith, 1999; Tynan et al., 2007) and who make up the majority of the participants in this research. The prevalence study results (Bower et al., 2018) present clear evidence that considering routine screening for neurodevelopmental impairments in youth justice service provision will be critical in the future. The views, knowledge and understandings of the participants of this study inform the analysis, conclusion and recommendations for future directions presented in this thesis.

This discussion will explore the experiences and understandings of the value of receiving a diagnosis of FASD or neurodevelopmental impairment and accompanying diagnostic resources. Negative aspects such as the potential for medical dominance or stigma and labelling will be discussed with a view to better understanding how assessments might be conducted in a holistic and integrative way in the future. Exploring ways to combat potential stigma from diagnosis by privileging Indigenous ways of knowing and understanding will be discussed, with a focus on the importance of Indigenous governance and self-determined responses to future planning for the diagnostic assessment of justice-involved youth. This is critical given that there has been little acknowledgement of the complex intersections that exist and drive the over-representation of Indigenous people in criminal justice systems (Cunneen & Tauri, 2019; Cunneen & Rowe, 2014; Indig et al., 2016; Morrison, 2004; Tauri, 2018). There is a need for Australia as a nation to confront its colonial history, decolonise justice and address systemic racism, and recognise the potential benefit of embracing Indigenous knowledge systems for developing strategies or policies around crime control (Cunneen & Tauri, 2019; Simpson et al., 2012; Tauri, 2018). As, increasingly, solutions are sought to the growing rate of Aboriginal and Torres Strait Islander youth in detention (Australian Institute of Health and Welfare, 2018), the next aspect of the discussion will explore the development of an assessment model based on a recovery capital framework (Best & Laudet, 2010) and necessary adjustments to the framework (Hamilton, Maslen, Best et al., 2020) given the high level of FASD and associated neurodevelopmental impairments found in the prevalence study (Bower et al., 2018).

As important as it is for these youth to understand and communicate in their systems of care, they also need to be able to explore pathways to positive futures. How we inclusively support and empower these youth, their families and communities will be the final aspect of this discussion. The discussion will conclude by providing some potential answers to the thesis questions and aims, which sought to understand whether conducting routine assessments for youth involved with the justice system could be beneficial and, if so, how they could be developed to ensure minimum harm and best benefits for all. I argue that for children and youth who are involved, or at risk of involvement, with the law, we must ensure equitable access to assessments for neurodevelopmental impairments that are affordable and that have long-term viability as part of youth justice service delivery. We must also ensure that assessments are beneficial and provide effective and meaningful support for the young people and their families. I further argue then, that for Aboriginal and Torres Strait Islander communities, this will be most effective when the narrative becomes about healing and recovery, and where solutions and interventions are led, designed and driven by Aboriginal and Torres Strait Islander peoples and communities.

7.2 Screening and Diagnosis: A Necessary Inclusion for Youth Justice

Eighty-nine per cent of the young people who participated in the research had at least one severe undiagnosed neurodevelopmental impairment (Bower et al., 2018). This statistic provides significant evidence that screening and diagnostic services should be implemented as a routine aspect of youth justice service provision. Screening for neurodevelopmental impairments both on entry to, and throughout involvement with the justice system provides an efficient mechanism for gathering information, identifying risks and needs, and promoting consistency in practice (Young et al., 2006). This then supports appropriate referrals to external services to ensure successful transition between detention and life in the community (Altschuler & Armstrong, 1994; Hancock, 2017; Potter, 2014; Wasserman et al., 2003). Importantly, there is a high likelihood that ascertaining confirmation of maternal alcohol consumption in youth of this age will be difficult (Freeman et al., 2019), suggesting that a broad focus on assessing neurodevelopmental impairments would be more equitable. Focusing narrowly on prenatal alcohol exposure and the potential for FASD risks too many youth living with neurodevelopmental impairments remaining undiagnosed and therefore not having access to the necessary support that should accompany the receipt of a diagnosis (Bowker & Star, 1999; Jutel, 2009).

How the non-custodial staff who participated in focus groups experienced the prevalence study will valuably inform future youth justice service delivery. These staff viewed comprehensive assessments for young people as a necessary and worthwhile part of their service provision (Hamilton, Reibel et al., 2019). Together with having access to the multidisciplinary diagnostic reports, staff were provided with a comprehensive understanding of the strengths and challenges faced by the young people in their care. This information gave them valuable tools to plan service delivery that was responsive to the young people’s neurodevelopmental and functional needs. Further, the diagnostic reports provided comprehensive information that they can use to assist young people affected by neurodevelopmental impairments (Bower et al., 2018; Hamilton, Reibel et al., 2019; Kippin, 2018; Passmore et al., 2018). This is important given that it is a critical function of diagnosis to provide a pathway to treatment, education and support (Bowker & Star, 1999; Jutel, 2009). There were challenges which impacted on the benefits gained for non-custodial staff, which will be examined later in this discussion.

7.3 Screening and Diagnosis: The Hazards

The young people who underwent assessments and diagnosis learnt valuable information about themselves. However, the findings show that with or without neurodevelopmental impairments, and regardless of whether they are Aboriginal or non-Aboriginal, they need unique considerations when participating in interviews, one-to-one conversations and with other forms of communication (Hamilton, Reibel et al., 2020; Kippin et al., 2018). In the prevalence study (Bower et al., 2018), diagnosis was a product of communication between the young people and a multidisciplinary team of clinicians. That is, the young people were not passive recipients of their diagnosis (Turowetz & Maynard, 2019). Care must be taken when undertaking clinical assessments with vulnerable populations such as Indigenous children and young people (Ogilvie & Lynch, 2001); thus, it is critical to understand and guard against clinical assessments as a practice of medical dominance and power (Conrad & Schneider, 1980; Freidson, 1972; Nettleton & Jutel, 2011).

The practice of diagnostic assessment by professionals is often taken for granted, and the ways in which diagnostic work is embodied is overlooked (Freidson, 1972; Gardner & Williams, 2015). Diagnosis can be a contested space and place of resistance, uncertainty and ambivalence (Brown, 2008; Gill et al., 2010; Malacrida, 2001) and diagnostic labels can be sources of stigma and labelling (Brown, 2008; Goffman, 1963; Link & Phelan, 2001; Link et al., 1989; Major & Schmader, 2017; Scheff, 1974). As such, when a diagnosis has a label such as FASD, it is critical to consider the potential for stigma (Bagley & Badry, 2019; Choate & Badry, 2019; Coons et al., 2018). Stigma (and labelling) only serve to stereotype, devalue and discriminate against those who are not considered to be meeting desired and acceptable social standards (Dovidio et al., 2000; Link & Phelan, 2001). Whether labels occur through scientific measurements or are inferred from observations, they are acts of domination, marginalisation and stigmatisation. Indeed, Link and Phelan (2001) argue that those with power use stereotypical beliefs, feelings of prejudice and behaviours of discrimination to marginalise people and rob them of status.

Indigenous scholars have argued for an increased adoption of Indigenous ontologies and methodologies that build bridges for both conducting research and sharing benefits of research across Indigenous and non-Indigenous people, and for reducing the potential for harm and stigma (Bessarab & Ngandu, 2010; Doyle et al., 2017; Laycock et al., 2011; Moreton-Robertson, 2000; Rigney, 2001; Tuhiwai Smith, 1999; Tauri, 2018). This is particularly relevant for Indigenous children and their caregivers receiving a diagnosis for FASD or neurodevelopmental impairments who can experience and understand shame and stigma at the interface of traditional and contemporary culture and institutions (McKnight et al., 2018; Morgan et al., 1997).

This research has found important and necessary factors for consideration in the future development of models for assessment which can assist in reducing harm and the potential for stigma (Hamilton, Maslen, Best et al., 2020). Yarning with the young people using a variety of tools (Bryan et al., 2019; Meyer et al., 2018) provided flexibility and a space to manage poor listening and offered scope to be responsive to young people who were confused or who had difficulty understanding aspects of their impairments (Hamilton, Reibel et al., 2020). Using visual tools facilitated relationships (Driessnack, 2006; Glegg, 2019; Horstman et al., 2008), assisted the young people to better understand their assessments and provided necessary flexibility for participants. This component of the research suggests that yarning with young people during and after clinical assessments and diagnosis can enhance the sharing of knowledge with professionals and ensure mutual understanding. Providing information about strengths and challenges specific to their individual needs was empowering for the young people and, in this process, mitigated the potential for future harm and helped reduce shame and the potential for stigma.

Like these results from yarning with the young people at Banksia, there was also evidence of ways to mitigate harm for their caregivers, by taking note of cultural differences when receiving a diagnosis (Hamilton, Maslen, Conigrave et al., 2020). Highlighting the different understandings and worldviews of Indigenous people (Velarde, 2018; Vicary & Bishop, 2005; Vicary & Westerman, 2004), there was a distinct cultural patterning embedded in a community context for understanding and interpreting a diagnosis among the Aboriginal young people and caregivers who participated in this research. Non-Aboriginal caregivers did not discuss diagnosis in relation to their child's participation in community and focused on individual factors such as their children's education. These differences also applied to the way diagnostic information was understood and utilised (Hamilton, Maslen, Conigrave et al., 2020; Hamilton, Reibel et al., 2020). In keeping with the knowledge that Indigenous cultures are 'visual' (Hughes et al., 2004; Pewewardy, 2002; Thomas et al., 2019), the Aboriginal participants successfully reported using visual strategies to help their children. Non-Aboriginal caregivers also spoke of the potential for visual strategies, albeit to a lesser extent. As was the case with many of their children (Hamilton, Reibel et al., 2020), the diagnostic information was not as easily understood by the Aboriginal caregivers (Hamilton, Maslen, Conigrave et al., 2020). Reference to 'whitefulla speaking' making it difficult to understand the reports, and the need for additional assistance to translate and understand the content of the report in 'blackfulla ways' were all present needs for young people and their caregivers.

7.4 Screening and Diagnosis: The Context of Culture and Community

Diagnosis and its practices, like clinical assessments, must be understood in the wider context of culture and community, family relationships, social structures and interactions (Blaxter, 2004; Jutel, 2009). An expanded picture of diagnosis and its potential outcomes is critical for mitigating potential harm from receiving a diagnosis. Relatively little attention has been paid to the ways in which Indigenous peoples receive and understand diagnosis (Ayunerak et al., 2014; Rotenburg, 2016). Interviews with the young people's caregivers found that shame and stigma were both evident (Hamilton, Maslen, Conigrave et al., 2020). Shame responses (Olsvold et al., 2019; Zimmerman et al., 2015) such as not wanting to know about a child's diagnosis are of concern, whether it be for fear of stigma from the diagnosis, messages relating to maternal alcohol consumption and parental incompetence (Blum, 2015; Francis, 2012), or other negative labelling. Additionally, the research found that for many participants, insufficient community resources, poor service access and previously being let down by services likely affected their ability or willingness to engage with diagnostic interventions, education and support (Badry & Choate, 2015; Blum, 2015; Ennis-Cole et al., 2013; Garro & Yarris, 2009; Johnson et al., 2012; Malacrida, 2001).

For the Aboriginal caregivers, a diagnosis of FASD was not necessarily seen as negative because wellbeing and happiness were situated in the community. For some, this focus on community participation for their children was more important than having a diagnosis (Jutel, 2009; Pollack, 2009; Riessman, 2002; Velarde, 2018). There was an emphasis on diagnosis and its effect on cultural aspects of community life such as participation in cultural lore. There was a shared absence of the use of medical terminology and referral to FASD as ‘that thing in his head’ by the Aboriginal participants. Aboriginal grandmothers in this research were looking after high numbers of grandchildren with little support and with very different understandings of Western concepts of ‘disability’. They do not consider or view their grandchildren as disabled, and they see their grandchildren’s difference from other children as being unrelated to neurodevelopmental disability and more related to their community and social activities.

Traditionally, Indigenous children were assigned their community role by Elders and senior community members according to their strengths and community benefit (Gilroy et al., 2013). In Australian Aboriginal culture, there is no known word for disability and the concept can be a potential source of shame that may deter support-seeking (Gilroy et al., 2013). The concept of FASD is foreign, and we must consider this to both minimise harm and gain the best benefits from screening and diagnostic processes and resources. It is also important to note that although foreign, the participants linked the diagnostic information to clinical indicators for FASD and neurodevelopmental impairments such as difficulty with attention, impulsivity, problems understanding and following instructions, and conduct disorders (Baldry et al., 2015; McLachlan et al., 2014; Riessman, 2001). A diagnosis validated or provided an explanation for what the caregivers already knew about their children (Chamberlain et al., 2017; Sanders & Buck, 2010). This is important because it allows us to consider the knowledge that already exists and that can be drawn upon to inform ways to identify children and young people who are at risk of negative life outcomes and who may need neurodevelopmental assessments much earlier than when they are involved with the justice system.

As has long been argued, diagnosis must consider how illness and disease are framed and defined, and how these definitions and meanings are understood in the context of medical dominance and power (Conrad & Schneider, 1980; Freidson, 1972; Nettleton & Jutel, 2011). The practice of medicine, as well as its authority, is now more socially contingent and embedded in broader societal and technological changes (Lupton, 1997; Maslen & Lupton, 2019a, 2019b; Nettleton et al., 2004). As with other diagnoses (Magana et al., 2013), this thesis argues that translating medical information about FASD and neurodevelopmental impairments into culturally appropriate resources is critical for Aboriginal participants (Hamilton. Reibel et al., 2020; Hamilton, Maslen, Conigrave et al., 2020). This will assist in developing resources that will be used and that will allow Indigenous knowledge systems to contribute to strategies that can also help their families and communities to address broader community issues such as crime (Simpson et al., 2012; Tauri, 2018). It is imperative, though, that this be done ‘with’ rather than ‘to’ Indigenous people and communities (Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Tauri, 2018; Thomas et al., 2019; Tuhiwai Smith, 1999).

For justice-involved youth, a medical diagnosis for FASD or neurodevelopment impairments invites a different response and the opportunity for new approaches for their management. A diagnosis of FASD or neurodevelopmental impairments in children and young people in trouble with the law should encourage a shift in what is expected of them, as well as recognition of the effect that neurodevelopmental impairments have had on them. A diagnosis should provide an opportunity to support young people to develop strategies to deal with their impairments. Along with the likelihood that they have experienced significant trauma (Cunneen & Tauri, 2019; Hafekost et al., 2017; Hamilton, Maslen, Best et al., 2020; Indig et al., 2016), the relationships that the young people have within their families and networks, and their access to and participation in education, employment and prosocial activity, are all important to their future wellbeing. This research stresses the need to understand that children and young people with neurodevelopmental impairments do not learn from punishment (Blagg et al., 2015; Farrington, 2007; Goldson & Muncie, 2012). As such, there is a need to move towards PYJ strategies (Butts et al., 2010) and recovery (Best & Laudet, 2010) narratives and frameworks. The research data provide an important opportunity to consider strength-based, future-focused screening and diagnostic models for recovery in combination with assessments for neurodevelopmental impairments.

7.5 Considering Recovery

In the context of a population of mostly Aboriginal youth involved with the justice system, many of whom live with neurodevelopmental disability, this thesis has examined how the young people viewed their futures, the things that made them happy, what they hoped for and their views on their education and school (Hamilton, Maslen, Best et al., 2020). Their stories were filled with challenges that most people could only imagine, yet they were like the majority of teenagers their age. They yarned about their families being significantly important to their lives regardless of circumstances, and central to their happiness, support and connections. Without question, some families were a source of negative influence, such as for those who yarned about AOD use among family members and about the incarceration of other family members. Ultimately, as was the case with their caregivers, the yarning findings highlight how colonisation and consequent intergenerational trauma have resulted in high levels of community alcohol use (Fogarty et al., 2018; Memmott et al., 2001; Rynne & Cassematis, 2015) and high rates of FASD for justice-involved youth in some communities in WA (Blagg et al., 2015). Describing these negative colonising forces, young people spoke about being removed from their families and communities and growing up, or in some cases, ‘growing themselves up’ in state care (Hamilton, Maslen, Best et al., 2020).

When we consider the trauma and the resultant mental health and AOD problems in the general population of justice-involved youth (Baldry et al., 2012; Dias et al., 2013; Indig et al., 2011, 2016), there is a clear need for PYJ frameworks and service models that promote healing and recovery. Recovery can be understood in different ways: clinical recovery versus social recovery (Secker et al., 2002), scientific models versus consumer models of recovery (Bellack, 2006), and service-based recovery versus individual-based recovery (Schrank & Slade, 2007). Mostly these models argue that symptoms can be eliminated, and functional improvement can be assessed through a variable set of key factors (Slade et al., 2008). Other narratives of recovery have emerged from lived experience (Davidson & Strauss, 1992), emphasising an understanding of recovery as something other than the absence of symptom markers that indicate forms of functional impairment. These narratives view recovery as an ongoing individual and personal process whereby attitudes, values, feelings, goals, skills and roles change over time, and are developed to enable a fulfilling and meaningful life despite the limitations presented by an illness or disability (Slade et al., 2008). It is this narrative of recovery that this thesis draws on, supporting the idea that rather than imposing treatments, personally defined recovery may be achieved by offering long-term evidence-based interventions as a resource for the young people and their families to choose from and use in their recovery journey (Best, 2019). This narrative focuses on the wellbeing of individuals being developed holistically (Best, 2019), and finds common ground with concepts of relational governance, community empowerment and self-determination (Best, 2019; Burford et al., 2019; Cloud & Granfield, 2009; Nash et al., 2019; Slade, 2010; Tauri, 2018).

As has been discussed in this thesis, recovery is conceptualised in a recovery capital framework equally at three levels - personal, social and community (Best & Laudet, 2010) and allows for consideration of the well-evidenced trauma, AOD use and mental health problems that exist in the Australian youth justice population (Baldry et al., 2012; Cunneen & Tauri, 2019; Dias et al., 2013; Indig et al., 2011, 2016). Strength-based models that apply a recovery lens to addiction (White, 2008) and mental health problems (Leamy et al., 2011) have been significantly developed over the past two decades. Understanding the potential benefits of examining relational strength-based recovery frameworks (Best, 2019; Burford et al., 2019; Cloud & Granfield, 2009; Nash et al., 2019; Slade, 2010) is critical to successfully increase knowledge about individual and community assets. It is also critical to providing ways to build on strengths and understand what is missing or in need of development to assist and support youth to acquire the resources they need to build and sustain a meaningful life (Best, 2019; Nash et al., 2019).

A key aspect of recovery, and the main message for policy-makers, is that getting to the point of abstinence from AOD use or desistance from crime, or whatever the recovery objective may be, is not the end of the recovery journey. Moving away from crime and establishing prosocial identities involves building personal recovery capital like communication skills, interpersonal skills and other resources such as self-esteem, self-efficacy and resilience (Best & Laudet, 2010; Cloud & Granfield, 2009). It includes engagement with prosocial groups and institutions, and with meaningful activity (De'Ath et al., 2018; Irving, 2016; Sampson & Laub, 2003). Long-term recovery is about growth, development and finding things that sustain recovery, healthy communities and lifestyles by replacing crime, antisocial behaviour, violence and the causes of community dysfunction. Rather than a focus on individuals and symptoms, the focus ultimately, is on building up the capital assets and connectedness of individuals and communities (Maruna, 2009; Weaver, 2012).

Given the high level of neurodevelopmental impairments found in the prevalence study, existing recovery capital models for assessing wellbeing and growth in justice-involved youth must consider neurodevelopmental disability. Currently this is not the case, and adjustments are required (Hamilton, Maslen, Best et al., 2020). The individualised scaffolding of support is required for these youth to equitably participate in criminal justice processes. Not understanding support needs related to neurodevelopmental disability has long-term negative consequences, particularly in relation to recidivism (Boland et al., 1998; Streissguth et al., 1999). Much of the work drawn together in this thesis offers a framework with which to take inventory of the (capital) assets that justice-involved young people may or may not possess. The idea of considering 'justice capital' (Hamilton Maslen, Best et al., 2020) as part of the recovery process is a balancing act of creating a model based on the cultural principles of open communication. This is a core concept that is not just about assisting these young people to actively engage in the criminal justice process or to navigate their pathways to positive futures. It is an essential mechanism for building a future and building strength-based relationships. This is critical because networks, relationships and connectedness are the most important and influential components of recovery (Best, 2019). Justice capital presents an essential mechanism for ensuring that neurodevelopmental disability is detected and managed. It is an essential element for recognising unmet needs. In many ways, justice capital is the diagnostic tool of recovery capital—it provides avenues for treatment within a strength-based framework that promotes healing and growth, healthy relationships with families, communities and country, and information and support to facilitate equitable service access.

More broadly, community recovery capital (Brunelle et al., 2005; White & Cloud, 2008) plays an important role in healing. Significant influences such as having safe housing and being provided with meaningful opportunities for education and employment are built by promoting positive community attitudes. This is then bolstered by developing policies, providing resources such as recovery-focused rehabilitation centres and promoting a focus on recovery that can support the resolution of problems and reduce stigma (Best, 2014, 2019; Brunelle et al., 2005; White & Cloud, 2008). Recovery-focused policies and institutions play an important role not just in changing the lives of individuals, but in changing the capacity, health and wellbeing of the community, breaking down stigma and exclusion barriers, and integrating individuals with community resources (Best, 2014, 2019; Brunelle et al., 2005), particularly for those with FASD (Bagley & Badry, 2019; Choate & Badry, 2019; Coons et al., 2018; Hamilton, Maslen, Best et al., 2020). This research has highlighted that particular attention is needed to understand neurodevelopmental impairments and the education system. Although most of the participants said they liked school, they spoke of being negatively labelled or being ‘given up on’. They had often attended multiple schools, had been repeatedly suspended and many had disengaged from school prior to their incarceration. Disengagement and exclusion from school meant they did not have access to a wide range of peer support and influences that inform and promote recovery (Humphreys & Lembke, 2013). There was little evidence in the research of key relationships with professionals, nor that the education system is one which is currently providing turning points to recovery. Williams et al. (2015) point out that turning points in individual recovery are linked to authentic professional experiences and relationships, suggesting that critical measures are not what is done, but how it is done and what is offered. Recognition of the relationship between neurodevelopmental impairments and learning and behavioural problems (Carpenter, 2011; Page, 2001; Peadon et al., 2009) and providing assessments early could enable individual strategies to support relationships and improve educational outcomes.

Ultimately, for many of the young people there were limited opportunities and fewer resources to draw on to pursue their goals. As it is, schools are institutions of shame that present barriers to success for Indigenous students (McKnight et al., 2018). Despite their incarceration and disrupted schooling, the findings from this research clearly demonstrated that school was a significant source of learning, social and sporting opportunities. In the future, ideas from participants, such as ‘bush school’, which could influence how education is designed for future generations should be acknowledged, and young people should be engaged in the development of different types of education, particularly in the remote and regional communities. Many of these young people attended school because sport was on their timetable. Using sport, as a tool to engage youth in education and as a means of improving self-awareness and providing skills for managing impairments has much potential for these youth (Hamilton, Finlay-Jones, & Scrine 2019).

In addition to schools, this research has also shown that Banksia is not an institution providing turning points to recovery (Williams et al., 2015). The non-custodial staff were working with many young people who had complex trauma and unrecognised and undiagnosed FASD and neurodevelopmental impairments (Bower et al., 2018). The staff had minimal knowledge of the effects of neurodevelopmental impairments or FASD, little to no previous professional development opportunities and no access to clinical or support information (Hamilton, Reibel et al., 2020). They were understaffed and working with minimal resources, including a lack of teaching aids that are usually available for teaching children and young people with learning difficulties. The nature of the environment meant that there were high numbers of youth in classrooms and more of a focus on security than on rehabilitation and teaching (Hamilton, Reibel et al., 2020). As a result, the education staff spoke of the difficulty in justifying resources specifically related to managing neurodevelopmental disability. They described youth who were unable to access hearing and eye testing or be provided with glasses, and they overwhelmingly raised concerns about their ability to provide any quality education for the young people in their care. They described poor information sharing and a lack of access to comprehensive information about social, educational and medical histories (Hamilton, Reibel et al., 2020). In addition, despite 75% of the population of Banksia being Aboriginal, there were few Aboriginal staff and no Aboriginal staff in senior leadership roles at the time of the study. None of these factors are conducive to assisting recovery and rehabilitation for children and young people in their care.

Currently there are few affordable pathways to screening and diagnostic services for FASD or for detecting neurodevelopmental impairments in Australian justice-involved youth. WA has seen the emergence of FASD assessment clinics; however, these assessments are costly and do not offer a long-term economically viable option for youth justice services to ensure that justice-involved youth are routinely screened, and neurodevelopmental impairments detected and appropriately managed in a justice setting. A recent US article showed that, globally, there are 11.3 million young people aged 18 years and younger affected by FASD (Burd & Popova, 2019). These authors argue that routine screening and diagnosis by multidisciplinary teams is beyond the capacity of even the wealthiest of countries and, ultimately, is unnecessary for system change to occur. The authors highlighted that the phenotype of FASD is conveyed in systems of care such as foster care, criminal justice, health/mental health system and education system (Burd & Popova, 2019), and they argued that with simple modifications, these systems can make a big difference to the care of children and families.

Ultimately, the aim should be to view a diagnosis as a protective factor and to help develop the capacity of families to recognise the potential for their child to be struggling with neurodevelopmental impairments. By developing, with and for communities, a range of culturally relevant and informed resources, and encouraging early diagnosis there is potential to promote recovery and avoid exposure to adverse experiences that can lead to disengagement from school, mental health problems, AOD use and subsequent involvement with the criminal justice system (Hamilton, Reibel et al., 2020; Hamilton, Maslen, Best et al., 2020).

Chapter 8: Conclusions and Moving Forward

In general, we recognise that colonisation has had an array of negative effects on Aboriginal and Torres Strait Islander peoples and communities, yet we fail to apply a healing or recovery focus when managing these youth. The ‘Aboriginal problem’ lens in the justice, child protection and health arenas has been, and continues to be used to construct Aboriginal and Torres Strait Islander identities in contemporary Australia (Sherwood, 2013). This thesis has focused on Indigenous methods and knowledge, the concept of healing and recovery and on equitable access to services and support in the context of youth justice involvement. The peer-reviewed articles for this thesis show that there is great potential for change in youth justice. We now have new knowledge that provides an opportunity to rethink the way we understand, view and portray young offenders, and how youth justice service provision is delivered. It is impossible to ignore the high prevalence and impact of FASD and neurodevelopmental impairments in the WA justice system and how these might affect the life trajectory of diagnosed young people.

The key finding from this study is that there is a need to implement routine screening for neurodevelopmental impairments on first contact with the criminal justice system. The potential implications of not assessing and recognising neurodevelopmental impairments in children when they come into contact with the law, are that they will continue to be in trouble, will likely be repeatedly incarcerated into adulthood, and they will experience little to no improvement in their physical or mental health. Their futures will be costly in terms of both the social costs for individuals, their families and communities, and the high and increasing economic costs to governing Australian youth justice and broader social services (Productivity Commission, 2018). The findings from this research highlight the necessity to implement routine screening and diagnosis when children come into contact with the law and, moreover that this requires a multi-government agency approach. Securing a commitment from the youth justice, child protection, education and health sectors to meeting the neurodevelopmental assessment and diagnostic needs of children, particularly those involved with, or at risk of involvement with the law, must be prioritised.

The knowledge gained from the assessments was useful and provided explanations and reasons for what had been previously undiagnosed or unexplained. Professionals, caregivers and families gained insights into what young people need assistance with to understand or make the best out of the assessment and diagnostic process, how they made sense of the process, and their potential to use the experience to change their future pathways. The thesis has argued that to shape and implement comprehensive, integrated and efficient assessments for neurodevelopmental disability, there is great value in broadening the focus of assessments to include capturing information about recovery assets. Therefore, considering the development of a comprehensive assessment tool for neurodevelopmental impairments and recovery capital assets for justice-involved youth is recommended. Broadly, this would require five considerations.

First, it is critical to provide pathways for access to assessments that are viable long-term and affordable options for the youth justice system. There is potential to conduct neurodevelopmental assessments within youth justice settings that employ relevant clinicians (speech pathologists, neuropsychologists, occupational therapists and paediatricians) as part of the youth justice workforce. This would provide staff with knowledge of neurodevelopmental strengths and challenges for each individual.

Second, to assist recovery, assessments be holistic and capture the professional relationships, family networks and broader social relationships that can be used to assist young people. Developing an approach that employs community connectors or social workers to conduct yarning or conversational interviews with young people during assessments will provide an opportunity to share and gain knowledge about diagnostic results and needs, and to gather information about a young person’s life circumstances. This is important for enhancing the knowledge gained from the results of the assessments and predicting the need for effective future interventions.

Third, the information collected during assessments should be made available to all those working with the young person to enable a coordinated and holistic approach to interventions and recovery. Designing information systems that give staff the information they require to do their jobs is critical, particularly to assist with the care of youth in detention and in transition planning for returning to their family and community.

Fourth, any development of routine assessments requires a mechanism for regular evaluation. There is value in establishing pilot demonstration sites around WA that are designed and delivered with, for and by communities, and which are regularly evaluated. This allows for constant refinement and development, and a way to capture the information required to influence positive system transformation.

Fifth, and the most critical aspect of developing routine assessments for neurodevelopmental disability is consideration of the diverse nature of Aboriginal and Torres Strait Islander Australia. There cannot be a ‘one-size-fits-all’ approach to assessments, communities, organisations and programs. In some regions, infrastructure is significantly lacking, particularly in rural and remote areas where communities have suffered extreme social harms and cultural loss as a result of dispossession and colonisation (Human Rights and Equal Opportunity Commission, 1997).

Culturally and neurodevelopmentally responsive systems and policies and resources that support the resolution of problems and promote treatment, rehabilitation, care and recovery in all aspects of service delivery is critically required in the Australian youth justice system. Sound governance and processes that recognise empowerment, community ownership, leadership and decision-making, and that prioritise strong connection to land, family and culture, lead to positive outcomes in Indigenous health and wellbeing (Finlayson, 2007). Recovery will depend on how much external interference communities have experienced, how well communities are supported to govern their own affairs, the extent to which community-identified, led and controlled programs are supported (Dodson & Smith, 2003; Finlayson, 2007; McPhail-Bell et al., 2015; Morley, 2015) and how interactions and power relations between individuals, groups and institutions occur (Smith, 2005; Tauri, 2018). Communities need to be able to define their own needs and to design and control the required responses to problems or concerns (McPhail-Bell et al., 2015; Morley, 2015; Tauri, 2018). If the Australian government is committed to addressing the over-representation of Aboriginal and Torres Strait Islander people in prisons and reducing the ever-widening gaps in social and health disparities, it must first and foremost demonstrate that it is willing to begin addressing problems of systemic and institutional racism and discrimination (Blagg, 2008; Harmes et al., 2019; Wacquant, 2009; Weatherburn & Ramsey, 2016) and commit to reforming institutions and embracing culturally designed and led recovery-focused strategies which shift the focus to healing the extreme harms which have been incurred across generations of Aboriginal and Torres Strait Islander families and communities.

Comprehensive Reference List

Aboriginal Legal Service of Western Australia [ALSWA]. (2013). *Submission to the Australian Human Rights Commission—Access to justice for People with Disability: Issues Paper, April 2013.* https://www.humanrights.gov.au/sites/default/files/Sub45%20Aboriginal%20Legal%20Service%20of%20Western%20Australia_0.pdf

Absolon, K., & Willett, C. (2004). Aboriginal research: Berry picking and hunting in the 21st century. *First Peoples Child and Family Review, 1*(1), 5–17. http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/5/2

Alfred, T. (2009). Colonialism and state dependency. *Journal of Aboriginal Health*, *5*(22), 42–60. https://doi.org/10.3138/ijih.v5i2.28982

Altheide, D. L., & Johnson, J. M. (1994). Criteria for assessing interpretive validity in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 485–499). Sage Publications.

Altschuler, D. M., & Armstrong, T. L. (1994). *Intensive aftercare for high-risk juveniles: Policies and procedures*. Office of Juvenile Justice and Delinquency Prevention. https://www.ncjrs.gov/pdffiles/juvcc.pdf

Anderson, S. A. S., Hawes, D. J., & Snow, P. C. (2016). Language impairments among youth offenders: A systematic review. *Children and Youth Services Review, 65*, 195–203. https://doi.org/10.1016/j.childyouth.2016.04.004

Arabena, K., & Moodie, D. (2014). The Lowitja Institute: Building a national strategic research agenda to improve the health of Aboriginal and Torres Strait Islander peoples. *The Medical Journal of Australia*, *194*(10), 532–534. https://doi.org/10.5694/j.1326-5377.2011.tb03091.x

Astley, S. (2014). Twenty years of patient surveys confirm a FASD 4-digit-code interdisciplinary diagnosis afforded substantial access to interventions that met patients' needs. *Journal of*

Population Therapeutics and Clinical Pharmacology, *21*(1), e81–e105. http://depts.washington.edu/fasdpn/pdfs/FAR_13_22_e81_e105_Astleypublished.pdf

Atkins, T., Bullis, M., & Todis, B. (2005). Converging and diverging service delivery systems in alternative education programs for disabled and non-disabled youth involved in the juvenile justice system. *The Journal of Correctional Education*, *56*(3), 253–285. http://www.jstor.org/stable/23282590

Atkinson, J. (2002). *Trauma trails, recreating song lines: The transgenerational effects of trauma in Indigenous Australia*. Spinifex Press.

Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research*, *1*(3), 385–405. https://doi.org/10.1177/146879410100100307

Australian Bureau of Statistics. (2017a). *Prisoners in Australia, 2017* (cat. no. 4517.0).

Australian Bureau of Statistics. (2017b). *Recorded Crime—Offenders, 2015–16: Youth Offenders* (cat. no. 4519.0).

Australian Government, Royal Commission into the Protection and Detention of Children in the Northern Territory (‘The Don Dale Royal Commission’), Final Report (2017). https://www.royalcommission.gov.au/royal-commission-detention-and-protection-childrennorthern-territory

Australian Institute of Health and Welfare. (2016). *Youth Detention Population in Australia 2016* (bulletin no 138. cat. no. AUS 210).

Australian Institute of Health and Welfare. (2018). *Youth Justice in Australia 2016–2017* (cat. no. JUV 196).

Ayunerak, P., Alstrom, D., Moses, C., Charlie, J., & Rasmus, S. (2014). Yup’ik culture and context in Southwest Alaska: Community member perspectives of tradition, social change, and prevention. *American Journal of Community Psychology*, *54*(1–2), 91–99. https://doi.org/10.1007/s10464-014-9652-4

Badry, D., & Choate, P. (2015). Fetal Alcohol Spectrum Disorder: A disability in need of social work education, knowledge and practice. *Social Work & Social Sciences Review*, *17*(3), 20–32. https://doi.org/10.1921/12703170303

Badry, D., & Wight Felske, A. (2013). An examination of three key factors: Alcohol, trauma and child welfare: Fetal Alcohol Spectrum Disorder and the Northwest Territories of Canada. Brightening Our Home Fires. *First Peoples Child and Family Review, 8*(1), 143-160. https://fncaringsociety.com/sites/default/files/FPCFR%20journal%208(1)%202013_1.pdf#page=143

Baer, J., Sampson, P., Barr, H., Connor, P., & Streissguth, A. P. (2003). A 21-year longitudinal analysis of the effects of prenatal alcohol exposure on young adult drinking. *Archives of General Psychiatry*, *60*(4), 377–385. https://doi.org/10.1001/archpsyc.60.4.377

Bagley, K. (2019). Responding to FASD: What social and community service professionals do in the absence of diagnostic services and practice standards. *Advances in Dual Diagnosis*, *12*(1/2), 14–26. https://doi.org/10.1108/ADD-05-2018-0007

Bagley, K., & Badry, D. (2019). How personal perspectives shape health professionals' perceptions of Fetal Alcohol Spectrum Disorder and risk. *International Journal of Environmental Research and Public Health*, *16*(11), 1936. https://doi.org/10.3390/ijerph16111936

Bainbridge, R., Tsey, K., McCalman, J., Kinchin, I., Saunders, V., Watkin Lui, F., Cadet-James, Y., Miller, A., & Lawson, K. (2015). No-one's discussing the elephant in the room: Contemplating questions of research impact and benefit in Aboriginal and Torres Strait Islander Australian health research. *BMC Public Health*, *15*, 1–10. https://doi.org/10.1186/s12889-015-2052-3

Baines, M., & Alder, C. (1996). Are girls more difficult to work with? Youth workers' perspectives in juvenile justice and related areas. *Crime & Delinquency*, *42*(3), 467–485. https://doi.org/10.1177/0011128796042003008

Baldry, E., Dowse, L., & Clarence, M. (2012). *People with intellectual and other cognitive disability in the criminal justice system.* University of New South Wales. https://www.adhc.nsw.gov.au/__data/assets/file/0003/264054/Intellectual_and_cognitive_disability_in_criminal_justice_system.pdf

Baldry, E., McCausland, R., Dowse, L., & McEntyre, E. (2015). *A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system*. University of New South Wales. http://unsworks.unsw.edu.au/fapi/datastream/unsworks:37093/binb10f2bda-8816-4112-aeeb-6cd6d8efe6f7?view=true

Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: Concordance, contrasts, and implications. *Schizophrenia Bulletin*, *32*, 432–442. https://doi.org/10.1093/schbul/sbj044

Bennett, T., & Holloway, K. (2009). The causal connection between drug misuse and crime. *British Journal of Criminology*, *49*(4), 513–531. https://doi.org/10.1093/bjc/azp014

Bessarab, D., & Ng’andu, B. (2010). Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies*, *3*(1), 37–50. https://doi.org/10.5204/ijcis.v3i1.57

Best, D. (2014). *Strength, support, setbacks and solutions: The developmental pathway to addiction recovery*. Pavilion Publishing.

Best, D. (2019). *Pathways to recovery and desistance: The role of the social contagion of hope*. Policy Press.

Best, D., & Laudet, A. (2010). *The potential of recovery capital*. RSA.

Best, D., & Savic, M. (2015). Substance abuse and offending: Pathways to recovery. In R. Sheehan & J. Ogloff (Eds.), *Working within the forensic paradigm: Cross-discipline approaches for policy and practice* (pp. 259–271). Routledge.

Bird, H., Gould, M., & Staghezza, B. (1992). Aggregating data from multiple informants in child psychiatry epidemiological research. *Journal of American Academy Child & Adolescent Psychiatry*, *31*(1), 78–85. https://doi.org/10.1097/00004583-199201000-00012

Blagg, H. (2008). *Crime, Aboriginality and the decolonisation of justice*. Hawkins Press.

Blagg, H., Tulich, T., & Bush, Z. (2015). Diversionary pathways for Indigenous youth with FASD in Western Australia: Decolonising alternatives. *Alternative Law Journal*, *40*(4), 257–260. https://doi.org/10.1177/1037969X1504000409

Blaxter, M. (2004). Life narratives, health and Identity. In D. Kelleher & G. Leavey (Eds.), *Identity and health* (pp. 170–199). Routledge.

Blodgett, A., Schinke, R. J., Smith, B., Peltier, D., & Pheasant, C. (2011). In Indigenous words: Exploring vignettes as narrative strategy for presenting the research voices of Aboriginal community members. *Qualitative Inquiry*, *17*(6), 522–533. https://doi.org/10.1177/1077800411409885

Bloor, M. (2001). Techniques of validation in qualitative research: A critical commentary. In R. M. Emerson (Ed.), *Contemporary field research* (pp. 383-396). Prospect Heights, IL: Waveland Press.

Blum, L. (2015). *Raising generation Rx: Mothering kids with invisible disabilities in an age of inequality*. New York University Press.

Boland, F. J., Burrill, R., Duwyn, M., & Karp, J. (1998). *Fetal Alcohol Syndrome: Implications for correctional service*. Correctional Service Canada. https://www.csc-scc.gc.ca/recherche/092/r71_e.pdf

Bougie, E., & Senecal, S. (2010). Registered Indian children's school success and intergenerational effects of residential schooling in Canada. *The International Indigenous Policy Journal*, *1*(1), 1–41. https://doi.org/10.18584/iipj.2010.1.1.5

Bourdieu, P. (1985). The forms of capital. In J. G. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (pp. 241–258). Greenwood.

Bower, C., Elliott, E. J., Zimmet, M., Doorey, J., Wilkins, A., Russell, V., & Watkins, R. (2017). Australian guide to the diagnosis of foetal alcohol spectrum disorder: A summary. *Paediatrics & Child Health*, *53*(10), 1021–1023. https://doi.org/10.1111/jpc.13625

Bower, C., Watkins, R. E., Mutch, R. C., Marriott, R., Freeman, J., Kippin, N. R., Safe, B., Pestell, C., Cheung, C. S. C., Shield, H., Tarratt, L., Springall, A., Taylor, J., Walker, N., Argiro, E., Leitão, S., Hamilton, S., Condon, C., Passmore, H. M., & Giglia, R. (2018). Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia. *BMJ Open*, *8*(2), e019605. https://doi.org/10.1136/bmjopen-2017-019605

Bowker, G. C., & Star, S. L. (1999). *Sorting things out: Classification and its consequences*. MIT Press.

Brossard, B., & Carpentier, N. (2016). To what extent does diagnosis matter? Dementia diagnosis, trouble interpretation and caregiving network dynamics. *Sociology of Health & Illness*, *39*(4), 566–580. https://doi.org/10.1111/1467-9566.12501

Brown, P. (2008). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior, Extra Issue*, 34–52. https://doi.org/10.2307/2626956

Brown J, Spiller V, Jesna V, Carter MN, Asp, E. (2019). Fetal Alcohol Spectrum Disorder (FASD) and Confabulation: A Call to Action and a Need for Increased Awareness, Understanding, and Training Among Criminal Justice, Forensic Mental Health, and Legal Professionals. *Dual Diagnosis 4*(2). 1-7 https://dual-diagnosis.imedpub.com/fetal-alcohol-spectrum-disorder-fasd-and-confabulation-a-call-to-action-and-a-need-for-increased-awareness-understanding-and-train.pdf

Brunelle, N., Cousineau, M., & Brochu, S. (2005). Juvenile drug use and delinquency: Youths' accounts of their trajectories. *Substance Use & Misuse*, *40*(5), 721–734. https://doi.org/10.1081/JA-200055404t

Bryan, G., Bluebond-Langner, M., Kelly, D., Kumpunen, S., Oulton, K., & Gibson, F. (2019). Studying children's experiences in interactions with clinicians: Identifying methods fit for purpose. *Qualitative Health Research, 29*(3), 393–403. https://doi.org/10.1177/1049732318801358

Burd, L., & Popova, S. (2019). Fetal Alcohol Spectrum Disorders: Fixing our aim to aim for the fix. *International Journal of Environmental Research and Public Health, 16*(20), 3978. https://doi.org/10.3390/ijerph16203978

Burd, L., Rachael, H., Selfridge, B. S., Klug, M. G., & Juelson, T. (2003). Fetal alcohol spectrum disorder in the Canadian corrections system. *The Journal of FAS International, e14*, 1–10. http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.522.3938&rep=rep1&type=pdf

Burd, L., Selfridge, R., Klug, M., & Bakko, S. (2004). Fetal alcohol syndrome in the United States corrections system. *Addiction Biology, 9*(2), 169–176. https://doi.org/10.1080/13556210410001717060

Burford, G., Braithwaite, J., & Braithwaite, V. (Eds.). (2019). *Restorative and responsive human services*. Routledge.

Butts, J., Bazemore, G., & Meroe, A. S. (2010). *Positive youth justice: Framing justice interventions using the concepts of positive youth development*. Coalition for Juvenile Justice.

Carmichael Olson, H., & Montague, R. A. (2011). An innovative look at early intervention for children affected by prenatal alcohol exposure. In S. A. Adubato & D. E. Cohen (Eds.), *Prenatal alcohol use and FASD: Diagnosis, assessment and new directions in research and multimodal treatment* (pp. 64–107). https://depts.washington.edu/fasdpn/pdfs/chapter%204%20Early%20Interventions%20for%20Children.pdf

Carpenter, B. (2011). Pedagogically bereft! Improving learning outcomes for children with foetal alcohol spectrum disorders. *British Journal of Special Education*, *38*(1), 37–43. https://doi.org/10.1111/j.1467-8578.2011.00495.x

Catalano, R. F., Haggerty, K. P., Hawkins, J. D., & Elgin, J. (2011). Prevention of substance use and substance use disorders: Role of risk and protective factors. In Y. Kaminer & K. C. Winters (Eds.), *Clinical manual of adolescent substance abuse treatment* (pp. 25–63). American Psychiatric Publishing.

Caudy, M., Tillyer, M., & Tillyer, R. (2018). Jail versus probation: A gender-specific test of differential effectiveness and moderators of sanction effects. *Criminal Justice & Behavior*, *45*(7), 949–968. https://doi.org/10.1177/0093854818766375

Cavadino, M., & Dignan, J. (2006). *Penal systems: A comparative approach*. Sage Publications.

Cederborg, A. C., La Rooy, D., & Lamb, M. E. (2008). Repeated interviews with children who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 21*, 103–113. https://doi.org/10.1111/j.14683148.2007.00372.x

Chamberlain, K., Reid, N., Warner, J., Shelton, D., & Dawe, S. (2017). A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. *Research in Developmental Disability*, *63*, 99–106. https://doi.org/10.1016/j.ridd.2016.06.007

Choate, P., & Badry, D. (2019). Stigma as a dominant discourse in fetal alcohol spectrum disorder. *Advances in Dual Diagnosis*, *12*(1/2), 36–52. https://doi.org/10.1108/ADD-05-2018-0005

Christensen, P. H. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children and Society*, *18*(2), 165–176. https://doi.org/10.1002/chi.823

Chudley, A. E. (2008). Fetal alcohol spectrum disorder: Counting the invisible—Mission impossible? *Archives of Disease in Childhood*, *93*(9), 721–722. https://doi.org/10.1136/adc.2008.137109

Clark, C. D. (2011). *In a younger voice: Doing child-centered qualitative research*. Oxford University Press.

Clark, C., Prior, M., & Kinsella, G. (2002). The relationship between executive function abilities, adaptive behaviour, and academic achievement in children with externalising behaviour problems. *Journal of Child Psychology and Psychiatry, 43*(6), 785–796. https://doi.org/10.1111/1469-7610.00084

Cleary, J. (2016, 2 November). The last six months are proof enough: It’s not just Don Dale. *Amnesty International*. https://www.amnesty.org.au/the-last-six-months-are-proof-enough-its-not-just-don-dale/

Cloud, W., & Granfield, R. (2009). Conceptualising recovery capital: Expansion of a theoretical construct. *Substance Use and Misuse*, *43*(12–13), 1971–1986. https://doi.org/10.1080/10826080802289762

Commonwealth of Australia, Royal Commission into Aboriginal Deaths in Custody (1991).

Conley, D. J. (1994). Adding color to a black and white picture: Using qualitative data to explain racial disproportionality in the juvenile justice system. *Journal of Research in Crime and Delinquency*, *31*(2), 135–148. https://doi.org/10.1177/0022427894031002003

Conrad, P., & Schneider, J. W. (1992). *Deviance and medicalization: From badness to sickness*. Temple University Press.

Coons, K., Watson, S., Yantzi, N., & Schinke R. (2018). Adaptation in families raising children with fetal alcohol spectrum disorder. Part II: What would help? *Journal of Intellectual & Developmental Disability*, *43*(2), 137–151. https://doi.org/10.3109/13668250.2016.1267718

Corrigan, P., Lara, J., Shah, B., Mitchell, K., Simmes, D., & Jones, K. (2017). The public stigma of birth mothers of children with fetal alcohol spectrum disorders. *Alcoholism: Clinical & Experimental Research*, *41*, 1166–1173. https://doi.org/10.1111/acer.13381

Cox, L. V., Clairmont, D., & Cox, S. (2008). Knowledge and attitudes of criminal justice professionals in relation to fetal alcohol spectrum disorder. *The Canadian Journal of*

Clinical Pharmacology, *15*(2), e306–e313. https://pdfs.semanticscholar.org/8b78/1d1a6bb9a8a03054a4b0ae1acb4e95d7a699.pdf

Coyhis, D., & White, W. (2006). *Alcohol problems in Native America: The untold story of resistance and recovery—The truth about the lie*. White Bison.

Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Sage Publications.

Cunneen, C. (2016, 28 July). Abuse in youth detention is not restricted to the Northern Territory. *The Conversation*. https://theconversation.com/abuse-in-youth-detention-is-notrestricted-to-the-northern-territory-63101

Cunneen, C., Goldson, B., & Russell, S. (2016). Juvenile justice, young people and human rights in Australia. *Current Issues in Criminal Justice*, *28*(2), 173–189. https://doi.org/10.1080/10345329.2016.12036067

Cunneen, C., & Rowe, S. (2014). Changing narratives: Colonised people, criminology and social work. *International Journal for Crime, Justice and Social Democracy*, *3*(1), 49–67. https://doi.org/10.5204/ijcjsd.v3i1.138

Cunneen, C., & Tauri, J. (2019). Indigenous peoples, criminology, and criminal justice. *Annual Review of Criminology*, *2*, 359–381. https://doi.org/10.1146/annurev-criminol-011518-024630

Davidson, L., & Strauss, J. (1992). Sense of self in recovery from severe mental illness. *The British Psychological Society*, *65*(2), 131–145. https://doi.org/10.1111/j.2044-8341.1992.tb01693.x

Davison, J., McLean, C., & Warren, S. (2015). Looking back: Ten years of visual qualitative research. *Qualitative Research in Organizational Management*, *10*, 355–359. https://doi.org/10.1108/QROM-07-2015-1311

De Maio, J. A., Zubrick, S. R., Silburn, S. R., Lawrence, D. M., Mitrou, F. G., Dalby, R. B., Blair, E. M., Griffin, J., Milroy, H., & Cox, A. (2005). *The Western Australian Aboriginal child health survey: Measuring the social and emotional wellbeing of Aboriginal children and* *intergenerational effects of forced separation*. Curtin University of Technology and Telethon Institute for Child Health Research.

De Swaan, A. (1989). The reluctant imperialism of the medical profession. *Social Science and Medicine*, *28*(11), 1165–1170. https://doi.org/10.1016/0277-9536(89)90009-9

De'Ath, S., Flynn, C., & Field-Pimm, M. (2018). Building knowledge of consumer participation in Australia: A case study. *International Journal for Crime, Justice and Social Democracy*, *7*(1), 76–90. https://doi.org/10.5204/ijcjsd.v7i1.396

Dell Clark, C. (2011). *In a younger voice: Doing child-centred qualitative research*. Oxford University Press.

Denzin, N. K., & Lincoln. Y. S. (2003). *The SAGE handbook of qualitative research* (2nd ed.). Sage Publications.

Department of Justice. (2017). *Department of Corrective Services: Final Report 2016–2017*. Government of Western Australia.

Department of Justice. (2018). *Department of Justice annual report 2017/18*. Government of Western Australia.

Dias, S., Ware, R. S., Kinner, S. A., & Lennox, N. G. (2013). Co-occurring mental disorder and intellectual disability in a large sample of Australian prisoners. *Australian & New Zealand Journal of Psychiatry*, *47*(10), 938–944. https://doi.org/10.1177/0004867413492220

Dingle, G. A., Stark, C., Cruwys, T., & Best, D. (2014). Breaking good: Breaking ties with social groups may be good for recovery from substance misuse. *British Journal of Social Psychology*, *54*(2), 236–254. https://doi.org/10.1111/bjso.12081

Doak, J., Katsikitis, M., Webster, H., & Wood, A. (2019). A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families. *Research in Developmental Disabilities*, *93*, e103428. https://doi.org/10.1016/j.ridd.2019.103428

Dodson, M., & Hunter, B. (2006). Selected crime and justice issues for Indigenous families. *Family Matters*, *75*, 38–41. https://search.informit.com.au/documentSummary;dn=347075762839657;res=IELHSS

Dodson, M., & Smith, D. E. (2003). *Governance for sustainable development: Strategic issues and principles for Indigenous Australian communities* (CAEPR Discussion Paper No. 250/2003). Australian National University.

Douglas, H., Hammill, J., Russell, E., & Hall, W. (2012). Judicial views of foetal alcohol spectrum disorder in Queensland's criminal justice system. *Journal of Judicial Administration, 21*(3), 178–188. https://ssrn.com/abstract=2611419

Dovidio, J. F., Major, B., & Crocker, J. (2000). Stigma: Introduction and overview. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 1–28). Guilford Press.

Dowse, L., Cumming, T. M., Strnadova, I., Lee, J.-S., & Trofimovs, J. (2014). Young people with complex needs in the criminal justice system. *Research and Practice in Intellectual and Developmental Disabilities*, *1*(2), 174–185. https://doi.org/10.1080/23297018.2014.953671

Doyle, K., Cleary, M., Blanchard, D., & Hungerford, C. (2017). The Yerin Dilly Bag Model of Indigenist health research. *Qualitative Health Research*, *27*, 1288–1301. https://doi.org/10.1177/1049732317700125

Driessnack, M. (2006). Draw-and-tell conversations with children about fear. *Qualitative Health Research*, *16*, 1414–1435. https://doi.org/10.1177/1049732306294127

Dudgeon, P. (2008). Empowering research with Indigenous communities. *Ngoonjook: A Journal of Australian Issues*, *32*, 8–26. https://search.informit.com.au/documentSummary;dn=888676226146816;res=IELIND

Dunkel, F. (2014). Juvenile justice systems in Europe—Reform developments between justice, welfare and 'new punitiveness'. *Criminological Studie*s, *1*, 31–76. http://eigep.eu/wp-content/uploads/2018/01/Dunkel2014_juvenile_justice_Europe.pdf

Durkheim, E. (1984). (1893). *The division of labor in society*. Free Press.

Elliott, E. J., Payne, J., Morris, A., Haan, E., & Bower, C. (2008). Fetal alcohol syndrome: A prospective national surveillance study. *Archives of Disease in Childhood*, *93*(9),732–737. https://doi.org/10.1136/adc.2007.120220

Emerson, A. M. (2018). Strategizing and fatalizing: Self and other in the trauma narratives of justice-involved women. *Qualitative Health Research*, *28*(6), 873–887. https://doi.org/10.1177/1049732318758634

Ennis-Cole, D., Durodoye, B., & Harris, H. (2013). The impact of culture on autism diagnosis and treatment: Considerations for counselors and other professionals. *The Family Journal*, *21*(3), 279–287. https://doi.org/10.1177/1066480713476834

Farrington, D. P. (2007). Childhood risk factors and risk-focused prevention. In M. Maguire, R. Morgan, & R. Reiner (Eds.), *The Oxford handbook of criminology* (pp. 602–640). Oxford University Press.

Fast, D., & Conry, J. (2004). The challenge of fetal alcohol syndrome in the criminal legal system. *Addiction Biology*, *9*(2), 161–166. https://doi.org/10.1080/13556210410001717042

Fast, D., & Conry, J. (2009). Fetal alcohol spectrum disorders and the criminal justice system. *Developmental Disabilities Research Reviews*, *15*(3), 250–257. https://doi.org/10.1002/ddrr.66

Fast, D. K., Conry, J., & Loock, C. A. (1999). Identifying fetal alcohol syndrome among youth in the criminal justice system. *Journal of Developmental & Behavioral Pediatrics*, *20*(5), 370–372. http://www.davidboulding.com/uploads/2/4/1/4/24146766/identifying_fetal_alcohol_syndrome_among_youth_in_the_criminal_justice_system.pdf

Feinstein, R., Greenblatt, A., Hass, L., Kohn, S., & Rana, J. (2000). *Justice for all? A report on lesbian, gay, bisexual and transgendered youth in the New York juvenile justice system*. https://files.eric.ed.gov/fulltext/ED471676.pdf

Field, S. (2007). Practice cultures and the ‘new’ youth justice in (England and) Wales. *British Journal of Criminology, 47*(2), 311–330. https://doi.org/10.1093/bjc/azl088

Finlayson, J. (2007). *Organising for success: Policy report—Successful strategies in Indigenous organisations*. Australian Institute of Aboriginal and Torres Strait Islander Studies and the Australian Collaboration.

Flannigan, K., Pei, J., Stewart, M., & Johnson, A. (2018). Fetal Alcohol Spectrum Disorder and the criminal justice system: A systematic literature review. *International Journal of Law and Psychiatry, 57*, 42–52. https://doi.org/10.1016/j.ijlp.2017.12.008

Fogarty, W., Lovell, M., Langenberg, J., & Heron, M.-J. (2018). *Deficit discourse and strengths-based approaches: Changing the narrative of Aboriginal and Torres Strait Islander health and wellbeing*. The Lowitja Institute.

France, A., & Homel, R. (2006). Societal access routes and developmental pathways: Putting social structure and young people’s voice into the analysis of pathways into and out of crime. *Australian and New Zealand Journal of Criminology, 39*(3), 295–309. https://doi.org/10.1375/acri.39.3.295

Francis, A. (2012). Stigma in an era of medicalisation and anxious parenting: How proximity and culpability shape middle-class parents’ experiences of disgrace. *Sociology of Health & Illness, 34*(6), 927–942. https://doi.org/10.1111/j.1467-9566.2011.01445.x

Fredericks, B., Adams, K., Finlay, S., Fletcher, G., Andy, S., Briggs, L., Briggs, L., & Hall, R. (2011). Engaging the practice of yarning in action research. *Action Learning and Action Research Journal, 17*(2), 7–19. https://eprints.qut.edu.au/48053/

Freeman, J., Condon, C., Hamilton, S. L., Mutch, R. C., Bower, C., & Watkins, R. E. (2019). Challenges in accurately assessing prenatal alcohol exposure in a study of Fetal Alcohol Spectrum Disorder in a youth detention center. *Alcoholism: Clinical & Experimental Research*. https://doi.org/10.1111/acer.13926

Freidson, E. (1972). *Profession of medicine: A study of the sociology of applied knowledge*. Dodd, Mead and Company.

Frize, M., Kenny, D., & Lennings, C. (2008). The relationship between intellectual disability, Indigenous status and risk of reoffending in juvenile offenders on community orders. *Journal of Intellectual Disability Research, 52*(6), 510–519. https://doi.org/10.1111/j.1365-2788.2008.01058.x

Gardner, J., & Williams, C. (2015). Corporal diagnostic work and diagnostic spaces: Clinicians' use of space and bodies during diagnosis. *Sociology of Health & Illness, 37*(5), 765–781. https://doi.org/10.1111/1467-9566.12233

Garland, A., Hough, R., McCabe, K., Yeh, M., Wood, P., & Aarons, G. (2001). Prevalence of psychiatric disorders in youths across five sectors of care. *Journal of the American Academy of Child & Adolescent Psychiatry, 40*, 409–418. https://doi.org/10.1097/00004583-200104000-00009

Garner, A. S., Shonkoff, J. P., Siegel, B. S., Dobbins, M. I., Earls, M. F., McGuinn, L., Pascoe, J., & Wood, D. L. (2012). Early childhood adversity, toxic stress, and the role of the pediatrician: Translating developmental science into lifelong health. Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, and Section on Developmental and Behavioral Pediatrics. *Pediatrics, 129*(1), e224–e231. https://doi.org/10.1542/peds.2011-2662

Garro, L., & Yarris, K. (2009). 'A massive long way': Interconnecting histories, a 'special child', ADHD, and everyday family life. *Culture, Medicine and Psychiatry, 33*, 559–609. https://doi.org/10.1007/s11013-009-9155-1

Gill, V. T., Pomerantz, A., & Denvir, P. (2010). Pre-emptive resistance: Patients' participation in diagnostic sense-making activities. *Sociology of Health & Illness, 32*(1), 1–20. https://doi.org/10.1111/j.1467-9566.2009.01208.x

Gilroy, J., Donelly, M., Colmar, S., & Parmenter, T. (2013). Conceptual framework for policy and research development with Indigenous people with disabilities. *Australian Aboriginal Studies*, *2*, 42–58. https://search.informit.com.au/documentSummary;dn=751842945817584;res=IELIND

Glegg, S. (2019). Facilitating interviews in qualitative research with visual tools: A typology. *Qualitative Health Research*, *29*(2), 301–310. https://doi.org/10.1177/1049732318786485

Goddard, T., & Myers, R. (2017). Against evidence-based oppression: Marginalized youth and the politics of risk-based assessment and intervention. *Theoretical Criminology*, *21*(2), 151–167. https://doi.org/10.1177%2F1362480616645172

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice Hall.

Goldson, B. (2005). Child imprisonment: A case for abolition. *Youth Justice, 5*(2), 77–90. https://doi.org/10.1177/147322540500500202

Goldson, B., & Muncie, J. (2012). Towards a global 'child friendly' juvenile justice? *International Journal of Law, Crime and Justice, 40*(1), 47–64. https://doi.org/10.1016/j.ijlcj.2011.09.004

Granfield, R., & Cloud, W. (2001). Social context and 'natural recovery': The role of social capital in the resolution of drug-associated problems. *Substance Use and Misuse, 36*, 1543–1570. https://doi.org/10.1081/JA-100106963

Hafekost, K., Lawrence, D., O'Leary, C., Bower, C., Semmens, J., & Zubrick, S. R. (2017). Maternal alcohol use disorder and risk of child contact with the justice system in Western Australia: A population cohort record linkage study. *Alcoholism: Clinical & Experimental Research, 41*(8), 1452–1460. https://doi.org/10.1111/acer.13426

Hamilton, S., Cleland, D., & Braithwaite, V. (2019). 'Why can't we help protect children too?' Stigma by association among community workers in child protection and its consequences. *Oxford Community Development Journal*. https://pdfs.semanticscholar.org/f650/9240b8670e4bd6f341669fc547df92bdc92b.pdf

Hamilton, S., Finlay-Jones, A., & Scrine, C. (2019). *Game Changers, Tracking better® at Football evaluation report, Derby, Western Australia*. Telethon Kids Institute. https://static1.squarespace.com/static/5b7346574611a05795e9ec6c/t/5d1d8ad2fe4a970001fc10d6/1562217211191/Game+Changers+Evaluation+Report_.pdf

Hamilton, S., Maslen, S., Best, D., Freeman, J., O'Donnell, M., Reibel, T., Mutch, R., & Watkins, R. (2020). Putting 'justice' in recovery capital: Yarning about hopes and futures with young people in detention. *International Journal for Crime, Justice and Social Democracy*. 9(2), 20-36. https://doi.org/10.5204/ijcjsd.v9i2.1256

Hamilton, S., Maslen, S., Conigrave, K., Mutch, R., Watkins, R., O'Donnell, M., Freeman, J., & Bower, C. (2020). 'That thing in his head': Aboriginal and non-Aboriginal caregiver responses to Fetal Alcohol Spectrum Disorder diagnosis. *Sociology of Health and Illness*. Early view. doi: 10.1111/1467-9566.13146

Hamilton, S., Reibel, T., Maslen, S., Watkins, R., Freeman, J., Passmore, H., Mutch, R., O'Donnell, M., Braithwaite, V., & Bower, C. (2020). Disability 'in-justice': The benefits and challenges of 'yarning' with young people undergoing diagnostic assessment for Fetal Alcohol Spectrum Disorder in a youth detention centre. *Qualitative Health Research*, *30*(2), 314–327. https://doi.org/10.1177/1049732319882910

Hamilton, S. L., Reibel, T., Watkins, R., Mutch, R. C., Kippin, N. R., Freeman, J., Passmore, H. M., Safe, B., O'Donnell, M., & Bower, C. (2019). 'He has problems; he is not the problem …' A qualitative study of noncustodial staff providing services for young offenders assessed for Foetal Alcohol Spectrum Disorder in an Australian youth detention centre. *Youth Justice*, *19*(2), 137–157. https://doi.org/10.1177/1473225419869839

Hancock, K. (2017). Facility operations and juvenile recidivism. *Journal of Juvenile Justice*, *6*(1), 1–14. http://betasite.csrincorporated.com/JOJJ/JOJJ0601/JOJJ0601.pdf#page=6

Harmes, M., Hopkins, S., & Farley, H. (2019). Beyond incarcerated identities: Identity, bias and barriers to higher education in Australian prisons. *International Journal of Bias, Identity and Diversities in Education*, *4*(1), 211–234. https://doi.org/10.4018/IJBIDE.2019010101

Haslam, S. A., Reicher, S. D., & Levine, M. (2012). When other people are heaven, when other people are hell: How social identity determines the nature and impact of social support. In J. Jetten, C. Haslam, & S. A. Haslam (Eds.), *The social cure: Identity, health and well-being* (pp. 157–174). Psychology Press.

Hemphill, S., Smith, R., Toumbourou, J., Herrenkohl, T., Catalano, R., McMorris, B., & Romaniuk, H. (2009). Modifiable determinants of youth violence in Australia and the United States: A longitudinal study. *Australian and New Zealand Journal of Criminology*, *42*(3), 289–309. https://doi.org/10.1375/acri.42.3.289

Hemphill, S., Toumbourou, J., Herrenkohl, T., McMorris, B., & Catalano, R. (2006). The effect of school suspensions and arrests on subsequent adolescent antisocial behavior in Australia and the United States. *Journal of Adolescent Health*, *39*(4), 736–744. https://doi.org/https://doi.org/10.1016/j.jadohealth.2006.05.010

Heneker, K. J., Zizzo, G., Awata, M., & Goodwin-Smith, I. (2017). *Engaging culturally and linguistically diverse communities in the National Disability Insurance Scheme*. Australian Centre for Community Services Research, Flinders University.

Hennessy, E. A. (2017). Recovery capital: A systematic review of the literature. *Addiction Research & Theory*, *25*(5), 349–360. https://doi.org/10.1080/16066359.2017.1297990

Hickey, H., & Wilson, D. L. (2017). Whānau Hauā: Reframing disability from an Indigenous perspective. *Mai Journal*, *6*(1), 82–94. https://doi.org/10.20507/MAIJournal.2017.6.1.7

Holley, L., & VanVleet, R. (2008). Racism and classism in the youth justice system: Perspectives of youth and staff. *Journal of Poverty*, *10*(1), 45–67. https://doi.org/10.1300/J134v10n01_03

Horstman, M., Aldiss, S., Richardson, A., & Gibson, F. (2008). Methodological issues when using the draw and write technique with children aged 6 to 12 years. *Qualitative Health Research, 18*, 1001–1011. https://doi.org/10.1177/1049732308318230

House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs. (2011). *Doing time—Time for doing: Indigenous youth in the criminal justice system.* Australian Government.

Hovane, V., Dalton, T., & Smith, P. (2014). Aboriginal rehabilitation programs. In P. Dudgeon, H. Milroy, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (2nd ed., pp. 509–522). Australian Government Department of the Prime Minister and Cabinet.

Hughes, N., Ungar, M., Fagan, A., Murray, J., Atilola, O., Nichols, K., Garcia, J., & Kinner, S. (2020). Health determinants of adolescent criminalisation. *The Lancet Child & Adolescent Health, 4*(2), 151–162. https://doi.org/10.1016/S2352-4642(19)30347-5

Hughes, P., More, A. J., & Williams, M. (2004). *Aboriginal ways of learning*. Flinders Press.

Human Rights and Equal Opportunity Commission. (1997). *Bringing them home: Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families.* Human Rights and Equal Opportunity Commission.

Humphreys, K., & Lembke, A. (2013). Recovery-oriented policy and care systems in the UK and USA. *Drug and Alcohol Review, 33,* 12–18. https://doi.org/10.1111/dar.12092

Hunter, K. M. (1991). *Doctors' stories*. Princeton University Press.

Indig, D., Frewan, A., & Moore, E. (2016). Predictors and correlates of re-incarceration among Australian young people in custody. *Australian and New Zealand Journal of Criminology, 49*(1), 73–89. https://doi.org/10.1177/0004865814550534

Indig, D., Vecchiato, C., Haysom, L., Beilby, R., Carter, J., Champion, U., Gaskin, C., Heller, E., Kumar, S., Mamone, N., Muir, P., van den Dolder, P., & Whitton, G. (2011). *2009 NSW young people in custody health survey: Full report*. Justice Health and Justice.

Irving, J. (2016). Alcoholics anonymous—Sustaining behavioural change. In A. Robinson & P. Hamilton (Eds.), *Transforming identities: Seeking successful lives* (pp. 195–228). Policy Press.

Irwin, L. G., & Johnson, J. (2005). Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research, 15*, 821–831. https://doi.org/10.1177/1049732304273862

Jetten, J., Haslam, C., Haslam, S. A., Dingle, G., & Jones, J. M. (2014). How groups affect our health and well-being: The path from theory to policy. *Social Issues and Policy Review*, *8*(1), 103–130. https://doi.org/10.1111/sipr.12003

Jirikowic, T., Kartin, D., & Carmichael Olson, H. (2008). Children with fetal alcohol spectrum disorders: A descriptive profile of adaptive function. *Canadian Journal of Occupational Therapy*, *75*(4), 238–248. https://doi.org/10.1177/000841740807500411

Johnson, J. L., Oliffe, J. L., Kelly, M. T., Galdas, P., & Ogrodniczuk, J. S. (2012). Men's discourses of help-seeking in the context of men's depression. *Sociology of Health & Illness*, *34*, 345–361. https://doi.org/10.1111/j.1467-9566.2011.01372.x

Johnson, T., Cho, Y., Pendrich, M., Graf, I., Kelly-Wilson, L., & Pickup, L. (2004). Treatment need and utilization among youth entering the juvenile corrections system. *Journal of Substance Abuse Treatment*, *26, 17*(1), 117–128. https://doi.org/https://doi.org/10.1016/S0740-5472(03)00164-8

Jordan, K., Anthony, T., Walsh, T., & Markham, F. (2018). *Joint response to the Deloitte review of the implementation of the recommendations of the Royal Commission into Aboriginal Deaths in Custody* (CAEPR Topical Issue No. 4/2018). Australian National University.

Jutel, A. (2009). Sociology of diagnosis: A preliminary review. *Sociology of Health & Illness*, *31*(2), 278–299. https://doi.org/10.1111/j.1467-9566.2008.01152.x

Jutel, A. (2019). Diagnosis: A critical social reflection in the genomic era. *Ciência & Saúde Coletiva*, *24*(10), 3619–3626. https://doi.org/10.1590/1413-812320182410.34502018

Kaemingk, K., & Paquette, A. (1999). Effects of prenatal alcohol exposure on neuropsychological functioning. *Developmental Neuropsychology, 15*(1), 111–140. https://doi.org/10.1007/s10882-007-9050-z

Kaplan, A. (1973). *The conduct of inquiry*. Transaction Publishers.

Kaspar, V. (2014). The lifetime effect of residential school attendance on Indigenous health status. *American Journal of Public Health*, *104*(11), 2184–2190. https://doi.org/10.2105/AJPH.2013.301479

Kelley, A., Bingham, D., Brown, E., & Pepion, L. (2017). Assessing the impact of American Indian peer recovery support on substance use and health. *Journal of Groups in Addiction & Recovery*, *12*(4), 296–308. https://doi.org/10.1080/1556035X.2017.1337531

Kevers, R., Rober, P., & Haene, L. D. (2018). Unraveling the mobilization of memory in research with refugees. *Qualitative Health Research*, *28*(4), 659–672. https://doi.org/10.1177/1049732317746963

Kippin, N. R., Leitão, S., Watkins, R., Finlay-Jones, A., Condon, C., Marriott, R., Mutch, R. C., & Bower, C. (2018). Language diversity, language disorder, and fetal alcohol spectrum disorder among youth sentenced to detention in Western Australia. *International Journal of Law and Psychiatry*, *61*, 40–49. https://doi.org/10.1016/j.ijlp.2018.09.004

Knowles, S., Townsend, E., & Anderson, M. (2012). Youth justice staff attitudes toward screening for self-harm. *Health and Social Care in the Community*, *20*(5), 506–515. https://doi.org/10.1111/j.1365-2524.2012.01061.x

Koren, G., Roifman, I., & Nulman, I. (2004). Hypothetical framework: FASD and criminality—Causation or association? The limits of evidence-based knowledge. *Journal FAS International*, *2*(e6). https://pdfs.semanticscholar.org/fde4/ee43346b9a05a9d2bc2ca5abb553c6b018c4.pdf

Kovach, M. (2010). *Indigenous methodologies: Characteristics, conversations, and contexts*. University of Toronto Press.

Kumwenda, M., Nzala, S., & Zulu, J. (2017). Health care needs assessment among adolescents in correctional institutions in Zambia: An ethical analysis. *BMC Health Services Research, 17*, 581. https://doi.org/10.1186/s12913-017-2532-5

Kvale, S. (1994). *InterViews: An introduction to qualitative research interviewing*. Sage Publications.

Lambert, V., & Glacken, M. (2011). Engaging with children in research: Theoretical and practical implications of negotiating informed consent/assent. *Nursing Ethics*, *18*(6), 781–801. https://doi.org/10.1177/0969733011401122

Landsman, G. H. (2010). *Reconstructing motherhood and disability in the age of 'perfect' babies*. Routledge.

Lanskey, C. (2011). Promise or compromise? Education for young people in secure institutions in England. *Youth Justice, 11*(1), 47–60. https://doi.org/10.1177/1473225410394286

Laudet, A., Morgen, K., & White, W. (2006). The role of social supports, spirituality, religiousness, life meaning and affiliation with 12-step fellowships in quality of life satisfaction among individuals in recovery from alcohol and drug use. *Alcoholism Treatment Quarterly*, *24*(102), 33–73. https://doi.org/10.1300/J020v24n01_04

Laycock, A., Walker, D., Harrison, N., & Brands, J. (2011). *Researching Indigenous health: A practical guide for researchers*. The Lowitja Institute.

Leamy, M., Bird, V., Le Bouthillier, C., Williams, J., & Slade, M. (2011). A conceptual framework for personal recovery in mental health: Systematic review and narrative synthesis. *British Journal of Psychiatry*, *199*(6), 445–452. https://doi.org/https://doi.org/10.1192/bjp.bp.110.083733

Lees, A., Payler, J., Ballinger, C., Lawrence, P., Faust, S. N., & Meads, G. (2017). Positioning children's voice in clinical trials research: A new model for planning, collaboration, and reflection. *Qualitative Health Research*, *27*, 2162–2176. https://doi.org/10.1177/1049732317726760

Leonard, J. (2016). Aboriginal justice: The challenges of FASD & implications for the legal system. *Bulletin Law Society of South Australia*, *38*, 38–39. https://search.informit.com.au/fullText;dn=213513661873311;res=IELHSS.

Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, *45*(3), 400–423. www.jstor.org/stable/2095613

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Liu, G. (2005). Best practices: Developing cross-cultural competence from a Chinese perspective. In J. H. Stone (Ed.), *Culture & disability: Providing culturally competent services* (pp. 65–85). Sage Publications.

Lohmeyer, B. A. (2018). ‘Calling bullshit’ in the age of hollow government: Hyper-governed young people’s rejection of fair process and the subversion of restorative practices. *Journal of Applied Youth Studies*, *2*(4), 57–70. http://cayr.info/wp-content/uploads/2018/06/JAYSv2n4_final_small.pdf#page=61

Long, C. (2015). Disadvantage undiagnosed. *Australian Educator*, 88, 22-24.

Lount, S. A., Hand, L., Purdy, S., & France, A. (2017). Tough talk: Youth offenders’ perceptions of communicating in the youth justice system in New Zealand. *Australian and New Zealand Journal of Criminology*, *51*(4), 593–618. https://doi.org/10.1177/0004865817740404

Lupton, C., Burd, L., & Harwood, R. (2004). Cost of fetal alcohol spectrum disorders. *Journal of Medical Genetics (Part C: Seminars in Medical Genetics)*, *127C*(1), 42–50. https://doi.org/10.1002/ajmg.c.30015

Lupton, D. (1997). Consumerism, reflexivity and the medical encounter. *Social Science and Medicine*, *45*(3), 373–381. https://doi.org/10.1016/s0277-9536(96)00353-x

Lynch, M. E., Coles, C. D., Corley, T., & Falek, A. (2003). Examining delinquency in adolescents differentially prenatally exposed to alcohol: The role of proximal and distal risk factors. *Journal of Studies on Alcohol*, *64*(5), 678–686. https://doi.org/10.15288/jsa.2003.64.678

Lys, C., Gesink, D., Strike, C., & Larkin, J. (2018). Body mapping as a youth sexual health intervention and data collection tool. *Qualitative Health Research*, *28,* 1185–1198. https://doi.org/10.1177/1049732317750862

MacDonald, C., & Steenbeek, A. (2015). The impact of colonization and Western assimilation on health and wellbeing of Canadian Aboriginal people. *International Journal of Regional and Local History*, *10*(1), 32–46. https://doi.org/10.1179/2051453015Z.00000000023

Magana, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*, *51*(3), 141–153. https://doi.org/10.1352/1934-9556-51.3.141

Major, B., & Schmader, T. (2017). Stigma, social identity threat and health. In B. Major, J. F. Dovidio, & B. G. Link (Eds.), *The Oxford handbook of stigma, discrimination, and health* (pp. 85–103). Oxford University Press.

Malacrida, C. (2001). Motherhood, resistance and attention deficit disorder: Strategies and limits. *Canadian Review of Sociology*, *38*(2), 141–165. https://doi.org/10.1111/j.1755-618X.2001.tb00968.x

Malacrida, C. (2004). Medicalization, ambivalence and social control: Mothers' descriptions of educators and ADD/ADHD. *Health: An Interdisciplinary Journal for the Social Study of Health Illness and Medicine*, *8*(1), 61–80. https://doi.org/10.1177/1363459304038795

Malbin, D. V. (2004). Fetal Alcohol Spectrum Disorder (FASD) and the role of family court judges in improving outcomes for children and families. *Juvenile and Family Court Journal*, *55*(2), 53–63. https://doi.org/10.1111/j.1755-6988.2004.tb00161.x

Malvaso, C. G., Delfabbro, P. H., & Day, A. (2017a). The child protection and juvenile justice nexus in Australia: A longitudinal examination of the relationship between maltreatment and offending. *Child Abuse & Neglect*, *64,* 32–46. https://doi.org/10.1016/j.chiabu.2016.11.028

Malvaso, C. G., Delfabbro, P. H., & Day, A. (2017b). Child maltreatment and criminal convictions in youth: The role of gender, ethnicity and placement experiences in an Australian population. *Children and Youth Services Review*, *73*, 57–65. https://doi.org/10.1016/j.childyouth.2016.12.001

Marmot, M., & Wilkinson, R. G. (1999). *Social determinants of health*. Oxford University Press.

Martin, K. (2008). *Please knock before you enter: Aboriginal regulation of outsiders and the implications for researchers*. Post Pressed.

Martin, R., Fernandes, C., Taylor, C., Crow, A., Headland, D., Shaw, N., & Zammit, S. (2019). ‘We don’t want to live like this’: The lived experience of dislocation, poor health, and homelessness for Western Australian Aboriginal people. *Qualitative Health Research, 29*(2), 159–172. https://doi.org/10.1177/1049732318797616

Maruna, S. (2001). *Making good: How ex-convicts reform and rebuild their lives*. American Psychological Association.

Maruna, S. (2009). Looking-glass identity transformation: Pygmalion and Golem in the rehabilitation process. In B. Veysey, J. Christian, & D. J. Martinez (Eds.), *How offenders transform their lives* (pp. 30–55). Willan.

Maslen, S. (2016). Sensory work of diagnosis: A crisis of legitimacy. *The Senses & Society, 11*(2), 158-176. https://doi.org/10.1080/17458927.2016.1190065

Maslen, S., & Lupton, D. (2019a). ‘Keeping it real’: Women’s enactments of lay health knowledges and expertise on Facebook. *Sociology of Health and Illness*, *41*(8), 1637–1651. https://doi.org/10.1111/1467-9566.12982

Maslen, S., & Lupton, D. (2019b). Enacting chronic illness with and through digital media: A feminist new materialist approach. *Information, Communication & Society*. https://doi.org/10.1080/1369118X.2019.1602665

Mattson, S. N., Riley, E. P., Gramling, L., Delis, D. C., & Jones, K. L. (1998). Neuropsychological comparison of alcohol-exposed children with or without physical features of fetal alcohol syndrome. *Neuropsychology*, *12*(1), 146–153. https://doi.org/10.1037/0894-4105.12.1.146

McKnight, A. D., Harwood, V., McMahon, S., Priestly, A., & Trindorfer, J. (2018). 'No shame at AIME': Listening to Aboriginal philosophy and methodologies to theorise the 'removal' of shame from educational contexts. *Australian Journal of Indigenous Education*. https://doi.org/10.1017/jie.2018.14

McLachlan, K., Roesch, R., Viljoen, J., & Douglas, K. (2014). Evaluating the psycholegal abilities of young offenders with Fetal Alcohol Spectrum Disorder. *Law and Human Behavior, 38,* 10–22. https://doi.org/10.1037/lhb0000037

McNally, S., & Latham, S. (2009). *Recognising and responding to hepatitis C in Indigenous communities in Victoria*. ARCSHS.

McNeill, F., & Maruna, S. (2007). Giving up and giving back: Desistance, generativity and social work with offenders. In G. McIvor & P. Raynor (Eds.), *Developments in social work with offenders. Research highlights in social work* (pp. 224–339). Jessica Kingsley.

McNeill, F., & Whyte, B. (2007). *Reducing reoffending: Social work and community justice in Scotland*. Willan.

McPhail-Bell, K., Bond, C., Brough, M., & Fredericks, B. (2015). 'We don't tell people what to do': Ethical practice and Indigenous health promotion. *Health Promotion Journal of Australia*, *26*(3), 195–199. https://doi.org/10.1071/HE15048

Memmott, P., Stacy, R., Chambers, C., & Keys, C. (2001). *Violence in Aboriginal communities*. Attorney-General's Department.

Meyer, R., Drewniak, D., Hovorka, T., & Schenk, L. (2018). Questioning the questionnaire: Methodological challenges in measuring subjective quality of life in nursing homes using cognitive interviewing techniques. *Qualitative Health Research*, e1–15. https://doi.org/10.1177/1049732318812042

Minore, J. B., & Hill, M. E. (1990). Native language broadcasting: An experiment in empowerment. *Canadian Journal of Native Studies*, *10*(1), 97–119. http://www3.brandonu.ca/cjns/10.1/minore.pdf

Mishler, E. G. (1995). Models of narrative analysis: A typology. *Journal of Narrative and Life History*, *5*, 87–123. https://doi.org/10.1075/jnlh.5.2.01mod

Moore, T. E., & Green, M. (2004). Fetal alcohol spectrum disorder (FASD): A need for closer examination by the criminal justice system. *Criminal Reports*, *19*(1), 99–108. http://www.acbr.com/FAS/FASDCrimRep.pdf

Morgan, D., Slade, M., & Morgan, C. (1997). Aboriginal philosophy and its impact on health care outcomes. *Australian and New Zealand Journal of Public Health*, *21*(6), 597–601. https://doi.org/10.1111/j.1467-842x.1997.tb01762.x

Morley, S. R. (2015). *What works in effective Indigenous community-managed programs and organisations*. Australian Institute of Family Studies.

Morris, A., & Giller, H. (1983). *Providing criminal justice for children*. Hodder Arnold.

Morrison, W. (2004). Criminology, genocide and modernity: Remarks on the companion that criminology ignored. In C. Sumner (Ed.), *The Blackwell companion to criminology* (pp. 68–88). Blackwell Publishing.

Moreton-Robinson, A. (2000). *Talkin' Up to the White Woman: Indigenous Women and Feminism*. University of Queensland Press.

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child Care Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

Mutch, R. (2013). *Fetal alcohol spectrum disorder: Knowledge, attitudes and practice within the Western Australian justice system*. Telethon Institute for Child Health Research.

Mutch, R., Jones, H., Bower, C., & Watkins, R. (2016). Fetal alcohol spectrum disorders: Using knowledge, attitudes and practice of justice professionals to support their educational needs. *Journal of Population Therapeutics and Clinical Pharmacology, 23*(1), e77–e89. https://pdfs.semanticscholar.org/6d5c/aeec39048e315434f298900ff8a1d7c09952.pdf

Mutch, R. C., Watkins, R., & Bower, C. (2015). Fetal alcohol spectrum disorders: Notifications to the Western Australian Register of Developmental Anomalies. *Paediatrics and Child Health, 51*(4), 433–436. https://doi.org/10.1111/jpc.12746

Nash, A. J., Hennessy, E. A., & Collier, C. (2019). Exploring recovery capital among adolescents in an alternative peer group. *Drug and Alcohol Dependence, 199*, 136–143. https://doi.org/10.1016/j.drugalcdep.2019.02.025

Nettleton, S., & Jutel, A. (2011). Towards a sociology of diagnosis: Reflections and opportunities. *Social Science & Medicine*, *73*, 793–800. https://doi.org/10.1016/j.socscimed.2011.07.014

Nettleton, S., O’Malley, L., Watt, I., & Duffey, P. (2004). Enigmatic illness: Narratives of patients who live with medically unexplained symptoms. *Social Theory and Health, 2,* 47–66.

Nevin, A. C., Parshuram, C., Nulman, I., Koren, G., & Elnarson, A. (2002). A survey of physicians knowledge regarding awareness of maternal alcohol use and the diagnosis of FAS. *BMC Family Practice, 3*(2), 1–5. https://doi.org/10.1186/1471-2296-3-2

NVivo Pro Qualitative Data Analysis Software Version 11 [computer program]. (2016). QSR International.

O’Connor, M., Shah, B., Whaley, S., Cronin, P., Gunderson, B., & Graham, J. (2002). Psychiatric illness in a clinical sample of children with prenatal alcohol exposure. *The American Journal of Drug and Alcohol Abuse, 28*(4), 743–754. https://doi.org/10.1081/ADA-120015880

O'Donoghue, L. (1999). Towards a culture of improving health in Australia. *Australian Journal of Rural Health*, 7, 64–69. https://doi.org/10.1046/j.1440-1584.1999.00218.x

O'Leary, C. M., Nassar, N., Kurinczuk, J., de Klerk, N., Geelhoed, E., Elliott, E., & Bower, C. (2010). Prenatal alcohol exposure and risk of birth defects. *Pediatrics*, *126*(4), e843–e850. https://doi.org/10.1542/peds.2010-0256

Office of the Inspector of Custodial Services. (2015). *Report of an announced inspection of Banksia Hill Juvenile Detention Centre.* Office of the Inspector of Custodial Services.

Office of the Inspector of Custodial Services. (2018). *Report of an announced inspection of Banksia Hill Juvenile Detention Centre.* Office of the Inspector of Custodial Services.

Ogilvie, E., & Lynch, M. (2001). Responses to incarceration: A qualitative analysis of adolescents in juvenile detention centres. *Current Issues in Criminal Justice*, *12*(3), 330–346. http://www.austlii.edu.au/au/journals/CICrimJust/2001/5.pdf

Olsvold, A., Aarseth, A., & Bondevik, H. (2019). 'I think my son is a wonderful chap': Working-class and middle-class fathers' narratives of their son's ADHD diagnosis and medication. *Families, Relationships and Societies*, *8*(1), 105–120. https://doi.org/10.1332/204674317X15034051559819

Page, K. (2001). Fetal Alcohol Spectrum–The hidden epidemic in our courts. *Juvenile and Family Court Journal*, *52*(4), 21–31. https://doi.org/10.1111/j.17556988.2001.tb00048.x

Pain, H. (2012). A literature review to evaluate the choice and use of visual methods. *International Journal of Qualitative Methods*, *11*, 303–319. https://doi.org/10.1177/160940691201100401

Passmore, H. M., Giglia, R., Watkins, R. E., Mutch, R. C., Marriott, R., Pestell, C., Zubrick, S. R., Rainsford, C., Walker, N., Fitzpatrick, J. P., Freeman, J., Kippin, N., Safe, B., & Bower, C. (2016). Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open*, *6*(6), e012184. https://doi.org/10.1136/bmjopen-2016-012184

Passmore, H. M., Mutch, R. C., Burns, S., Watkins, R., Carapetis, J., Hall, G., & Bower, C. (2018). Fetal Alcohol Spectrum Disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce. *International Journal of Law and Psychiatry, 59,* 44–52. https://doi.org/10.1016/j.ijlp.2018.05.008

Payne, J., France, K., Henley, N., D'Antoine, H., Bartu, A., O'Leary, C., Elliott, E. J., & Bower, C. (2011). Changes in health professionals' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal alcohol exposure and fetal alcohol spectrum disorder. *Paediatric Perinatal Epidemiology, 25*(4), 316–327. https://doi.org/10.1111/j.1365-3016.2011.01197.x

Peadon, E., Rhys-Jones, B., Bower, C., & Elliott, E. J. (2009). Systematic review of interventions for children with fetal alcohol spectrum disorders. *BMC Pediatrics, 9*(1), 35. https://doi.org/10.1186/1471-2431-9-35

Petersen, A., Tanner, C., & Munsie, M. (2019). Navigating the cartographies of trust: how patients and carers establish the credibility of online treatment claims. *Sociology of Health & Illness*, Online *41*(S1), 50–64. https://doi.org/10.1111/1467-9566.12872

Pewewardy, C. (2002). Learning styles of American Indian/Alaska native students: A review of the literature and implications for practice. *Journal of American Indian Education*, *41*(3), 22–56. https://www.jstor.org/stable/24398583

Pollack, K. (2009). Maintaining face in the presentation of depression: Constraining the therapeutic potential of the consultation. *Health*, *11*(2), 163–180. https://doi.org/10.1177/1363459307074692

Popay, J., Bennett, S., Thomas, C., Williams, G., Gartrell, A., & Bostock, L. (2003). Beyond 'beer, fags and chips'? Exploring lay understandings of social inequalities in health. *Sociology of Health and Illness*, *25*(1), 1–23. https://doi.org/101111/1467-9566.t01-1-00322

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: Analysing qualitative data. *BMJ*, *320*, 114–116. https://doi.org/10.1136/bmj.320.7227.114

Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm, J. (2011). Fetal alcohol spectrum disorder prevalence estimates in correctional systems: A systematic literature review. *Canadian Journal of Public Health*, *5*(102), 336–340. http://dx.doi.org/10.17269/cjph.102.2718

Potter, C., Kelly, L., Hunter, C., Fitzpatrick, R., & Peters, M. (2018). The context of coping: A qualitative exploration of underlying inequalities that influence health services support for people living with long-term conditions. *Sociology of Health and Illness*, *40*(1), 130–145. https://doi.org/10.1111/1467-9566.12624

Potter, R. H. (2014). Service utilization in a cohort of criminal justice-involved men: Implications for case management and justice systems. *Criminal Case Studies*, *27*(1), 82–95. https://doi.org/10.1080/1478601X.2013.873206

Productivity Commission. (2018). *Report of government services. Chapter 17: Youth justice services*. Australian Government. https://www.pc.gov.au/research/ongoing/report-on-government-services/2018/community-services/youth-justice/rogs-2018-partf-chapter17.pdf

Putnam, R. D. (2000). *Bowling alone: The collapse and revival of American community*. Simon & Schuster.

Rafalovich, A. (2005). Exploring clinician uncertainty in the diagnosis and treatment of attention deficit hyperactivity disorder. *Sociology of Health & Illness*, *27*(3), 305–323. https://doi.org/10.1111/j.1467-9566.2005.00444.x

Rasmussen, C., & Bisanz, J. (2009). Executive functioning in children with fetal alcohol spectrum disorders: Profiles and age-related differences. *Child Neuropsychology*, *15*(3), 201–215. https://doi.org/10.1080/09297040802385400

Rasmussen, E. (2017). Balancing medical accuracy and diagnostic consequences: Diagnosing medically unexplained symptoms in primary care. *Sociology of Health & Illness*, *39*(7), 1227–1241. https://doi.org/10.1111/1467-9566.12581

Reed, C., Sheehan, M., Chapman, R., Divola, S., & Keen, J. (2015). The challenge of normative influences for program design for youth in detention. *Journal of Offender Rehabilitation, 54*(5), 350–370. https://doi.org/10.1080/10509674.2015.1044152

Reitano, J. (2017). *Adult Correctional Statistics in Canada 2015/2016* (cat. no. 85-002-x). Canadian Centre for Justice Statistics. http://www.statcan.gc.ca/pub/85-002-x/2017001/article/14700-eng.htm

Rennie, E., Yunkaporta, T., & Holcombe-James, I. (2018). Privacy versus relatedness: Managing device use in Australia's remote Aboriginal communities. *International Journal of Communication, 12*, 1291–1309. https://pdfs.semanticscholar.org/7caa/d173127364d20fdf4f2e5c1820044fdef4b4.pdf

Riessman, C. (2002). *Illness narratives: Positioned identities*. Invited Annual Lecture, Health Communication Research Center, Cardiff University. https://www.researchgate.net/publication/241501264_Illness_Narratives_Positioned_Identities

Rigney, L.-I. (2001). A first perspective of Indigenous Australian participation in science: Framing Indigenous research towards Indigenous Australian intellectual sovereignty. *Kaurna Higher Education Journal, 7*, 1–13. https://ncis.anu.edu.au/_lib/doc/LI_Rigney_First_perspective.pdf

Roach, K., & Bailey, A. (2009). The relevance of fetal alcohol spectrum disorder and the criminal law from investigation to sentencing. *University of British Columbia Law Review, 42*, 1–68. https://ssrn.com/abstract=1616843

Rose, D. B. (1996). *Nourishing terrains: Australian Aboriginal views of landscape and wilderness*. Australian Heritage Commission.

Rudd, K. (2008). *Apology to Australia's Indigenous peoples*. https://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/2008-02-13/0003/hansard_frag.pdf;fileType=application/pdf

Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society, 23*(3), 199–210. https://doi.org/10.1080/09687590801953937

Rynne, J., & Cassematis, P. (2015). Assessing the prison experience for Australian First Peoples: A prospective research approach. *International Journal for Crime, Justice and Social Democracy, 4*(1), 96–112. https://doi.org/10.5204/ijcjsd.v4i1.208

Safe, B., Joosten, A., Bower, C., Condon, C., Watkins, R., Mutch, R., & Giglia, R. (2018). A comparison of the motor skills of young people in a youth detention centre with diagnosed Fetal Alcohol Spectrum Disorder, prenatal alcohol exposure, and a reference population. *Journal of Fetal Alcohol Spectrum Risk and Prevention, 1*(1), e17–e32. https://doi.org/10.22374/jfasrp.v1i1.5

Safe, B., Joosten, A., & Giglia, R. (2018). Assessing motor skills to inform a Fetal Alcohol Spectrum Disorder diagnosis focusing on persons older than 12 years: A systematic review of the literature. *Journal of Population Therapeutics and Clinical Pharmacology, 25*(1), e25–e38. https://doi.org/10.22374/1710-6222.25.1.3

Sampson, R., & Laub, J. (2003). Life-course desisters? Trajectories of crime among delinquent boys followed to age 70*. *Criminology, 41*(3), 555–592. https://doi.org/10.1111/j.1745-9125.2003.tb00997.x

Sanders, A., & Buck, G. (2010). A long journey: Biological and non-biological parents' experiences raising children with FASD. *Journal of Population Therapy and Clinical Pharmacology, 17*(2), e308–e322. https://pdfs.semanticscholar.org/3dc8/770904be31bba06fde15ec5f56593882e88e.pdf

Scheff, T. (1974). The labelling theory of mental illness. *American Sociological Review, 3*, 444–452. www.jstor.org/stable/2094300

Schrag, A., Modi, S., Hotham, S., Merritt, R., Khan, K., & Graham, L. (2018). Patient experiences of receiving a diagnosis of Parkinson's disease. *Journal of Neurology, 265*(5), 1151–1157. https://doi.org/10.1007/s00415-018-8817-8

Schrank, B., & Slade, M. (2007). Recovery in psychiatry. *Psychiatric Bulletin*, *31,* 321–325. https://doi.org/10.1192/pb.bp.106.013425

Scott, D., & Gosling, H. (2016). Before prison, instead of prison, better than prison: Therapeutic communities as an abolitionist real utopia. *International Journal for Crime, Justice and Social Democracy, 5*(1), 52–66. https://doi.org/10.5204/ijcjsd.v5i1.282

Secker, J., Membrey, H., Grove, B., & Seebohm, P. (2002). Recovering from illness or recovering your life? Implications of clinical versus social models of recovery from mental health problems for employment support services. *Disability & Society*, *17*(4), 403–418. https://doi.org/10.1080/09687590220140340

Sherwood, J. (2013). Colonisation—It's bad for your health: The context of Aboriginal health. *Contemporary Nurse*, *46*(1), 28–40. https://doi.org/10.5172/conu.2013.46.1.28

Shepherd, S., & Phillips, G. (2017). Cultural 'Inclusion' or Institutional Decolonisation: How should prisons address the mental health needs of Indigenous prisoners? *Australian and New Zealand Journal of Psychiatry, 1-2.* https://doi.org/10.1177/0004867415616696

Sigstad, H. M. H., & Garrels, V. (2017). Facilitating qualitative research interviews for respondents with intellectual disability. *European Journal of Special Needs Education*, *33*(5), 1–15. https://doi.org/10.1080/08856257.2017.1413802

Simpson, L., Nanibusg, W., & Williams, C. (2012). The resurgence of Indigenous women's knowledge, research and resistance: *Transnational and Interdisciplinary Perspectives, InTensions Journal*, *6,* 1–7. http://opus.uleth.ca/bitstream/handle/10133/3646/notefromtheeditor.pdf?sequence=1

Slade, M. (2010). Mental illness and well-being: The central importance of positive psychology and recovery approaches. *BMC Health Services Research, 10*(1). https://doi.org/10.1186/1472-6963-10-26

Slade, M., Amering, M., & Oades, L. (2008). Recovery: An international perspective. *Epidemiology and Psychiatric Sciences, 17*(2), 128–137. https://doi.org/10.1017/S1121189X00002827

Smith, J., Flower, P., & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, method and research. *Qualitative Research in Psychology*, *6*(4), 346–347. https://doi.org/10.1080/14780880903340091

Snow, P., Bagley, K., & White, D. (2017). Speech-language pathology intervention in a youth justice setting: Benefits perceived by staff extend beyond communication. *International Journal of Speech-Language Pathology*, *20*(4), 458–467. https://doi.org/10.1080/17549507.2017.1297484

Snow, P., Powell, M., Sanger, D., Nippold, M., & Schneider, P. (2012). Oral language competence, young speakers, and the law. *Language, Speech & Hearing Services in Schools*, *43*(4), 496–506. https://doi.org/10.1044/0161-1461(2012/11-0065)

Sotiri, M., & Simpson, J. (2006). Indigenous people and cognitive disability: An introduction to issues in police stations. *Current Issues in Criminal Justice, 17*, 431–443. https://doi.org/10.1080/10345329.2006.12036369

Spohr, H., Willms, J., & Steinhausen, H. (2007). Fetal alcohol spectrum disorders in young adulthood. *The Journal of Pediatrics, 150*(2), 175–179. https://doi.org/10.1016/j.jpeds.2006.11.044

Stake, R. E. (2013). *Multiple case study analysis*. Guilford Press.

Steinhausen, H. C., Willms, J., & Spohr, H. L. (1993). Long-term psychopathological and cognitive outcome of children with fetal alcohol syndrome. *Journal of the American Academy of Child & Adolescent Psychiatry*, *32*(5), 990–994. https://10.1097/00004583-199309000-00016

Stiglitz, J. (2012). *The price of inequality: How today's divided society endangers our future*. W. W. Norton & Company.

Streissguth, A. P., Barr, H. M., Bookstein, F. L., Sampson, P. D., & Olson, H. C. (1999). The long-term neurocognitive consequences of prenatal alcohol exposure: A 14-year study. *Psychological Science, 10*, 186–190. https://doi.org/10.1111/1467-9280.00131

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics, 25*(4), 228–238. https://doi.org/10.1097/00004703-200408000-00002

Streissguth, A. P., & O'Malley, K. (2000). Neuropsychiatric implications and long-term consequences of fetal alcohol spectrum disorders. *Seminars in Clinical Neuropsychiatry, 5*(3), 177–190. https://doi.org/10.1053/scnp.2000.6729

Strnadova, I., O'Neill, S., & Cumming, T. (2017). A snapshot of education behind the fence: Supporting engagement in education of incarcerated youth in Australia. *International Journal of Education Research, 85,* 33–42. https://doi.org/10.1016/j.ijer.2017.06.004

Tauri, J. M. (2018). The masters tools will never dismantle the masters house: An indigenous critique of criminology. *Journal of Global Indigeneity, 3*(1), 1–20. https://ro.uow.edu.au/jgi/vol3/iss1/6

Teachman, G., & Gibson, B. E. (2013). Children and youth with disabilities: Innovative methods for single qualitative interviews. *Qualitative Health Research, 23,* 264–274. https://doi.org/10.1177/1049732312468063

Teplin, L., Abram, K., McClelland, G., Dulcan, M., & Mericle, A. (2002). Psychiatric disorders in youth in juvenile detention. *Archives of General Psychiatry, 59*(12), 1133–1143. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2861992/pdf/nihms171651.pdf

Thomas, C., Novy, C., Gifford, W., Grandpierre, V., Poudrier, J., & Thomas, O. (2019). Exploring the intersections of storytelling and visual arts: Indigenous peoples' experiences of cancer.

Storytelling, Self, Society Special Issue: Storytelling for Health, *15*(1), 71–91. https://doi.org/10.13110/storselfsoci.15.1.0071

Thomas, D. P., Bainbridge, R., & Tsey, K. (2014). Changing discourses in Aboriginal and Torres Strait Islander health research, 1914–2013. *The Medical Journal of Australia*, *201*(1), 5–8. https://doi.org/10.5694/mja14.00114

Thurmond, V. (2001). The point of triangulation. *Journal of Nursing Scholarship, 33*(3), 253–258. https://doi.org/10.1111/j.1547-5069.2001.00253.x

Tilbury, C. (2009). The over-representation of Indigenous children in the Australian child welfare system. *International Journal of Social Welfare*, *18*(1), 57–64. https://doi.org/10.1111/j.1468-2397.2008.00577.x

Tobin, T., & Sprague, J. (2000). Alternative education strategies: Reducing violence in school and the community. *Journal of Emotional and Behavioral Disorders*, *8*(3), 177–186. https://doi.org/10.1177/106342660000800305

Toumbourou, J., Baksheev, G., Day, A., Leung, R., & Miller, P. (2013). The role of psychology in the prevention of youth violence. *InPsych: The Bulletin of the Australian Psychological Society*, *35*(3), 12–13.

Toumbourou, J., Leung, R., Homel, R., Freiberg, K., Satyen, L., & Hemphill, S. A. (2015). Violence prevention and early intervention: What works? In A. Day and E. Fernandez (Eds.), *Preventing violence in Australia: Policy, practice and solutions* (pp. 1–14). Federation Press. https://research-repository.griffith.edu.au/handle/10072/93783

Tracy, S. J. (2010). Qualitative quality: Eight ‘big-tent’ criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837–851. https://doi.org/10.1177/1077800410383121

Tsey, K., Lawson, K., Kinchin, I., Bainbridge, R., McCalman, J., Watkin, F., Cadet-James, Y., & Rossetto, A. (2016). Evaluating research impact: The development of a Research for Impact Tool. *Frontiers in Public Health*, *4*. https://doi.org/10.3389/fpubh.2016.00160

Tuhiwai Smith, L. (1999). *Decolonizing methodologies: Research and Indigenous peoples*. Zed Books.

Turowetz, J., & Maynard, D. (2019). Documenting diagnosis: Testing, labelling, and the production of medical records in an autism clinic. *Sociology of Health & Illness, 41*(6), 1023–1039. https://doi.org/10.1111/1467-9566.12882

Tynan, M., Atkinson, P., Bourke, L., & Atkinson, V. (2007). If you don't have health, what's the use of living? In I. Anderson, F. Baum, & M. Bentley (Eds.), *Beyond bandaids: Exploring the underlying social determinants of Aboriginal health* (pp. 1–19). Cooperative Research Centre for Aboriginal Health.

Ulmer, J., & Bradley, M. (2018). Punishment in Indian country: Ironies of federal punishment of Native Americans. *Justice Quarterly, 35*(5), 751–81. https://doi.org/10.1080/07418825.2017.1341540

Ungunmerr, M. R. (1988). *Dadirri: Inner Deep Listening and Quiet Still Awareness*. Miriam Rose Foundation. http://www.miriamrosefoundation.org.au/about-dadirri

United Nations. (1985). United Nations Standard Minimum Rules for the Administration of Juvenile Justice ('The Beijing Rules'). GA Res 40/33, UN GAOR, 40th sess, 96th plen mtg, UN Doc. A/RES/40/33 (29 November 1985). http://www.ohchr.org/Documents/ProfessionalInterest/beijingrules.pdf

Velarde, R. (2018). Indigenous perspectives of disability. *Disability Studies Quarterly, 38*(4). http://dsq-sds.org/article/view/6114/5134

Vicary, D., & Bishop, B. (2005). Western psychotherapeutic practice: Engaging Aboriginal people in culturally appropriate and respectful ways. *Australian Psychologist, 40*, 8–19. https://doi.org/10.1080/00050060512331317210

Vicary, D., & Westerman, T. (2004). 'That's just the way he is': Some implications of Aboriginal mental health beliefs. *Advanced Mental Health, 3*, 1–9. https://doi.org/10.5172/jamh.3.3.103

Viljoen, D., Croxford, J., Gossage, P., & Kodituwakku, P. (2002). Characteristics of mothers of children with fetal alcohol syndrome in the Western Cape Provence of South Africa: A case control study. *Journal of Studies on Alcohol and Drugs*, *63*(1), 6–17. https://pdfs.semanticscholar.org/c0bd/44deec36f18bb8a012c399645640903946d5.pdf?_ga=2.161431486.2074640424.1579127943-1394165864.1539736880

Viner, R., Ozer, E., Denny, S., Marmot, M., Resnick, M., Fetusi, A., & Currie, C. (2012). Adolescence and the social determinants of health. *Lancet*, *379*(9826), 1641–1652. https://doi.org/10.1016/S0140-6736(12)60149-4

Wacquant, L. (2009). *Punishing the poor: The neoliberal government of social insecurity*. Duke University Press.

Walker, J. (2015). Establishing a sense of belong in looked after children: The journey from fear and shame to love and belonging. In A. Briggs (Ed.), *Toward belonging* (pp. 85–104). Karmac.

Walker, M., Fredericks, B., Mills, K., & Anderson, D. (2014). 'Yarning' as a method for community-based health research with Indigenous women: The Indigenous women's wellness research program. *Health Care for Women International*, *35*, 1216–1226. https://doi.org/10.1080/07399332.2013.815754

Wandji, D. (2019). Rethinking the time and space of resilience beyond the West: an example of the post-colonial border. *Resilience*, 7, 3, 288-303. https://doi.org/10.1080/21693293.2019.1601861

Ward, T., & Maruna, S. (2007). *Rehabilitation: Beyond the risk paradigm*. Routledge.

Wasserman, G., Jensen, P., Ko, S., Cocozza, J., Trupin, E., Angold, A., Cauffman, E., & Grisso, T. (2003). Mental health assessments in juvenile justice: Report on the Consensus Conference. *Journal of American Academy Child Adolescent Psychiatry*, *42*(7), 751–761. https://doi.org/10.1097/01.CHI.0000046873.56865.4B

Wasserman, G., Larkin, S., McReynolds, S., Ko, L., Katz, J., & Carpenter, R. (2005). Gender differences in psychiatric disorders at juvenile probation intake. *American Journal of Public Health, 95*(1), 131–137. https://doi.org/10.2105/AJPH.2003.024737

Wasserman, G., McReynolds, L., Lucas, S., Fisher, C., & Santos, P. (2002). The voice DISC-IV with incarcerated male youths: Prevalence of disorder. *Journal of American Academy Child Adolescent Psychiatr*y, *41*(3), 314–321. https://doi.org/10.1097/00004583-200203000-00011

Weatherburn, D., & Ramsey, S. (2016). *What's causing the growth in indigenous imprisonment in NSW?* (Issue Paper No. 118). NSW Bureau of Crime Statistics and Research. https://www.bocsar.nsw.gov.au/Documents/BB/Report-2016What%27s-causing-the-growth-in-Indigenous-Imprisonment-in-NSW-BB118.pdf

Weaver, B. (2012). The relational context of desistance: Some implications and opportunities for social policy. *Social Policy and Administration, 46*(4), 395–412. https://doi.org/10.1111/j.1467-9515.2012.00840.x

Weick, K. E. (2007). The generative properties of richness. *Academy of Management Journal*, *50*(1), 14–19. https://doi.org/10.5465/amj.2007.24160637

Whaley, S. E., O'Connor, M. J., & Gunderson, B. (2001). Comparison of the adaptive functioning of children prenatally exposed to alcohol to a nonexposed clinical sample. *Alcoholism: Clinical & Experimental Research, 25*(7), 1018–1024. https://doi.org/10.1111/j.1530-0277.2001.tb02311.x

Whelan, E. (2007). 'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community. *Sociology of Health & Illness*, *29*(7), 957–982. https://doi.org/10.1111/j.1467-9566.2007.01024.x

White, W. (2008). Recovery: Old wine, flavor of the month or new organizing paradigm? *Substance Use and Misuse*, *43*(12–13), 1987–2000. https://doi.org/10.1080/10826080802297518

White, W., & Cloud, A. (2008). Recovery capital: A primer for addictions professionals. *Counselor*, *9*(5), 22−27. http://www.williamwhitepapers.com/pr/2008RecoveryCapitalPrimer.pdf

Williams, J., Leamy, M., Bird, V., Le Boutillier, C., Norton, S., Pesola, F., & Slade, M. (2015). *Development and evaluation of the INSPIRE measure of staff support for personal recovery*. *Social Psychiatry and Psychiatric Epidemiology*, *50*(5), 777–786. https://doi.org/10.1007/s00127-014-0983-0

Winterdyck, J. (2014). *Juvenile justice: International perspectives, models and trends*. CRC Press.

Worthen, E. (2010). Sensory-based interventions in the general education classroom: A critical appraisal of the topic. *Journal of Occupational Therapy, Schools and Early Intervention*, *3*(1), 76–94. https://doi.org/10.1080/19411241003684217

Young, J., Fisher, K. and Kirkman, M. (2019) Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis. *Feminism & Psychology*. Online. https://doi.org/10.1177/0959353519826170

Yin, R. K. (2013). *Case study research: Design and methods*. Sage Publications.

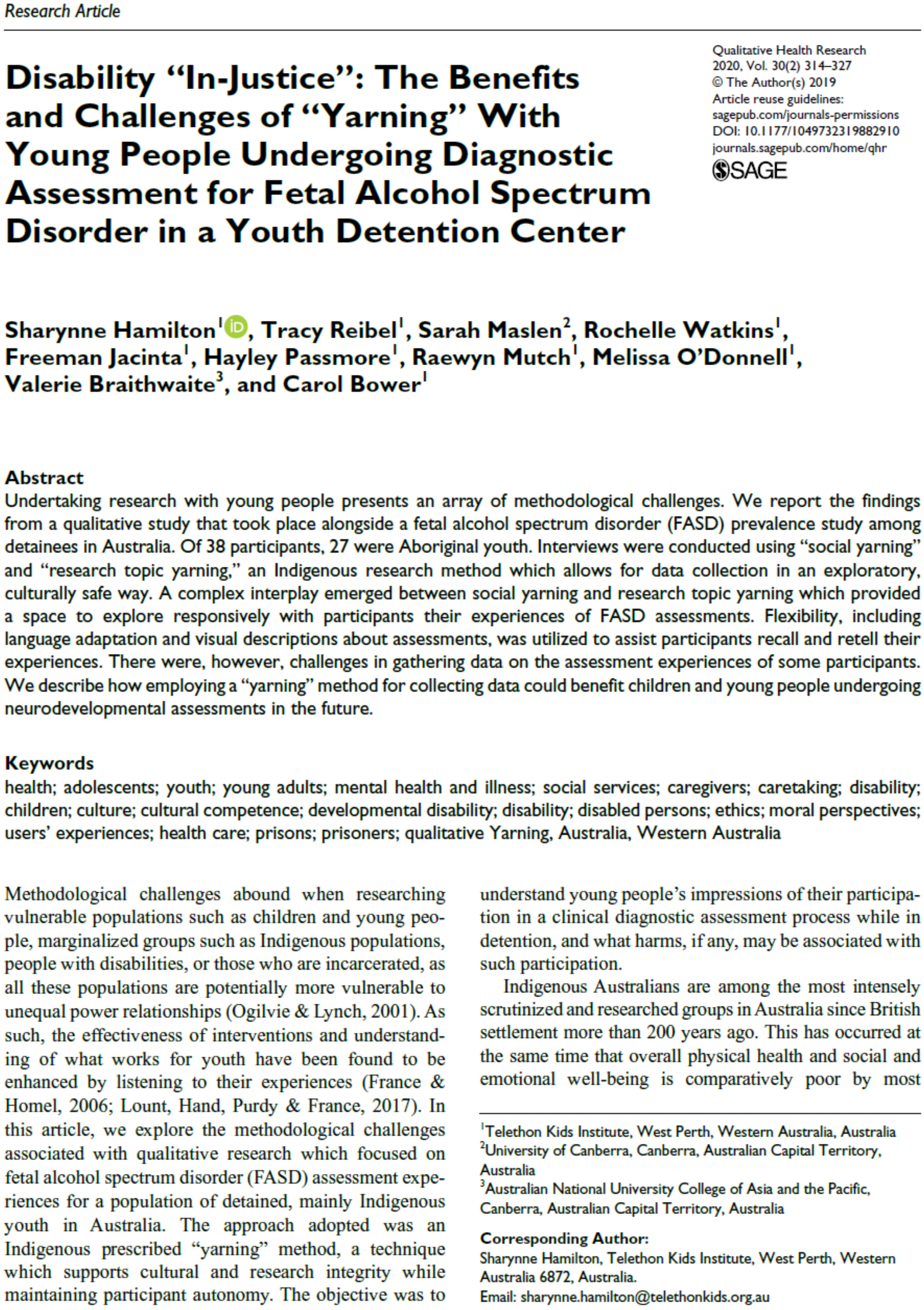
Zarhin, D. (2015). Contesting medicalisation, doubting the diagnosis: Patients’ ambivalence towards the diagnosis of Obstructive Sleep Apnoea. *Sociology of Health & Illness*, *37*(5), 715–730. https://doi.org/10.1111/1467-9566.12229

Zimmerman, J., Morrison, A., & Heimberg, R. (2015). Social anxiety, submissiveness, and shame in men and women: A moderated mediation analysis. *British Journal of Clinical Psychology*, *54*, 1–15. https://doi.org/10.1111/bjc.12057

Zubrick, S. R., Shepherd, C., Dudgeon, P., Gee, G., Paradies, Y., Scrine, C., & Walker, R. (2014). Social determinants of social and emotional wellbeing. In P. Dudgeon, H. Milroy, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (pp. 96–112). Australian Government Department of Health and Ageing.

Appendices

Appendix 1: Journal Article: *Qualitative Health Research*



Research Article

Qualitative Health Research
2020, Vol. 30(2) 314–327
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1049732319882910
journals.sagepub.com/home/qhr
SAGE

Disability "In-Justice": The Benefits and Challenges of "Yarning" With Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center

Sharynne Hamilton[1], Tracy Reibel[1], Sarah Maslen[2], Rochelle Watkins[1], Freeman Jacinta[1], Hayley Passmore[1], Raewyn Mutch[1], Melissa O'Donnell[1], Valerie Braithwaite[3], and Carol Bower[1]

Abstract

Undertaking research with young people presents an array of methodological challenges. We report the findings from a qualitative study that took place alongside a fetal alcohol spectrum disorder (FASD) prevalence study among detainees in Australia. Of 38 participants, 27 were Aboriginal youth. Interviews were conducted using "social yarning" and "research topic yarning," an Indigenous research method which allows for data collection in an exploratory, culturally safe way. A complex interplay emerged between social yarning and research topic yarning which provided a space to explore responsively with participants their experiences of FASD assessments. Flexibility, including language adaptation and visual descriptions about assessments, was utilized to assist participants recall and retell their experiences. There were, however, challenges in gathering data on the assessment experiences of some participants. We describe how employing a "yarning" method for collecting data could benefit children and young people undergoing neurodevelopmental assessments in the future.

Keywords

health; adolescents; youth; young adults; mental health and illness; social services; caregivers; caretaking; disability; children; culture; cultural competence; developmental disability; disability; disabled persons; ethics; moral perspectives; users' experiences; health care; prisons; prisoners; qualitative Yarning, Australia, Western Australia

Methodological challenges abound when researching vulnerable populations such as children and young people, marginalized groups such as Indigenous populations, people with disabilities, or those who are incarcerated, as all these populations are potentially more vulnerable to unequal power relationships (Ogilvie & Lynch, 2001). As such, the effectiveness of interventions and understanding of what works for youth have been found to be enhanced by listening to their experiences (France & Homel, 2006; Lount, Hand, Purdy & France, 2017). In this article, we explore the methodological challenges associated with qualitative research which focused on fetal alcohol spectrum disorder (FASD) assessment experiences for a population of detained, mainly Indigenous youth in Australia. The approach adopted was an Indigenous prescribed "yarning" method, a technique which supports cultural and research integrity while maintaining participant autonomy. The objective was to understand young people's impressions of their participation in a clinical diagnostic assessment process while in detention, and what harms, if any, may be associated with such participation.

Indigenous Australians are among the most intensely scrutinized and researched groups in Australia since British settlement more than 200 years ago. This has occurred at the same time that overall physical health and social and emotional well-being is comparatively poor by most

---

[1] Telethon Kids Institute, West Perth, Western Australia, Australia
[2] University of Canberra, Canberra, Australian Capital Territory, Australia
[3] Australian National University College of Asia and the Pacific, Canberra, Australian Capital Territory, Australia

Corresponding Author:
Sharynne Hamilton, Telethon Kids Institute, West Perth, Western Australia 6872, Australia.
Email: sharynne.hamilton@telethonkids.org.au

measures (Arabena & Moodie, 2014; Bainbridge et al., 2015; Thomas, Bainbridge, & Tsey, 2014; Tsey et al., 2016). While explanations for this state of affairs is complex, Indigenous scholars have argued for increased adoption of Indigenous ontologies and methodologies that build bridges for both conducting research and sharing benefits of research across Indigenous and non-Indigenous people (Bessarab & Ng'andu, 2010; Moreton-Robertson, 2000; O'Donoghue 1999; Rigney, 2001; Tuhiwai Smith, 1999). These Indigenous scholars do not discourage non-Indigenous research continuing to attempt to understand and address the health inequalities between Indigenous and non-Indigenous people. Rather, they seek to emphasize the importance of privileging Indigenous epistemologies and ontologies and prioritizing cultural safety when Indigenous people are the main focus of research. Similarly, ontological approaches in conventional interviewing techniques are also underpinned by an acknowledgment that participant realities are subjective and diverse, and what people say they experience has the potential to influence future outcomes (Creswell, 2012).

Guiding principles for harm reduction in research have been outlined by the Lowitja Institute (Laycock, Walker, Harrison, & Brands, 2011). According to these principles, research which aims to benefit Indigenous people should be designed to hold at its center consultation with, and leadership by, Indigenous people. It should also aspire to authentic engagement with communities and a commitment to deep analysis of the impact of the research and its influences on Indigenous health. Researching incarcerated youth, when the largest proportion of participants is Indigenous, could therefore reasonably be seen as intrusive and upsetting for participants and their communities. Stigmatization and greater discrimination against Indigenous youth might be feared, and with justification. Minimizing potential harm, therefore, is imperative (Bessarab & Ng'andu, 2010; Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Tuhiwai Smith, 1999).

In addition to minimizing harm, how we come to acquire knowledge, the concepts we use, and the value we attach to things vastly differs between Indigenous and non-Indigenous people in Australia. As such it is important to keep evolving research techniques for respectful sharing of information and the use of these knowledges (Doyle, Cleary, Blanchard, & Hungerford, 2017). The Indigenous voice in research has continually been suppressed and using an Indigenous data collection tool such as yarning is one vehicle through which the knowledges and values important to Indigenous participants can be prioritized in research (Bessarab & Ng'andu, 2010).

Background

Underpinning the critiques which have been offered as to how and why Western approaches to health research do not deliver the best possible outcomes for Indigenous people is the idea that power differentials have engendered suspicion and distrust of research and researchers. Methodologically sound approaches for undertaking qualitative research with vulnerable populations are continually developing, including both conventional interviewing techniques and research techniques specific for Indigenous peoples.

Conventional Qualitative Methods

Conventional qualitative techniques such as structured, semi-structured, and unstructured interviewing (Creswell, 2012; Kvale, 1994) can be used to collect data, where the aim is to describe the experiences and views of participants. Interviewing is broadly understood to be about a participant giving information on a particular topic to a researcher. Scholars, though, have long advocated that research should not be done "to" children, but rather "with them" (Christensen, 2004) and methodologies have been developed to allow more relational engagements when undertaking qualitative research, particularly with vulnerable groups such as children and youth with cognitive disabilities.

For children with cognitive disabilities, repeated interviewing has been found to have benefits, particularly when each child's unique characteristics, abilities, and difficulties are known to the interviewer and the interview format is adapted accordingly (Cederborg, La Rooy, & Lamb, 2008). Flexible communication, including periods of silence, using prompts, rephrasing questions, and summarizing and repeating responses back to participants, has been found to be necessary when interviewing individuals with cognitive disabilities (Sigstad & Garrels, 2017). Preparedness to be adaptable when interviewing can assist in meeting the special needs of children and young people with cognitive disabilities (Teachman & Gibson, 2013), and this is particularly important when the research explores challenging topics such as the experience participating in assessments for FASD (Pain, 2012).

Much has also been written on tools to assist in interviewing young people who are vulnerable, disadvantaged, or who have difficulty recalling or reporting their experiences, particularly in relation to health assessments and crime interrogation (Driessnack, 2006; Glegg, 2019; Horstman, Aldiss, Richardson, & Gibson, 2008). Other interviewing techniques, such as "cognitive interviewing," use a variety of tools to assist in data collection (Bryan et al., 2019; Meyer, Drewniak, Hovorka, & Schenk, 2018). The use of a "toolbox" of interviewing techniques such as drawing and writing and the use of pictures have been identified as critical to seeking the views of children who are subject to health assessments or research (Bryan et al., 2019; Lees et al., 2017; Lys, Gesink, Strike, & Larkin, 2018). Furthermore, the merits of interviewing children who are able to move around in what is termed by Irwin and Johnson (2005, p. 826) as having a "kinetic conversation" and the use of visual tools have been explored (Glegg, 2019; Davison, McLean, & Warren, 2015). These techniques facilitate relationships and provide opportunities for participants to express their thoughts and feelings in a non-threatening and honest way (Driessnack, 2006; Glegg, 2019; Horstman et al., 2008).

Underpinning all these techniques is the concept of "do no harm" to participants. Arguments for research to be done "with" rather than "to" Indigenous populations are also consistently articulated (Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Thomas et al., 2014; Tsey et al., 2016; Tuhiwai Smith, 1999). On the basis of the critiques of conventional interviewing techniques and their use with Indigenous populations, the processes used for information gathering have undergone change in both professional and research contexts. One example that has become particularly popular in the Australian context is "yarning."

Yarning as a Distinct Indigenous Qualitative Method

Yarning has become established as a research method, both in Indigenous Australian and global Indigenous studies (Bessarab & Ng'andu, 2010; Fredericks et al., 2011; Kovach, 2010; Martin et al., 2019; Rigney, 2001; Walker, Fredericks, Mills, & Anderson, 2014). Having a "yarn" is "an Indigenous cultural form of conversation" (Bessarab & Ng'andu, 2010, p. 37). The essence of a yarn is listening and exchange, with each side being willing to give information and show genuine connection to, empathy with, and interest in the other. The suitability of yarning, however, for Indigenous people stems from its everydayness—drawing as it does on long-standing cultural practices used by families and communities. Control in a yarning conversation is shared, with more emphasis on connection than on separateness, mutual respect, and knowledge exchange (Bessarab & Ng'andu, 2010; Martin et al., 2019; Walker et al., 2014).

Yarning is arguably more flexible than many conventional interviewing approaches, even though overlap and compatibility with some conventional methods is apparent. For example, as with yarning, narrative and conversational interviewing draw on storytelling as a way in which people are encouraged to make sense of their experiences and communicate through description of what is broadly meaningful to them rather than just retelling events (Emerson, 2018; Mishler, 1995).

When considering the interviewing needs of vulnerable participants such as incarcerated youth, researchers need to scrutinize the relational aspects of the research and the inherent power dynamics with a traumatized or vulnerable population (Kevers, Rober, & Haene, 2018). Yarning is a method that respects the "stories" participants "want to share" as opposed to participants being expected to give the researcher what they "want to hear." The yarning approach represents an opportunity for two-way learning and knowledge sharing which is not dependent on an unequal power relationship in which the researcher maintains control.

Depending on context and purpose, yarning can both orient the social interaction approach and center the research topic (Bessarab & Ng'andu, 2010). In this study, social yarning was used at the beginning of conversations with young people to establish a connection not strongly associated with the actual purpose of the yarn. In more conventional interviewing situations, this goal might be stated as establishing rapport. Social yarning goes further in setting the tone for research topic yarning by encouraging the participant to lead the yarn, with the researcher valuing the participant as a whole person—valuing their story and knowledges and minimizing power imbalances between the researcher and participant (Bessarab & Ng'andu, 2010). Ideally, no assumption is made that the researcher is in control. In fact, the role of "researcher" carries little weight during this early stage of "summing" each other up. Through social yarning, the intent is deeper, achieved through purposeful exchanges and trust-building, in which the researcher shares information about themselves with the participant, and the level of information exchange is controlled by the participant.

Throughout this process, the continuing responsibility of the researcher is to find shared ground through authentic interest in participant's lives. This might be achieved through sharing information about culture and family, sports, hobbies, or interests. The research remains flexible to finding the shared ground, which requires some knowledge about and empathy toward the participant's circumstances. For example, asking a participant "do you want to have a yarn about the research" promotes an approach of "let's explore what we feel, think, see together rather than saying 'this is what I want to know about the research, let's talk.'" By conducting a relational exchange in this way and establishing a genuine rapport, yarning becomes a tool of authentic information exchange, which when done well, with respect and by mutual agreement, has the potential to reveal information relevant to the research without necessarily asking direct questions (Bessarab & Ng'andu, 2010; Martin et al., 2019; Walker et al., 2014).

For Indigenous people, storytelling is a traditional form of knowledge sharing and respectful communication. Yarning provides a safe space for Indigenous people to share their feelings, hopes, and fears through storytelling. Moving between social and research topic yarning is, therefore, a fluid process (Bessarab & Ng'andu, 2010). Even when the research topic is introduced, yarning remains informal and relaxed. Interspersing answers to research questions within stories provides a fuller more meaningful and detailed engagement with the research topic than providing one- or two-word answers. Although this will not guarantee that an Aboriginal person will engage in a yarning process, more often than not, yarning provides participants with an opportunity to assess the potential threat or ulterior motives of the researcher/interviewer through a process of sharing knowledge and building mutual understandings. Yarning then becomes a journey of mutual discovery and learning through storytelling.

In both social yarning and research topic yarning, deviations from the purpose of the research are tolerated more than is the case in conventional interviewing, operating as a sign of respect for the connection established through the yarn. This is carried through to other forms of yarning. Collaborative yarning expands the opportunity for sharing information, through exploring other topics which lead to new understandings (Bessarab & Ng'andu, 2010). Therapeutic yarning occurs when very personal or traumatic information is disclosed by a participant. In such situations, the researcher needs to seamlessly switch from data collection to listening and supporting the participant (Bessarab & Ng'andu, 2010). Yarning requires the researcher to have sensitivity toward the participant and deep listening, or "dadirri," a spiritual form of trust and rapport building (Atkinson, 2002).

Overall, yarning creates relationships and governs the responsibility of both parties to be good listeners and genuine contributors and supporters of the other (Martin, 2008). Yarning as research method was, therefore, the most culturally safe means of gathering information, for the majority of the research population who were Indigenous youth. In addition, the language of "having a yarn" is colloquially well understood to mean "having a conversation," certainly among most Indigenous people but also in the broader Australian society. Thus, understanding of having a yarn and its suitability was readily extended to the non-Indigenous youth who were involved in this study.

In this analysis, we consider whether the use of yarning is an appropriate research data collection tool for both Indigenous and non-Indigenous youth in detention, particularly those with a neurodevelopmental disability.

Study Context

FASD is a lifelong, preventable brain injury caused by alcohol exposure during pregnancy (Fast & Conry, 2009; Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011). People with FASD can have a myriad of secondary problems including an increased likelihood that they will come into contact with the law (Fast & Conry, 2004). Streissguth and colleagues (2004) found that 60% of adolescents and adults with an FASD diagnosis in the United States had engagement with the justice system. Those with FASD have difficulty with language and communication (Kippin et al., 2018), understanding, and linking consequences to actions; they have memory problems, difficulty with attention and judgment, and are prone to impulsivity and suggestibility (McLachlan, Roesch, Viljoen, & Douglas, 2014).

In Australia, a House of Representatives Standing Committee on Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Aboriginal) Affairs (2011) report described receiving "compelling evidence on the issue of Fetal Alcohol Spectrum Disorder and [its] links with offending." The Aboriginal Legal Service of Western Australia (Inc) (2013) has also expressed concern that youth with unrecognized FASD are coming before the law in Australia. Despite representing 3% of the population, 27% of prisoners in Australia are Aboriginal (Australian Bureau of Statistics, 2017a) and almost half of all youth in custody are Aboriginal (Australian Bureau of Statistics, 2017b). In Western Australia (WA), Aboriginal youth are 54 times more likely to be incarcerated as non-Aboriginal youth (Australian Institute of Health and Welfare, 2016) and represent 75% of the youth detention population (Office of the Inspector of Custodial Services, 2015). There is a lack of understanding and knowledge of FASD and its implications in youth detention in WA in both the custodial (Passmore et al., 2018) and noncustodial workforce (Hamilton et al., 2019).

In response to these concerns, a first-of-its-kind multistrand research study was undertaken to establish the prevalence of FASD among youth in detention in WA (Bower et al., 2018; Passmore et al., 2016, Passmore et al., 2018). The prevalence study found that 36% of participants had FASD. In addition, 89% of participants had at least one domain of severe neurodevelopmental impairment, and 21% were impaired in cognition (Bower et al., 2018). It is important to note that, due to the age of the participants, ascertaining maternal alcohol consumption was challenging (Freeman et al., 2019), and as such, the FASD prevalence rate is likely to be underestimated (Bower et al., 2018).

Concurrent with the FASD prevalence study, a qualitative study was undertaken. Participants included the young people who had participated in FASD assessments, noncustodial staff who provide rehabilitative services to them while in detention, and the young people's parents, family members, and support networks. A core aim of the qualitative study was to determine whether the benefits of young people's participation in the assessment process outweighed potential harms that may have occurred in the course of the prevalence study. This determination would be made based on the cumulative evidence that young people provided during yarning, how they expressed their experiences of participation and what the assessment outcomes meant to them. This article aims to provide insight into the experiences of undergoing assessments for FASD and seeks evidence of how the assessment process might produce possible harm or benefit for those who undertook the testing.

Method

Study Setting

Banksia Hill Detention Centre (Banksia), the only youth detention facility in WA, houses male and female young offenders aged 10 to 18 (Department of Justice, 2018). At the time of the study, Banksia housed approximately 155 youth and 75% of the population was Aboriginal (Office of the Inspector of Custodial Services, 2015). Of these youth, 95% were male and more than half were aged between 16 and 17 years. More than half (57%) were urban youth and 43% were from regional and remote areas of WA (Office of the Inspector of Custodial Services, 2015).

All youth who had been sentenced to a minimum of 2 weeks in detention and were aged between 10 and 17 years, 11 months were eligible to participate. Participants were recruited using a face-to-face approach by a research officer based at, who identified eligible young people from the center census each week.

Assessments

Clinicians in the research team undertook comprehensive assessments with participating sentenced youth (Kippin et al., 2018; Passmore et al., 2016). Assessments began with a research officer collecting biosocial information from the young person about their life history, schooling, and general health and well-being. The participants then undertook clinical assessments: (a) a comprehensive health and medical assessment, (b) a neuropsychology assessment, (c) a speech and language assessment, and (d) a motor skills assessment.

On completion of clinical assessments of the assessment results, a multidisciplinary team of clinicians undertook a comprehensive review of the findings and, if relevant, formed a diagnosis for the participants. An Assessment Results and Recommendations Report was compiled of comprehensive assessment results, including the young person's strengths and difficulties, and proposed individualized strategies to assist in their future care.

Researchers met with the young person and their parent or guardian to provide feedback for the assessment results. Where relevant, interpreter services were used when English was an additional language. Additional information for follow-up services in Banksia for young people and community services for supporting those who care for the young people to understand, translate, or cope with the content of the reports was provided.

Informed Consent

Written assent from the young person and written consent from their parent or guardian to participate in the prevalence and qualitative studies were undertaken by a research officer. Because of the vulnerability of this population, a child-centered approach to seeking assent was followed (Dell Clark, 2011). The research officer explained the purpose of the study using simple language and pictorial information sheets and assent forms allowing time for the participant to review and ask questions (Bower et al., 2018).

Upon assent, written consent was then sought from their identified parent or guardian. Written assent and consent recognized the capacity of young participants to be involved in informed decision-making about research participation, while respecting the responsibility of their parents as their guardians to provide informed consent for participation (Lambert & Glacken, 2011).

Qualitative Study Participants

The qualitative study began at Banksia 12 months after the prevalence study had commenced. As a result, some earlier prevalence study participants did not have an opportunity to participate as they had been released prior to the qualitative study commencing. Sixty-one participants had been released and seven returned to Banksia. Three of these participants received feedback during this time, following which they undertook a yarning interview.

A purposive sampling method was used to identify qualitative study participants from the 99 young people who completed assessments in the prevalence study (Bower et al., 2018). Of these 99 participants, 38 agreed to participate in a yarning interview (see Supplemental Table). Most participants (27/38) self-identified as Aboriginal and the remaining 11 non-Aboriginal Australian, three of whom were born overseas. To protect the identity of participants, two descriptors are used in this article: Aboriginal and non-Aboriginal Australian.

At the time of the yarning interviews, the researcher had no knowledge of participants' diagnostic outcomes although was familiar with background information about the participant's circumstances. Subsequent analysis showed that of the qualitative participants, 24% had FASD. Of these participants, 90% had an additional diagnosis (mental health and conduct disorders), which were identified by their parent or guardian or derived from available health, justice, or child protection records. Of the participants diagnosed with neurodevelopmental disorder (ND), 26% of participants had one or more additional diagnoses. The remaining 42% of participants did not receive an FASD or ND diagnosis.

Qualitative Study Data Collection

Data were collected primarily using social yarning, progressing to research topic yarning. The researcher and participant first exchanged information about family, where they lived, their education experiences, and their hopes for the future. The research was undertaken by an Aboriginal woman from Eastern Australia with a background in social work. Yarning, therefore, involved sharing information about Aboriginal heritage and country—a cultural protocol essential to honest and identifiable engagement between Aboriginal people and highly relevant to the young people in this study. When opportunity arose, the researcher moved from social yarning to the research topic yarn. This transition into research topic yarning occurred at different times, depending on how engaged the young person was in their own storytelling. The research topic yarning explored assessment experiences, what the participants liked or were challenged by, and discussed specific assessment information.

All but two interviews took place in an outdoor area at Banksia and all yarns were in sight, but not in hearing of custodial officers. Yarns took place in the residential units ($n = 3$ male units, $n = 3$ female units). Two yarns were undertaken with young people attending but not participating in sporting activities and the remainder ($n = 30$) took place during Banksia's school and vocational activities and were undertaken in the education quadrangle. The yarns lasted between 10 and 30 minutes.

Most yarns were undertaken with the researcher and participant seated side by side with a respectful distance between and an intent to maintain a natural and nonthreatening engagement. At the same time, the proximity allowed the researcher to observe the participant's body language, demeanors, and other nonverbal cues.

Every effort was made to undertake research topic yarning as close to the assessments as possible. The yarns typically took place within 1 week following completion of each young person's assessment but ranges from the same day as an assessment up to 16 days. Not all the young people in the qualitative study had completed all the clinical assessments. However, all had undertaken at a minimum the biosocial interview with a research officer and had completed one clinical assessment. At the time of yarning, only seven participants had received feedback about their assessments. As such, the majority of participants were only in a position to yarn about their assessment experiences.

To minimize potential harm to participants, a voice-recording device was not used during yarning. Brief handwritten notes were taken during the interview, with salient points recorded in writing (verbatim) and double-checked with participants for accuracy at the time of the interview. Immediately following the yarn, the researcher comprehensively documented details of the interview, including multiple reflective field notes.

Ethics Approval

Ethics approval was granted by the Western Australian Aboriginal Health Ethics Committee (Approval Number 582) and University of Western Australia Human Research Ethics Committee (Approval Number RA/4/1/7116). Research approvals were also gained from the (former) Department of Corrective Services (project ID 335) and the (former) Department for Child Protection and Family Support (Approval Number 2015/8981).

Data Analysis

These data were analyzed using thematic analysis (Attride-Stirling, 2001). The research topic yarning data were entered into NVivo 11 Pro (2016) by the lead researcher and multiple reviews and coding were conducted. Study team members, as well as clinicians undertaking the assessments, regularly met and discussed emerging themes from these data. Two researchers, one senior qualitative researcher independent from the study, separately reviewed these data and identified, compared, and finalized key themes.

Findings: Yarning as a Data Collection Method

The findings presented here focus on observations identified in the young people's yarning data related to the benefits and challenges of yarning as a data collection method. This analytical perspective focused on participants' experiences with the clinical assessments, what the process meant to them. The analysis is presented under descriptive headings which seek to untangle the nuances of yarning as a research data collection method and demonstrate the fluidity of the approach particular to each individual circumstance. Beginning with a description of how yarning was conducted culturally with Aboriginal participants, and in a "two-way" conversation with non-Aboriginal participants, we then explore the challenges and strategies used when yarning with participants with a neurodevelopmental disability. The exchange between social yarning and research topic yarning as an interconnected entity, and the necessity for researcher flexibility is explored. Finally, the prior knowledge of participant disability and social circumstances as a prerequisite knowledge for researchers is then discussed.

Yarning and Language Adaptation

Yarning provided an opportunity for sharing information between the researcher and the participants. An Aboriginal participant, who identified English as his first language, and who was diagnosed in the study with FASD, provides a good example. This participant remembered his assessment experience and said "the assessments were all good, though there were some silly words." In yarning about the "silly words," the researcher explained these to the participant in a way that Aboriginal people commonly communicate. For example, FASD was yarned about between the participant and the researcher as "that thing in your head" or feeling confused or not understanding became "when your head feeling silly." When describing a personal strength identified in the assessment, the researcher described it as "solid" or a "deadly thing," terms which Aboriginal people use to describe something as very good. Toward the end of the yarn, the researcher asked the participant whether he understood better the "silly words" and his response was "yes, now you said it blackfulla way."

It was not only Aboriginal young people who required changes in descriptive language during yarning. For one non-Aboriginal participant who did not understand what confusion was, the researcher said, "when your head is feeling all mixed up."

Silences

Using yarning did not necessarily mean participants were able to communicate their thoughts and feelings about the assessments or their experience of these. One Aboriginal participant diagnosed with ND in the study was noted by the researcher as "difficult to engage." The field notes went on to describe

> a difficult interview. [The participant] continually stood up and sat down during the yarn. He was very hyper-vigilant, continually looking over his shoulder (we had our backs to the wall of a main classroom), and almost startled at every noise. He was fidgety and his legs never stopped . . . Although he smiled a lot and seemed happy he actually said very little.

Another non-Aboriginal participant was noted by the researcher as "not really wanting to [yarn] even though he said he did." More than once this young person, due to a lack of responses, was asked whether he would like to return to the class he had been in before the yarn. Even though he said very little, he declined to return to the class. This raises interesting questions about his agreement to participate in the study and whether participation in yarning was a way to escape the daily routine of detention life.

One non-Aboriginal participant with no diagnosis from the study, and no previously noted diagnosis, had completed assessments over 3 weeks, and the yarning interview took place 3 days after his final assessment. Although this participant had on the surface a much greater ability of social connection and capacity to comment on and remember his assessment process than some of his peers, yarning was, nonetheless, difficult for him. For example, he said "it is hard to remember specifics about the assessments," while the field notes recorded he was "happy and talked openly . . . maintained eye contact and was smiling most of the time. He wasn't fidgety and was able to focus on our conversation." As such, it was interesting that this participant had no view of his participation in the assessments. Possibly the experience was just not worthy of his attention in the context of incarceration where so much else was going on, and which was possibly more relevant to his well-being.

Walking and Yarning: Visual Cues to Promote Yarning

An Aboriginal participant, diagnosed with many impairments including in his communication, was happy to have a yarn about assessments and feedback when invited. When the researcher asked the participant where he would like to sit for the yarn, he indicated a brick wall in the education block. He politely invited the researcher to sit and then proceeded to stand right in front of the researcher less than a meter away. Although not intentionally threatening, the participant was a tall and solid young person and the researcher was not comfortable. The researcher repeated a request to him to take a seat on the wall; however, he continued to just look at the researcher, smiling. In response, the researcher stood and suggested "we walk and yarn." The flexibility of yarning, which could arguably have been more difficult using traditional qualitative methods, provided an opportunity for this participant to share what he could about his experience in a way which affected neither the researcher nor the participant but gave some choice of the environment in which the yarn took place. In this case, yarning flexibility provided a way to manage this young person's poor social skills and inability to understand the concept of "personal space."

Using Additional Tools to Facilitate Yarning

It is apparent that to effectively contribute their experiences in yarning, many participants needed additional assistance. This section explores the use of additional tools to assist participants tell their stories.

One of the benefits of yarning over other qualitative research methods, especially in this study, is that it directs the researcher toward considerations such as the appropriate use of language, visual illustrations, and different ways to conduct conversations according to individual participant needs. Therefore, its emphasis is on the researcher's responsibility to ensure that a safe space is created in which to engage with participants.

During research topic yarning, a non-Aboriginal participant diagnosed with ND and an intellectual disability (ID) said "assessments were all good, nothing special." In words alone, the research yarn revealed very little. However, in the yarn it became apparent that this participant struggled to understand his diagnosis of ID. The young person was eligible for disability services support but was worried about meeting with personnel from the service. The researcher visually demonstrated what he could not understand. This included using a flowchart created with post-it notes and drawing a number of pictures to assist the participant's understanding, including visuals on different parts of the brain affected. Working through this process in the context of the yarn had immediate benefits for the young person. It also suggests that such approaches may be valuable in communicating about the research and assessment processes. It is important to note that although fidget tools were mostly useful additions to yarning, they did not help this participant. During the first yarning session, he was given a stress ball to help him focus, but its use was noted by the researcher to provide "not too much effect."

Another non-Aboriginal participant had difficulty remembering his strengths and challenges provided in his report feedback. In response, his strengths were written on post-it notes for him to put in his room. The researcher also showed him a blank copy of one of the pictorial assessment protocols, to which he responded, "oh yes, I remember." While browsing through the protocol, the participant went on to say, "I don't remember anything particularly bad about them," but then shared his feelings about the speech pathology component, saying he "didn't like the mouth stuff . . . moving my mouth and tongue around. It felt funny." Using these tools in the context of the yarn, he was able to reflect on and benefit from his participation in the assessment experience and enhance his understanding of his assessment results.

One non-Aboriginal participant with ND, attention deficit hyperactivity disorder (ADHD), and post traumatic stress disorder (PTSD) was very conversant during the research yarn; however, his complex problems resulted in displays of some inappropriate behaviors during the yarning. Rather than abandon the yarn, the researcher instead provided fidget tools, such as a stress ball and picture cards, to minimize the potential for his actions and to assist the young person to maintain his personal space without imposing this on him.

Like conventional qualitative methods, tools assisted the participants to understand and communicate. However, unlike the more linear fashion associated with conventional interviewing, yarning allowed the flexibility to weave between the social and the research topic.

Transitioning From the Social to the Research Yarn

Social yarning was also an important way to get through to some of the participants whose problems with things like substance use dominated other thoughts. A participant with confirmed ADHD, PTSD, and conduct disorder was one example. The young person, who had lived in foster care with "too many homes to count," was noted in the yarning field notes as being "highly focused on drug use," with the yarn terminated as the researcher "was unable to divert his attention from the topic of drug use." While, in this case, there were limited data collected on the research topic, the process of yarning was perceived as of benefit to this young person, highlighting that social yarning, in particular, is about more than "data collection." This participant was noted in this yarn as being "so so sad." During the yarn, the participant said to the researcher "you don't know nuffin miss," indicating a barrier from the perspective of the young person to sharing their experience. In the context of the yarn, the researcher shared with the young person some similarities in their teenage lives in the hope that the young person could see a future outside of detention and drug use. The participant engaged with this aspect of the yarn, the researcher recording this response from the participant: "[name] looked me fair and square in the eye and said 'really'?" This suggests that yarning encouraged a conversational exchange of information through building trust and arousing interest. Furthermore, it indicates that yarning as method, while not completely successful in terms of moving to research topic yarning, was able to open a space for communication between the research participant and the researcher that would have been even more difficult using conventional qualitative interviewing methods.

Three yarns were ceased during social yarning due to inappropriate conversations about the young people's crimes or drug use and an inability by the researcher to shift the young people to yarning about the assessments. In fieldwork notes, the researcher recorded reasons for ceasing the yarn: "high levels drug use ceased yarn due to an inability to move the young person away from the topic"; "no engagement or interest in, and possibly no memory of assessments." Later analysis of the diagnostic results revealed two of these participants had been diagnosed in the prevalence study: one with FASD and one with ND. The other participant had confirmed diagnosis of ADHD, PTSD, and conduct disorder. All three youths were Aboriginal.

Yarning Flexibility and Fluidity

For the most part, the focus of the observations has been on research topic yarning. However, in most cases, social and research topic yarning were intertwined, at times extending to therapeutic yarning. We have presented these findings to directly illustrate this intertwining, as well as noting the challenges in transitioning from the social into the research yarn, and occasionally, therapeutic contexts.

Yarning was a method which had the required flexibility to allow space for the participants to talk about what was important to them, even if it appeared off topic in the first instance. An Aboriginal participant with no diagnosis advised that they had undertaken the assessments to understand more about what a family member who had been assessed and diagnosed with FASD had experienced. The participant when asked about their thoughts on the assessments said, “I have much greater insight into his problems and what he went through.” In this case, moving between social and research topic yarning allowed increased knowledge for participants about themselves, as well as opening a space to talk about the assessment process.

These examples of difficulties with research topic yarning should not be interpreted as failures of the method. The participants were still able to provide information about their difficulties and what they needed. Prior to the yarn being stopped, a participant with FASD said, “don’t really care about them [the assessments].” He participated because it seemed “better than going to school.” A number of features of FASD and the reason for his difficulties were evident on later analysis of the transcript. First, managing his behavior and impulsivity was difficult for this young person. Yarning about not liking the consequences, the researcher asked this young person “do you think about whether you should not do something so you don’t get into trouble,” the participant said, “[laughing] aaaah too late—I would have done it before I thought about whether I should.” While this information was presented within the social yarning component, it provided important information related to the research topic yarning: that of difficulties with impulsivity, which is important to address for young offenders with FASD.

Researchers’ “Need to Know”

Much of the feedback presented here emphasizes the need for researchers to be armed with information regarding a young person’s neurodevelopmental and social challenges following assessments. One participant, an Aboriginal youth diagnosed in the study with ND, was positive about his experience: “it has helped me to understand more about myself.” He then explained that he “struggled with the story part, I got confused trying to tell the story back, but everything else was ok.” His acknowledgment of his “struggle with the story part” of the assessment suggests that he had some good awareness of his own challenges. It also suggests that had the researcher known previously that this young person struggled with comprehending and relaying information because of impairments in language, communication, and his executive functioning, this young person may have been “yarned” with differently to provide him with a better opportunity to tell his story. This was a predicament in the yarning related to not always being aware of young people’s diagnoses, having limited knowledge of their personal circumstances or their assessment outcomes. Prior knowledge may assist with approaching the yarn in a more tailored way. At the same time, no prior knowledge reduces researcher bias. This, therefore, emphasizes the need for research flexibility and using the fluid nature of yarning to create the best possible circumstances for the yarn to take place.

Discussion

The findings presented here have focused on the benefits and challenges of yarning as a data collection method and suggest that yarning provided a way to acquire knowledge about research experiences from vulnerable young participants while giving them some control over the interview process (Ogilvie & Lynch, 2001). The findings also suggest that with or without neurodevelopmental disability, young people may not answer questions for a variety of reasons. They may not be listening, they may not understand, they may not know the answer, or they may not want to give an answer. The findings provide some insight into how youth in detention approach the issue of researchers wanting to know about their capacities and experiences.

The findings also suggest that yarning allows the flexibility to deal with poor listening and understanding, to work out the likelihood of youth not having an answer through not noticing or not remembering and identifying cases where youth may not want to share knowledge. Yarning assisted young people, who were confused or had difficulty understanding aspects of their impairments to better understand their assessments. Yarning also provided flexibility for participants who struggled because of poor social skills or impairments in memory and attention. As with conventional interviewing methods (Bryan et al., 2019; Meyer et al., 2018; Teachman & Gibson, 2013), this flexibility offered accommodation of specific needs such as walking, descriptive explanations, assistance with focus, and for the structure or flow of the interview. The findings suggest that yarning gives scope to be responsive to the many different reasons for not receiving an answer and working out most likely explanations. By employing changes in language such as plain language or "blackfulla way" explanations and drawing or providing visual imagery, yarning assisted participants to understand more about their strengths and difficulties. The flexibility of yarning in combination with a variety of tools provided examples for participants to be able to ask for or get what they need in the future. Although the use of fidget tools and other devices can be used to assist young people with sensory difficulties with their education (Worthen, 2010), there is no known literature on the use of fidget tools and yarning with youth with neurodevelopmental disability. The way fidget and visual tools were used both to maintain engagement in yarning and as an educational resource which had benefits both during the research and for the participant's future needs provides a significant contribution to future qualitative health research methods for young people undergoing clinical assessments in the future.

Although there were many benefits, the yarning method was not a silver bullet. Bessarab and Ng'andu's (2010) description of "social yarning" as a process which can be used to build participant rapport ahead of "research topic yarning" would seem a reasonably straightforward process. In this research, however, there was a necessary back-and-forth movement between social and research topic yarning to maintain rapport, to maintain engagement, and to gain information relevant to research topic yarning. Talking with detained youth, many of whom had a range of complex problems, with or without neurodevelopmental disabilities, is tough. It is, therefore, no surprise that there were participants who could not provide the information we were seeking about the assessments in the research topic yarning. Importantly, there is no evidence to suggest that it was more difficult for any particular group, Aboriginal or non-Aboriginal, or those with or without a diagnosis. Moreover, yarning as a method for collecting data with non-Aboriginal participants had resonance with other more conventional qualitative interviewing techniques for children with cognitive disabilities (Sigstad & Garrels, 2017).

Continually yarning and providing feedback following assessments appears to be generally a useful process regardless of neurodevelopmental capability. Furthermore, in order for the researcher to be flexible and responsive to participant needs, diagrams, drawings, and printed information can be used to enhance the sharing of knowledge and ensure mutual understanding in accordance with different communication, language, life experiences, and preferred learning styles.

This research was undertaken to invite the participants to express their thoughts about their assessment experiences. Difficulties which can be experienced by those with FASD such as an impaired ability to understand and communicate, memory problems, and difficulty with attention and judgment (McLachlan et al., 2014) were all found to be present among the participants. It is imperative to consider the views and experiences of participants to minimize the potential for harm, particularly for Aboriginal youth (Bessarab & Ng'andu, 2010; Fredericks et al., 2011; Kovach, 2010; Rigney, 2001; Tuhiwai Smith, 1999).

Documenting neurodevelopmental disability through clinical assessments for justice-involved youth has the potential to identify and direct future assessments and interventions which could initiate a process of supported pathways for youth away from crime. Recognizing and supporting individuals with FASD or ND in the youth justice system facilitates understandings of these youth and their needs. Undiagnosed neurodevelopmental disabilities mean that these youth are being dealt with by a justice system that is blind to their disability, and in so doing, perpetrates a "disability in-justice." Knowledge of how those assessed as having a neurodevelopmental disability such as FASD regard their experience with the process of assessment may open new pathways for understanding and assisting these youth in future.

Limitations

The study was limited by the nature of the sample, a select cohort of detained youth, and was determined by the availability and willingness of participants to be involved in yarning interviews. At times, there were limited opportunities to access the young people due to factors associated with the operation of the detention center. This affected the time between the assessment and the interview, potentially affecting their recollections. It was also limited by being unable to link reactions to testing to different categories of neurodevelopmental impairments due to not have these data at the time of interviewing.

A decision was made by the researcher not to use recording devices with the participants in the detention center. Discussing the use of a voice recorder with one young person who immediately associated the device with his police interview, the researcher decided it would be less harmful for the participants not to have this means of data recording associated with the yarning aspect of the research. As such yarning was dependent on note taking, with verbatim quotes written during the interviews and detailed reflective field notes prepared immediately following yarning. In addition, the participants' neurodevelopmental disabilities meant that the researcher needed to ask different questions or use different approaches. Both of these factors meant there was variability in the amount of data between participants at times which resulted in one-word or short answers.

The participants had difficult lives and histories and at times the researcher, although externally composed, was disturbed by the trauma experienced by the participants. In one or two cases, this influenced the direction yarning took and influenced the questions the researcher both chose to ask and how they were asked. In these cases, this may have influenced participant responses in both the social yarning and in moving to research topic yarning.

Conclusion

Using a yarning methodology to interview young people assessed for neurodevelopmental disability enables a partnership to develop between researcher and participants in which information can be shared between the two. Researchers can gain insight into how young people make sense of the process of clinical assessment and elements that need further refinement to meet their needs. Yarning with young people opens the possibility for building relationships between researchers and participants in such a way that researchers can give something back reciprocating the "gift" of participation. This analysis has also revealed that researchers could benefit from being armed with information about a participant's neurodevelopmental strengths and impairments ahead of yarning. Having such insights suggests that the use of additional techniques such as fidget tools, walking while yarning, or through using visual aids such as diagrams or drawing may provide benefits for participants. The research suggests that there is much value in evolving shared knowledges which enable improvement in future assessment processes and provide participants with an opportunity to gain valuable information about themselves.

Author's note

Any material published or made publicly available by the authors cannot be considered as either endorsed by the Department of Justice or an expression of the policies or the views of the Department. Any errors of omission or commission are the responsibility of the researchers.

Acknowledgement

The authors thank the young people and staff at Banksia Hill Detention Centre. SLH thanks Professor Dawn Bessarab from the University of WA for expert advice on 'yarning'. SLH is grateful for the valuable contribution from the Elder Co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project, Telethon Kids Institute for sharing their knowledge and wisdom and contribution to the interpretation of the data from this research.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research is funded by the National Health and Medical Research Council (grant number APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341). SLH is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award, the FASD Research Australia Centre of Research Excellence and the Centre of Research Excellence Indigenous Health and Alcohol, University of Sydney. HMP is supported by an Australian Government Research Training Program Scholarship and the Stan and Jean Perron Award for Postgraduate Excellence.

ORCID iD

Sharynne Hamilton https://orcid.org/0000-0002-3057-8992

Supplemental Material

Supplemental Material for this article is available online at journals.sagepub.com/home/qhr. Please enter the article's DOI, located at the top right hand corner of this article in the search bar, and click on the file folder icon to view.

References

Aboriginal Legal Service of Western Australia (Inc). (2013). *Submission to the Australian Human Rights Commission—Access to justice for people with disability: Issues paper, April 2013*. Retrieved from http://www.als.org.au/wp-content/uploads/2013/09/publications_Submissions_alswa%20ahrc%20submission%20website%20version%20august%202013.pdf

Arabena, K., & Moodie, D. (2014). The Lowitja Institute: Building a national strategic research agenda to improve the health of Aboriginal and Torres Strait Islander peoples. *Medical Journal of Australia*, *194*, 532–434. doi:10.5694/j.1326-5377.2011.tb03091.x

Atkinson, J. (2002). *Trauma trails, recreating song lines: The transgenerational effects of trauma in Indigenous Australia*. North Melbourne: Spinifex Press.

Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research*, *1*, 385–405. doi:10.1177/146879410100100307

Australian Bureau of Statistics. (2017a). *Prisoners in Australia, 2017* (Cat. no. 4517.0). Canberra: Australian Bureau of Statistics.

Australian Bureau of Statistics. (2017b). *Recorded Crime—Offenders, 2015-16: Youth Offenders* (Cat. no. 4519.0). Canberra: Australian Bureau of Statistics.

Australian Institute of Health and Welfare. (2016). *Youth detention population in Australia 2016* (AIHW bulletin no. 138. Cat. no. AUS 210). Canberra: Australian Institute of Health and Welfare.

Bainbridge, R., Tsey, K., McCalman, J., Kinchin, I., Saunders, V., Watkin Lui, F., . . . Lawson, K. (2015). No one's discussing the elephant in the room: Contemplating questions of research impact and benefit in Aboriginal and Torres

Strait Islander Australian health research. *BMC Public Health*, *15*, 1–10. doi:10.1186/s12889-015-2052-3

Bessarab, D., & Ng'andu, B. (2010). Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies*, *3*, 37–50. doi:10.5204/ijcis.v3i1.57

Bower, C., Watkins, R., Mutch, R., Marriott, R., Freeman, J., Kippin, N. R., & Giglia, R. (2018). Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia. *BMJ Open*, *8*, e019605. doi:10.1136/bmjopen-2017-019605

Bryan, G., Bluebond-Langner, M., Kelly, D., Kumpunen, S., Oulton, K., & Gibson, F. (2019). Studying children's experiences in interactions with clinicians: Identifying methods fit for purpose. *Qualitative Health Research*, *29*, 393–403. doi:10.1177/1049732318801358

Cederborg, A. C., La Rooy, D., & Lamb, M. E. (2008). Repeated interviews with children who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *21*, 103–113. doi:10.1111/j.14683148.2007.00372.x

Christensen, P. H. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children and Society*, *18*, 165–176. doi:10.1002/chi.823

Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.

Davison, J., McLean, C., & Warren, S. (2015). Looking back: Ten years of visual qualitative research. *Qualitative Research in Organizational Management*, *10*, 355–359. doi:10.1108/QROM-07-2015-1311

Dell Clark, C. (2011). *In a younger voice. Doing child-centred qualitative research*. London: Oxford University Press.

Department of Justice. (2018). *Department of Justice annual report 2017/18*. Perth: Government of Western Australia.

Doyle, K., Cleary, M., Blanchard, D., & Hungerford, C. (2017). The Yerin Dilly bag model of Indigenist health research. *Qualitative Health Research*, *27*, 1288–1301. doi:101177/1049732317700125

Driessnack, M. (2006). Draw-and-tell conversations with children about fear. *Qualitative Health Research*, *16*, 1414–1435. doi:10.1177/1049732306294127

Emerson, A. M. (2018). Strategizing and fatalizing: Self and other in the trauma narratives of justice-involved women. *Qualitative Health Research*, *28*, 873–887. doi:10.1177/1049732318758634

Fast, D., & Conry, J. (2004). The challenge of fetal alcohol syndrome in the criminal legal system. *Addiction Biology*, *9*, 161–166. doi:10.1080/13556210410001717042

Fast, D., & Conry, J. (2009). Fetal alcohol spectrum disorders and the criminal justice system. *Developmental Disabilities Research Reviews*, *15*, 250–257. doi:10.1002/ddrr.66

France, A. & Homel, R. (2006). Societal access routes and developmental pathways: Putting social structure and young people's voice into the analysis pathways into and out of crime. *Australian and New Zealand of Criminology* *39*(3), 287–94. doi: 10.1375/acri.39.3.295

Fredericks, B., Adams, K., Finlay, S., Fletcher, G., Andy, S., Briggs, L., & Hall, R. (2011). Engaging the practice of yarning in action research. *Action Learning and Action Research Journal*, *17*(2), 7–19. Retrieved from https://eprints.qut.edu.au/48053/

Freeman, J., Condon, C., Hamilton, S. L., Mutch, R. C., Bower, C., & Watkins, R. (2019). Challenges in accurately assessing prenatal alcohol exposure in a Study of Fetal Alcohol Spectrum Disorder in a Youth Detention Centre. *Alcoholism: Clinical and Experimental Research*, *43*, 309–316. doi:10.1111/acer.13926

Glegg, S. (2019). Facilitating interviews in qualitative research with visual tools: A typology. *Qualitative Health Research*, *29*, 301–310. doi:10.1177/1049732318786485

Hamilton, S. L., Reibel, T., Watkins, R., Mutch, R. C., Kippin, N. R., Freeman, J., & Bower, C. (2019). "He has problems; he is not the problem . . ." A qualitative study of noncustodial staff providing services for young offenders assessed for Foetal Alcohol Spectrum Disorder in an Australian youth detention centre. *Youth Justice*, *19*, 137–157. doi:10.1177/1473225419869839

Horstman, M., Aldiss, S., Richardson, A., & Gibson, F. (2008). Methodological issues when using the draw and write technique with children aged 6 to 12 years. *Qualitative Health Research*, *18*, 1001–1011. doi:10.1177/1049732308318230

House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs. (2011). *Doing time—Time for doing—Indigenous youth in the criminal justice system*. Retrieved from https://www.aph.gov.au/Parliamentary_Business/Committees/Committees_Exposed/atsia/sentencing/report

Irwin, L. G., & Johnson, J. (2005). Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research*, *15*, 821–831. doi:10.1177/1049732304273862

Kevers, R., Rober, P., & Haene, L. D. (2018). Unraveling the mobilization of memory in research with refugees. *Qualitative Health Research*, *28*, 659–672. doi:10.1177/1049732317746963

Kippin, N., Leitão, S., Watkins, R., Finlay-Jones, A., Condon, C., & Bower, C. (2018). Language diversity, language disorder, and fetal alcohol spectrum disorder among youth sentenced to detention in Western Australia. *International Journal of Law and Psychiatry*, *61*, 40–49. doi:10.1016/j.ijlp.2018.09.004

Kovach, M. (2010). *Indigenous methodologies: Characteristics, conversations, and contexts*. Toronto: University of Toronto Press.

Kvale, S. (1994). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.

Lambert, V., & Glacken, M. (2011). Engaging with children in research: Theoretical and practical implications of negotiating informed consent/assent. *Nursing Ethics*, *18*, 781–801. doi:10.1177/0969733011401122

Laycock, A. Walker, D., Harrison, N. & Brands, J. (2011). *Researching Indigenous Health: A Practical Guide for Researchers*. Melbourne: The Lowitja Institute.

Lees, A., Payler, J., Ballinger, C., Lawrence, P., Faust, S. N., & Meads, G. (2017). Positioning children's voice in clinical trials research: A new model for planning, collaboration, and reflection. *Qualitative Health Research*, *27*, 2162–2176. doi:10.1177/1049732317726760

Lount, A., Hand, L., Purdy, S.C., & France, A. (2017). Tough talk: Youth offenders' perceptions of communicating in the youth justice system in New Zealand. *Australian and New Zealand Journal of Criminology*, *51*(4), 1–26, doi: 10.1177/0004865817740404

Lys, C., Gesink, D., Strike, C., & Larkin, J. (2018). Body mapping as a youth sexual health intervention and data collection tool. *Qualitative Health Research*, *28*, 1185–1198. doi:10.1177/1049732317750862

Martin, K. (2008). *Please knock before you enter: Aboriginal regulation of outsiders and the implications for researchers*. Brisbane: Post Pressed.

Martin, R., Fernandes, C., Taylor, C., Crow, A., Headland, D., Shaw, N., & Zammit, S. (2019). "We Don't Want to Live Like This": The lived experience of dislocation, poor health, and homelessness for Western Australian aboriginal people. *Qualitative Health Research*, *29*, 159–172. doi:10.1177/1049732318797616

McLachlan, K., Roesch, R., Viljoen, J., & Douglas, K. (2014). Evaluating the psycholegal abilities of young offenders with fetal alcohol spectrum disorder. *Law and Human Behavior*, *38*, 10–22. doi:10.1037/lhb0000037

Meyer, R., Drewniak, D., Hovorka, T., & Schenk, L. (2018). Questioning the questionnaire: Methodological challenges in measuring subjective quality of life in nursing homes using cognitive interviewing techniques. *Qualitative Health Research*, *29*, 972–986. doi:10.1177/1049732318812042

Mishler, E. G. (1995). Models of narrative analysis: A typology. *Journal of Narrative and Life History*, *5*, 87–123. doi:10.1075/jnlh.5.2.01mod

Moreton-Robinson, A. (2000). *Talkin' Up to the White Woman: Indigenous Women and Feminism*. Queensland: University of Queensland Press.

NVivo Pro. (2016). Qualitative data analysis software Version 11 [Computer program]. QSR International Pty Ltd. Melbourne.

O'Donoghue, L. (1999). Towards a Culture of Improving Health in Australia. *Australian Journal of Rural Health 7*, 64–69. doi: 10.1046/j.1440-1584.1999.00218.x

Office of the Inspector of Custodial Services. (2015). *Report of an announced inspection of Banksia Hill Juvenile Detention Centre*. Perth: Author.

Ogilvie, E., & Lynch, M. (2001). Responses to incerceration: A qualitative analysis of adolescents in Juvenile Detention Centres. *Current Issues in Criminal Justice*, *12*, 330–346. Retrieved from http://www.austlii.edu.au/au/journals/CICrimJust/2001/5.pdf

Pain, H. (2012). A literature review to evaluate the choice and use of visual methods. *International Journal of Qualitative Methods*, *11*, 303–319. doi:10.1177/160940691201100401

Passmore, H. M., Giglia, R., Watkins, R., Mutch, R., Marriott, R., & Bower, C. (2016). Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open*, *6*(6), e012184. doi10.1136/bmjopen-2016-012184

Passmore, H. M., Mutch, R. C., Burns, S., Watkins, R., Carapetis, J., Hall, G., & Bower, C. (2018). Fetal alcohol spectrum disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce. *International Journal of Law & Psychiatry*, *59*, 44–52. doi:10.1016/j.ijlp.2018.05.008

Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm, J. (2011). Fetal alcohol spectrum disorder prevalence estimates in correctional systems: A systematic literature review. *Canadian Journal of Public Health*, *5*, 336–340. doi:10.17269/cjph.102.2718

Rigney, L.-I. (2001). A first perspective of indigenous Australian participation in science: Framing indigenous research towards indigenous Australian intellectual sovereignty. *Kaurna Higher Education Journal*, *7*, 1–13. Retrieved from https://ncis.anu.edu.au/_lib/doc/LI_Rigney_First_perspective.pdf

Sigstad, H. M. H., & Garrels, V. (2017). Facilitating qualitative research interviews for respondents with intellectual disability. *European Journal of Special Needs Education*, *33*(5), 1–15. doi:10.1080/08856257.2017.1413802

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics*, *25*, 228–238. doi:10.1097/00004703-200408000-00002

Teachman, G., & Gibson, B. E. (2013). Children and youth with disabilities: Innovative methods for single qualitative interviews. *Qualitative Health Research*, *23*, 264–274. doi:10.1177/1049732312468063

Thomas, D. P., Bainbridge, R., & Tsey, K. (2014). A brief history of Aboriginal and Torres Strait Islander health research, 1914–2013. *Medical Journal of Australia*, *201*, 5–8. doi:10.5694/mja14.00114

Tsey, K., Lawson, K., Kinchin, I., Bainbridge, R., McCalman, J., Watkin, F., . . . Rossetto, A. (2016). Evaluating research impact: The development of a research for impact tool. *Front Public Health*, *4*, Article 160. doi:10.3389/fpubh.2016.00160

Tuhiwai Smith, L. (1999). *Decolonizing methodologies: Research and indigenous peoples*. New York: Zed Books.

Walker, M., Fredericks, B., Mills, K., & Anderson, D. (2014). "Yarning" as a method for community-based health research with Indigenous women: The Indigenous women's wellness research program. *Health Care for Women International*, *35*, 1216–1226. doi:10.1080/07399332.2013.815754

Worthen, E. (2010). Sensory-based interventions in the general education classroom: A critical appraisal of the topic. *Journal of Occupational Therapy, Schools and Early Intervention*, *3*, 76–94. doi:10.1080/19411241003684217

Author Biographies

Sharynne Hamilton is a Ngunnawal woman, a PhD Candidate with the Telethon Kids Institute and the University of Western Australia. Her research interests include bettering family inclusion in statutory systems and improving the social and emotional wellbeing of Aboriginal and Torres Strait Islander families and communities.

Tracy Reibel BA (Hons) PhD has thirty years' experience conducting health and social equity research from positions in community organisations, research institutes and universities. She has expertise in qualitative methods, evaluation, and health professional educational development. She is currently the Principal Research Fellow at the Ngangk Yira Research Centre for Aboriginal Health and Social Equity at Murdoch University.

Sarah Maslen is assistant professor of Sociology in the Faculty of Business, Government and Law, University of Canberra. Her research focuses on learning, decision making and the senses in medicine, engineering, outdoor adventure and the arts. Her current research interests include use of digital media in knowing about health and disease

Rochelle Watkins is an Epidemiologist and a senior research fellow, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute.

Jacinta Freeman has a Masters in Public Health and a background in Nursing and Midwifery. Her most recent research work includes establishing the prevalence of FASD in youth detention and youth suicide prevention in Western Australia.

Hayley M. Passmore has qualifications in Criminology and Psychology and is a final year PhD candidate at The University of Western Australia and Telethon Kids Institute.

Raewyn Mutch (MBCHB, DipRACOG, FRACP, PhD) is an associate professor with the University of Western Australia and a paediatrician caring for children and adolescents with a special interest in refugee and asylum seeker health. Raewyn has a track record of clinical and research work among culturally and linguistically diverse families, neurodevelopment and justice disciplines

Melissa O'Donnell is a senior research fellow at Telethon Kids Institute, University of Western Australia. Her focus is in conducting policy relevant research to improve the outcomes for children through prevention and early intervention of child abuse and neglect. Her work has contributed to National and State policy and practice in the area of child protection and family support.

Valerie Braithwaite is an interdisciplinary social scientist with a psychology background and works with the Regulatory Institutions Network (RegNet) at the Australian National University. Valerie's work focuses on responsive regulation, trust and hope.

Carol Bower has qualifications in medicine, epidemiology and public health. Her research focuses on birth defects - understanding their causes, prevention and amelioration.

Supplemental Table 1: Participant characteristics

		Prevalence study participants (*n*=99)	Qualitative study participants (*n*=38)
		Number (%)	Number (%)
Ethnicity(a)	Aboriginal Australian	73 (74)	27 (71)
	Non-Aboriginal Australian	16 (26)	11 (29)
Age	13 years	4 (4)	2 (5)
	14 years	16 (16)	6 (16)
	15 years	23 (23)	11 (29)
	16 years	23 (23)	11 (29)
	17 years	33 (33)	8 (21)
Gender	Male	92 (93)	35 (92)
	Female	7 (7)	3 (8)
Residential area	Urban	51 (51)	6 (15)
	Regional/Remote	49 (49)	32 (85)
Consenting Adult	Parent	62 (63)	10 (26)
	Guardian	24 (24)	15 (40)
	DOC (b)	13 (13)	13 (34)

a) Includes young people of New Zealand, Asian, African ethnicity.
b) State guardianship: Department of Communities

Appendix 2: Journal Article: ***Sociology of Health and Illness***

SOCIOLOGY OF HEALTH & ILLNESS

Sociology of Health & Illness Vol. xx No. xx 2020 ISSN 0141-9889, pp. 1–16
doi: 10.1111/1467-9566.13146

'That thing in his head': Aboriginal and non-Aboriginal Australian caregiver responses to neurodevelopmental disability diagnoses

Sharynne L. Hamilton[1,2], Sarah Maslen[3], Rochelle Watkins[1], Katherine Conigrave[4], Jacinta Freeman[1], Melissa O'Donnell[1,2], Raewyn C. Mutch[1,2] and Carol Bower[1,2]

[1]*Telethon Kids Institute, The University of Western Australia, Perth, WA, Australia*
[2]*School of Paediatrics and Child Health, The University of Western Australia, Perth, WA, Australia*
[3]*Faculty of Business, Government and Law, University of Canberra, Canberra, Australia*
[4]*Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia*

Abstract Little is known about the significance of cultural differences to how caregivers receive a diagnosis of neurodevelopmental disability. As part of a Fetal Alcohol Spectrum Disorder prevalence study among sentenced, detained youth, our qualitative study explored the experiences of diagnostic assessment among detained young people and their caregivers. We present findings from the perspectives of caregivers. In conversation with the sociology of diagnosis literature, we present vignettes of three Aboriginal and two non-Aboriginal caregivers' experiences of the diagnostic assessment process. We found that Aboriginal caregivers conceptualised their children's diagnosis and ongoing management in the context of their family networks and community. In contrast, non-Aboriginal caregivers focused on how the diagnosis would affect their child and interactions with various institutions including healthcare systems and schools. Caregivers' engagement with diagnostic reports and resources also followed cultural lines. Reflections on intergenerational drinking were voiced by Aboriginal caregivers, who expressed shame at receiving diagnosis. These findings advance our appreciation of cultural difference in receiving a diagnosis, the examination of which is in its nascent stages. We also suggest ways to mitigate harm from a stigmatising diagnosis and soften the well-established effects of medical dominance over the process of defining a person's capacity and status.

Keywords: sociology of diagnosis, Aboriginal, caregivers, cultural understanding, neurodevelopmental disability

Introduction

Diagnosis serves a critical function in organising illness, identifying and providing pathways to treatments, and predicting likely outcomes. Fully appreciating diagnosis requires an

Published by John Wiley & Sons Ltd., 9600 Garsington Road, Oxford OX4 2DQ, UK and 350 Main Street, Malden, MA 02148, USA

appreciation of how diagnoses sit within the wider context of social forces, interactions and relationships (Blaxter 2004, Blum 2015, Jutel 2009, Jutel 2019). As sociological contributions have demonstrated, much of the practice of diagnosis is often taken for granted, with reported professional labels glossing over the ways in which diagnostic work is embodied (Gardner and Williams 2015, Maslen 2016), and a product of communication between the doctor and patient (Turowetz and Maynard 2019) with the potential for clinical uncertainty (Rafalovich 2005, Rasmussen 2017). The doing of diagnostic work is also embedded in relations of medical authority and power (Nettleton and Jutel 2011), giving diagnosticians the ability to define patients' behaviour and control access to health resources (De Swaan 1989, Whelan 2007). The extensive literature on medical dominance and patient expertise highlights how patients and caregivers are not passive recipients of a diagnosis. Instead, people receive and understand a diagnosis increasingly within social, cultural, and environmental circumstances, and their lived experience (Blaxter 2004, Blum 2015). The diagnostic process can also be a site of resistance (Gill *et al.* 2010, Maslen and Lupton, 2019a, 2019b, Zarhin 2015).

The social aspects of diagnosis have long been of interest to sociologists, though relatively little attention has been paid to the ways in which different social groups engage with diagnostic processes. Gendered aspects of diagnosis have received some attention, particularly via analysis of gender-specific conditions. Studies of women's engagements with endometriosis diagnoses have emphasised contestation of medical expertise (Whelan 2007, Young *et al.* 2019). The significance of masculinities to men's discourses about mental health diagnoses have also been subject to inquiry (Johnson *et al.* 2012), demonstrating that men are more reluctant than women to seek a diagnosis for a mental health condition (Zimmerman *et al.* 2015). Understanding diagnosis in relation to ageing has also been examined, particularly in cases such as Alzheimer's and dementia, revealing the importance of listening to both caregivers and patients about their experiences of receiving a diagnosis regardless of cognitive condition (Brossard and Carpentier 2012, Schrag *et al.* 2018).

Many of these studies involve examination of social status and stigma of diagnosis, including the potential harm from diagnostic labels (Brown 2008; Link and Phelan 2001). In a study of middle class fathers' experiences of ADHD for their child, fathers described feeling pressure to seek a medical diagnosis for what they felt was a social problem in order to receive support (Olsvold *et al*. 2019). Middle class fathers were more likely than fathers from a low socioeconomic group to describe shame and guilt about having a child who misbehaved or was uncontrollable (Olsvold *et al*. 2019). Studies of mothers' parenting children with disabilities have also captured the stigma associated with the difficult work they undertake navigating systems of care and advocating their children's needs (Blum 2015, Landsman 2009, Ryan and Runswick-Cole 2008). Cultural aspects of diagnosis have also been highlighted, with scholars demonstrating that racial and ethnic disparities can prevent accessing diagnostic services, prompting calls for culturally relevant community-based diagnostic services and interventions (Magana *et al*. 2013).

Studies of how different cultural groups respond to diagnoses are in their nascent stages. How health and illness is understood in the context of global Indigenous[1] cultures, particularly where these cultures have endured centuries of colonial oppression, has been the subject of inquiry in a range of scholarly areas, including anthropology, medicine, and post-colonial studies (Wandji 2019). Comprised mostly of deficit focused, Western-centred assumptions of Indigenous health and illness, these works have been extensively criticised for their lack of regard to Indigenous voices and knowledge systems (Sherwood 2013). Despite the well-established benefits of privileging Indigenous voices in health and illness research (Bessarab and Ng'andu 2010, Sherwood 2013), examination of the potential for shame and stigma to affect access to diagnostic services, or how a diagnosis is received, are largely absent in the context of Indigenous populations (Ayunerak *et al.* 2014).

This article begins to address this research gap through a comparative analysis of how caregivers from Aboriginal and non-Aboriginal Australian backgrounds respond to receiving a diagnosis of FASD or neurodevelopmental impairments for their child. These caregivers participated in a first-of-its-kind Australian study which was undertaken to establish the prevalence of Fetal Alcohol Spectrum Disorder (FASD) among youth sentenced to detention in Banksia Hill Detention Centre between 2015 and 2017 (Bower *et al*. 2018). FASD is a lifelong, preventable brain injury caused by alcohol exposure during pregnancy and those affected can have a myriad of secondary problems including trouble with the law (Fast and Conry 2004). Individuals with neurodevelopmental impairments (regardless of prenatal alcohol consumption) can have memory and attention problems, difficulty with language and communication, they are suggestible and prone to impulsivity (McLachlan *et al*. 2014). Of the 99 youth who underwent full assessments in the prevalence study, 74% were Aboriginal and half were from remote or regional WA. Thirty-six percent of participants were diagnosed with FASD and 89% were diagnosed with at least one severe neurodevelopmental impairment (Bower *et al.* 2018). In addition to providing important information about the prevalence of FASD, this study has opened a unique opportunity to explore cultural needs and understandings about receiving a diagnosis and diagnostic resources.

Variation between Indigenous and non-Indigenous peoples is signalled by the broader literature on Indigenous conceptualisations of health. The worldviews of Australian Aboriginal people are diverse and vary across Australian states. In WA, where this study was conducted, scholars have investigated the cultural intersections and different worldviews that affect the health of Aboriginal people (Vicary and Westerman 2004). Acknowledging the impact of colonisation and the connection between history and the current circumstances of Aboriginal families and communities, Vicary and Westerman (2004) argue that it is critical to appreciate Aboriginal people's engagement with Western models of diagnosis and treatment in the context of the multiplicity of factors that impact wellness, including employment, overcrowding and inadequate housing, high rates of family violence, crime, alcohol and other drug use, and poverty. Aspects of Aboriginal culture may also be significant to engagements with the diagnostic process. Indigenous cultures share knowledge through the oral transmission of stories and have visual-spatial strengths that assist understanding and learning (Hickey and Wilson, 2017, Hughes *et al.* 2004, Pewewardy 2002, Thomas *et al*. 2019).

We conducted interviews with 17 caregivers of diagnosed youth. The qualitative study is the first of its kind internationally to examine multiple participant experiences, understandings, and perceived implications of assessments and diagnoses for justice-involved youth in detention. We present five vignettes to provide a rich account of the lived reality and experience of receiving a diagnosis. We demonstrate cultural patterning in how caregivers conceptualise their children's diagnosis and ongoing management, with variation in whether diagnosis and care is considered principally in relation to individuals or their communities, and whether Western institutions (legal, health care, schools) are seen as sites of support. Shame is also significant in how Aboriginal caregivers receive a diagnosis of FASD in the context of intergenerational drinking.

Background

There is a paucity of literature exploring the way that caregivers receive a diagnosis for neurodevelopmental disabilities such as FASD. North American studies have found that caregivers typically reported high satisfaction with FASD diagnostic processes and outcomes (Astley 2014). Other studies have captured how receiving a diagnosis can have dual consequences, with birth mothers experiencing grief, guilt and regret, and simultaneously feeling validated and relieved to have answers to their child's difficulties (Sanders and Buck 2010). Caregivers have also expressed concern about the uncertainty of their child's future in the absence of community support as they age (Murphy *et al*. 2007).

Two Australian studies (Chamberlain *et al*. 2017, Doak, *et al.* 2019) have explored FASD diagnostic experiences for caregivers, though neither discussed nor differentiated between Aboriginal and non-Aboriginal Australian caregivers. The studies found that the experience of diagnosis was validating (Chamberlain *et al*. 2017) and a positive for caregivers, and that caregivers gained new knowledge and insight about their children. Caregivers saw benefit in diagnosis from raised awareness of children's problems being attributed to neurodevelopmental impairments, and from recommendations and supports provided during the diagnostic process (Doak *et al.* 2019). However, a lack of access to long-term services tailored to children's needs left caregivers feeling alone and unsupported (Chamberlain *et al*. 2017). Factors such as age, socioeconomic status, and geographical proximity to services obstructed benefits from diagnosis (Doak *et al*. 2019).

The broader literature on caregivers posits that social and biomedical explanations of diagnosis are interwoven narratives, and that network and resource mobilisation can be preferred to medical intervention (Blaxter 2004; Malacrida 2004, Riessman 2008, Ryan and Runswick Cole, 2008). Interwoven narratives can produce collective understandings and connections which can assist caregivers (Blum 2015, Garro and Yarris 2009, Malacrida 2001). With increasing use of digital and internet sources, concerns have been raised by patients and caregivers about privacy and a lack of access to credible information (Petersen *et al*., 2019).

Caregivers' experiences of shame in response to diagnosis has also been raised in relation to mental health conditions and conduct disorders (Olsvold *et al*. 2019), and autism and FASD (Corrigan *et al.* 2017). In each of these cases, shame relates to caregivers' perceptions or awareness of having caused their children's problems and being subjected to messages of parental incompetence. Caregivers can feel shame because they anticipate negative labelling and stigma from a diagnosis, with blame and shame often occurring simultaneously (Francis 2012). Avoidance of a diagnosis in some cultural groups has also been identified, as diagnosis of disability is shameful (Heneker *et al.* 2017, Liu 2005).

This existing scholarship on the sociology of diagnosis and caregiver experience leads us towards a series of research questions:

1. How might understanding of, and engagement with, a diagnosis for FASD or for neurodevelopmental impairments be different for Aboriginal and non-Aboriginal people?
2. In what ways are engagements with diagnostic resources affected by cultural background?
3. Are there observable patterns in how caregivers conceptualise the needs of their children?
4. How do feelings of shame manifest in response to the diagnostic process?

Methods

Participants

Purposive sampling was used to recruit caregivers. Nineteen caregivers who provided consent for their young person's participation in a FASD prevalence study were approached for an informal 'yarn' to explore their understandings and experiences of the research. Fifteen yarns with 17 participants were conducted, including two dads, two couples, six mothers, and five grandmothers. There were 12 Aboriginal and five non-Aboriginal Australian participants. Six participants were from urban WA, five were from remote areas, and four from regional areas.

Participants had previously met with researchers from the multi-disciplinary clinical team and, where relevant, had been given their child's diagnosis. All participants were provided with a Multi-Disciplinary Diagnostic Report (hereafter 'diagnostic report') prepared by the multi-disciplinary clinical team. Researchers met with the participants to provide feedback and translation of the diagnostic report.

The researchers were aware of the need to minimise the harm that caregivers may have experienced. Some of these interviews were attended by the qualitative researcher in company with the Research Officer because of the rapport that had already been built between them. In two interviews, both researchers were present for the entirety. The remainder were undertaken by the lead qualitative researcher. Remote and regional interviews were set up in community, with the assistance of youth justice personnel who worked with the families.

Data collection

Data were collected using 'yarning' (Bessarab and Ng'andu 2010). Having a 'yarn' is embedded in the language of Australian Aboriginal people and is an 'Indigenous cultural form of conversation' (Bessarab and Ng'andu 2010: 37). Yarning creates relationships and governs responsibility and although yarning data can seem superfluous or irrelevant, it often reveals rich, insightful and valuable contexts (Bessarab and Ng'andu 2010). The qualitative researcher was an Aboriginal woman, making yarning culturally safe and aligned with the cultural values of Aboriginal people. It was also considered to be appropriate for non-Aboriginal participants in the study (for more details on the yarning method, see Hamilton *et al*. 2020a, 2020b). It is important to note that while two Aboriginal fathers participated in this research, there were barriers to how much these participants could share with a female researcher, and so we focus on female caregivers in our analysis.

Six urban and five regional yarns were face-to-face. For remote participants, one interview took place in the detention centre and the remaining five in their community, four face-to-face and one via Skype. Location was chosen by the participants. On average, the yarns took half an hour. All participants were advised that the yarn was confidential and that neither they, nor their family members, would be identifiable. They were advised that they could stop the yarn at any time.

Prior to the yarn, participants were advised that the purpose of yarning was to get thoughts about receiving feedback about the results of their young person's diagnostic assessments and to explore their thoughts on the diagnostic reports. With verbal consent, interviews were voice recorded and transcribed verbatim. Immediately following the yarn, the researcher recorded reflective field notes.

Data analysis

Data from all participants were analysed using thematic network analysis (Attride-Stirling 2001) sensitised by an ontological approach which privileges what participants say they experience and how they make sense of these experiences (Creswell 2012). From such a perspective, participant reality is subjective and diverse.

Two researchers initially reviewed the data and identified key themes, with preliminary analysis undertaken immediately following data collection. Data were entered into NVivo 11 Pro (2016) for coding and themes compared. Study team members regularly met and reviewed themes from the participant data. These reviews helped to ensure consistency in data interpretation through multiple perspectives and iterations. The primary researcher also conducted multiple analysis reviews to compare, confirm and develop final data interpretations.

Vignettes were chosen to complement the narrative yarning approach taken to data collection. Constructing vignettes offered a comprehensive way to provide a rich account of the lived reality and experience of receiving a diagnosis. It also provided a culturally relevant and safe method (Blodgett *et al*. 2011) for presenting the unique stories of the participants in this research.

In preparing the vignettes, the data from all 17 participants were re-analysed through an interpretivist lens which acknowledges participant realities are socially constructed and changeable, and agreed within cultures, social setting and relationships (e.g. Denzin and Lincoln 2003). From this process, five participants were selected based cultural background, depth of available data, children's diagnosis and transcripts reflecting diverse of views of the diagnostic process. This allowed for a rich amount of data which reflects the stories of all participants in the qualitative study. All names are pseudonyms. Small details, such as immaterial but potentially identifying elements of examples, and reference to specific personnel and institutions, demographics and contextual information have been changed to protect participant identities. The vignettes were reviewed by members of the research team to ensure no story was identifiable.

Vignettes

Phyllis and Peter Phyllis is an Aboriginal grandmother who lives in a small community in very remote WA. The community is around 400 kilometres from the closest regional centre. Phyllis has many grandchildren, including 16-year-old grandson Peter, who was diagnosed with FASD in the prevalence study. At the time of the interview Peter had been released and was living with Phyllis.

When discussing whether Phyllis was surprised by the diagnosis she said:

> No, not really. I went to the school a lot because the kids were always in trouble, but school never tried to teach him special ways. Just saw them as naughty. Just put on band aids at school.

For Phyllis, diagnosis provided a way to explain the behaviour and combat the stigma Peter experienced:

> He is not an asshole like plenty of people think. It is because of that thing in his brain [FASD] . . . I send Peter to tell the other one to come home. Peter has forgotten what he is doing by the time he finds his brother, so neither of them get home and then they both end up getting into trouble. I want her [daughter's] other kids assessed you know, because she drank heavily, and they are still quite young, and they are running amok already.

Justice personnel assisted Phyllis with understanding and translating the contents of the diagnostic report. Diagnosis was useful in that it helped get assistance for Peter:

> I gave the report for [social services personnel] and Peter, he's been able to get help for disability. It much easier than for him remembering to go for job thing.

Phyllis liked the visual strategies that were provided as part of the diagnostic report. Relaying a story of how she sends Peter to the shop, she explained:

> He never get that right. I make it clear ORANGE JUICE [participant emphasis], but he always come back with an orange. Next time I drew a picture of a bottle of juice to take with him and he brought back the one; it worked!

The diagnosis also helped Phyllis recognise FASD in another family member:

> I think my son has it [FASD]. He has been in and out of prisons . . . I drank a lot, but I didn't know you know.

While there were a number of useful aspects about receiving the diagnosis, it also came with shame and concerns about supporting family members with FASD long-term. Phyllis commonly has a dozen or so grandchildren in her care, including Peter's brothers. Particularly in remote Aboriginal communities, this central role of the extended family in care is normal and accepted. 'All the sisters are aunties, all the nans are mums – it blackfulla way', she said. However, she had concerns about how long she would be able to keep caring for her grandchildren given her age. Peter's mum was unable to significantly contribute to care because she continued to drink. Her continued drinking, and drinking in pregnancy, was a source of shame for Phyllis, and yet she recognised the intergenerational mirroring of negative behaviour [drinking in pregnancy]:

> I am so mad with her but then I did it to [drink alcohol during pregnancy] and she was the same.

Katie and Kieran

Katie is a non-Aboriginal mother who lives in urban WA. Katie is a professional, working full-time and lives with her husband and children. Katie's 15-year-old son, Kieran, was diagnosed with neurodevelopmental impairments in the severe range in the prevalence study. At the time of the interview, Kieran was still incarcerated.

When asked about her thoughts on Kieran's diagnosis, Katie indicated that it confirmed what she already knew about his strengths and weaknesses. She linked the diagnosis to her observations of Kieran's difficulties with schooling:

> When we were told the diagnosis it made sense. About grade 2 it was obvious he had problems with reading and writing and was struggling with learning. We have been to the school so many times. By year 10 he stopped going and he had lots of detentions and suspensions from school. It is good that people are beginning to understand that it is not because he doesn't want to read and write, but because he actually cannot do it.

The diagnostic report, which she had read, while useful, did not provide new information:

> Well it [the diagnostic report] didn't really tell me anything new. It pretty well describes his strengths and challenges. And nothing in the report changes my view of him, because he is still my child. But the report is important because it provides knowledge of Kieran's challenges. The report is really very useful, it mostly helps to
> recognise and make people aware of his vulnerabilities.

Katie spoke of the usefulness of the diagnosis and diagnostic report in securing access to services:

> I think it was good for him to have the assessments so he can receive proper supports and understanding as to why he thinks way he does and does the things he does.

This understanding of diagnosis extended to how Katie imagined the diagnosis may have changed Kieran's interactions and outcomes with the legal system:

> I wish he had had the assessments years ago . . . things might have been very different for him and he may well not be in [name of detention centre]. Kieran didn't understand what was happening when he got arrested. He got confused and didn't understand the seriousness of what was happening. He is essentially a 15-year-old boy with a 7 or 8-year-old mind. He is easily influenced and was just at the wrong time, at the wrong place and with the wrong

> people. This might have been different if they [police/courts] knew he had impairments in his brain.

The diagnostic report had been shared with a service provider and was also being used to plan for Kieran's release:

> We have drawn up schedules to make sure he does what he needs to do. It will be hard for him so things like Medicare and Disability Services will be supporting him too when he gets out.

When asked if she would share the diagnostic report with these services, Katie said she would.

> "share it with anyone who would listen".

Jill and Jasper

Jill is a non-Aboriginal single mum with two children and lives in urban WA. Jill's 16-year-old son, Jasper, was diagnosed with neurodevelopmental impairments in the severe range in the prevalence study. At the time of the interview Jasper was still incarcerated. Like Katie, Jill viewed the diagnosis as a confirmation of her own observations about Jasper's challenges:

> Jasper always hated school. Even in primary school it was too hard for him. He was always on detention or being suspended from school. Why? Because he never got help. I tried and tried to get help, but none was forthcoming. He is a sweet kid who just couldn't stay out of trouble. Actually I don't think he just ever thinks that he might get into trouble. The fact that he can't focus, well this [diagnosis] kind of explains it.

As the diagnostic information was explored in more detail, Jill focused on the lack of support provided through the healthcare system in Jasper's early childhood years:

> Jasper's problems started with childhood anxiety, followed by sexual abuse which caused extreme anxiety and mental health problems for which there is a lack of services and little help, then and now apart from being prescribed drugs which never seemed to work and which he often refused to take no actual help was forthcoming . . . my pleas for help fell on deaf ears.

When discussing the diagnostic report and strategies and whether they were beneficial, Jill again came back to the amount of assistance she had tried to get:

> Maybe this [report] will help Jasper. We have tried and tried to get help for him. Maybe what you have given us can help him. There is lots of useful information in this report which can be used to help him.

Jill discussed what she thought was useful about the diagnostic report. She was not surprised by the information provided about Jasper's strengths:

> The strategies are valuable. I am looking forward to trying the strategies when he gets out and work on his strengths. Using pictures and flowcharts makes sense for him. It doesn't surprise me that he is good at these skills; it will be great to harness that in him.

Suzie and Samuel

Suzie is an Aboriginal mum of two children. She cares for her children full time and lives with her family in a remote town in WA. Suzie's 16-year-old son was diagnosed with FASD in the study. At the time of the interview he had been released and was living with Suzie.

Suzie felt positive about Samuel's participation in the assessments because it provided some insights into his behaviour that she was previously unaware of. She had wondered why Samuel had tended to play with much younger children. "That 'this thing in his head' (FASD) explains this", she said. However, Suzie had difficulties engaging with the diagnostic report:

> It [the diagnostic report] was hard cause the 'whitefulla speakin', I understand I ask [justice personnel] to tell me. Having it said simple helped me.

Suzie liked the strategies and ideas around using visual aids detailed in the diagnostic report to assist Samuel to remember things:

> I stuck picture on the door that said 'NO GROG' [alcohol] . . .he stopped, well at least in the house.

There was a sense of pride and achievement as Suzie spoke of how local community leaders had praised the initiative:

> They took photo to show other mob round ya know.

Concern about diagnosis for Suzie was very much embedded in Samuel's connection to culture and community:

> It doesn't matter [Samuel's diagnosis of FASD] it's just important that he is connected to his mob and knows who he is and where he fits eh. When he out in community they look after him and guide him and he is happy. He never gets into trouble out there and loves to go hunting. Last time went hunting for kangaroo and he got one, cut it all up and then bought it back to the family for sharing. He was proud and I want that for him.

Suzie commented that Samuel was different to many other children in the community, but not due to FASD:

> He isn't like other Aboriginal kids. He doesn't like sport and doesn't play sport. This is the 'weirdness' he has, not that he can't do school good.

Suzie then asked the researcher: 'Can he go through lore [traditional customs related to emerging adulthood]?' The researcher encouraged Suzie to discuss this with community Elders.

Sandra and Seb

Sandra is an Aboriginal mum of five children. Sandra cares for her children full time and lives with her family in a small town in regional WA. Sandra's 17-year-old son, Seb, was diagnosed with FASD in the prevalence study. At the time of the interview Seb had been released and was living with Sandra.

Sandra was visibly upset by her son's diagnosis. Crying, she said:

> I would rather not have known [Seb had FASD]. I feel shamed and sad and I don't not really know where to go or who to turn to . . . I feel ashamed and responsible for Seb's challenges because of my drinking.

Sandra also described confusion. Being the mother of a number of children, she was unsure why some of her children would be affected and not others:

> I don't really understand why Seb has many problems when [name, another child], well she is bright, finished school and works and is a good kid and I drank more with her, a lot more.

Sandra also discussed an older incarcerated child, wanting to know how he could be assessed:

> [Name] has been in trouble since before he could walk, he can't focus, he doesn't think about anyone, he is obsessed with fire and he can be really violent which is why he is in there [prison] now. How can he be assessed at [prison name]?

The diagnostic report for Seb came with a number of recommendations for health needs. Reflecting on the recommendations, Sandra said:

> What help he would really get – are there any services to help with kids with FASD? Anyway, do you know what is in [town name]? Nothing. It is a small community we can't even get proper food and I don't have enough money for bills let alone this stuff.

Discussion

In keeping with previous sociologies of diagnosis, our findings capture how diagnoses are understood in the wider context of culture and community, family relationships, and social structures and interactions (Blaxter 2004; Jutel 2009; Malacrida 2004).Our study demonstrates cultural patterns in responses to the diagnostic processes for neurodevelopmental impairments and FASD among Aboriginal and non-Aboriginal caregivers that have not previously been described.

Regardless of cultural background, there was a shared absence of the use of medical terms. Aboriginal participants used the term 'that thing in his head/brain' to refer to FASD. Neither of the non-Aboriginal participants used the terms FASD or neurodevelopmental impairments, but they did refer to their child's 'problems'. Avoidance of biomedical terminology should not be interpreted as an inability to understand the diagnosis. All participants linked the diagnosis to clinical indicators (Riessman 2002): Phyllis and Sandra to alcohol consumption during pregnancy, Suzie and Phyllis to poor memory and Phyllis, Jill and Sandra to difficulty with attention, impulsivity and difficulty understanding and following instruction. All participants also linked the diagnosis to their children's behavioural problems (McLachlan *et al.* 2014).With respect to these clinically recognised aspects of neurodevelopmental impairments, diagnosis principally validated or provided explanation for what the caregivers already knew about their children (Chamberlain *et al.* 2017, Sanders and Buck 2010). Only Suzie indicated that the diagnosis explained an element of her child's behaviour that she previously did not appreciate.

The Aboriginal caregivers, Phyllis, Suzie and Sandra, each demonstrated an understanding of the impact of diagnosis in the context of their families and communities (c.f. Popay *et al.* 2003). The unfortunate reality is that FASD is experienced for Aboriginal people in the context of intergenerational trauma and the resultant high levels of alcohol use (Fogarty *et al.* 2018, Vicary and Westerman 2004). Some communities in WA have very high rates of FASD for justice-involved youth (Blagg *et al.* 2015). Phyllis and Sandra raised concerns that other family members might also be affected by FASD.

This appreciation of the diagnosis in a community context was not necessarily negative. Despite Suzie's engagement with the diagnostic report and resources, for Suzie, Samuel's diagnosis of FASD did not carry negative connotations because her child's happiness and place in the community were more important than having a diagnosis (Jutel 2009, Riessman 2002, Velarde 2018). Reflective of this, Suzie raised a question about whether Samuel would be able to 'go through Lore', indicating that diagnosis would be problematic only if it affected her child's participation in the community. Suzie also described her perception of what makes Samuel different from his peers in the community: he does not like or play sport. High rates of FASD in communities may mean that, for Suzie, the diagnosis is not what makes Samuel different, but rather his unusual disinterest in sport.

In contrast, the two non-Aboriginal caregivers, Jill and Katie, spoke only about what the diagnosis meant for their children. They did not discuss the potential for diagnoses in other children or family members, or how the diagnosis may affect community participation.

The participants all viewed the strategies provided in their diagnostic report as useful. However, there were observable patterns to how they were engaged with. Aboriginal participants, Suzie and Phyllis, were particularly interested in visual strategies, in keeping with previous findings on the dominance of visual cultures among Aboriginal Australians including in respect to health care (Hickey and Wilson, 2017, Hughes *et al.* 2004, Pewewardy 2002, Thomas *et al*. 2019). They both reported successfully using visual strategies to assist their children. In Suzie's case, local community leaders identified this potential for this to help others, further evidence of the understanding of diagnosis within a community context (Potter *et al.* 2018). Jill and Katie did not speak of visual strategies to the same degree, although the two non-Aboriginal young people had not yet been released so their caregivers had not yet had a chance to implement strategies.

Of note, the diagnostic reports were not as easily understood by the Aboriginal participants. Suzie said that they were hard to understand because of the 'whitefulla speaking'. Both Phyllis and Suzie received additional assistance to translate and understand the diagnostic report, highlighting the different understandings and worldviews of Aboriginal people (Velarde 2018, Vicary and Westerman 2004). This suggest that translating Western medical information into culturally appropriate resources would be useful for Aboriginal caregivers (Magana *et al.* 2013). In this, it is imperative to pay attention to the colonial history and its complex relationship with many factors that impact on wellbeing for Aboriginal people. Ignoring or glossing over cultural understandings and knowledge can inflict harm in the assessment process (Vicary and Westerman 2004). Such approaches are also likely to create distrust, disengagement, and deter caregivers and family members from help-seeking.

There was also observable cultural patterning in how caregivers envisioned their children's needs being met following the diagnosis. As reflected in Phyllis's (Aboriginal) and Jill's (non-Aboriginal) accounts, experiences of struggling to access appropriate support for their child prior to a diagnosis were common and crossed cultural lines. Following the diagnosis, the non-Aboriginal caregivers envisioned more institutional assistance. Katie focused on Kieran's potential engagement with services, while Jill came back to the lack of assistance for Jasper, both discussing negotiating multiple systems for assistance (Blum 2015, Garro and Yarris 2009, Johnson *et al.* 2012, Landsman 2009, Malacrida 2001, Ryan and Runswick Cole 2008). This perspective is in keeping with sociologies of diagnosis that emphasise how a diagnosis from a practitioner controls access to care (De Swaan 1989, Whelan 2007).

However, for Aboriginal participants, receiving a diagnosis did not reorient how they imagined the support needs of their children being met towards institutions such as schools and healthcare system. Rather, they said that the support needs of diagnosed children continued to be met mostly within the community. While Phyllis was concerned about how she would continue to meet the needs of each of her grandchildren, she also said that the responsibility for care resting with nans (where parents were unable) was 'the blackfulla way' (Murphy *et al.* 2007, Popay *et al.* 2003). Sandra commented on the lack of access to services, highlighting the underlying social and structural inequalities that affect engagement in interventions, education, and support (Ennis-Cole *et al*. 2013), and the significant and complex burden of work and responsibility that mothers of children with disabilities assume (Landsman 2009).

Where there is potential for self-blame by caregivers for their children's conditions, such as in the case of FASD, shame responses to diagnosis are of particular concern (Olsvold *et al.*

2019, Zimmerman *et al.* 2015). Sandra's preference to not know that Seb had FASD suggests that she recognised the potential for stigma and messages of parental incompetence from diagnosis and anticipated negative labelling (Francis 2012). Similarly, Phyllis's discussion of alcohol use during her own pregnancy reflects the intergenerational shame which can be experienced by Aboriginal people at the interface of traditional and contemporary culture (Morgan *et al.* 1997).Such experiences of shame from receiving a diagnosis has the potential to affect taking up diagnostic support (Long 2015, McNally and Lathan 2009).

The vignettes presented in this article underscore the harm from stigma and labelling emphasised in the broader literature which can often accompany parenting children with disabilities (Blum 2015, Heneker *et al.* 2017, Landsman 2010, Liu 2005, Ryan and Runswick Cole 2008). Valuing and understanding more about cultural differences when receiving a diagnosis could serve to mitigate the shame and harm which can be incurred from diagnostic assessments.

Conclusion

Diagnosis can be a label, or it can be a key that opens the door to understanding and opportunity to access the resources and supports required to manage the constellation of impairments that accompany a diagnosis of a neurodevelopmental disability. This contribution of caregiver experiences to the sociology of diagnosis scholarship provides a unique account of cultural patterning when Aboriginal and non-Aboriginal caregivers receive a diagnosis for their child. Demonstrated preferences for visual strategies among Aboriginal caregivers for transferring knowledge provides valuable information on ways to formulate resources to manage the effects of 'that thing in his head'. Difficulties among Aboriginal caregivers in understanding diagnostic reports and the continuation of support needs being met within communities also highlights differences in experiences and potential unmet needs.

Further exploration of the cultural patterning of receipt of a diagnosis and provision of diagnostic resources could valuably inform future sociology of diagnosis scholarship. For cultural reasons, our article only reports on the experiences of female caregivers. A focus on the distinct experiences of male caregivers warrants further investigation. Moreover, how different cultures receive diagnoses and how diagnoses relate to individual or community understandings of health and wellbeing is currently under-investigated.

The translation and use diagnostic resources within cultural groups also demands attention, with a focus on alternative delivery of diagnoses and care strategies. Increasing access to and use of the internet and social media on mobile devices in remote Aboriginal communities (Rennie *et al.* 2018) introduces the potential for digital platforms to support provision of culturally relevant resources that build on visual strengths. There are also potential benefits in peer-to-peer knowledge sharing and support (c.f. Maslen and Lupton 2019a, 2019b).The experiences of shame and how it can be managed in the diagnostic process, particularly in the context of intergenerational trauma, warrants further inquiry.

Address for correspondence: Sharynne Hamilton, Hospital Ave, Nedlands Western Australia 6872. E-mail: sharynne.hamilton@telethonkids.org.au

Acknowledgements

This research is funded by the National Health and Medical Research Council (#APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research

Excellence (#1110341). SLH is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award, the FASD Research Australia Centre of Research Excellence and the Centre of Research Excellence Indigenous Health and Alcohol, University of Sydney (NHMRC #APP1117198). KC is supported by an NHMRC Practitioner Fellowship (APP1117582).

The authors thank all the parents and family members who have contributed their knowledge and views of the research. We thank the professionals in the community who provided vital support to the research and to the young people and their families during the research. The authors thank all at Banksia Hill Detention Centre, the study team, the members of the Consumer and Community Reference Group, the Steering Group and the studies Chief Investigators and Associate Investigators. SLH thanks the Elder Co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project, Telethon Kids Institute for sharing their knowledge and wisdom and for their contribution to the interpretation of the data from this research.

Author contributions

Sharynne Lee Hamilton: Conceptualization (lead); Formal analysis (lead); Investigation (lead); Methodology (lead); Project administration (supporting); Writing-original draft (lead); Writing-review & editing (lead). **Sarah Maslen:** Conceptualization (equal); Formal analysis (supporting); Methodology (supporting); Supervision (supporting); Writing-review & editing (equal). **Rochelle Watkins:** Conceptualization (supporting); Formal analysis (supporting); Investigation (equal); Methodology (supporting); Project administration (supporting); Writing-review & editing (equal). **Katherine Conigrave:** Conceptualization (supporting); Methodology (supporting); Writing-review & editing (equal). **Jacinta Freeman:** Conceptualization (supporting); Formal analysis (supporting); Methodology (supporting); Writing-review & editing (equal). **Melissa O’Donnell:** Conceptualization (supporting); Formal analysis (supporting); Methodology (supporting); Supervision (supporting); Writing-review & editing (equal). **Raewyn Mutch:** Conceptualization (supporting); Investigation (supporting); Methodology (supporting); Supervision (supporting); Writing-review & editing (equal). **Carol Bower:** Conceptualization (supporting); Formal analysis (supporting); Methodology (supporting); Project administration (lead); Supervision (lead); Writing-review & editing (equal).

Disclaimer

Any material published or made publicly available by the authors cannot be considered as either endorsed by the Department of Justice or an expression of the policies or the views of the Department. Any errors of omission or commission are the responsibility of the researchers.

Note

1 In this article, the term ‘Aboriginal’ is used with respect when referring to Australian Aboriginal and Torres Strait Islander peoples. The term ‘Indigenous’ is used when referring to global populations.

References

Astley, S. (2014) Twenty years of patient surveys confirm a FASD 4-digit-code interdisciplinary diagnosis afforded substantial access to interventions that met patients’ needs, *Journal of Population*

Therapeutics and Clinical Pharmacology, 21, 1, e81–105. https://jptcp.com/index.php/jptcp/article/view/348/289 .

Attride-Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research, *Qualitative Research*, 1, 3, 385–405.

Ayunerak, P., Alstrom, D., Moses, C., Charlie, J., *et al.* (2014) Yup'ik culture and context in southwest Alaska: community member perspectives of tradition, social change, and prevention, *American Journal of Community Psychology*, 54, 1–2, 91–9.

Bessarab, D. and Ng'andu, B. (2010) Yarning about yarning as a legitimate method in Indigenous research.*International*, *Journal of Critical Indigenous Studies*, 3, 1, 37–50.

Blagg, H., Tulich, T. and Bush, Z. (2015) Diversionary pathways for Indigenous youth with FASD in Western Australia: decolonising alternatives, *Alternative Law Journal*, 40, 4, 257–60.

Blaxter, M. (2004) Life narratives, health and Identity. In Kelleher, D. & Leavey, G. (eds.), *Identity and Health* (pp. 170–99). New York: Routledge.

Blodgett, A., Schinke, R.J., Smith, B., Peltier, D., *et al.* (2011) In Indigenous words: exploring vignettes as narrative strategy for presenting the research voices of Aboriginal community members, *Qualitative Inquiry*, 17, 522–33.

Blum, L. (2015) *Raising Generation Rx. Mothering Kids with Invisible Disabilities in an Age of Inequality*. New York, London: New York University Press.

Bower, C., Watkins, R.E., Mutch, R.C., Marriott, R., *et al.* (2018) Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia, *British Medical Journal Open*, 8, 2, e019605. https://doi.org/10.1136/bmjopen-2017-019605

Brossard, B. and Carpentier, N. (2017) To what extent does diagnosis matter? Dementia diagnosis, trouble interpretation and caregiving network dynamics, *Sociology of Health & Illness*, 39, 4, 566–80.

Brown, P. (2008) Naming and framing: the social construction of diagnosis and illness. *Journal of Health and Social Behavior, Extra Issue*, 34–52. https://doi.org/10.2307/2626956

Chamberlain, K., Reid, N., Warner, J., Shelton, D., *et al.* (2017) A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD, *Research in Developmental Disability*, 63, 99–106.

Corrigan, P., Lara, J., Shah, B., Mitchell, K., *et al.* (2017) The public stigma of birth mothers of children with fetal alcohol spectrum disorders, *Alcohol Clinical Experiment Research*, 41, 6, 1166–73.

Creswell, J.W. (2012) *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Thousand Oaks: Sage.

De Swaan, A. (1989) The reluctant imperialism of the medical profession, *Social Science and Medicine*, 28, 11, 1165–70.

Denzin, N.K. and Lincoln, Y.S. (2003) *The SAGE Handbook of Qualitative Research*, 2nd edn. Thousand Oaks: SAGE Publication.

Doak, J., Katsikitis, M., Webster, H. and Wood, A. (2019) A fetal alcohol spectrum disorder diagnostic service and beyond: outcomes for families, *Research in Developmental Disabilities*, 93, e103428. https://doi.org/10.1016/j.ridd.2019.103428

Ennis-Cole, D., Durodoye, B. and Harris, H. (2013) The impact of culture on autism diagnosis and treatment: considerations for counselors and other professionals, *The Family Journal*, 21, 3, 279–87.

Fast, D. and Conry, J. (2004) The challenge of fetal alcohol syndrome in the criminal legal system, *Addiction Biology*, 9, 2, 161–6.

Fogarty, W., Lovell, M., Langenberg, J. and Heron, M. (2018) *Deficit Discourse and Strengths-based Approaches: Changing the Narrative of Aboriginal and Torres Strait Islander Health and Wellbeing*. Melbourne: The Lowitja Institute.

Francis, A. (2012) Stigma in an era of medicalisation and anxious parenting: how proximity and culpability shape middle-class parents' experiences of disgrace, *Sociology of Health & Illness*, 34, 6, 927–42.

Gardner, J. and Williams, C. (2015) Corporal diagnostic work and diagnostic spaces: clinicians' use of space and bodies during diagnosis, *Sociology of Health & Illness*, 37, 5, 765–81.

Garro, L. and Yarris, K. (2009) "A Massive Long Way": interconnecting histories, a "Special Child," ADHD, and everyday family life, *Culture, Medicine, and Psychiatry*, 33, 4, 559–607.

Gill, V.T., Pomerantz, A. and Denvir, P. (2010) Pre-emptive resistance: patients' participation in diagnostic sense-making activities, *Sociology of Health & Illness*, 32, 1, 1–20.

Hamilton, S., Maslen, S., Best, D., Freeman, J., *et al.* (2020a) Putting 'justice' in recovery capital: yarning about hopes and futures with young people in detention, *International Journal of Crime, Justice and Social Democracy*, 9, 2, 20–36. https://doi.org/10.5204/ijcjsd.v9i2.1256

Hamilton, S., Reibel, T., Maslen, S., Watkins, R., *et al.* (2020b) Disability 'in-justice': the benefits and challenges of 'yarning' with young people undergoing diagnostic assessment for Fetal Alcohol Spectrum Disorder in a youth detention centre, *Qualitative Health Research*, 30, 2, 314–27.

Heneker, K.J., Zizzo, G., Awata, M. and Goodwin-Smith, I. (2017) *Engaging Culturally and Linguistically Diverse Communities in the National Disability Insurance Scheme.* Adelaide: Australian Centre for Community Services Research, Flinders University, Adelaide.

Hickey, H. and Wilson, D.L. (2017) Whānau Hauā: reframing disability from an indigenous perspective, *Mai Journal*, 6, 1, 82–94.

Hughes, P., More, A.J. and Williams, M. (2004) *Aboriginal Ways of Learning*. Adelaide: Flinders Press.

Johnson, J.L., Oliffe, J.L., Kelly, M.T., Galdas, P., *et al.* (2012) Men's discourses of help-seeking in the context of men's depression, *Sociology of Health & Illness*, 34, 345–61.

Jutel, A. (2009) Sociology of diagnosis: a preliminary review, *Sociology of Health & Illness*, 31, 2, 278–99.

Jutel, A. (2019) Diagnosis: a critical social reflection in the genomic era, *Ciência & Saúde Coletiva*, 24, 10, 3619–26.

Landsman, G.H. (2009) *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*. New York: Routledge.

Link, B. G. and Phelan, J. C. (2001) Conceptualizing stigma. *Annual Review of Sociology*, 27, 3, 365–85. https://doi.org/10.1146/annurev.soc.27.1.363

Liu, G. (2005) Best practices: developing cross-cultural competence from a Chinese perspective. In Stone, J.H. (ed.) *Culture & Disability: Providing Culturally Competent Services*. Thousand Oaks: Sage.

Long, C. (2015) Disadvantage undiagnosed, *Australian Educator*, 88, 22–4.

Magana, S., Lopez, K., Aguinaga, A. and Morton, H. (2013) Access to diagnosis and treatment services among latino children with autism spectrum disorders, *Intellectual and Developmental Disabilities*, 51, 3, 141–53.

Malacrida, C. (2001) Motherhood, resistance and attention deficit disorder: strategies and limits, *Canadian Review of Sociology*, 38, 2, 141–65.

Malacrida, C. (2004) Medicalization, ambivalence and social control: mothers' descriptions of educators and ADD/ADHD, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8, 1, 61–80.

Maslen, S. (2016) Sensory work of diagnosis: a crisis of legitimacy, *The Senses & Society*, 11, 2, 158–76. https://doi.org/10.1080/17458927.2016.1190065.

Maslen, S. and Lupton, D. (2019a) Enacting chronic illness with and through digital media: a feminist new materialist approach, *Information, Communication & Society*, 1–15. https://doi.org/10.1080/1369118X.2019.1602665

Maslen, S. and Lupton, D. (2019b) "Keeping It Real": women's enactments of lay health knowledges and expertise on facebook, *Sociology of Health and Illness*, 41, 8, 1637–51.

McLachlan, K., Roesch, R., Viljoen, J. and Douglas, K. (2014) Evaluating the psycholegal abilities of young offenders with fetal alcohol spectrum disorder, *Law and Human Behavior*, 38, 10–22.

McNally, S. and Latham, S. (2009) *Recognising and Responding to Hepatitis C in Indigenous Communities in Victoria*. Melbourne: ARCSHS.

Morgan, D., Slade, M. and Morgan, C. (1997) Aboriginal philosophy and its impact on health care outcomes, *Australian and New Zealand Journal of Public Health*, 21, 6, 597–601.

Murphy, N., Christian, B., Caplin, D. and Young, P.C. (2007) The health of caregivers for children with disabilities: caregiver perspectives, *Child Care Health and Development*, 33, 2, 180–7.

Nettleton, S. and Jutel, A. (2011) Towards a sociology of diagnosis: reflections and opportunities, *Social Science & Medicine*, 73, 793–800.

NVivo Pro 11. (2016) *Qualitative Data Analysis Software Version 11 [computer program]*. Melbourne: QSR International Pty Ltd.

Olsvold, A., Aarseth, A. and Bondevik, H. (2019) 'I think my son is a wonderful chap': working-class and middle-class fathers' narratives of their son's ADHD diagnosis and medication, *Families, Relationships and Societies*, 8, 1, 105–20.

Petersen, A., Tanner, C. and Munsie, M. (2019) Navigating the cartographies of trust: how patients and carers establish the credibility of online treatment claims, *Sociology of Health & Illness*, 41, S1, 50–64. https://doi.org/10.1111/1467-9566.12872.

Pewewardy, C. (2002) Learning styles of American Indian/Alaska native students: a review of the literature and implications for practice, *Journal of American Indian Education*, 41, 3, 22–56.

Popay, J., Bennett, S., Thomas, C., Williams, G., *et al.* (2003) Beyond 'beer, fags and chips'? Exploring lay understandings of social inequalities in health, *Sociology of Health and Illness*, 25, 1, 1–23.

Potter, C., Kelly, L., Hunter, C., Fitzpatrick, R., *et al.* (2018) The context of coping: a qualitative exploration of underlying inequalities that influence health services support for people living with long-term conditions, *Sociology of Health and Illness*, 40, 1, 130–45.

Rafalovich, A. (2005) Exploring clinician uncertainty in the diagnosis and treatment of attention deficit hyperactivity disorder, *Sociology of Health & Illness*, 27, 3, 305–23.

Rasmussen, E. (2017) Balancing medical accuracy and diagnostic consequences: diagnosing medically unexplained symptoms in primary care, *Sociology of Health & Illness*, 39, 7, 1227–41.

Rennie, E., Yunkaporta, T. and Holcombe-James, I. (2018) Privacy at the margins/privacy versus relatedness: managing device use in Australia's remote aboriginal communities, *International Journal of Communication*, 12, 1291–309.

Riessman, C. (2002) *Illness narratives: positioned identities. Invited Annual Lecture, Health Communication Research Center*. Wales: Cardiff University. https://www.researchgate.net/publication/241501264_Illness_Narratives_Positioned_Identities

Ryan, S. and Runswick-Cole, K. (2008) Repositioning mothers: mothers, disabled children and disability studies, *Disability & Society*, 23, 3, 199–210.

Sanders, A. and Buck, G. (2010) A long journey: biological and non-biological parents' experiences raising children with FASD, *Journal of Population Therapy and Clinical Pharmacology*, 17, 2, e308–22. https://jptcp.com/index.php/jptcp/article/view/524/453

Schrag, A., Modi, S., Hotham, S., Merritt, R., *et al.* (2018) Patient experiences of receiving a diagnosis of Parkinson's disease, *Journal of Neurology*, 265, 5, 1151–7.

Sherwood, J. (2013) Colonisation – it's bad for your health: the context of Aboriginal health, *Contemporary Nurse*, 46, 1, 28–40.

Thomas, C., Novy, C., Gifford, W., Grandpierre, V., *et al.* (2019) Exploring the intersections of storytelling and visual arts: indigenous peoples' experiences of cancer, *Storytelling, Self, Society Special Issue: Storytelling for Health*, 15, 1, 71–91.

Turowetz, J. and Maynard, D. (2019) Documenting diagnosis: testing, labelling, and the production of medical records in an autism clinic, *Sociology of Health & Illness*, 41, 6, 1023–39.

Velarde, R. (2018) Indigenous perspectives of disability, *Disability Studies Quarterly*, 38, 4. https://dsq-sds.org/article/view/6114/5134.

Vicary, D. and Westerman, T. (2004) 'That's just the way he is': some implications of Aboriginal mental health beliefs, *Advanced Mental Health*, 3, 1–9.

Wandji, D. (2019) Rethinking the time and space of resilience beyond the West: an example of the post-colonial border, *Resilience*, 7, 3, 288–303.

Whelan, E. (2007) ''No one agrees except for those of us who have it'': endometriosis patients as an epistemological community, *Sociology of Health & Illness*, 29, 7, 957–82.

Young, J., Fisher, K. and Kirkman, M. (2019) Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis, *Feminism & Psychology*, 30, 1, 22–41. https://doi.org/10.1177/0959353519826170

Zarhin, D. (2015) Contesting medicalisation, doubting the diagnosis: patients' ambivalence towards the diagnosis of Obstructive Sleep Apnoea, *Sociology of Health & Illness*, 37, 5, 715–30.

Zimmerman, J., Morrison, A. and Heimberg, R. (2015) Social anxiety, submissiveness, and shame in men and women: A moderated mediation analysis, *British Journal of Clinical Psychology*, 54, 1–15.

Appendix 3: Journal Article: *International Journal for Crime, Justice and Social Democracy*

IJCJ&SD 9(2) 2020 ISSN 2202-8005

International Journal for Crime, Justice and Social Democracy

Putting 'Justice' in Recovery Capital: Yarning About Hopes and Futures with Young People in Detention

Sharynne L. Hamilton
Telethon Kids Institute, Perth, Australia
Sarah Maslen
University of Canberra, Australia
David Best
University of Derby, United Kingdom
Jacinta Freeman
Telethon Kids Institute, Australia
Melissa O'Donnell
Telethon Kids Institute, Australia
Tracy Reibel
Murdoch University, Australia
Raewyn C. Mutch
Telethon Kids Institute, Australia
Rochelle Watkins
Telethon Kids Institute, Australia

Abstract

Aboriginal and Torres Strait Islander young people are over-represented in Australian youth detention centres and the justice system. In contrast to deficit-focused approaches to health and justice research, this article engages with the hopes, relationships and educational experiences of 38 detained youth in Western Australia who participated in a study of screening and diagnosis for fetal alcohol spectrum disorder. We report on a qualitative study that used a 'social yarning' approach. While the participants reported lives marred by substance use, crime, trauma and neurodevelopmental disability, they also spoke of strong connections to country and community, their education experiences and their future goals. In line with new efforts for a 'positive youth justice' and extending on models of recovery capital, we argue that we must celebrate success and hope through a process of mapping and building recovery capital in the justice context at an individual and institutional level.

Keywords

Youth Justice; Recovery Capital; Indigenous; Aboriginal; FASD; neurodevelopmental disability; hope.

Introduction

Globally, Indigenous peoples are over-incarcerated (Reitano 2017; Ulmer and Bradley 2018). Australia is no exception, with Indigenous peoples comprising 27 per cent of the prison population, which is 13 times the rate of non-Indigenous prisoners (Australian Bureau of Statistics 2017). Incarcerated Indigenous youth comprise 59 per cent of all youth in detention, despite only making up five per cent of the population (Australian Institute of Health and Welfare 2018). In Western Australia (WA), where this research was undertaken, Indigenous youth make up 70 per cent of youth in detention (Office of the Inspector of Custodial Services 2018).

Various key factors explain the over-representation of incarcerated Indigenous people in settler–colonial countries, including the shift away from traditional life (Bougie and Senecal 2010; Kaspar 2014; MacDonald and Steenbeek 2015) and systemic and institutional racism and discrimination (Blagg 2008; Harmes, Hopkins and Farley 2019; Weatherburn and Ramsey 2016). In Australia, the fabric of Aboriginal and Torres Strait law and society was disrupted by the intrusion of white settlers, and colonisation was advanced by policies and practices such as the forced removal of children from their parents, families and communities; compulsory land relinquishment and restricted freedoms through incarceration (De Maio et al. 2005; Memmott et al. 2001). This resulted in a pattern of over-incarceration, which is a situation that increases the likelihood that trauma and colonisation are continued (Blagg 2008; Rynne and Cassematis 2015).

It must be acknowledged that, generally, justice-involved youth are traumatised populations with high levels of mental health problems, conduct disorders, self-harm, and alcohol and other drug (AOD) use (Indig, Frewen and Moore 2016). The nexus between criminality, mental health problems, AOD problems and crime trajectories is well established internationally (Bennett and Holloway 2009; Caudy, Tillyer and Tillyer 2018; Hafekost et al. 2017; Indig, Frewen and Moore 2016). This is compounded among Indigenous youth, who have higher levels of neurocognitive disability (Baldry et al. 2015; Dias et al. 2013), intellectual disability (Indig et al. 2011) and fetal alcohol spectrum disorder (FASD) (Blagg, Tulich and Bush 2015; Bower et al. 2018) compared with their non-Indigenous peers.

In this article, we report the qualitative findings of a first-of-its-kind Australian study that was undertaken to establish the prevalence of FASD among youth sentenced to detention in Banksia Hill Detention Centre (Banksia) in WA between 2015 and 2017 (Bower et al. 2018; Passmore et al. 2016; Passmore et al. 2018; Freeman et al. 2018; Kippin et al. 2018; Hamilton et al. 2019a; Hamilton et al. 2019b). The article focuses on specific facets of participants' recovery capital: happiness and hopes for the future, family relationships, and networks and connections.

FASD, which is a lifelong condition, describes a range of anomalies in brain function caused by maternal alcohol consumption during pregnancy. Individuals with FASD have difficulty with memory, attention, judgement and impulse control (Fast and Conry 2004) and many have communication and language impairments (Snow, Bagley and White 2017; Kippin et al. 2018).

FASD limits an individual's understanding of social expectations (Fast and Conry 2004) and results in learning difficulties, poor school performance and reduced prospects for employment (McLachlan et al. 2014). Internationally, FASD is significantly correlated with criminal justice involvement and the number of individuals with FASD is disproportionate to the total number of justice-involved people (Fast and Conry 2004; Streissguth and O'Malley 2000).

Individuals with FASD who come into contact with the justice system raise serious concerns about fairness and equity. When they come into contact with police, they may experience an impaired understanding of why they are in trouble and have a poor understanding or comprehension of their arrest rights (Roach and Bailey 2009). They can be highly suggestible, have poor concepts of time and sequence, and have sporadic memory recall (Fast and Conry 2004). They are more likely to succumb to pressure to plead guilty without an understanding of legal or personal consequences (McLachlan et al. 2014). Finally, they may struggle to understand the effect of their behaviour, potentially leaving them vulnerable to being viewed as lacking remorse or compassion (Roach and Bailey 2009). Knowing the prevalence and understanding the effects of FASD in youth justice systems is imperative.

Internationally, youth justice systems ascribe to many narratives: 'child protection', 'punishment', 'public interest', 'public safety', 'welfare' and 'rights' (Goldson and Muncie 2012). 'Punitive justice' models, which give precedence to proportionate punishment, formal sentencing and administration of accountability (Morris and Giller 1983), and 'correctionalism' models, which seek to control and correct an individual's flaws and weaknesses (Farrington 2007), are dominant. These models assume children and young people make rational choices, offend with 'free will' and therefore require discipline, control and accountability for their actions. In their discussion on Indigenous youth with FASD in WA, Blagg, Tulich and Bush (2015) highlighted that Western criminal justice systems, and in particular their diversion practices, do not realistically consider that youth with FASD do not 'mature' out of crime or respond to desistance from offending, lessened police interaction or access to desired stability or productivity.

Given Australia's colonial history and the resulting challenges that bring youth into contact with the law, there is a need to explore relational frameworks (Slade 2010; Burford, Braithwaite and Braithwaite 2019) that privilege the voices and knowledges of these youth and consider the broader aspects of their lives. Positive youth justice (PYJ) is an approach that argues against the punitive youth justice policies and practices that dominate Western approaches to crime (Cavadino and Dignan 2006; Cunneen and Rowe 2014; Dunkel 2014; Goddard and Myers 2017; Winterdyck 2014). Rather than prioritising the prevention of youth crime, the focus of PYJ is on developing six key areas for youth: health, work, education, communities, creative skillsets, and social networks and relationships (Butts, Bazemore and Meroe 2010).

Consistent with these PYJ principles, this article investigates the potential for a 'recovery capital' lens to shift focus to the importance of relationships and networks for justice-involved young people's recovery and healing. Although this introduction has focused on Indigenous youth and the effects of colonisation, the authors consider a recovery capital approach to be beneficial for all youth involved in the criminal justice system. After outlining recovery capital approaches, we present the study findings and explore how recovery capital can benefit these justice-involved youth.

Applying Recovery Capital Approaches to Justice-Involved Youth

Recovery capital was originally developed in the context of recovery from severe AOD problems (Granfield and Cloud 2001). It is a dynamic and interactive strength-based model that attempts to measure the range of internal and external resources that can be used to initiate and sustain recovery (Cloud and Granfield 2009). Recovery capital has also been applied in the broader context of recovery from mental health issues and trauma, which are adversities that often encompass the lives of justice-involved youth (Hafekost et al. 2017; Indig, Frewen and Moore 2016).

Recovery is conceptualised at three levels: personal, social and community (Best and Laudet 2010). Personal recovery capital represents an individual's level of personal skills, abilities and personal resources including self-esteem, self-efficacy, coping mechanisms and resilience (Cloud and Granfield 2009; Best and Laudet 2010). It includes individual communication skills, interpersonal and educational/vocational skills, problem-solving capacities, hope, optimism and goals.

Social recovery capital refers to the recovery supports available to individuals (Cloud and Granfield 2009; Best and Laudet 2010). The concept of social capital was initially developed by Bourdieu (1985) and scholars have argued the importance of social capital and networks for providing a sense of belonging (Durkheim 1984) and as a resource rich in trust, mutual obligation and reciprocity (Putnam 2000). In the context of recovery capital, social capital allows for identification of intimate relationships, family networks and broader social relationships, and constitutes the availability of culturally prescribed pathways that resonate with particular individuals and families, including models for Indigenous peoples (Coyhis and White 2006). It supports analysis of the willingness and capacity of family members to participate in treatment, access to prosocial activities, and interpersonal connections to others in institutions such as school, work and community organisations.

Community recovery capital refers to the tangible influences on recovery such as having access to safe housing and meaningful opportunities (Brunelle, Cousineau and Brochu 2005; White and Cloud 2008). This can be built up through the promotion of community attitudes; policies and resources that support the resolution of problems; active community efforts to reduce stigma associated with addiction and recovery; increased visibility and diversity of peers and positive role models; comprehensive resource provision; and increased local recovery community support institutions (Brunelle, Cousineau and Brochu 2005). Resources can include specific recovery rehabilitation centres, playgroups, schools, healing initiatives, parenting centres, peer-led self-help groups and sporting clubs (White and Cloud 2008; Best 2014).

Within a recovery capital model, recovery is viewed as a staged process that involves destabilising a problem, initiating recovery and stability, and then maintaining recovery (Laudet, Morgen and White 2006; White and Cloud 2008) while acknowledging that individuals possess different aspects of recovery capital that can change over time. However, aspects of recovery capital interact with the severity or complexity of problems, which in turn shape the intensity of the support and the length of time for which support may be needed (Laudet, Morgen and White 2006). The process of destabilising a problem and initiating recovery possibilities can occur within institutions, whether they be hospitals, rehabilitation centres, psychiatric facilities or prisons (Laudet, Morgen and White 2006; White and Cloud 2008; Best 2014; Best 2019).

Many obstacles can stand in the way of recovery, which is a problem that creates what Cloud and Granfield (2009) refer to as ‘negative recovery capital’. Justice-involved individuals, particularly those with additional problems such as addiction, can be negatively labelled (Dingle et al. 2014), experience stigma and marginalisation (Scott and Gosling 2016) and thus be excluded from various forms of social and community capital. Moreover, some groups in communities do not have a positive effect on physical or psychological wellbeing, or the recovery process (Haslam et al. 2012; Jetten et al. 2014; Best and Savic 2015). Belonging to such groups sustains negative values and lifestyles and presents barriers to accessing and utilising resources in the community such as education, jobs and safe housing (Best and Savic 2015). Therefore, professional interventions need to provide opportunities to build positive social networks, enable access to community resources and reduce the potential for stigma (McNeill and Maruna 2007; McNeill and Whyte 2007; Ward and Maruna 2007; Best 2019).

Generally, the recovery capital approach has been targeted towards adult populations. Little is known about the benefits of establishing and building on the recovery capital assets possessed by youth (Hennessy 2017), and the authors found no literature that explored recovery capital models inclusive of Australian justice-involved youth or Australian Indigenous youth. The literature predominantly examines the role of peers in recovery from addiction; however, there are some related concepts that have been developed in the context of adolescents that point to the potential relevance of recovery capital approaches to these social groups. The peer recovery support model, which is closely related to Native American peoples’ traditional kinship systems and values, has shown improvement in housing stability, employment and health for Native American peoples (Kelley et al. 2017). According to Nash and colleagues (2017), alternative peer group models have also received attention for youth in recovery, the authors positing that building networks and new friendships can provide different influences, attitudes, values, ideas and ways of doing things that support recovery. Highlighting that there are many gaps in recovery capital for specific populations, Hennessy (2017) identified that some aspects of recovery capital may further marginalise youth and argued for the need to understand youth's perceptions of what forms of community participation would lead to a healthy and meaningful life.

A recovery capital model constitutes a framework to assess recovery while being cognisant of the AOD use and mental health problems that are well established in the justice-involved youth population in Australia. However, for the case that we address in this article, the recovery capital model does not systematically consider how assessments for recovery capital assets can be applied to justice-involved youth with neurodevelopmental disability. For its success, many of the features of developing recovery capital rely on individuals having the ability to focus, communicate and initiate and maintain positive relationships. For justice-involved youth with neurodevelopmental disability, an enhancement of the recovery capital model is necessary to support effective communication and equitable participation in decision-making about their futures.

Methods

The findings reported here are part of a broader program of work that sought to assess the prevalence of FASD among detained youth in WA (Bower et al. 2018). A qualitative study was designed to gain an understanding of the participants' perspectives of FASD assessment. To gather this data, the researchers adopted the yarning method (Bessarab and Ng'andu 2010; Fredericks et al. 2011; Martin 2008). The essence of a yarn is listening and exchanging, with each side being willing to give information and show genuine connection to, empathy with and interest in the other, drawing on longstanding cultural practices used by Indigenous families and communities. In this research interaction, the researcher is an 'active participant' and 'learner' as opposed to the 'possessor of knowledge'. Yarning can be approached in four ways: social yarning, research topic yarning, collaborative yarning and therapeutic yarning (Bessarab and Ng'andu 2010). Our study used both social and research topic yarning. A yarning methods paper reporting research topic data for this study is published elsewhere (Hamilton et al. 2019b). As the lead researcher (first author) was an Aboriginal woman from the eastern states of Australia, yarning involved sharing information about traditional heritage and country, which is essential to honest and identifiable engagement in yarning (Bessarab and Ng'andu 2010). The participants exchanged information with the researcher about their family, where they lived, their school experiences and their hopes for the future. The data we report on in this article are drawn from the social yarning.

Participants

Purposive sampling was used to identify qualitative study participants from the 99 young people who completed the assessments in the prevalence study. Of these participants, 38 agreed to participate in a yarning interview. They self-identified their ethnicity; 27 identified as Aboriginal and 11 as non-Aboriginal Australian. No Torres Strait Islander youth participated in this study. The participants will be referred to as Aboriginal or non-Aboriginal participants.

At the time of the yarning interviews, the researcher had no knowledge of the participants' diagnostic outcomes. Subsequent analysis of the qualitative study found that 24 per cent of the participants had FASD and 34 per cent were diagnosed with neurodevelopmental impairments (NI) in the severe range. The remaining 42 per cent of the participants had not received a diagnosis; however, 89 per cent of the prevalence study participants were found to have at least one severe NI, making yarning appropriate to their interviewing needs (Hamilton et al. 2019b).

Data Collection

All but two interviews took place outdoors at Banksia and all yarns were in sight, but not in hearing, of custodial officers. The length of time of the yarns was between 10 and 30 minutes. A voice-recording device was not used during yarning. So as not to interfere with the yarning process, brief handwritten notes were taken during the interview, with salient points recorded in writing (verbatim) and accuracy double checked with the participants at the time of the interview. Immediately following the yarn, the researcher comprehensively documented the details of the interview in writing, including multiple reflective fieldnotes.

Research Ethics

Ethics approval for both the study was granted by the Western Australian Aboriginal Health Ethics Committee (approval number 582) and the University of Western Australia Human Research Ethics Committee (approval number RA/4/1/7116). Research approvals were also gained from the (former) Department of Corrective Services (project ID 335) and the (former) Department for Child Protection and Family Support (approval number 2015/8981).

Informed Consent

Assent from the young person and consent from their guardian to participate in the study was obtained by a research officer. Due to the vulnerability of this population, a child-centred approach to seeking assent was followed (Clark 2011). If a young person expressed interest in being involved in the study, the research officer explained the purpose of the study using simple language and pictorial information sheets and assent forms (Passmore et al. 2016). Upon assent, written consent was then sought from the participant's identified legal guardian. This approach to assent and consent recognised the capacity of young participants to be involved in informed decision-making about research participation while respecting the responsibility of their parents as their guardians to provide informed consent (Lambert and Glacken 2011).

Data Analysis

Data were analysed using thematic analysis (Attride-Stirling 2001). We used the methods of interpretive phenomenological analysis (Smith, Flower and Larkin 2009) to interpret the interview data. Study team members met regularly and reviewed the themes in the data that had been noted by the lead researcher. These reviews helped to ensure consistency in data interpretation over the time of data analysis using diverse perspectives and many iterations. Initially, two researchers manually analysed and coded the data using NVivo Pro Qualitative Data Analysis Software (2016). The lead researcher also conducted multiple analysis reviews over time to confirm and develop final data interpretations. The authors then cross-analysed the data for these aspects of recovery capital.

Results

The following analysis examines the participants' yarns through the lens of the recovery capital model (i.e., personal, social and community recovery). Diagnosis is indicated for FASD [FASD], neurodevelopmental impairments [NI] and participants without diagnosis [WD]. Most of the young people experienced a confluence of difficulties, such as previously identified mental health and conduct disorders and AOD use (Bower et al. 2018).

Personal Recovery Capital: Happiness and Hope

Overwhelmingly, participants with and without a diagnosis found happiness within their family relationships. When asked by the researcher ‘what makes you happy?’, responses from the non-Aboriginal participants included ‘being home with my family makes me happy’ and ‘I’m happy when I have had a visit with Mum’. The Aboriginal participants also spoke of cultural activity: ‘I’m happy being with family, like getting out on country like and learning about medicines and catching bush meat’; ‘I’m really happy when I go hunting goanna and turtle with my dad’; and ‘I like fishing with Pop’. Four of the participants, two Aboriginal and two non-Aboriginal, had their own children and expressed that their children provided hope, purpose and happiness. One participant said, ‘I can’t wait to get out so I can spend some time with my little daughter’.

Personal Recovery Capital: Futures

Many participants yarned about going back to school or taking up trades on their release, particularly those from the urban region. They identified many occupations in which they would like the opportunity to work, including as a plumber, electrician, mechanic, welder, bricklayer and carpenter or builder.

One non-Aboriginal participant [FASD] said, ‘I want to do bricklaying or work in construction’. A non-Aboriginal participant [NI] yarned about wanting ‘to be an electrician’.

A non-Aboriginal participant [WD] saw opportunities to pursue these aspirations through Banksia: ‘I’m doing a construction certificate here [at Banksia]. It’s good cause I never got opportunities to succeed and I want to do cabinet making and get a carpentry certificate’. While in Banksia, this participant was proud that they had made ‘little wooden things’ for their child.

Most of the Aboriginal participants from remote and regional WA wanted to join an Indigenous rangers program, be a station hand or wanted to be involved at some level in community programs and looking after country. One participant [WD] said, ‘I hope to I can go back and live with Mum and Dad and I want to work on my country with the Indigenous Rangers’.

Another participant [NI] said, ‘I want to go and work on a station. I love animals and can’t wait to go home’. Other Aboriginal participants, all from remote or regional communities, said: [WD]: ‘I am hoping to go to an alternative type of schooling. I would like to see a bush school for the young people in my [remote] community’; [FASD]: ‘I want to get a [drivers] licence and work on the mines or on a station’; [FASD]: ‘I want to be a [Indigenous] ranger and look after the country’.

Some of the participants wanted more professional futures. One non-Aboriginal participant [WD] wanted to undertake a business course and run their own business, while others wanted to work with computers or in accountancy, graphic design or music. One non-Aboriginal participant [NI] wanted to join the navy. Another non-Aboriginal participant [WD] said, ‘I would like to be a custodial officer so then I could help kids like me’.

Some of the participants were more interested in having somewhere to live, a relationship and a family of their own. A non-Aboriginal participant [WD] said, ‘I dream of having a big house on the beach with lots of kids and stability’. The participant went on to say, ‘and I really want to travel’.

For a few participants, their goal was just to stay out of trouble and out of Banksia. One non-Aboriginal participant [FASD] said, ‘I just hope I don’t have to come back [to Banksia]’. Another Aboriginal participant [FASD] said:

> I just want to stay off the drugs and keep out of trouble. If I have cravings [for drugs] I will do sport. I plan to do bricklaying. I know where to get help to do bricklaying, but the community doesn't understand why I get into trouble [alluding to FASD].

While almost all the participants spoke of their hopes and dreams for their futures, a minority were unable to identify positive futures. One non-Aboriginal participant [WD] identified smoking cannabis as their 'future career aspiration'. Two participants [one FASD one NI] saw their futures as bleak and did not know what they wanted to do. One Aboriginal participant [NI] envisioned his future as being 'in the big house across the road [pointing to the adult prison]'. An Aboriginal participant [FASD] said, 'there is nothing to hope for, I'm just going to smoke dope every day'. Finally, a non-Aboriginal participant [NI] said, 'I have no plans for when I leave Banksia. I'm not sure I can get a job anyway cause I'm a criminal'.

Social Recovery Capital: Relationships and Networks

As noted earlier in these results, most participants described happiness as being embedded in family relationships. While family relationships were a source of identity, happiness and cultural connection, there were complicating factors that could impede the potential for recovery. A few participants talked about their parents' use of drugs and identified family members as initiating their drug use.

One non-Aboriginal participant [WD] said, 'I love my mum and dad, but they use all kinds of drugs'. Another Aboriginal participant [FASD] said, 'I smoked cigarettes and drink alcohol with my family since I was 14' and another Aboriginal participant [NI] said: 'me and my bro [brother] use meth'. One Aboriginal participant [WD] recognised that their family's AOD use made it difficult for them to deal with their own AOD problem: 'I smoke and drink with my family, they all do it, so I do too … it's pretty hard, you know'.

Many participants also spoke of other family members who were incarcerated, particularly male relatives. One Aboriginal participant [FASD] said, 'I don't know my dad 'cause he's been in the big house [adult prison] forever', while another Aboriginal participant [NI] said, 'My dad and brother are inside'. An Aboriginal participant [FASD] said, 'both my uncles were there [pointing across the road to the adult prison] but one of them hung himself'.

While the common experience of incarceration is devastating for communities, it can also be a source of support while in detention. An Aboriginal participant [WD] said, 'I'm ok, I'm in here with my cousins and nephews, and uncles'. This could extend to friendship networks, with a non-Aboriginal participant [NI] commenting: 'I'm happy being here at Banksia … because I feel safe and have friends here'.

Around a quarter of the participants had been in state child protection care prior to being incarcerated. These participants particularly yarned about instability. A non-Aboriginal participant [WD] said, 'I have lost count of how many foster homes I have lived in'. Another non-Aboriginal participant [WD] spoke of losing touch with family: 'I haven't seen my parents for a few years now'. Another non-Aboriginal participant [WD] yarned about being repeatedly removed from and reunified with their mother and said, 'I went home a lot, but it never worked out'. Another Aboriginal participant [NI] said, 'I been away from my family for half my life; I get sad and angry'. This participant echoed the experiences of the other participants when they said, 'Miss, I just grew myself up'.

Community Recovery Capital: Access to Education Opportunities

Participants yarned about school experiences. Some participants liked school and described achievement. One non-Aboriginal participant [WD] was a 'gifted' student prior to their incarceration, while another non-Aboriginal participant had successfully completed school and an apprenticeship. Two Aboriginal participants had attended school on football scholarships. One of these participants went to school interstate but discontinued to return home. He said, 'I liked it [school], but I missed being with my mob [family]'. Many of the participants liked the social aspects of school, particularly sport. An Aboriginal participant [FASD] said, 'I like hangin with my bruz [brothers] but not the work; it's too hard'. Another Aboriginal participant [WD] said that the 'best part [of school] is playing sport', while a non-Aboriginal participant [WD] said, 'I liked the social aspects of school like playing footy and being with my mates'.

For many, the complexity in their lives combined with their neurodevelopmental challenges meant that they were unable to complete their schooling. One Aboriginal participant [NI] said, 'I didn't attend school for years'. They went on to say, 'I am trying to do a course [high school] while I am here [at Banksia]'. Another Aboriginal participant [FASD] said, 'I went to primary school sometimes but not high school. I didn't mind school, but I don't go to school no more'.

A few participants said that they did not like school. One non-Aboriginal participant [WD] said, 'I didn't like school. I was told I was stupid regularly'. Another non-Aboriginal participant [WD] said, 'I was in trouble all the time'. After describing multiple suspensions, he said, 'Miss, I hated school' and then shrugged and said, 'anyway, school gave up on me'.

Although most participants were between 13 and 15 years of age and still in the early stages of high school, many described irregular attendance and disengagement. One non-Aboriginal participant [WD] said, 'I done ok in school. I liked school but I'm not going back'. When asked why, they said, 'I didn't like the teachers much and I hated having to wear a uniform. I also hate it when they say one thing and then do another. It does my head in when things change'. Another Aboriginal participant [NI] said, 'it's not worth going back to school; I will just fail'. Other reasons given for irregular attendance or school disengagement included multiple school changes linked to multiple foster placements.

A few participants were interested in returning to school on their release from Banksia. One Aboriginal participant [WD] from a remote community was keen to return to school if it was different from what they had previously experienced. They described an alternative 'bush school':

> Learning in a classroom first for reading and writing maybe, and the rest of the day learning how to survive—like our own first aid—how to eat, ya know, hunting and how to heal like, traditional medicines like. Then the kids might stay in school.

Discussion

Locating Recovery Capital

While most previous health and justice research have focused on the problems of young people, this research captured how young people in detention yarned about what makes them happy, what they hope for, their families and relationships, and their views about their education and school. Theirs were not only stories of the challenges of their circumstances, but also of their dreams for the future, their networks and their opportunities. The findings highlight the importance of family as a source of support and connection for participants. It was evident that being at home with family, having family members visit and the hope provided by the participants own children were all centrally important to participants' happiness.

However, the findings also suggest that some families are a source of negative recovery capital (Cloud and Granfield 2009), as evidenced by the participants' discussions about AOD use and the incarceration of family members. The participant who used AOD with their family because 'they all do it', and the participant who casually pointed to the adult prison as the location of their male relatives and their future, evidence the normalisation of family incarcerations for the Aboriginal participants. Both realities reflect the well-documented shift away from traditional norms and values held by pre-colonial Indigenous cultures (Kelley et al. 2017) and the subsequent trauma (Memmott et al. 2001; Rynne and Cassematis 2015).

Stability was a problem, particularly for those in the care of the state. Instability affects the capacity of individuals to build a sense of identity and connectedness. The participant who 'grew himself up' highlighted the vulnerability of the family and community structures and the influence that colonising forces have had on families and communities (Memmott et al. 2001). Nevertheless, there was an Aboriginal participant who recognised the potential for combining Western and traditional models in 'bush schools' to keep children and young people engaged with and attending school. These aspects of cultural capital held by the Aboriginal participants, positive or negative, can be supported by increasing social capital and positive social connections (Bougie and Senecal 2010; White and Cloud 2008) through positive peer support and role modelling (Nash, Hennessy and Collier 2019). This will be important for supporting these youth to shape their pathways to recovery.

The participants yarned about their education as a source of social and sporting opportunities for some and learning for others. Some participants liked school and said they did well. Some participants had attended multiple schools. Some spoke of being told they were 'stupid' and continually getting into trouble. Negative labelling fuels barriers to rehabilitation and should be challenged and rejected at a systemic level as part of establishing sustainable, recovery-oriented systems of change (Dingle et al. 2014). Many participants had ceased attendance or felt that schools had 'given up' on them. Assessing what activities may better suit these young people to increase positive community participation could better inform their recovery needs (Hennessy 2017). For children, schools are the place where peer relationships are built, and opportunities and resources are made available to pursue their goals. The findings show a clear need for services that help cultivate a strong culture and identity, and regular opportunities to participate in prosocial and cultural activities (Hovane, Dalton and Smith 2014).

The findings suggest that participants were not unmotivated in terms of their hopes for productive futures. While a few of the participants saw little in their futures, they still had hopes to be with family or stay out of prison. Many participants had job and study aspirations. Given the neurodevelopmental and other complex difficulties of the participants, the careers they identified such as bricklaying, working on a station, or working for ranger programs were not beyond their capacity with the right assistance and support. Significantly, participants did not yarn about relationships with teachers, officers or social support workers. While some participants saw their incarceration as an opportunity for education and futures (Laudet, Morgen and White 2006), there was little evidence of key professional relationships as sources of hope and inspiration. The absence of these relationships suggests that there is a need to consider applying relational, strength-based lenses (Slade 2010; Burford, Braithwaite and Braithwaite 2019) to policies which govern justice-involved youth, which factor in the effects of neurodevelopmental impairments and other complex difficulties that affect relationship building. By doing so, it would be possible to develop appropriate interventions, treatments and service responses based on trust and reciprocity (Putnam 2000).

A 'Justice' Lens for Youth with Neurodevelopmental Disability and FASD

The high prevalence of neurodevelopmental impairments and FASD diagnoses among the participants in this study alerts us to the widespread experience of impairments in this population (Baldry et al. 2015; Dias et al. 2013; Indig et al. 2011; Bower et al. 2018). The prevalence study results (Bower et al. 2018) should encourage a shift in the expectations of young people in the justice system and recognition of the effect of neurodevelopmental impairments on the behaviour of detained young people. Further, it provides an opportunity to support young people in developing strategies to deal with their neurodevelopmental disability and to find different pathways into the future. The relationships that the young people have within their families and networks; their participation in education, employment and prosocial activity for their futures; and their neurodevelopmental strengths and difficulties will all need consideration (Fast and Conry 2004; Bower et al. 2018; McLachlan et al. 2014; Snow, Bagley and White 2017; Kippin et al. 2018).

Youth with neurodevelopmental disabilities can have a range of impairments that result in impulsivity, poor attention, impaired memory and poor communication, and these youth are likely to be disadvantaged at all junctions of the criminal justice process. Their lack of (or different) understandings of social norms and inability to learn from experience exacerbate their involvement in crime (Blagg, Tulich and Bush 2015; Streissguth and O'Malley 2000), as do mental health problems, AOD problems and trauma (Hafekost et al. 2017; Indig, Frewen and Moore 2016).

Given the increased likelihood that these youth will come into contact with the law, there is a necessity to scaffold support for justice-involved youth differently. Whether young people in contact with the criminal justice system are fit to stand trial, have an ability to understand investigative procedures such as police interviews, can remember and retell their story accurately and can understand more broadly what may be required of them in court or detention is vitally important (Fast and Conry 2004; Streissguth and O'Malley 2000). Equally important is that they have their neurodevelopmental challenges considered in their rehabilitative efforts and the planning of their futures. Understanding their recovery capital assets in the justice context, including their neurodevelopmental resources that may help or hinder this process is imperative to achieving a PYJ (Butts, Bazemore and Meroe 2010).

The findings from this qualitative study suggest that it is possible to assess recovery capital assets in this population and to utilise those assets as part of a therapeutic process using neurodevelopmental diagnostic information. However, further research is required to confirm the salient dimensions of recovery capital in the context of justice. Table 1 provides a broad conceptualisation of the qualitative data connections with positive and negative justice capital. There is potential for developing an assessment model that measures recovery capital in the justice context and facilitates knowledge about neurodevelopmental disability, disadvantage, trauma and the recovery needs of justice-involved youth. This could also assist in establishing whether applying recovery-focused assessment models as a routine aspect of youth justice service provision can assist in reducing the rising imprisonment rates of Indigenous youth in Australia.

Table 1: Positive and Negative Justice Capital: Data Connections

Data connections	*Negative justice capital*	*Positive justice capital*
Neurodevelopmental Disability	Undiagnosed neurodevelopmental disability FASD, Neurodevelopmental impairments	Access to Strength base, holistic diagnostic assessments Disability services and support Access to special education support
	No access to legal advocacy services	Legal representation and advocacy
	Unrecognised language need No interpreters	Speaking multiple languages Interpreter services Plain language explanations Destigmatising narrative/optimistic language
	Lack of opportunity engagement with community activities or organisations Social exclusion from community and its assets	Hope and future aspirations Goal setting and skill development Engagement with community (sport and employment)
AOD Use	Untreated problematic AOD use	Access to rehabilitation
	Negative peer influences	Positive peer support and mentoring
Trauma and past harm	Removal from Family	Family relationships supported through contact visits Strong relationships with family Safe housing
	Negative family influences Social isolation	Relationships based on trust and mutual obligation Peer support and positive mentoring
	Intergenerational trauma Culture denied Disconnection from country Fractured cultural identity	Recovery and healing services Commitment to culture, community and country Opportunity for cultural activity Strong Cultural identity

Conclusion

Justice-involved youth are well understood to be a traumatised population with high levels of neurodevelopmental disability. The examination of recovery initiatives is consistent with a move towards PYJ for justice-involved youth, regardless of cultural identity. The views presented in this article of young people in detention provide the opportunity for an improved understanding of recovery capital in the justice context and to consider strength-based, future-focused assessment models for recovery. Most of the young people described backgrounds of adversity, with three-quarters of the participants identifying as Aboriginal and therefore likely to be carrying additional intergenerational trauma. As such, the application of a recovery-focused model of assessment that explores the personal, social and community capital assets possessed by justice-involved youth provides a way to understand and respond to their neurodevelopmental needs, build on their skills and assist them to plan pathways to achieve their goals. A complete appreciation of the challenges and support needs of these young people requires the specific consideration of recovery capital in the justice context and, as such, we advocate developing a broad assessment tool that measures the positive and negative recovery capital assets of justice-involved youth.

Acknowledgments

The authors thank the young people who participated in the study for sharing their stories. We thank all at Banksia Hill Detention Centre. We thank the study team, the members of the Consumer and Community Reference Group, the Steering Group and the Reference Group, and the Chief Investigators and Associate Investigators. Sharynne Hamilton thanks the Elder Co-researchers with the Ngulluk Koolunga Ngulluk Koort (Our Children, Our Heart) Project, Telethon Kids Institute for sharing their knowledge and wisdom and for their contribution to the interpretation of the data from this research.

This research is funded by the National Health and Medical Research Council (# APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341). SLH is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award, the FASD Research Australia Centre of Research Excellence, and the Centre of Research Excellence Indigenous Health and Alcohol, University of Sydney (NHMRC #APP1117198).

Disclaimer: Any material published or made publicly available by the authors cannot be considered as either endorsed by the Department of Justice or an expression of the policies or the views of the Department. Any errors of omission or commission are the responsibility of the researchers.

Correspondence: Sharynne Hamilton, PhD Candidate, Telethon Kids Institute, Hospital Ave, Nedlands WA 6001. Email: sharynne.hamilton@telethonkids.org.au

References

Attride-Stirling J (2001) Thematic networks: An analytic tool for qualitative research. *Qualitative Research* 1(3): 385–405. https://doi.org/10.1177/146879410100100307

Australian Bureau of Statistics (2017) *4517.0 Prisoners in Australia, 2017*. Released 6 December 2018. Available at https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4517.0~2018~Media%20Release~Prisoner%20numbers%20up%204%20per%20cent%20from%202017%20(Media%20Release)~100 (accessed 9 December 2019).

Australian Institute of Health and Welfare (2018) *Youth Detention Population in Australia 2018* Available at https://www.aihw.gov.au/reports/youth-justice/youth-detention-population-in-australia-2018/contents/table-of-contents (accessed 9 December 2019).

Baldry E, McCausland R, Dowse L and McEntyre E (2015) *A Predictable and Preventable Path: Aboriginal People with Mental and Cognitive Disabilities in the Criminal Justice System*. Available at https://www.mhdcd.unsw.edu.au/ (accessed 9 December 2019).

Bennett T and Holloway K (2009) The causal connection between drug misuse and crime. *British Journal of Criminology* 49(4): 513–531. https://doi.org/10.1093/bjc/azp014

Bessarab D and Ng'andu B (2010) Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies* 3(1): 37–50. https://doi.org/10.5204/ijcis.v3i1.57

Best D and Laudet A (2010) *The Potential of Recovery Capital*. London: RSA.

Best D (2014) *Strength, Support, Setbacks and Solutions: The developmental pathway to addiction recovery*. Brighton: Pavilion Publishing.

Best D and Savic M (2015) Substance abuse and offending: pathways to recovery. In Sheehan R and Ogloff J (eds) *Working within the Forensic Paradigm: Cross-Discipline Approaches for Policy and Practice*: 259-271. Abingdon, Oxon: Routledge.

Best D, Beckwith M, Haslam C, Haslam A, Jetten J, Mawson E and Lubman D (2016) Overcoming alcohol and other drug addiction as a process of social identity transition: The Social Identity Model of

Recovery (SIMOR). *Addiction Research and Theory* 24 (2): 111-123 https://doi.org/10.3109/16066359.2015.1075980

Best D (2019) *Pathways to recovery and desistance: The role of the social contagion of hope*. Bristol: Policy Press.

Blagg H (2008) *Crime, Aboriginality and the Decolonisation of Justice*. Sydney: Federation Press.

Blagg H, Tulich T and Bush Z (2015) Diversionary pathways for Indigenous youth with FASD in Western Australia: Decolonising alternatives. *Alternative Law Journal* 40(4): 257–260. https://doi.org/10.1177/1037969X1504000409

Bower C, Watkins R, Mutch R, Marriott R, Freeman J, Kippin N, Safe B et al. (2018) Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open* 8 e019605. http://dx.doi.org/10.1136/bmjopen-2017-019605

Bougie E and Senecal S (2010) Registered Indian children's school success and intergenerational effects of residential schooling in Canada. *The International Indigenous Policy Journal* 1(1): 1–41. https://doi.org/10.18584/iipj.2010.1.1.5

Bourdieu P (1985) The forms of capital. In Richardson JG (ed.) *Handbook of Theory and Research for the Sociology of Education*: 241–258. New York: Greenwood.

Brunelle N, Cousineau M and Brochu S (2005) Juvenile drug use and delinquency: Youths' accounts of their trajectories. *Substance Use & Misuse* 40(5): 721–734. https://doi.org/10.1081/JA-200055404t

Burford G, Braithwaite J and Braithwaite V (eds) (2019) *Restorative and Responsive Human Services*. New York: Routledge.

Butts J, Bazemore G and Meroe AS (2010) *Positive Youth Justice: Framing Justice Interventions Using the Concepts of Positive Youth Development*. Washington: Coalition for Juvenile Justice.

Caudy M, Tillyer M and Tillyer R (2018) Jail versus probation: A gender-specific test of differential effectiveness and moderators of sanction effects. *Criminal Justice & Behavior* 45(7): 949–968. https://doi.org/10.1177/0093854818766375

Cavadino M and Dignan J (2006) *Penal Systems: A Comparative Approach*. Thousand Oaks and New Delhi: Sage Publications.

Clark CD (2011) *In a Younger Voice: Doing Child-Centered Qualitative Research.* New York: Oxford University Press.

Cloud W and Granfield R (2009) Conceptualizing recovery capital: Expansion of a theoretical construct. *Substance Use and Misuse* 43(12–13): 1971–1986. https://doi.org/10.1080/10826080802289762

Coyhis D and White W (2006) *Alcohol Problems in Native America: The Untold Story of Resistance and Recovery—The Truth about the Lie*. Colorado Springs: White Bison, Inc.

Cunneen C and Rowe S (2014) Changing narratives: Colonised people, criminology and social work. *International Journal for Crime, Justice and Social Democracy* 3(1): 49–67. https://doi.org/10.5204/ijcjsd.v3i1.138

De Maio JA, Zubrick SR, Silburn SR, Lawrence DM, Mitrou FG, Dalby RB, Blair EM, Griffin J, Milroy H and Cox A (2005) *The Western Australian Aboriginal Child Health Survey: Measuring the Social and Emotional Wellbeing of Aboriginal Children and Intergenerational Effects of Forced Separation.* Available at https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/measuring_social_and_emotional_wellbeing.pdf (accessed 9 December 2019).

Dias S, Ware RS, Kinner SA and Lennox NG (2013) Co-occurring mental disorder and intellectual disability in a large sample of Australian prisoners. *Australian & New Zealand Journal of Psychiatry* 47(10): 938–944. https://doi.org/10.1177%2F0004867413492220

Dingle GA, Stark C, Cruwys T and Best D (2014) Breaking good: Breaking ties with social groups may be good for recovery from substance misuse. *British Journal of Social Psychology* 54(2): 236–254. https://doi.org/10.1111/bjso.12081

Dunkel F (2014) Juvenile justice systems in Europe—Reform developments between justice, welfare and 'new punitiveness'. *Criminological Studies* 1: 31–76. Available at http://eigep.eu/wp-content/uploads/2018/01/Dunkel2014_juvenile_justice_Europe.pdf (accessed 17 August 2019).

Durkheim E (1984) *The Division of Labor in Society*. New York: Free Press.

Farrington DP (2007) Childhood risk factors and risk-focused prevention. In Maguire M, Morgan R and Reiner R (eds) *The Oxford Handbook of Criminology*: 602-640. Oxford: Oxford University Press.

Fast D and Conry J (2004) The challenge of fetal alcohol syndrome in the criminal legal system. *Addiction Biology* 9(2): 161–166. https://doi.org/10.1080/13556210410001717042

Fredericks B, Adams K, Finlay S, Fletcher G, Andy S, Briggs L, Briggs L and Hall R (2011) Engaging the practice of yarning in Action Research. *Action Learning and Action Research Journal* 17(2): 7–19. Available at https://eprints.qut.edu.au/48053/1/Engaing_yarning_in_Action_Research%2C_ALAR_Journal.pdf (accessed 14 July 2019).

Freeman J, Condon C, Hamilton S, Mutch R, Bower C and Watkins R (2018) Challenges in Accurately Assessing Prenatal Alcohol Exposure in a Study of Fetal Alcohol Spectrum Disorder in a Youth Detention Center. *Alcohol Clinical Experimental Research* 43(2): 309-316. https://doi.org/10.1111/acer.13926

Goddard T and Myers R (2017) Against evidence-based oppression: Marginalized youth and the politics of risk-based assessment and intervention. *Theoretical Criminology* 21(2): 151–167. https://doi.org/10.1177%2F1362480616645172

Goldson B and Muncie J (2012) Towards a global 'child friendly' juvenile justice? *International Journal of Law, Crime and Justice* 40(1): 47–64. https://doi.org/10.1016/j.ijlcj.2011.09.004

Granfield R and Cloud W (2001) Social context and 'natural recovery': The role of social capital in the resolution of drug-associated problems. *Substance Use and Misuse* 36: 1543–70. https://doi.org/10.1081/JA-100106963

Hafekost K, Lawrence D, O'Leary C, Bower C, Semmens J and Zubrick SR (2017) Maternal alcohol use disorder and risk of child contact with the justice system in Western Australia: A population cohort record linkage study. *Alcoholism: Clinical and Experimental Research* 41(8): 1452–1460. https://doi.org/10.1111/acer.13426

Hamilton S, Reibel T, Watkins R, Mutch R, Kippin N, Freeman J, Passmore H et al. (2019a). "He has problems; he is not the problem …" A qualitative study of noncustodial staff providing services for young offenders assessed for Foetal Alcohol Spectrum Disorder in an Australian youth detention centre. *Youth Justice* 19(2): 137-157. https://doi.org/10.1177/1473225419869839

Hamilton S, Reibel T, Maslen S, Watkins R, Freeman J, Passmore H, Mutch R et al. (2019b). Disability "in-justice": The benefits and challenges of "yarning" with young people undergoing diagnostic assessment for Fetal Alcohol Spectrum Disorder in a youth detention centre. *Qualitative Health Research* 30(2): 314-327. https://doi.org/10.1177/1049732319882910

Harmes M, Hopkins S and Farley H (2019) Beyond incarcerated identities: Identity, bias and barriers to higher education in Australian prisons. *International Journal of Bias, Identity and Diversities in Education* 4(1): 211–234. https://doi.org/10.4018/IJBIDE.20190101

Haslam SA, Reicher SD and Levine M (2012) When other people are heaven, when other people are hell: How social identity determines the nature and impact of social support. In Jetten J, Haslam C and Haslam SA (eds) *The Social Cure: Identity, Health and Well-Being*. 157–174. New York, NY: Psychology Press.

Hennessy EA (2017) Recovery capital: a systematic review of the literature. *Addiction Research & Theory* 25(5): 349–360. https://doi.org/10.1080/16066359.2017.1297990

Hovane V, Dalton T and Smith P (2014) Aboriginal rehabilitation programs. In Dudgeon P, Milroy H and Walker R (eds) *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice* 2nd edn: 509–522. Canberra: Australian Government Department of the Prime Minister and Cabinet.

Indig D, Frewen A and Moore E (2016) Predictors and correlates of re-incarceration among Australian young people in custody. *Australian and New Zealand Journal of Criminology* 49(1): 73–89. https://doi.org/10.1177%2F0004865814550534

Indig D, Vecchiato C, Haysom L, Beilby R, Carter J, Champion U, Gaskin C, Heller E, Kumar S, Mamone N, Muir P, van den Dolder P and Whitton G (2011) *2009 NSW Young People in Custody Health Survey: Full Report*. Sydney: Justice Health and Juvenile Justice.

Jetten J, Haslam C, Haslam SA, Dingle G and Jones JM (2014) How groups affect our health and well-being: The path from theory to policy. *Social Issues and Policy Review* 8(1): 103–130. https://doi.org/10.1111/sipr.12003

Kaspar V (2014) The lifetime effect of residential school attendance on Indigenous health status. *American Journal of Public Health* 104(11): 2184–2190. https://doi.org/10.2105/AJPH.2013.301479

Kelley A, Bingham D, Brown E and Pepion L (2017) Assessing the impact of American Indian peer recovery support on substance use and health. *Journal of Groups in Addiction & Recovery* 12(4): 296–308. https://doi.org/10.1080/1556035X.2017.1337531

Kippin N, Leitãoa S, Watkins R, Finlay-Jones A, Condon C, Marriott R, Mutch R et al. (2018) Language diversity, language disorder, and fetal alcohol spectrum disorder among youth sentenced to detention in Western Australia. *International Journal of Law and Psychiatry* 61: 40-49. https://doi.org/10.1016/j.ijlp.2018.09.004

Lambert V and Glacken M (2011) Engaging with children in research: Theoretical and practical implications of negotiating informed consent/assent. *Nursing Ethics* 18(6): 781–801. https://doi.org/10.1177%2F0969733011401122

Laudet A, Morgen K and White W (2006) The role of social supports, spirituality, religiousness, life meaning and affiliation with 12-step fellowships in quality of life satisfaction among individuals in recovery from alcohol and drug use. *Alcoholism Treatment Quarterly* 24(102): 33–73. https://doi.org/10.1300/J020v24n01_04

MacDonald C and Steenbeek A (2015) The Impact of colonization and Western assimilation on health and wellbeing of Canadian Aboriginal people. *International Journal of Regional and Local History* 10(1): 32–46. https://doi.org/10.1179/2051453015Z.00000000023

Martin K (2008) *Please Knock Before You Enter: Aboriginal Regulation of Outsiders and the Implications for Researchers*. Brisbane: Post Pressed.

McLachlan K, Roesch R, Viljoen J and Douglas K (2014) Evaluating the psycholegal abilities of young offenders with fetal alcohol spectrum disorder. *Law and Human Behavior* 38: 10–22. Available at https://psycnet.apa.org/doi/10.1037/lhb0000037 (accessed 4 August 2019).

McNeill F and Maruna S (2007) Giving up and giving back: Desistance, generativity and social work with offenders. In McIvor G and Raynor P (eds) *Developments in Social Work with Offenders (Research Highlights in Social Work 48)*:224–339. London: Jessica Kingsley.

McNeill F and Whyte B (2007) *Reducing Reoffending: Social Work and Community Justice in Scotland.* Cullompton, England: Willan.

Memmott P, Stacy R, Chambers C and Keys C (2001) *Violence in Aboriginal Communities.* Canberra: Attorney-General's Department.

Morris A and Giller H (1983) *Providing Criminal Justice for Children*. London: Hodder Arnold.

Nash AJ, Hennessy EA and Collier C (2019) Exploring recovery capital among adolescents in an alternative peer group. *Drug and Alcohol Dependence* 199: 136–143. https://doi.org/10.1016/j.drugalcdep.2019.02.025

NVivo Pro Qualitative Data Analysis Software 2016, Version 11, software, QSR International Pty Ltd, Melbourne.

Office of the Inspector of Custodial Services (2018) *Report of an Announced Inspection of Banksia Hill Juvenile Detention Centre*. Perth: Office of the Inspector of Custodial Services.

Passmore H, Giglia R, Watkins R, Mutch R, Marriott R, Pestell C, Zubrick S et al. (2016) Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open* 6(6): e012184. https//doi.org/10.1136/bmjopen-2016-012184

Passmore H, Mutch R, Burns S, Watkins R, Carapetis J, Hall G and Bower C. (2018) Fetal Alcohol Spectrum Disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce. *International Journal of Law and Psychiatry* 59: 44-52. https://doi.org/10.1016/j.ijlp.2018.05.008

Putnam RD (2000) *Bowling Alone: The Collapse and Revival of American Community.* London: Simon & Schuster.

Reitano J (2017) *Adult Correctional Statistics in Canada 2015/2016*. Available at http://www.statcan.gc.ca/pub/85-002-x/2017001/article/14700-eng.htm (accessed 14 July 2019).

Roach K and Bailey A (2009) The relevance of fetal alcohol spectrum disorder and the criminal law from investigation to sentencing. *University of British Columbia Law Review* 42: 1–68. Available at https://ssrn.com/abstract=1616843 (accessed 20 May 2019).

Rynne J and Cassematis P (2015) Assessing the prison experience for Australian First Peoples: A prospective research approach. *International Journal for Crime, Justice and Social Democracy* 4(1): 96–112. https://doi.org/10.5204/ijcjsd.v4i1.208

Scott D and Gosling H (2016) Before prison, instead of prison, better than prison: Therapeutic communities as an abolitionist real utopia. *International Journal for Crime, Justice and Social Democracy* 5(1): 52–66. https://doi.org/10.5204/ijcjsd.v5i1.282

Slade M (2010) Mental illness and well-being: The central importance of positive psychology and recovery approaches. *BMC Health Services Research* 10(1): https://doi.org/10.1186/1472-6963-10-26

Smith J, Flower P and Larkin M (2009) Interpretative Phenomenological Analysis: Theory, Method and Research. *Qualitative Research in Psychology* 6(4): 346-347. https://doi.org/10.1080/14780880903340091

Snow P, Bagley K and White D (2017) Speech-language pathology intervention in a youth justice setting: Benefits perceived by staff extend beyond communication. *International Journal of Speech-Language Pathology* 20(4): 458-467. https://doi.org/10.1080/17549507.2017.1297484

Streissguth AP and O'Malley K (2000) Neuropsychiatric implications and long-term consequences of fetal alcohol spectrum disorders. *Semin Clin Neuropsychiatry* 5(3): 177–190. https://doi.org/10.1053/scnp.2000.6729

Ulmer J and Bradley M (2018) Punishment in Indian country: Ironies of federal punishment of Native Americans. *Justice Quarterly* 35(5): 751–81. https://doi.org/10.1080/07418825.2017.1341540

Ward T and Maruna S (2007) *Rehabilitation: Beyond the Risk Paradigm*. London: Routledge.

Weatherburn D and Ramsey S (2016) *What's Causing the Growth in Indigenous Imprisonment in NSW?* Sydney: NSW Bureau of Crime Statistics and Research. Available at https://www.bocsar.nsw.gov.au/Documents/BB/Report-2016What%27s-causing-the-growth-in-Indigenous-Imprisonment-in-NSW-BB118.pdf (accessed 17 June 2019).

White W and Cloud A (2008) Recovery capital: A primer for addictions professionals. *Counselor* 9(5): 22–27. Available at http://www.williamwhitepapers.com/pr/2008RecoveryCapitalPrimer.pdf (accessed 17 January 2019).

Winterdyck J (2014) *Juvenile Justice: International Perspectives, Models and Trends*. Boca Raton: CRC Press.

Please cite this article as:
Hamilton, S L, Maslen S, Best D, Freeman J, O'Donnell M, Reibel T, Mutch R C and Watkins R (2020) Putting 'justice' in recovery capital: Yarning about hopes and futures with young people in detention. *International Journal for Crime, Justice and Social Democracy* 9(2): 20-36. https://doi.org/10.5204/ijcjsd.v9i2.1256

Appendix 4: Journal Article: ***Youth Justice***

Original Article

Youth Justice
2019, Vol. 19(2) 137–157

DOI: 10.1177/1473225419869839
journals.sagepub.com/home/yjj
SAGE

'He Has Problems; He Is Not the Problem . . .' A Qualitative Study of Non-Custodial Staff Providing Services for Young Offenders Assessed for Foetal Alcohol Spectrum Disorder in an Australian Youth Detention Centre

Sharynne L. Hamilton, Tracy Reibel, Rochelle Watkins, Raewyn C. Mutch, Natalie R. Kippin, Jacinta Freeman, Hayley M. Passmore, Bernadette Safe, Melissa O'Donnell and Carol Bower

Abstract

Little is known about the challenges non-custodial youth detention centre staff face supporting young people with foetal alcohol spectrum disorder (FASD). We undertook qualitative inquiry to identify and describe the perspectives of non-custodial staff detention staff regarding the value of an FASD prevalence study. Data were collected using semi-structured interviews and focus groups and analysed using thematic network analysis. Staff held few concerns about the prevalence study and its impact on participating young people; however, they identified barriers related to study processes, and practices and culture within their workplace, which hindered gaining maximum benefit from the research and its findings.

Keywords

assessments, detention centre, FASD, rehabilitation staff, youth justice

Introduction

The United Nations (1985) Standard Minimum Rules for the Administration of Juvenile Justice, Rule 26.1 espouses that 'the objective of training and treatment of juveniles placed in institutions is to provide care, protection, education and vocational skills, with a view

---

Corresponding author:
Sharynne L. Hamilton, Telethon Kids Institute, The University of Western Australia, PO Box 855, West Perth, WA 6872, Australia.
Email: Sharynne.Hamilton@telethonkids.org.au

to assisting them to assume socially constructive and productive roles in society' (p. 14), highlighting the importance of the roles a youth detention centre workforce undertake. Staff are central to nurturing incarcerated young people to move from involvement in criminal activity towards more life-affirming opportunities and goals.

On any given night around Australia, 980 children and young people are in youth detention facilities (Australian Institute of Health and Welfare, 2018). Aboriginal young people are significantly overrepresented in these facilities, comprising 54 percent of incarcerated young people nationally, despite only being 3 percent of the population (Australian Institute of Health and Welfare, 2018). This article describes a qualitative study undertaken with non-custodial staff as part of a larger study (described in section 'Methods') establishing the prevalence of foetal alcohol spectrum disorder (FASD) in a youth detention centre. At the time of the study, the detention centre housed approximately 155 male and female young people aged 10–18 (Office of the Inspector of Custodial Services (OICS), 2015). Of these young people, 95 per cent were male and more than half were aged between 16 and 17 years, and 75 per cent were Aboriginal young people. Just over half of the young people (57%) lived in urban areas and 43 per cent were from regional and remote regions (OICS, 2015). While in detention, young people are provided with opportunities to attend school, vocational training and other personal development and sporting activities (Department of Justice, 2017). Staff at the detention centre use the Offender Management System (OMS), an electronic database containing demographic, programme and assessment information about the young people, to access and share information. These staff perform a vital role in the care and rehabilitation of young people in detention.

Previous literature

Young people involved with justice systems are often living with numerous conditions that can affect their social and emotional well-being (Dias et al., 2013). Research has found, for example, that Australian Aboriginal young people have higher levels of neurocognitive disability (Baldry et al., 2012; Dias et al., 2013) and intellectual disability (Indig et al., 2011) compared with non-Aboriginal young people involved with the justice system. Research has also found that many young people have not had diagnosable conditions previously identified. High numbers of young people involved in justice systems, for example, were found to have undiagnosed neurodevelopmental and mental health disorders (Bower et al., 2018; Dias et al., 2013; Garland et al., 2001; Teplin et al., 2002; Wasserman et al., 2002, 2003). Previously unidentified health problems (Dias et al., 2013; Kumwenda et al., 2017), cognitive and intellectual disabilities (Dias et al., 2013; Leonard, 2016; Sotiri and Simpson, 2006) and language disorders (Anderson et al., 2016; Kippin et al., 2018) have also been found among young people in contact with youth justice. There is also a small but growing body of evidence identifying high prevalence of FASD in Australian justice populations (Bower et al., 2018; Flannigan et al., 2018).

The availability of data about the potential prevalence of FASD among both Aboriginal and non-Aboriginal children and young people in Australia is limited, and the rate of young people living with FASD who come before the courts is unknown. However, due to the high number of Aboriginal young people who end up in prison, FASD has been recognised as a potentially significant underlying contributor to youth crime (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, 2011). It is vitally important for young people with FASD to have their conditions recognised when involved with youth justice. The range of neurocognitive impairments, together with broader psycho-social risks often experienced by those with FASD, can result in young people having limited understanding of judicial processes (Baldry et al., 2015; Flannigan et al., 2018; Frize et al., 2008). Unrecognised neurodevelopmental disabilities such as FASD among young people who encounter the justice system can have serious implications, as it may mean that these young people have not had their health and well-being needs met and have received punitive approaches in response to their maladaptive behaviours rather than supportive pro-active responses (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, 2011). Developing screening instruments for the recognition of young people with FASD and neurodevelopmental disability when they encounter the law is, therefore, critically important.

Screening for undiagnosed disorders both on entry and throughout involvement with the justice system can be an efficient mechanism for gathering information (Young et al., 2006). This, however, needs to occur at various points of a young person's contact with the justice system to inform both the identification of risk and the needs of young offenders and promote fairness and consistency in practice. Moreover, there is a need for the ongoing screening and assessment of potential difficulties young people may be experiencing to assist with connections to external services; with screening and assessment critical for detention case management, and for assisting a successful transition from a highly organised detention setting to a more unstructured life in the community (Altschuler and Armstrong, 1994; Hancock, 2017; Potter, 2014; Wasserman et al., 2003). The most effective programmes in youth detention are those which are designed to meet the needs of individuals, based on the assessment of multiple possible contributing factors such as prior service involvement, previous assessments, school reports, and familial and social histories to identify both genetic and social stressors which may impair individual functioning (Murphy et al., 2010).

Qualitative studies have explored the experiences of youth justice staff working with and providing services for detained young people. These have explored themes of race and the overrepresentation of minority populations (Conley, 1994; Holley and VanVleet, 2008), behaviour management and perceptions of differences in gender (Baines and Alder, 1996), sexual diversity (Feinstein et al., 2000), general practice and work culture (Field, 2007), and injury prevention for detained young people (Reed et al., 2015). Health and mental health services have received attention (Knowles et al., 2012; Kumwenda et al., 2017). The studies found that a lack of comprehensive health care histories and the inadequate knowledge of the health care needs of young people, and inadequate resources and financing all have negative implications for young people in detention. Only by identifying, and thereby reducing the factors contributing to health problems of young offenders, will it be possible to reduce future harms and increase the likelihood that young people will increase knowledge of their needs and seek assistance (Kumwenda et al., 2017). Youth justice staff views of mental health services provided to justice-involved young people have also received some scholarly attention (Knowles et al., 2012), providing insight into understanding the barriers to youth justice staff screening young offenders for self-harm and mental health issues and highlighting the need to improve the knowledge and responses of these staff to young people presenting with problematic mental health. This body of work also highlights the necessity for the ongoing training of all staff in youth detention settings. A lack of knowledge, inadequate training and the inconsistent sharing of information have been found to inhibit the ability of custodial staff to provide appropriate care for young people with FASD in detention (Passmore et al., 2018).

A recent Royal Commission (Australian Government, 2017), which inquired into allegations of abuse and operational problems at Don Dale Youth Detention Centre in Australia, found numerous failings relating to poor case management practices and poorly skilled, inadequately trained youth justice staff who reported they were unsupported and under-resourced. These failings resulted in appalling abuses of young people, the majority of whom were Aboriginal (Australian Government, 2017). Although not the focus of this article, it must be recognised that the overrepresentation of Indigenous young people in justice systems globally cannot be separated from the well-understood problems of systemic and institutional racism and discrimination (Blagg, 2008; Harmes et al., 2019; Wacquant, 2009; Weatherburn and Ramsey, 2016). There is a small amount of literature specifically relating to the lack of focus on the employment and advancement of Indigenous staff in Australian prisons, which highlights that too few Aboriginal people have senior positions in these organisations, and as a result, they have little to no ability to contribute to leadership provision, decision-making, representing the views and wishes of the broader Indigenous community or training in cultural competency (Shepherd and Phillips, 2016). Without a concerted effort to build the numbers and capacity of an Indigenous workforce, institutional racism will continue unabated (Shepherd and Phillips, 2016). These authors argue a commitment from the top to bottom levels of organisations is required to facilitate the 'unbuilding of racism' in institutions (Shepherd and Phillips, 2016: 308).

In their inquiry, the NT Royal Commission (Australian Government, 2017) also found there were inadequate needs assessments of young people being undertaken. The report highlighted the importance of case-managed throughcare planning which can assist in smoother transitions back to communities for young offenders and enable greater consistency in transitional support for their education and rehabilitation.

The views of staff in education services in youth detention have received some qualitative inquiry. One US study explored an 'Alternative Education Initiative', which examined the way schools could play a role in curbing offending from the perspective of youth justice staff (Atkins et al., 2005). Ninety five per cent of participants in that study cited inadequate funding and a lack of resources as the main barriers to providing successful alternative education programmes. An Australian study which explored the education of young people in detention (Strnadova et al., 2017), acknowledged the complex needs and lives of incarcerated young people and highlighted the well-known high levels of disengagement from school for young offenders. Education provided within a youth detention facility can, therefore, present an opportunity for incarcerated young people to address learning deficits as classes are usually small, and education is mandatory (Tobin and Sprague, 2000). An Australian study of youth detention staff, which explored their views of having a speech–language intervention, found staff valued the speech pathology service, and moreover, the intervention assisted staff to understand more about the young people and provided them with strategies and support to better engage with the young people (Snow et al., 2017). Even though delivering effective interventions can be challenging within a detention centre environment (Goldson, 2005; Lanskey, 2011), these studies suggest that education, health and welfare services in custodial settings play a vital role in improving well-being and creating positive futures for young offenders.

Due to the lack of knowledge about FASD in detention facilities and the need for workforce support to assist in the management of young people with FASD and other neurodevelopmental disabilities, a feasibility study was undertaken in an Australian youth detention centre (Bower et al., 2018; Passmore et al., 2016). The study established an FASD prevalence of 36 per cent, the highest known estimate in a justice setting worldwide. In addition, 89 per cent of young people were identified with at least one neurodevelopmental impairment in the severe range, including 21 per cent of young people with impairment in cognition (Bower et al., 2018). There are no known published qualitative studies which explore the views and experiences of non-custodial detention centre staff who provide services to young people with FASD or who have been working in a detention centre facility during an FASD prevalence study. To provide understanding of the impact and value of the prevalence study, this qualitative research we report now aimed to capture the perspectives of non-custodial detention centre staff to identify the value of the study and to describe the impact the study had on their services.

Study setting

The feasibility study is the first of its kind undertaken in an Australian youth detention centre. The aims of the feasibility study were fourfold: to estimate the prevalence of FASD among young people sentenced to detention; to develop and evaluate an FASD screening instrument; to design, administer and evaluate a workforce development intervention with custodial staff; and to conduct a qualitative evaluation of the prevalence study.

Clinicians undertook comprehensive medical, neuropsychological, motor skills, and speech and language assessments with participating young people. Following assessments, multi-disciplinary meetings were undertaken with the clinical research team, and an extensive Assessment Results and Recommendations Report containing diagnostic information and individualised recommendations was written for each young person (Passmore et al., 2016). The formal workforce development component of the feasibility study involved the production of training resources and a structured training intervention for custodial staff, but the intervention stage had not commenced at the time this study was undertaken (see Passmore et al., 2018).

Upon request by the education staff at the centre, members of the research team who conducted clinical assessments also provided information about FASD to non-custodial staff via a series of professional development sessions, which took place simultaneously to this study. These sessions also included classroom-specific strategies for young people with neurodevelopmental disability and information about age-appropriate resources. The views of those who participated in two of these professional development sessions are reported here.

Methods

Participants

A case study research methodology (Yin, 2013) was used to capture the views of non-custodial staff in education, health, psychological, case management and Aboriginal welfare services in the detention centre. Purposive sampling was used to recruit participants. Initial planning for focus groups occurred through email contact with the lead researcher and team leaders for each service. All team leaders agreed to their team's participation in a focus group which was scheduled during existing team meeting times. Although this maximised the opportunity for inclusion, it also meant competing priorities influenced the length of time of the focus groups, which ranged between 20 and 45 minutes. Focus groups were held on-site with the following participants: case managers ($n=6$), psychologists ($n=5$), educators ($n=18$), and a follow-up educator focus group ($n=14$) with overlap of some participants in the two groups. Individual meetings were held with staff members from the health service ($n=1$) and Aboriginal welfare officers ($n=2$).

Data collection

Focus groups and interviews were used as the methods for data collection. Five topics for discussion were provided to the detention centre staff team leaders from each service, who shared these topics with group members prior to the focus group. The topics were (1) FASD assessments, (2) impacts of the research for staff and for the young people, (3) access to and use of the young people's Assessment Results and Recommendations Reports, (4) participants' thoughts on the value of the strategies generated by the research team and entered into the OMS and (5) any questions, comments, concerns or suggestions the staff have about FASD, cognitive disabilities or the research itself.

At the beginning of the focus groups and interviews, a summary of the topics for discussion was provided to the group. Following explanation that participant responses would remain anonymous, verbal consent was received from all participants. For some meetings, two researchers attended, one facilitating and the other scribing verbatim quotes and noting non-verbal observations. One researcher paraphrased the content of the focus group back to participants at the time of discussion to acknowledge their input and ensure data validity from participant perspectives. Furthermore, the two researchers met immediately following each focus group meeting and recorded a discussion of their observations for later analysis.

Due to the large number of teaching staff involved in two focus groups, they are referred to as educators. To protect the identity of participants in focus groups and single interviews, they are identified only as 'participants'.

Data analysis

Two researchers independently reviewed the data to identify key themes, with preliminary analysis undertaken immediately following data collection. The lead researcher entered the data into NVivo 11 Pro (2016). Data were analysed using thematic network analysis

(Attride-Stirling, 2001) and triangulated across all focus groups and interviews. Study team members regularly met and reviewed themes noted by the lead researcher from the participant data. These reviews helped to ensure consistency in data interpretation through multiple perspectives and iterations. The lead researcher also conducted multiple analysis reviews at regular time points over a 12-month period to compare, confirm and develop final data interpretations.

Results

We present our findings according to the following themes: (1) FASD assessments, sub-theme (i) impact on service delivery; (2) Assessment Results and Recommendation Reports; and (3) identified barriers to maximising benefit from the prevalence study. Subthemes from Theme 3 included (i) professional development opportunities, (ii) resourcing and staffing and (iii) communication and information access.

Theme 1: FASD assessments

The first theme relates to the multi-disciplinary team assessments conducted with 99 young people in the prevalence study (Bower et al., 2018). Concern for the young people was expressed by some participants. Several participants reported the young people often returned from assessments ‘tired’, ‘exhausted’ and ‘needing quiet time’. One participant said that some of the young people felt they were involved in the research ‘because they are stupid’ or because ‘the courts think they are idiots’. Other participants were concerned about trauma. They said,

> I hope the [research] team take into account the amount of trauma these young people have been through.

Overall though, no participants observed any major problems in the young people who were involved in the assessments. One participant, for example, said,

> everything is going well. We have no concerns about the project,

while another said,

> the young people aren’t really fussed [about the assessments] that I’m aware of.

Participants from across the different groups provided positive examples of outcomes for some young people whom they worked with. In one focus group, an educator highlighted a raised awareness for the young people from the assessments about their difficulties when they said,

> the young people often have ‘light bulb’ moments following the assessments . . . they will impulsively do something and then go ‘oh but I do that because my brain’s a bit different’. It has made them think about why they do things.

Another participant said a young person was identified through the assessments as having an intellectual disability and was subsequently referred to appropriate disability services from which;

> he is now receiving additional support which has made it much easier for working toward better support in all aspects of his life on his release.

Another participant said that,

> having a FASD assessment and subsequent diagnosis has had a positive effect on sentencing and on the court personnel's understanding of FASD.

There were a small number of participants who were sceptical about FASD and its relationship with the young people's criminality. One participant asked,

> what does it all really mean? [a FASD diagnosis] Is it around lesser sentences?

Another asked of FASD and crime generally, 'is it a cop-out?' Most participants, though, were supportive of assessments for young people in detention. The importance of the assessment and diagnosis and the necessity to develop behavioural management strategies were captured by one educator who said,

> He has problems, he is not the problem. We must be part of the solutions for him.

Subtheme (i): Impact on service delivery. Communication problems and consultation about the research were central to the feedback on the impact of the research for non-custodial staff. One participant said,

> Communication gets lost and people are often not informed about what is going on, particularly when staff are transient and staff changes are significant over time.

Across all groups, there were comments such as the following:

> we didn't have any input into how it [the research] was going to be run and what was required.

and,

> there is a need for courtesy to be given to the . . . staff [by the research team] about what is expected from the staff on site.

Participants felt their own service provision had been impacted by the study, and for some it was intrusive on their time. There were educators who expressed frustration when the young people were called out of the classroom for assessments or interviews conducted for the research. One participant said,

> it was frustrating when young people were removed from programs or recreation times as they are really important for the young people.

Participants commented,

> . . . [we] are extremely unhappy about the lack of consultation by the research team;

> Communication about the testing should have been more effective;

and,

> Communication has been the central problem in the conduct of this project.

Theme 2: Assessment Results and Recommendations Reports

The second theme refers to participant views on the Assessment Results and Recommendations Reports (report/s). Comprehensive reports were generated for each young person who completed assessments. Most participants had seen a report, and for many, the reports provided clarity about a young person's behaviour and, as put by one participant, their 'ways of being'. Participants said that the reports and the research had a positive impact on their own professional practices. One participant said,

> the reports and the project generally, have positively impacted on our own practices and the way we talk to and work with the young people.

Another participant said that a report they had read for a young person,

> is very thorough and addresses what problems were found.

Several participants commented on the limitations of acting on the recommendations provided in the reports. One participant said,

> we are often not sure of whose responsibility it is to organise things recommended in the reports.

Another participant said,

> various recommendations made in the reports are outside the scope or funding of the service. For example, recommendation for eye testing and glasses.

The value of the reports external to the detention centre was also raised. One participant suggested,

> it would be useful if the reports were incorporated into a release plan for Youth Justice Officers. This could provide some continuity of management of the young people in the community.

Not all staff had access to completed reports, as this was dependent on dissemination from detention centre management. However, staff were provided with prioritised strategies for managing young people via OMS. Across all the groups, participants advised that in the current format 'TOMS strategies are not useful'. Another participant said,

> it is often difficult to find things – strategies are often not available for a young person or are hard to find.

The participants explained that there can be many case notes and that they,

> would not have the time or the willingness to trawl through TOMS to find three strategies which may or may not be useful.

Another participant said,

> access to TOMS strategies are inconsistently recorded and often difficult to find.

A participant had not seen any of the strategies provided for the OMS system. Participants also provided solutions. One participant felt that,

> strategies and recommendations should be independently available immediately if effective in addressing concerns about the young person,

while an educator suggested that,

> a simple format could be developed which uses codes/stickers to indicate diagnosis or disability or individual difficulty, but at the same time, maintain the confidentiality and dignity of the young person.

Theme 3: Identified barriers to maximising benefit from the study

Participant questions and statements across all the focus groups and interviews illustrated the many barriers to gaining maximum benefit from the research. This theme is related to barriers identified by participants which inhibit their ability to support the needs of young people in their care. Participants across all groups identified essential requirements to realise the full value of the research and assist the young people's rehabilitation.

Subtheme (i): Limited professional development opportunities. The most prevalent need identified was for training and information about FASD and neurodevelopmental disability and its effect on young people. Participants had concerns about how to address the implications of a young person's FASD diagnosis and how well equipped they were in their professional roles to address this sensitively with a young person. Participants commented:

> training and information would be useful;

> we need training and information sessions – on FASD, ID [Intellectual Disability], and other co-morbidities such as ADHD [Attention Deficit Hyperactivity Disorder];

> training specific to FASD in justice would be good;

and,

> more training and information on FASD, and specifically FASD and justice would be useful.

A participant also added, ‘We need time off [*for training and professional development*]’.

Educators also provided feedback on the value of the professional development sessions provided by the research staff, saying,

> The professional development sessions [run by the research staff] were fantastic, really beneficial in terms of understanding sensory issues particularly;

> Information on motor skills [in relation to handwriting] was very useful;

and,

> Information during the professional development session provided by the speech therapist and occupational therapist was very useful.

Subtheme (ii): Inadequate resourcing and insufficient staffing. Participants were keen to ensure relevant support which, as put by one participant, ‘reflects the special needs of the young people’ were available for young people with FASD and other disabilities. An educator said,

> teaching is very difficult because the usual teaching aids are not available to educators [in youth detention].

The researchers in an education focus group asked what, from the project and in general, they had not found useful and any gaps they see in relation to delivery of education to children/young people at the detention centre who have been or may be diagnosed with FASD. Specific resource needs were overwhelmingly identified for the education of these young people. A number of times, participants and educators discussed eye testing and the provision of glasses for the young people. One educator said,

> eye and hearing testing is needed for all – with glasses provided if required.

Another educator said,

> Literacy and numeracy programs need to be developed specific to those with cognitive disabilities because the young people experience shame of not being able to read.

Other needs identified were:

> ‘access to computers and programs’; ‘sensory objects such as headphones, beanbags, weight blankets’; ‘a variety of workstations to provide young people with flexibility’; ‘air-conditioning in the workshops’; ‘reading specialists’; and ‘education assistants’.

An educator talked of sensory resources not being understood within the system in which the teaching is taking place and that resourcing:

> does not reflect the usual classroom experience that teachers would anticipate in an external environment where there was an identified student need . . . it is hard to justify resources, for example, soft furnishing or headphones to address sensory processing in the security environment . . . these are not seen as usual in our education environment.

Concern about the teacher/student ratio and insufficient staffing was raised by several educators. One educator said that,

> the current teacher to student [meaning student to teacher] ratio is 9:1 – one over that of a custodial officer who has an 8:1 ratio and this has direct implications on teachers managing the daily classroom environment.

Participants considered that entry to be a relief teacher involved too much red tape. As a result, they spoke of:

> custodial officers are taking activities groups and teachers are being moved around.

Another educator described this as:

> plugging holes, rather than maintaining consistent teaching practice with a group of young people and this has a destabilising effect.

One participant suggested that,

> reviewing the current 9:1 student/teacher ratio to be consistent with other juvenile justice services around the country would be very beneficial for the young people.

Participants identified the employment of specific professionals as integral to successful future interventions which may result from the research findings, necessary because as identified by an educator,

> we are not able to provide quality education. In other settings outside [the detention centre], supports are put in place when children have special learning needs.

One participant said,

> It would be good to employ an Educational Psychologist to develop individual learning plans which focus on the young peoples' identified strengths and weaknesses.

Another said,

> employing a speech therapist will be integral to successful future interventions which may result from the findings in the study.

Subtheme (iii): Poor communication and information access. Problems with communication and sharing information across services were discussed in all the focus groups. Participants identified the operation of service silos as a major factor impeding access to information about the young people, both internally, within the detention centre and externally, across the community and education sectors. Educators said that they are not provided with the information they need about the young people. They provided examples such as the following:

> having no knowledge of a young person's family history or their circumstances

and,

> [not knowing] whether a young person had a previous diagnosis or is on medications.

Of significant concern to the educators was their inability to access the young peoples school records:

> they [school records] do not accompany the young person from either primary or high school to [the detention centre].

Identified communication problems extended outside the detention centre. Another educator said,

> [the detention centre] and 'the outside' don't communicate well to assist young people with transition to the community to maintain continuity of education.

Similarly, a participant talking about working with the community sector said,

> they either don't communicate or communicate poorly.

Discussion

We have presented the voices of non-custodial staff who delivered support and rehabilitative services to young people who participated in a FASD prevalence study at an Australian youth detention centre. Importantly, the study findings suggest that the assessments did not appear to have a detrimental effect on the young people and have positively increased the awareness of staff about the young people's difficulties and some of the reasons for them. Although there were some negative comments regarding the broader impact of assessments on the young people, there were positive individual outcomes identified by the participants. Overall, assessments completed with the young people were deemed by the non-custodial staff to be beneficial.

The project was governed by a leadership team, cross-sector senior government representatives (health, education, child protection and justice) and other representatives over the term of the study to ensure the project was applied smoothly. For many reasons, including the necessity to prioritise security over research requirements (see 'Limitations and Strengths' section), communication across the detention centre about the project was the responsibility of the detention centre management and was largely out of the hands of the research team. Despite the study being a carefully planned and detailed process (Study protocol: Passmore et al., 2016), communication problems, relating both to the research and more broadly in the detention centre featured in participant feedback about the impact of the research for non-custodial staff. The results suggest that future research would benefit from broader consultation with all centre staff throughout the development of the research. Furthermore, regular consultation between the research team and all staff could help overcome challenges or clarify misunderstandings about the research. Moreover, in order to manage security priorities, it is important that future research consider adopting a flexible approach to the time span of the research and to consider the potential for conducting staff interviews in external settings.

Some participants felt that they had not effectively been included in the design of the research and had trouble accessing information provided for them by research staff. Participants expressed concern at having young people taken out of programmes to attend aspects of the research project including interviews and assessments. Participants also raised concern about some young people experiencing fatigue. Much time was invested in minimising harm to young people undergoing assessments in the development phase of the research. Researchers conducting the assessments were flexible. If the young people were tired or appeared to be unable to perform the required assessments, they were offered food drinks and breaks. In some cases, assessments were split into two sessions. These aspects of the results from the interviews and focus groups in this study provide valuable guidance if future studies of this nature are to be undertaken in a youth detention centre.

The perspectives of the non-custodial staff in this study also provide an important contribution to understanding the factors which have an impact on the abilities of the workforce to support and rehabilitate incarcerated young people living with FASD and other neurodevelopmental disability. Participants articulated the benefits they gained from the information provided about the young people in the reports generated in the study. It was evident, however, that recommendations in the reports caused confusion, and there was a lack of understanding of the purpose of the reports. Considering the high level of neurodevelopmental disability identified among the representative sample of 99 young people assessed, and the likelihood that more than one in two will return to detention (Department of Justice, 2017), these strategies and reports need to be made accessible to all staff to enable better management and smoother transitions back into the community for these young people. This was particularly evident in the comments about staff access to the OMS and access to strategies and reports on the young people. Notably, the Office of the Inspector for Custodial Services (OICS, 2018) also identified poor information sharing and limited access to important information, including on the OMS. This included information sharing about the young people and resulted in staff not having the information they needed to plan services and interventions conducive to rehabilitation. The research team requested the development of a specific tabulated area on the OMS so as to easily communicate assessment results and individualised management recommendations. This tabulated area on the OMS was not established during the study period. The Department of Justice initially mandated the mechanism for recording no more than three priority management options into the body of daily OMS recordings and so explains frustration described by the participants.

Effectiveness of programmes for young people in detention is dependent on both early assessments and drawing data from a variety of sources to reliably capture the broad range of issues known to exist in young offenders (Bird et al., 1992; Murphy et al., 2010; Wasserman et al., 2003). A lack of comprehensive social, educational and medical histories has implications for understanding and responding to the complex needs of young people in detention (Knowles et al., 2012) and their care on return to communities (Kumwenda et al., 2017). The results of this study with non-custodial staff suggest that there are significant problems with siloed operations and difficulty with accessing and sharing information across the services. Educators, for example, highlighted their inability to access information, including previous assessment or diagnostic information, family histories and, of significant concern, the young people's school records. Participants identified this as a major factor affecting their ability to provide effective services to the young people.

Not having the resources to undertake their jobs effectively was a major concern identified by participants. For education participants, they identified an inappropriate teacher/student ratio which directly impacts their ability to teach. The OICS (2018) report identified the school at the detention centre as being understaffed for years and described education services as 'one of the biggest casualties of [the detention centres] instability and lack of direction' (p. xi). Due to teacher shortages, OICS (2018) found that it was almost daily practice for classes to be supervised by a custodial officer, saying, 'this is not a standard that would be accepted in the community, and it should not be accepted at [the detention centre]' (p. 49). While the teacher/student ratio would be suitable in mainstream education, working with a population where 89 per cent have significant neurodevelopmental impairments makes it incredibly challenging to provide appropriate individual attention when teaching. Provision of resources for young people, such as hearing and eye testing, along with the provision of glasses, was also raised a number of times across educators and participants. Given the already significant challenges experienced by these young people, not having access to hearing testing, eye testing or glasses is likely to further impede any chance of progress, particularly in school. Training and professional development about neurodevelopmental disability and FASD (and having allocated time to attend training) was also a need identified by many participants in this research. As highlighted in the literature (Hancock, 2017; Passmore et al., 2018; Wasserman et al., 2003), ongoing training is essential for staff to better understand the needs of young offenders and to develop skills that can enable staff to design and deliver rehabilitative programmes.

Many of the young people assessed during the prevalence study did not have their disabilities previously recognised despite significant involvement with services such as child protection, youth justice, and health and education services (Bower et al., 2018). This is consistent with international scholarly literature indicating that young people enter the justice system without having a variety of health and cognitive disabilities recognised (Anderson et al., 2016; Dias et al., 2013; Leonard, 2016; Sotiri and Simpson, 2006; Wasserman et al., 2003). It demonstrates that despite high levels of neurodevelopmental disability warranting earlier assessment of these young people, they have slipped through the cracks in multiple systems of care and education over their lives. It is essential to consider assessment for previously unidentified health, mental health and neurodevelopmental problems, both on entry to detention and throughout their incarceration. This could potentially provide a key turning point to enable the rehabilitation of youth in detention.

Limitations and strengths

The feasibility study is the first to determine the prevalence rates of FASD among young people in an Australian youth detention centre. Significant work on the design of the study took place with widespread consultation occurring within the detention centre and in the broader community. Conducting research within a youth detention centre poses unexpected challenges and environmental limitations. Over the time the focus groups occurred, the detention centre was experiencing considerable instability and research processes were adapted according to operational and security requirements of the detention centre. There were frequent critical incidents which escalated between 2016 and 2017, creating an unpredictable and unstable environment. Staff assaults, roof ascents by detainees and regular violent incidents commonly occurred (OICS, 2018). The detention centre was frequently attended by the tactical response agency, the Special Operations Group, which resorted numerous times to deploying flash bombs using chemical agents and other distraction devices to restore order at the centre (OICS, 2018). As a result in parallel and preceding the commencement of the research project, human resource grievances and workload issues were chronic points of tension. The challenges faced by non-custodial staff in such a complex setting contributed to the themes which were raised by participants.

A strength of the study was that the research team were present on the campus for more than 2 years. Participants in all components were advised that there was opportunity for follow-up or clarification from the research staff about any aspect of the study, including supporting assessed or diagnosed young people. Detention centre staff and participating young people frequently took advantage of this opportunity.

Conclusion

Comprehensive assessments for FASD and neurodevelopmental disabilities were viewed by non-custodial staff participants as a necessary and worthwhile part of their service provision. Moreover, the Reports were considered to provide a comprehensive understanding of the strengths and difficulties of the young people assessed. Participants, however, identified barriers to gaining full benefit from the study. Insufficient resources, including training and professional development, and inadequate staffing were key challenges. Furthermore, inconsistent accessibility to information stored across electronic platforms designed to share assessment information and management strategies between rehabilitative services at the detention centre was identified as a potential barrier to utilising this information and providing effective rehabilitation services specific to the special needs of young people with FASD and neurodevelopmental disability. These findings are beneficial for youth detention centre staff working with young people with FASD or neurodevelopmental disability. Furthermore, they are more broadly applicable in youth justice populations. Assessments can provide valuable information for rehabilitative support about the well-known complex health, mental health and support needs of young people in detention. If rehabilitative staff are to provide young people with opportunities for change, then participants in this study provide key insights to inform variations in service delivery which will be required to meet the unique and complex needs of incarcerated young people.

Authors' note

Any material published or made publicly available by the authors cannot be considered as either endorsed by the Department of Justice or an expression of the policies or view of the Department. Any errors of omission or commission are the responsibility of the researchers.

Acknowledgements

The authors thank all at Banksia Hill Detention Centre for their engagement in, and support of, the study. They thank the Banksia Hill study team, the members of the Consumer and Community Reference Group, the Steering Group and the Reference Group, and the Chief Investigators and Associate Investigators for their ongoing contribution to, and support of, the study. The authors thank the (former) Department of Corrective Services and (former) Department for Child Protection and Family Support for their support of the study. The authors acknowledge the staff with these services who have been involved with and continue to support this important work.

Authors' contributions

S.L.H.: qualitative researcher; literature search; conducted interviews; thematic analysis and data interpretation; wrote the first and final draft. T.R.: thematic analysis; data interpretation; editing and writing. R.W.: data interpretation; editing and writing. R.C.M.: Clinical assessor; data interpretation; editing and writing. N.R.K.: Clinical assessor; data interpretation; editing and writing. J.F.: thematic analysis; data interpretation; editing and writing. H.M.P.: thematic analysis; data interpretation; editing and writing. B.S.: Clinical assessor; data interpretation; editing and writing. M.O.: editing and writing. C.B.: data interpretation; editing and writing. All authors read and had the opportunity to contribute to all drafts of the paper. All authors approved the final paper.

Availability of data and materials

For further information about the data, please contact the corresponding author.

Ethical approval

Ethics approval has been granted by the Western Australian Aboriginal Health Ethics Committee (approval number 582) and University of Western Australia Human Research Ethics Committee (approval number RA/4/1/7116). Research approvals were also gained from the (former) Department of Corrective Services (project ID 335) and the (former) Department for Child Protection and Family Support (approval number 2015/8981).

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research is funded by the National Health and Medical Research Council (grant number APP1072072) and supported by the NHMRC Reducing the Effects of Antenatal Alcohol on Child Health Centre of Research Excellence (#1110341). S.L.H. is supported by an Australian Government Research Training Program Scholarship, the Peter and Ann Hector Award and the Centre of Research Excellence: Indigenous Health and Alcohol, University of Sydney. N.R.K. is supported by an FASD Research Australia Centre for Research Excellence Scholarship and Australian Government Research Training Program Scholarship. H.M.P. is supported by an Australian Government Research Training Program Scholarship and the Stan and Jean Perron Award for Postgraduate Excellence.

ORCID iDs

Sharynne L. Hamilton https://orcid.org/0000-0002-3057-8992
Jacinta Freeman https://orcid.org/0000-0001-8784-7295

References

Altschuler DM and Armstrong TL (1994) *Intensive Aftercare for High-Risk Juveniles: Policies and Procedures*. Washington, DC: Office of Juvenile Justice and Delinquency Prevention. Available at: https://www.ncjrs.gov/pdffiles/juvcc.pdf

Anderson SAS, Hawes DJ and Snow PC (2016) Language impairments among youth offenders: A systematic review. *Children and Youth Services Review* 65: 195–203.

Atkins T, Bullis M and Todis B (2005) Converging and diverging service delivery systems in alternative education programs for disabled and non-disabled youth involved in the juvenile justice system. *The Journal of Correctional Education* 56(3): 253–285.

Attride-Stirling J (2001) Thematic networks: An analytic tool for qualitative research. *Qualitative Research* 1(3): 385–405.

Australian Government (2017) Royal commission into the protection and detention of children in the northern territory ('The Don Dale Royal Commission'). Final Report. Canberra: Australian Government. Available at: https://www.royalcommission.gov.au/royal-commission-detention-and-protection-children-northern-territory

Australian Institute of Health and Welfare (2018) *Youth detention population in Australia 2018* (AIHW Bulletin no. 145. Cat. no. Juv 128). Canberra, ACT, Australia: Australian Institute of Health and Welfare.

Baines M and Alder C (1996) Are girls more difficult to work with? Youth workers' perspectives in juvenile justice and related areas. *Crime & Delinquency* 42(3): 467–485.

Baldry E, Dowse L and Clarence M (2012) *People with Intellectual and Other Cognitive Disability in the Criminal Justice System*. Sydney, NSW, Australia: University of New South Wales. Available at: https://www.facs.nsw.gov.au/download?file=591368

Baldry E, McCausland R, Dowse L and McEntyre E (2015) *A Predictable and Preventable Path: Aboriginal People with Mental and Cognitive Disabilities in the Criminal Justice System*. Sydney, NSW, Australia: The University of New South Wales. Available at: http://unsworks.unsw.edu.au/fapi/datastream/unsworks:37093/binb10f2bda-8816-4112-aeeb-6cd6d8efe6f7?view=true

Bird H, Gould M and Staghezza B (1992) Aggregating data from multiple informants in child psychiatry epidemiological research. *Journal of American Academy Child & Adolescent Psychiatry* 31(1): 78–85.

Blagg H (2008) *Crime, Aboriginality and the Decolonisation of Justice*. Sydney, NSW, Australia: Federation Press.

Bower C, Watkins R, Mutch R, Marriott R, Freeman J, Kippin N, Safe B, Pestell C, Cheung C, Shield H, Tarratt L, Springall A, Taylor J, Walker N, Argiro E, Leitao S, Hamilton S, Condon C, Passmore H and Giglia R (2018) Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia. *BMJ Open* 8: e019605.

Conley DJ (1994) Adding color to a black and white picture: Using qualitative data to explain racial disproportionality in the juvenile justice system. *Journal of Research in Crime and Delinquency* 31(2): 135–148.

Department of Justice (2017) *Department of Corrective Services: Final Report 2016–2017*. Perth, WA, Australia: Australia Government. Available at: http://www.correctiveservices.wa.gov.au/_files/about-us/statistics-publications/annual-reports/dcs-final-report-2016-2017.pdf

Dias S, Ware RS, Kinner SA and Lennox NG (2013) Co-occurring mental disorder and intellectual disability in a large sample of Australian prisoners. *Australian & New Zealand Journal of Psychiatry* 47(10): 938–944.

Feinstein R, Greenblatt A, Hass L, Kohn S and Rana J (2000) *Justice for A*ll? A Report on Lesbian, Gay, Bisexual and Transgendered Youth in the New York Juvenile Justice System. Available at: https://files.eric.ed.gov/fulltext/ED471676.pdf

Field S (2007) Practice cultures and the 'new' youth justice in (England and) Wales. *British Journal of Criminology* 47(2): 311–330.

Flannigan K, Pei J, Stewart M and Johnson A (2018) Fetal alcohol spectrum disorder and the criminal justice system: A systematic literature review. *International Journal of Law and Psychiatry* 57: 42–52.

Frize M, Kenny D and Lennings C (2008) The relationship between intellectual disability, Indigenous status and risk of reoffending in juvenile offenders on community orders. *Journal of Intellectual Disability Research* 52(6): 510–519.

Garland A, Hough R, McCabe K, Yeh M, Wood P and Aarons G (2001) Prevalence of psychiatric disorders in youths across five sectors of care. *Journal American Academy of Child Adolescent Psychiatry* 40: 409–418.

Goldson B (2005) Child imprisonment: A case for abolition. *Youth Justice* 5(2): 77–90.

Hancock K (2017) Facility operations and juvenile recidivism. *Journal of Juvenile Justice* 6(1): 1–14.

Harmes M, Hopkins S and Farley H (2019) Beyond incarcerated identities: Identity, bias and barriers to higher education in Australian prisons. *International Journal of Bias, Identity and Diversities in Education* 4(1): 211–234.

Holley L and VanVleet R (2008) Racism and classism in the youth justice system: Perspectives of youth and staff. *Journal of Poverty* 10(1): 45–67.

House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs (2011) Doing Time, Time for Doing: Indigenous youth in the criminal justice system. Canberra ACT: Commonwealth of Australia. Available at: https://www.aph.gov.au/binaries/house/committee/atsia/sentencing/report/fullreport.pdf

Indig D, Vecchiato C, Haysom L, Beilby R, Carter J, Champion U, Gaskin C, Heller E, Kumar S, Mamone N, Muir P, Van den Dolder P and Whitton G (2011) *2009 NSW Young People in Custody Health Survey: Full Report*. Sydney, NSW, Australia: Justice Health and Juvenile Justice. Available at: https://www.justicehealth.nsw.gov.au/publications/ypichs-full.pdf

Kippin N, Leitão S, Watkins R, Finlay-Jones A, Condon C, Marriott R, Mutch R and Bower C (2018) Language diversity, language disorder, and fetal alcohol spectrum disorder among youth sentenced to detention in Western Australia. *International Journal of Law and Psychiatry* 61: 40–49.

Knowles S, Townsend E and Anderson M (2012) Youth Justice staff attitudes toward screening for self-harm. *Health, Society Care Community* 20(5): 506–515.

Kumwenda M, Nzala S and Zulu J (2017) Health care needs assessment among adolescents in correctional institutions in Zambia: An ethical analysis. *BMC Health Services Research* 17: 581.

Lanskey C (2011) Promise or compromise? Education for young people in secure institutions in England. *Youth Justice* 11(1): 47–60.

Leonard J (2016) Aboriginal justice: The challenges of FASD & implications for the legal system. *Bulletin (Law Society of South Australia)* 38: 38–39. Available at: https://search.informit.com.au/fullText;dn=213513661873311;res=IELHSS

Murphy P, McGinness A and McDermott T (2010) *Review of Effective Practice in Juvenile Justice: Report for the Minister for Juvenile Justice*. Canberra, ACT, Australia: Noetic Solutions. Available at: http://www.juvenile.justice.nsw.gov.au/Documents/Juvenile%20Justice%20Effective%20Practice%20Review%20FINAL.pdf

NVivo 11 Pro (2016) *NVivo Pro Qualitative Data Analysis Software Version 11* [computer program]. Melbourne, VIC, Australia: QSR International Pty Ltd.

Office of the Inspector of Custodial Services (OICS) (2015) *Report of an Announced Inspection of Banksia Hill Juvenile Detention Centre*. Perth, WA, Australia: Office of the Inspector of Custodial Services. Available at: http://www.oics.wa.gov.au/wp-content/uploads/2015/06/OIC-Banksia-Report-97.pdf

Office of the Inspector of Custodial Services (OICS) (2018) *Report of an Announced Inspection of Banksia Hill Juvenile Detention Centre*. Perth, WA, Australia: Office of the Inspector of Custodial Services. Available at: http://www.oics.wa.gov.au/wp-content/uploads/2018/04/Banksia-Hill-Report-116-FINAL.pdf

Passmore HM, Giglia R, Watkins R, Mutch R, Marriott R, Pestell C, Zubrick S, Rainsford C, Walker N, Fitzpatrick J, Freeman J, Kippin N, Safe B and Bower C (2016) Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open* 6(6): e012184.

Passmore HM, Mutch RC, Burns S, Watkins R, Carapetis J, Hall G and Bower C (2018) Fetal alcohol spectrum disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce. *International Journal of Law & Psychiatry* 59: 44–52.

Potter RH (2014) Service utilization in a cohort of criminal justice-involved men: Implications for case management and justice systems. *Criminal Case Studies* 27(1): 82–95.

Reed C, Sheehan M, Chapman R, Divola S and Keen J (2015) The challenge of normative influences for program design for youth in detention. *Journal of Offender Rehabilitation* 54(5): 350–370.

Shepherd S and Phillips G (2016) Cultural 'inclusion' or institutional decolonisation: How should prisons address the mental health needs of indigenous prisoners? *Australian and New Zealand Journal of Psychiatry* 50(4): 307–308.

Snow P, Bagley K and White D (2017) Speech-language pathology intervention in a youth justice setting: Benefits perceived by staff extend beyond communication. *International Journal of Speech-Language Pathology* 20(4): 458–467.

Sotiri M and Simpson J (2006) Indigenous people and cognitive disability: An introduction to issues in police stations. *Current Issues in Criminal Justice* 17: 431–443.

Strnadova I, O'Neill S and Cumming T (2017) A snapshot of education behind the fence: Supporting engagement in education of incarcerated youth in Australia. *International Journal of Education Research* 85: 33–42.

Teplin L, Abram K, McClelland G, Dulcan M and Mericle A (2002) Psychiatric disorders in youth in juvenile detention. *Archives of General Psychiatry* 59: 1133–1143.

Tobin T and Sprague J (2000) Alternative education strategies: Reducing violence in school and the community. *Journal of Emotional and Behavioral Disorders* 8(3): 177–186.

United Nations (1985) United Nations Standard Minimum Rules for the Administration of Juvenile Justice ('The Beijing rules'). General Assembly Resolution 40/33 of 29 November 1985, UN GAOR, 40th sess, 96th plen mtg, UN Doc A/RES/40/33. Available at: http://www.ohchr.org/Documents/ProfessionalInterest/beijingrules.pdf

Wacquant L (2009) *Punishing the Poor: The Neoliberal Government of Social Insecurity*. Durham, CA: Duke University Press.

Wasserman G, Jensen P, Ko S, Cocozza J, Trupin E, Angold A, Cauffman E and Grisso T (2003) Mental health assessments in juvenile justice: Report on the consensus conference. *Journal of American Academy Child Adolescent Psychiatry* 42(7): 751–761.

Wasserman G, McReynolds L, Lucas S, Fisher C and Santos P (2002) The voice DISC-IV with incarcerated male youths: Prevalence of disorder. *Journal of American Academy Child Adolescent Psychiatry* 41(3): 314–321.

Weatherburn D and Ramsey S (2016) *What's causing the growth in indigenous imprisonment in NSW?* Issue Paper no. 118. Sydney, NSW, Australia: NSW Bureau of Crime Statistics and Research. Available at: https://www.bocsar.nsw.gov.au/Documents/BB/Report-2016-What%27s-causing-the-growth-in-Indigenous-Imprisonment-in-NSW-BB118.pdf

Yin RK (2013) *Case Study Research: Design and Methods*, 5th Edition. Thousand Oaks, CA: Sage.

Young D, Moline K, Farrell J and Biere D (2006) Best implementation practices: Disseminating new assessment technologies in a juvenile justice agency. *Crime & Delinquency* 52(1): 135–158.

Author biographies

Sharynne L. Hamilton is a Ngunnawal woman, with a background in social work and child protection research and is a PhD Candidate with the Telethon Kids Institute and the University of Western Australia.

Tracy Reibel, BA (Hons), PhD, has thirty years' experience conducting health and social equity research from positions in community organisations, research institutes and universities. She has expertise in qualitative methods, evaluation, and health professional educational development.

Rochelle Watkins is an Epidemiologist and a Senior Research Fellow, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute.

Raewyn C. Mutch, MBCHB, DipRACOG, FRACP, PhD, is a Clinical Associate Professor and a paediatrician caring for children and adolescents with a special interest in refugee and asylum seeker health. Raewyn has a track record of clinical and research work among culturally and linguistically diverse families, neurodevelopment and justice disciplines.

Natalie R. Kippin was the lead Speech Pathologist on the Prevalence Study. She has also worked in health promotion and as a Youth Custodial Officer in Western Australia's YJ system.

Jacinta Freeman has a Masters in Public Health and a background in Nursing and Midwifery. Her most recent research work includes establishing the prevalence of FASD in youth detention and youth suicide prevention in Western Australia.

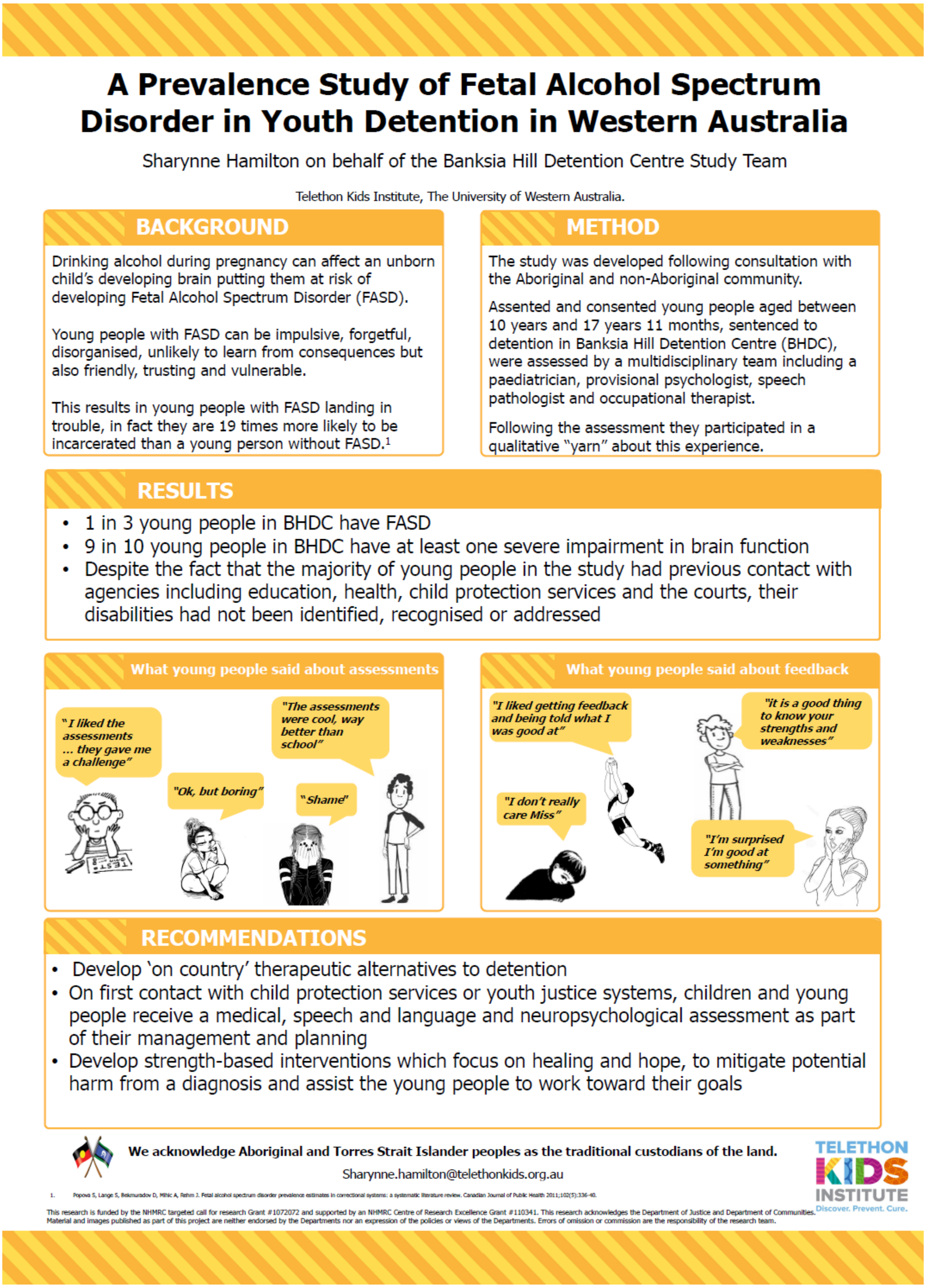
Hayley M. Passmore has qualifications in Criminology and Psychology, and is a final year PhD candidate at The University of Western Australia and Telethon Kids Institute.

Bernadette Safe has a Masters in Child Health Research. Bernadette is an Occupational Therapist and was the Clinician responsible for assessing participants motor skills for the prevalence study.

Melissa O'Donnell is a Senior Research Fellow at Telethon Kids Institute, University of Western Australia. Her focus is in conducting policy relevant research to improve the outcomes for children through prevention and early intervention of child abuse and neglect.

Carol Bower has qualifications in medicine, epidemiology and public health. Her research focuses on birth defects - understanding their causes, prevention and amelioration.

Appendix 5: Presentation Poster



A Prevalence Study of Fetal Alcohol Spectrum Disorder in Youth Detention in Western Australia

Sharynne Hamilton on behalf of the Banksia Hill Detention Centre Study Team

Telethon Kids Institute, The University of Western Australia.

BACKGROUND

Drinking alcohol during pregnancy can affect an unborn child's developing brain putting them at risk of developing Fetal Alcohol Spectrum Disorder (FASD).

Young people with FASD can be impulsive, forgetful, disorganised, unlikely to learn from consequences but also friendly, trusting and vulnerable.

This results in young people with FASD landing in trouble, in fact they are 19 times more likely to be incarcerated than a young person without FASD.[1]

METHOD

The study was developed following consultation with the Aboriginal and non-Aboriginal community.

Assented and consented young people aged between 10 years and 17 years 11 months, sentenced to detention in Banksia Hill Detention Centre (BHDC), were assessed by a multidisciplinary team including a paediatrician, provisional psychologist, speech pathologist and occupational therapist.

Following the assessment they participated in a qualitative "yarn" about this experience.

RESULTS

- 1 in 3 young people in BHDC have FASD
- 9 in 10 young people in BHDC have at least one severe impairment in brain function
- Despite the fact that the majority of young people in the study had previous contact with agencies including education, health, child protection services and the courts, their disabilities had not been identified, recognised or addressed

What young people said about assessments

"I liked the assessments … they gave me a challenge"

"Ok, but boring"

"The assessments were cool, way better than school"

"Shame"

What young people said about feedback

"I liked getting feedback and being told what I was good at"

"it is a good thing to know your strengths and weaknesses"

"I don't really care Miss"

"I'm surprised I'm good at something"

RECOMMENDATIONS

- Develop 'on country' therapeutic alternatives to detention
- On first contact with child protection services or youth justice systems, children and young people receive a medical, speech and language and neuropsychological assessment as part of their management and planning
- Develop strength-based interventions which focus on healing and hope, to mitigate potential harm from a diagnosis and assist the young people to work toward their goals

We acknowledge Aboriginal and Torres Strait Islander peoples as the traditional custodians of the land.

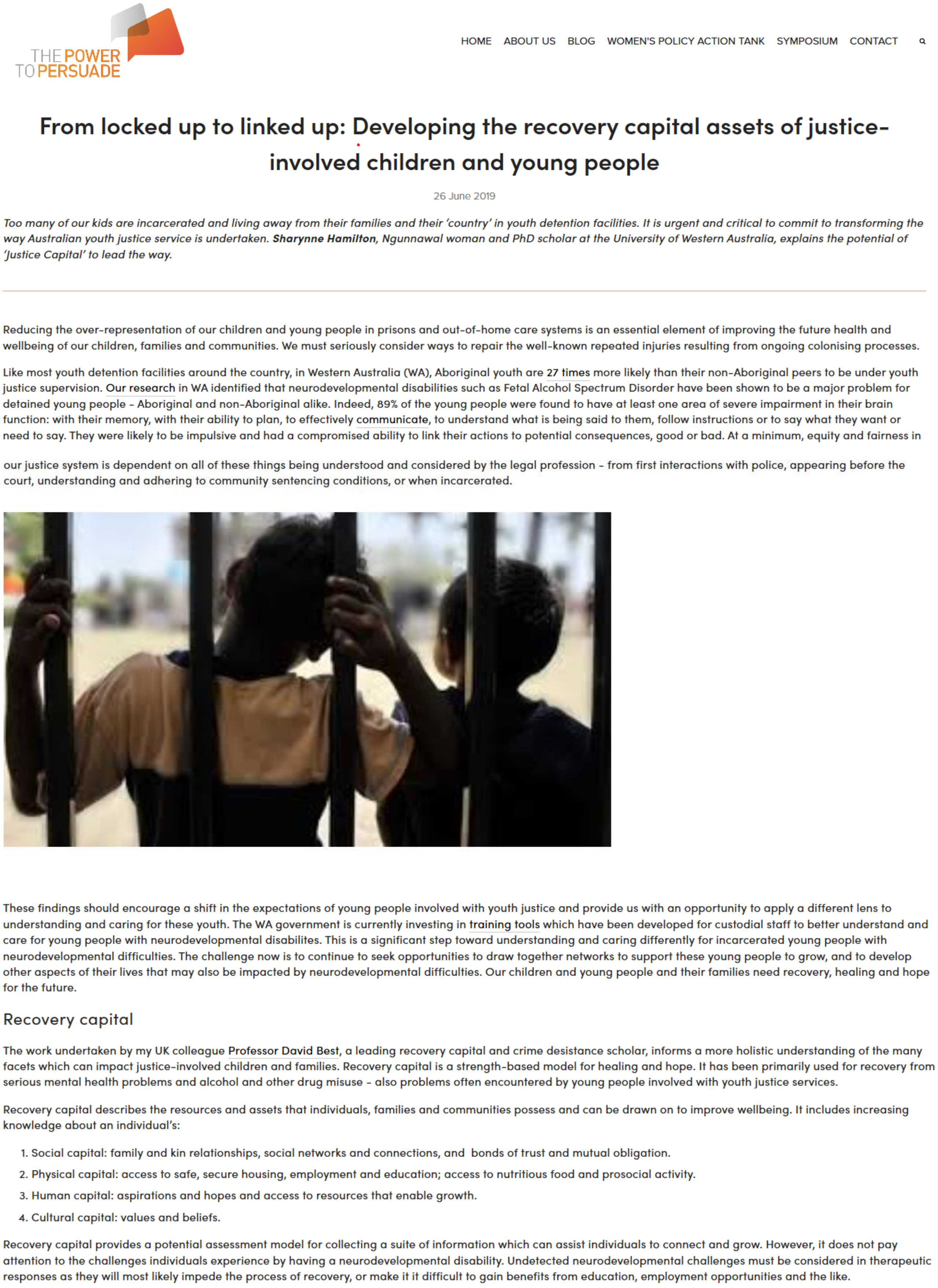
Sharynne.hamilton@telethonkids.org.au

1. Popova S, Lange S, Bekmuradov D, Mihic A, Rehm J. Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review. Canadian Journal of Public Health 2011;102(5):336-40.

This research is funded by the NHMRC targeted call for research Grant #1072072 and supported by an NHMRC Centre of Research Excellence Grant #110341. This research acknowledges the Department of Justice and Department of Communities.

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

Appendix 6: Power to Persuade: From Locked Up to Linked Up



From locked up to linked up: Developing the recovery capital assets of justice-involved children and young people

26 June 2019

Too many of our kids are incarcerated and living away from their families and their 'country' in youth detention facilities. It is urgent and critical to commit to transforming the way Australian youth justice service is undertaken. ***Sharynne Hamilton****, Ngunnawal woman and PhD scholar at the University of Western Australia, explains the potential of 'Justice Capital' to lead the way.*

Reducing the over-representation of our children and young people in prisons and out-of-home care systems is an essential element of improving the future health and wellbeing of our children, families and communities. We must seriously consider ways to repair the well-known repeated injuries resulting from ongoing colonising processes.

Like most youth detention facilities around the country, in Western Australia (WA), Aboriginal youth are 27 times more likely than their non-Aboriginal peers to be under youth justice supervision. Our research in WA identified that neurodevelopmental disabilities such as Fetal Alcohol Spectrum Disorder have been shown to be a major problem for detained young people – Aboriginal and non-Aboriginal alike. Indeed, 89% of the young people were found to have at least one area of severe impairment in their brain function: with their memory, with their ability to plan, to effectively communicate, to understand what is being said to them, follow instructions or to say what they want or need to say. They were likely to be impulsive and had a compromised ability to link their actions to potential consequences, good or bad. At a minimum, equity and fairness in our justice system is dependent on all of these things being understood and considered by the legal profession – from first interactions with police, appearing before the court, understanding and adhering to community sentencing conditions, or when incarcerated.

These findings should encourage a shift in the expectations of young people involved with youth justice and provide us with an opportunity to apply a different lens to understanding and caring for these youth. The WA government is currently investing in training tools which have been developed for custodial staff to better understand and care for young people with neurodevelopmental disabilites. This is a significant step toward understanding and caring differently for incarcerated young people with neurodevelopmental difficulties. The challenge now is to continue to seek opportunities to draw together networks to support these young people to grow, and to develop other aspects of their lives that may also be impacted by neurodevelopmental difficulties. Our children and young people and their families need recovery, healing and hope for the future.

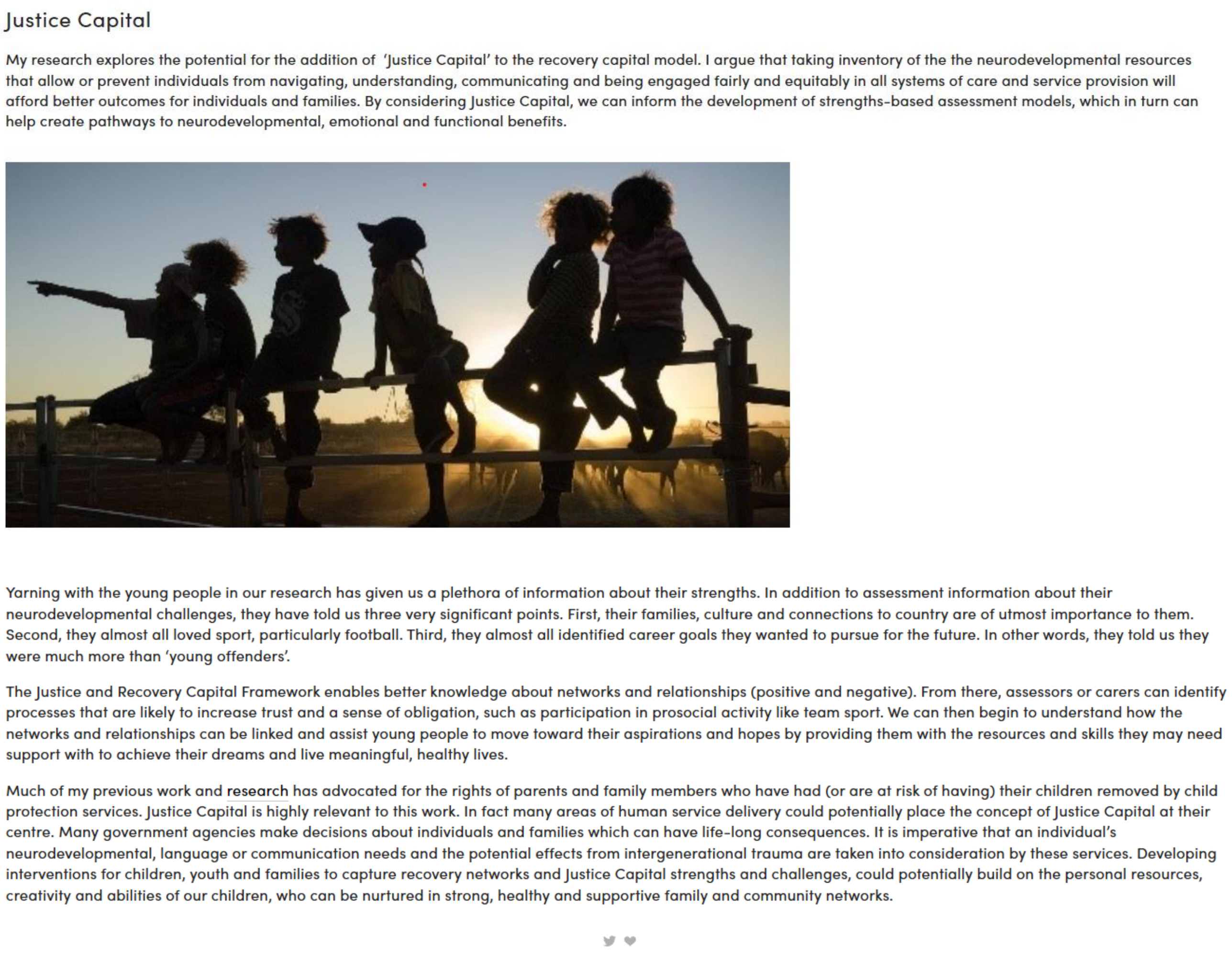
Recovery capital

The work undertaken by my UK colleague Professor David Best, a leading recovery capital and crime desistance scholar, informs a more holistic understanding of the many facets which can impact justice-involved children and families. Recovery capital is a strength-based model for healing and hope. It has been primarily used for recovery from serious mental health problems and alcohol and other drug misuse – also problems often encountered by young people involved with youth justice services.

Recovery capital describes the resources and assets that individuals, families and communities possess and can be drawn on to improve wellbeing. It includes increasing knowledge about an individual's:

1. Social capital: family and kin relationships, social networks and connections, and bonds of trust and mutual obligation.
2. Physical capital: access to safe, secure housing, employment and education; access to nutritious food and prosocial activity.
3. Human capital: aspirations and hopes and access to resources that enable growth.
4. Cultural capital: values and beliefs.

Recovery capital provides a potential assessment model for collecting a suite of information which can assist individuals to connect and grow. However, it does not pay attention to the challenges individuals experience by having a neurodevelopmental disability. Undetected neurodevelopmental challenges must be considered in therapeutic responses as they will most likely impede the process of recovery, or make it it difficult to gain benefits from education, employment opportunities and the like.



Justice Capital

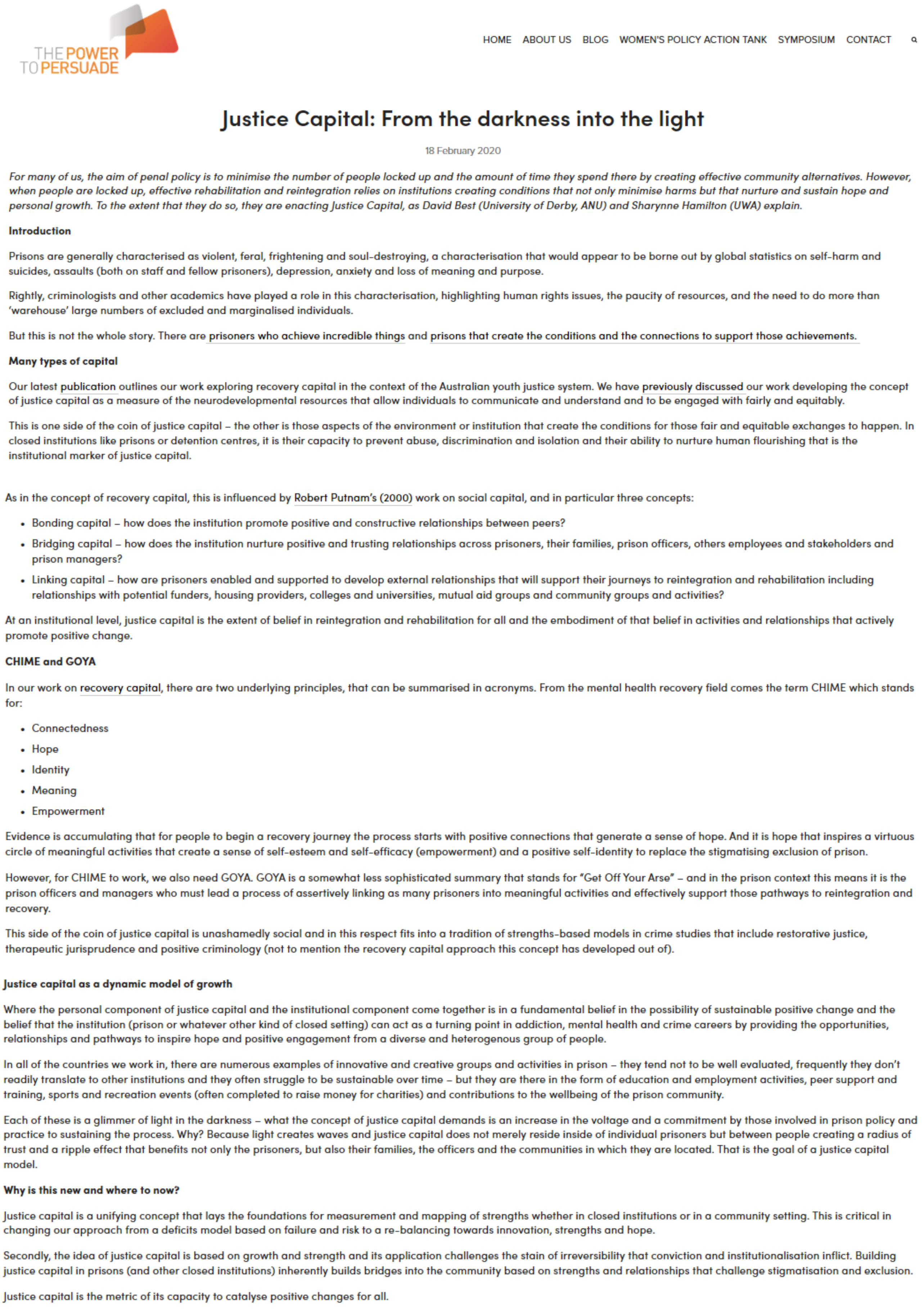
My research explores the potential for the addition of 'Justice Capital' to the recovery capital model. I argue that taking inventory of the the neurodevelopmental resources that allow or prevent individuals from navigating, understanding, communicating and being engaged fairly and equitably in all systems of care and service provision will afford better outcomes for individuals and families. By considering Justice Capital, we can inform the development of strengths-based assessment models, which in turn can help create pathways to neurodevelopmental, emotional and functional benefits.

Yarning with the young people in our research has given us a plethora of information about their strengths. In addition to assessment information about their neurodevelopmental challenges, they have told us three very significant points. First, their families, culture and connections to country are of utmost importance to them. Second, they almost all loved sport, particularly football. Third, they almost all identified career goals they wanted to pursue for the future. In other words, they told us they were much more than 'young offenders'.

The Justice and Recovery Capital Framework enables better knowledge about networks and relationships (positive and negative). From there, assessors or carers can identify processes that are likely to increase trust and a sense of obligation, such as participation in prosocial activity like team sport. We can then begin to understand how the networks and relationships can be linked and assist young people to move toward their aspirations and hopes by providing them with the resources and skills they may need support with to achieve their dreams and live meaningful, healthy lives.

Much of my previous work and research has advocated for the rights of parents and family members who have had (or are at risk of having) their children removed by child protection services. Justice Capital is highly relevant to this work. In fact many areas of human service delivery could potentially place the concept of Justice Capital at their centre. Many government agencies make decisions about individuals and families which can have life-long consequences. It is imperative that an individual's neurodevelopmental, language or communication needs and the potential effects from intergenerational trauma are taken into consideration by these services. Developing interventions for children, youth and families to capture recovery networks and Justice Capital strengths and challenges, could potentially build on the personal resources, creativity and abilities of our children, who can be nurtured in strong, healthy and supportive family and community networks.

Appendix 7: Power to Persuade: Justice Capital: From the Darkness into the Light



Justice Capital: From the darkness into the light

18 February 2020

For many of us, the aim of penal policy is to minimise the number of people locked up and the amount of time they spend there by creating effective community alternatives. However, when people are locked up, effective rehabilitation and reintegration relies on institutions creating conditions that not only minimise harms but that nurture and sustain hope and personal growth. To the extent that they do so, they are enacting Justice Capital, as David Best (University of Derby, ANU) and Sharynne Hamilton (UWA) explain.

Introduction

Prisons are generally characterised as violent, feral, frightening and soul-destroying, a characterisation that would appear to be borne out by global statistics on self-harm and suicides, assaults (both on staff and fellow prisoners), depression, anxiety and loss of meaning and purpose.

Rightly, criminologists and other academics have played a role in this characterisation, highlighting human rights issues, the paucity of resources, and the need to do more than 'warehouse' large numbers of excluded and marginalised individuals.

But this is not the whole story. There are prisoners who achieve incredible things and prisons that create the conditions and the connections to support those achievements.

Many types of capital

Our latest publication outlines our work exploring recovery capital in the context of the Australian youth justice system. We have previously discussed our work developing the concept of justice capital as a measure of the neurodevelopmental resources that allow individuals to communicate and understand and to be engaged with fairly and equitably.

This is one side of the coin of justice capital – the other is those aspects of the environment or institution that create the conditions for those fair and equitable exchanges to happen. In closed institutions like prisons or detention centres, it is their capacity to prevent abuse, discrimination and isolation and their ability to nurture human flourishing that is the institutional marker of justice capital.

As in the concept of recovery capital, this is influenced by Robert Putnam's (2000) work on social capital, and in particular three concepts:

- Bonding capital – how does the institution promote positive and constructive relationships between peers?
- Bridging capital – how does the institution nurture positive and trusting relationships across prisoners, their families, prison officers, others employees and stakeholders and prison managers?
- Linking capital – how are prisoners enabled and supported to develop external relationships that will support their journeys to reintegration and rehabilitation including relationships with potential funders, housing providers, colleges and universities, mutual aid groups and community groups and activities?

At an institutional level, justice capital is the extent of belief in reintegration and rehabilitation for all and the embodiment of that belief in activities and relationships that actively promote positive change.

CHIME and GOYA

In our work on recovery capital, there are two underlying principles, that can be summarised in acronyms. From the mental health recovery field comes the term CHIME which stands for:

- Connectedness
- Hope
- Identity
- Meaning
- Empowerment

Evidence is accumulating that for people to begin a recovery journey the process starts with positive connections that generate a sense of hope. And it is hope that inspires a virtuous circle of meaningful activities that create a sense of self-esteem and self-efficacy (empowerment) and a positive self-identity to replace the stigmatising exclusion of prison.

However, for CHIME to work, we also need GOYA. GOYA is a somewhat less sophisticated summary that stands for "Get Off Your Arse" – and in the prison context this means it is the prison officers and managers who must lead a process of assertively linking as many prisoners into meaningful activities and effectively support those pathways to reintegration and recovery.

This side of the coin of justice capital is unashamedly social and in this respect fits into a tradition of strengths-based models in crime studies that include restorative justice, therapeutic jurisprudence and positive criminology (not to mention the recovery capital approach this concept has developed out of).

Justice capital as a dynamic model of growth

Where the personal component of justice capital and the institutional component come together is in a fundamental belief in the possibility of sustainable positive change and the belief that the institution (prison or whatever other kind of closed setting) can act as a turning point in addiction, mental health and crime careers by providing the opportunities, relationships and pathways to inspire hope and positive engagement from a diverse and heterogenous group of people.

In all of the countries we work in, there are numerous examples of innovative and creative groups and activities in prison – they tend not to be well evaluated, frequently they don't readily translate to other institutions and they often struggle to be sustainable over time – but they are there in the form of education and employment activities, peer support and training, sports and recreation events (often completed to raise money for charities) and contributions to the wellbeing of the prison community.

Each of these is a glimmer of light in the darkness – what the concept of justice capital demands is an increase in the voltage and a commitment by those involved in prison policy and practice to sustaining the process. Why? Because light creates waves and justice capital does not merely reside inside of individual prisoners but between people creating a radius of trust and a ripple effect that benefits not only the prisoners, but also their families, the officers and the communities in which they are located. That is the goal of a justice capital model.

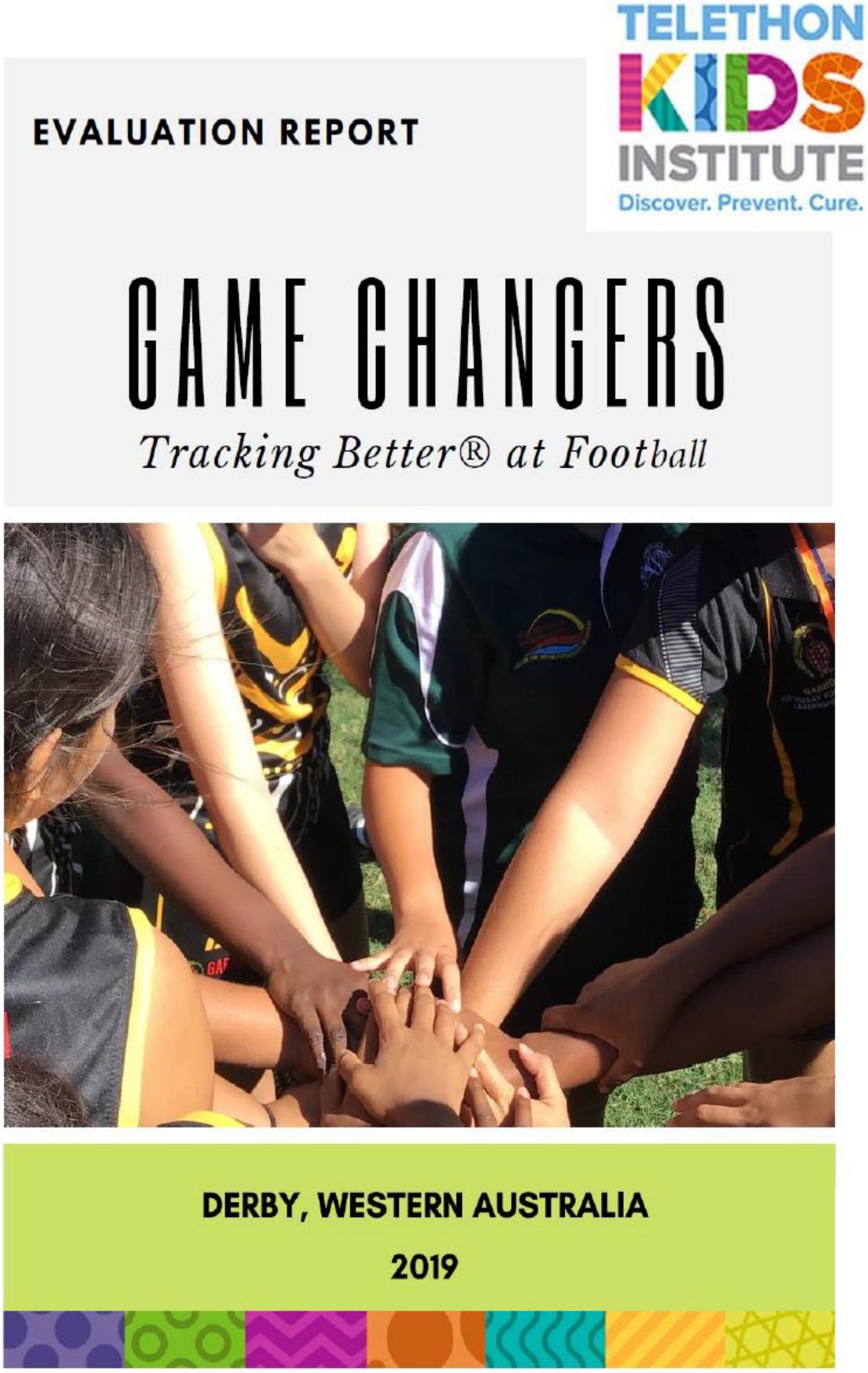
Why is this new and where to now?

Justice capital is a unifying concept that lays the foundations for measurement and mapping of strengths whether in closed institutions or in a community setting. This is critical in changing our approach from a deficits model based on failure and risk to a re-balancing towards innovation, strengths and hope.

Secondly, the idea of justice capital is based on growth and strength and its application challenges the stain of irreversibility that conviction and institutionalisation inflict. Building justice capital in prisons (and other closed institutions) inherently builds bridges into the community based on strengths and relationships that challenge stigmatisation and exclusion.

Justice capital is the metric of its capacity to catalyse positive changes for all.

Appendix 8: Game Changers Evaluation, Derby



EVALUATION REPORT

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

GAME CHANGERS

Tracking Better® at Football

DERBY, WESTERN AUSTRALIA

2019

OUR PARTNERS

Department of
Local Government, Sport and Cultural Industries
GOVERNMENT OF
WESTERN AUSTRALIA

TRACKING BETTER® AT FOOTBALL

GARNDUWA

KIMBERLEY ABORIGINAL MEDICAL SERVICES LTD

DERBY TIGERS

COURAGE DILIGENCE STRENGTH
DERBY
D.H.S.

Derby Aboriginal Health Service Council Aboriginal Corporation

Shire of Derby /
West Kimberley

WINUN
NGARI
ABORIGINAL CORPORATION

ALCOHOL ASSOCIATION
GARL GARL
WALBU
ABORIGINAL CORPORATION

Government of **Western Australia**
WA Country Health Service

WA
POLICE

Table of Contents

Executive Summary

In response to high levels of trauma, problems with mental health and violence and a threat of disengagement from school with girls living in and around Derby in the Kimberley region of Western Australia, the professional community sought an opportunity to run a pilot project and provide the girls with a 'Game Changers' football camp. Many young people living in the Kimberley communities experience multiple and complex layers of disadvantage and trauma, resulting in high levels of mental health problems, poor prospects for the future, and in some cases, suicide. Developing skills which assist youth to recognise and manage their thoughts and feelings and develop strategies for self-regulation and impulse control is imperative. Using sport as a vehicle to assisted youth to develop these skills is one way to achieve this. In 2018, the 'Game Changers' project was piloted as a week's camp in Derby, Western Australia using the Tracking Better® at Football program which teaches participants the core principles of self-regulation in order to improve their sporting performance, and more broadly their everyday coping skills.

The purpose of the evaluation was to first understand participant experiences of the one day Tracking Better® training for professionals and mentors, and to identify the suitability of the four day Game Changers football camp delivery and content and whether the anticipated objectives were achieved. The evaluation, second, sought to assess the impact of participation on participants; the girls, coaching staff and community partners involved in the delivery of the program. Specifically, the evaluation sought to understand:

- the barriers and enablers to delivering the Game Changers program
- engagement with the content of Tracking Better® at Football materials
- the benefits and broader outcomes from participating in the program for all participants

The evaluation also sought to provide useful insights for the future design and delivery of the Game Changers program and other services directed at young girls in Derby and the potential for its application more broadly in the Kimberley communities.

This report begins with an overview of the background to the project and a description of the Game Changers program and the use of the Tracking Better® at Football tools which aimed to:

- develop and enhance positive coping skills, reduce the use of negative coping strategies by the girls
- increase stress management skills
- increase resilience within a structured 4-day Game Changers football camp.

It then presents the results of qualitative data collected from participants. Interviews were conducted to explore their experiences of the Game Changers project.

The evaluation found that developing initiatives such as the Game Changers project were vital to address the complex and difficult lives of the young people. Addressing interpersonal and community violence, disengagement from school, problems with the use of social media which resulted from boredom was viewed as essential to address the social and emotional wellbeing needs of youth in the region. Results from the evaluation suggest that, overall the pilot was a very worthwhile initiative, however there were several areas which could improve future delivery of the program.

Participants who attended the Monday training session offered feedback on using the Tracking Better® tools and manual. They identified that there was a large amount of information, both delivered in the one-day training, and in the written material, and one day was not sufficient to truly understand and benefit from the program. Participants also suggested that resources be more culturally relevant for the Kimberley. For the young girls, the four day Tracking Better® at Football camp was positive, however behaviour management was at times problematic, and so setting ground rules at the beginning of the program is important for future delivery of the program. For professionals and mentors in the Tracking Better® at Football camp, better definition of their roles and including broader family and community members would greatly benefit, both the project and community development.

The evaluation found, however that the benefits for the girls far outweighed the challenges. Despite the complexity of their lives the girls gained valuable skills and self-confidence. They were engaged and attended for the week, their relationships improved, and they gained skills in self-management and self-control which were apparent not only during the camp, but in the weeks following at school. Significant to the success of the program were the programs mentors. Overall, the Game Changers pilot project provided hope for future improvement in the self-regulatory skills of youth and was a welcome future initiative for addressing the many problems which confront youth living in communities in the Kimberley.

Acknowledgements

The Telethon Kids Institute in Perth, Western Australia wish to thank the following people and organisations for their support of the project and their engagement with the project evaluation:

Funder: Department of Local Government, Sport and Cultural Industries, Broome *Youth Engagement Scheme "Yes" Grant*	**Kristina Dickman**
Tracking Better® at Football	**Dr Deeta Kimber**
Kimberley Mental Health and Drug Service	**Jo Allan** **Santana Rose** **Gaye Yu** **Leon Khan**
Garnduwa Amboorny Wirnan	**Fiona Smith**
Derby District High School	**Heath Johnstone** **Sam Little**
Garl Garl Walbu Alcohol Association	**Janine Wallis** **Karcela Aitkin** **Marika Ross**
Youth Crime Prevention Services; Derby Police	**Jodie Parker** **Paul Webb**
Derby Aboriginal Health Service	**Bec Ingram**
Shire of Derby West Kimberley	**Ayla-May Delvin**
Telethon Kids Kimberley	**John Jacky** **Janine McNamara**

We acknowledge the program emerged from the commitment and determination to provide an opportunity to support the youth, particularly the girls and young women in Derby, and more broadly in the Kimberley regions and communities, to positively experience the acquisition of skills for self-care, self-regulation, and self-determination through football.

We thank all the participants for their time and contribution to yarning circles, yarning interviews, for their deep reflections on the things that have contributed to the difficulties the young people in the Kimberley regions experience and acknowledge their commitment to developing flourishing communities. Although we were unable to interview the girls who participated in the Game Changers project, we acknowledge their commitment to participating in and completing the program despite their challenges, and hope the project provided them with an opportunity to learn more about themselves in a fun way.

Sharynne Hamilton, Amy Finlay Jones & Clair Scrine

Sharynne Hamilton acknowledges the valuable support of the **Peter and Anne Hector Award** which made undertaking this evaluation possible.

Suggested Citation:

Hamilton, S., Finlay-Jones, A. & Scrine, C. (2019). ***Game Changers, Tracking better® at Football Evaluation Report, Derby, Western Australia*** **. Telethon Kids Institute: Perth.**

1. Project Background

It is well documented that young people living in the Kimberley communities in Northern Western Australia are exposed to multiple layers of cumulative trauma and are at increased risk of destructive behaviours such as substance misuse, crime, self-harm and suicide which (Ralph, Hamaguchi & Cox, 2006). Young people who have been exposed to multiple and chronic stressors often experience complex trauma, which can lead to long term behavioural and mental health difficulties, as well as social exclusion, disengagement from education and employment, and are at increased risk of contact with the justice and child protection system (Malvaso, Delfabbro, and Day 2017). A common theme underpinning these issues are the self-regulatory difficulties that young people with complex needs frequently experience, which undermine their capacity to express and manage emotions, engage in goal-directed behaviours, and respond adaptively to stress. Clinical and research consensus suggests that promoting self-regulation, increasing engagement with peers and significant others, and enhancing positive affect are foundational to effectively working with youth complex trauma and related needs to increase self-regulatory capacities and promote resilience (Kinniburgh et al. 2017). Additionally, there is a need to recognise and respond to individual strengths and needs and help young people to develop both internal and external resources (Kinniburgh, et al., 2017). Nothing else highlights this need more than the recent Western Australian Coroner's report into the recent suicide deaths of 13 youth in the Kimberley (WA Government, 2019). Learning how to recognise challenging thoughts and feelings and engage healthy coping strategies is a first step in building internal resources and developing a sense of self-efficacy for coping with difficulties and engaging with goal directed behaviours.

The majority of community-based sport programs described in the literature have targeted young men and have highlighted a dire need for sporting programs that are more inclusive of girls and women (Stronach, Maxwell, & Taylor, 2015). Community-based sport programs represent a feasible and acceptable means of engaging young people in order to support self-regulatory capacities, promote self-efficacy, and enhance peer relationships and sense of community (Eime, et al, 2013). Football clubs often act as social hubs in rural Australian communities and may act as an accessible conduit to programs designed to support social and emotional wellbeing (Stronach, Maxwell, & Taylor, 2015). Such programs may be particularly important for disengaged youth, who may also have low mental health literacy and complex needs such as youth living in the Kimberley communities and regional centres. In response to the difficulties being experienced by young girls and women in the Kimberley, specifically in Derby, youth and other support services came together to consider delivering a program which would provide a fun way for the girls to learn skills in self-regulation, learn to support each other and develop skills for working together as a team.

1.1 Game Changers

Game Changers is a new program being piloted by Garnduwa, Kimberley Mental Health and Drug Services, Derby District High School and Derby Youth Services; supported by the Department of Sports and Recreation, that aims to engage at-risk girls from the Derby community. Game Changers was a five day program (Appendix A) which utilised the Tracking Better® at Football tools (Infographic: Appendix B) for developing and enhancing positive coping skills, reducing negative coping strategies, managing stress and increasing resilience within a structured four day football training camp.

The primary aims of the Game Changers program were to:

- engage at-risk girls across the full four day program;
- increase the girls engagement with Derby youth and community services; and
- to have the young women who attended the Game Changers program continue to train with the Derby Tiger's Football Club and potentially register for the West Kimberley Women's Football Season.

Game Changers uses the vehicle of sport to demonstrate application of the Tracking Better® at Football self-regulation skills in a practical and experienced manner. A community working party was assembled to identify the current issues facing the participants and explore how football, sports performance skills and a camp experience could best address their struggles and equip them to manage in a more helpful way. The Working Group, comprised of local community organisations, were also to be taken through the same modules using a sequenced and stepwise model that parallels the program as they prepare for the 4-day program, to provide them with a lived experience of the program that will be delivered to the girls. This facilitate some skill acquisition that can be applied to the challenges the Working Group face themselves in the preparation and delivery of the program. The program was funded by The Department of Sport and Recreation and was administered by Garnduwa. The final design of the program was determined by the Community Working Group.

1.2 Game Changers Camp

The Game Changers Camp represented the one week program that engaged the community participants for the first day to outline the tools the participants would be taught. The second to fifth day of the Game Changers camp delivered a program that taught football skills, included team building skills such as the "Crossing the River" activity, making lanyards (Appendix C). The Game Changers camp delivered the Tracking Better® at Football curriculum, provided nutritious food and transport for the participants. The football training, games and team building activities were used as opportunities to explore and practice some of the skills taught in the Tracking Better® at Football curriculum. An important component of the Game Changers camp was that multiple teachers and trainers from community youth and mental health services the girls would often meet in a school or after school context, were also participating with the girls in a positive context.

1.3 Tracking Better® at Football

The program integrates the Tracking Better® at Football tools for developing and enhancing positive coping skills, reducing negative coping strategies, managing stress and increasing resilience within a structured 4-day football training camp.

The Tracking Better® at Football program has been developed by a child and adolescent psychiatrist working in the Kimberley region, Dr Deeta Kimber, and teaches participants the four core principles of resilience (goal setting, body regulation, stress regulation and feeling regulation) in order to improve their sporting performance.

The sub-text of the Tracking Better® at Football program is "how to bring your best game exactly when you need it" and aims to increase skills in self efficacy in training preparation and sporting performance and their overall wellbeing. Sporting performance is taught through three key aspects of the game:

- Self-management before the game (training and match day);
- during the game; and
- building a positive team culture.

In addition, participants are encouraged to bring these resilience skills to their daily life and build their sense of hope and self-efficacy. The program is visual, teaching from pictures, visual prompts and real-life examples which are reinforced by sporting drills. It was anticipated that at the end of the 4-day program participants will have been introduced to key ideas in the following domains:

- Domain 1: Goal setting
- Domain 2: Stress regulation
- Domain 3: Body regulation
- Domain 4: Feeling regulation

More detail on the specific skills the program participants were taught are set out in the attached program (Appendix B).

2. Evaluation

Researchers at the Telethon Kids Institute in Perth were approached by representatives of the organisations designing and delivering the Game Changers program to evaluate the pilot program. The aim was to provide the relevant stakeholders with a preliminary indication of the extent to which the program is fit for purpose. For example, to identify the extent to which the program's delivery and content suited the context and target group and enabled the anticipated objectives to be achieved. To the extent possible, the evaluation also looked to assess the impact of participation on participants, both the young girls, coaching staff and community partners involved in the Working Group, and the sustainability of any outcomes over a short term.

2.1. Aims and Objectives

Because of the emergent nature of this pilot program, the evaluation sought to understand the feasibility and acceptability and future format of the Game Changers program and provide feedback on the Tracking Better® materials. The key evaluation questions to be answered were:

1. What were the barriers and enablers to delivering the Game Changers program?
2. How well did the target group engage with the Game Changers program and the Tracking Better® content?
3. What benefits and broader outcomes, both intended and unintended, resulted from participation in the Game Changers program and to what extent were these sustained for the participating girls, the coaching staff and community partners?

The evaluation also sought to provide useful insights for the future design and delivery of the Game Changers program and other services directed at young girls in Derby.'

2.2. Methods

2.2.1 Participants

Eight participants consented to an interview about the project. Three participants were interviewed, 2 participants provided responses to interview questions on email, and 3 participants participated in a yarning circle. Participants included police, Community Workers, facilitators and peer mentors in the project. Three participants were Aboriginal Australian and five were non-Aboriginal Australian.

2.2.2 Data Collection

The evaluation used qualitative interviewing for data collection, consisting of:

- Interviews with coaches and community working group members
- Interviews with young women mentors
- Daily journal and interviews with Dr Deeta Kimber
- The girls who participated in Game Changers were not interviewed due to their age, circumstances and potential vulnerability, however a small amount of data has been included in this analysis from three girls who participated in a yarning session at the end of Day 2 with Dr Deeta Kimber.

Participants provided written consent to participate in a semi-structured interview and were emailed nine questions for discussion (Table One). At the commencement of interviews participants were asked for verbal consent to voice record the interview. All participants verbally consented. They were advised that they could finish the interview at any time. Interviews were conducted over the phone and via SKYPE, and other responses were provided through email feedback. At the conclusion of the interviews, the researcher transcribed interviews and where possible, sent the transcript to the participant for double checking content and accuracy of interpretation.

What was participating in the Game Changers project like for you?
What did you like about it?
What challenged you?
How useful did you find the Tracking Better® skills for you?
How suitable do you think Tracking Better® is for working with the community?
What new skills did you gain from participating in the project?
What skills do you think the girls can take away from the week that will help them in other areas of their life?
Is there anything you would change? – for instance about the content (language / graphics), delivery, time involved?
What are your recommendations for next steps?

Table One: Participant Interview Questions

2.2.3 Data Analysis

The data were analysed using thematic analysis (Attride-Stirling, 2001). Researchers reviewed the data and identified, compared and finalised key themes. Multiple reviews of the data were conducted, and team members met and discussed themes from the interviews.

2.2.4 Ethics

Ethics Approval was granted by the Western Australian Aboriginal Health Ethics Committee, Approval **844**, and the evaluation received support from the Kimberley Aboriginal Health Planning Forum Research Subcommittee: Reference **2018 – 003**.

3. Results

The Game Changers project was undertaken in the Kimberley region to assist girls who had been identified in the community as 'at-risk' of crime and poor life outcomes. We present the main findings from the interviews and yarning circles in three sections: 1) Game Changers participants and the community; 2), aspects for improvement, 3) what worked, and 4) the future.

3.1. Game Changers participants and the community

All participants identified that the girls who participated in the Game Changers camp were at risk from harmful behaviours, problems with conduct and violence. Professionals in the community spoke of the complexity of the girls lives:

> *... we see youths within the community coping with stress and trauma in an unhealthy way. Some of these coping mechanisms include drug abuse, alcohol consumption, violence, bullying, thrill seeking behaviour and self-harm.*
>
> *This was a challenging group of girls, many with strong personalities and girls dealing with a range of personal issues.*

Problems with school and disengagement were also identified:

> *Kind of the reason they were chosen was because there were constant battles at school.*
>
> *There is a lot of bullying and conflict that goes on.*
>
> *Truancy is a significant issue in Derby and many of the youths selected for Game Changers fail to attend school regularly*

Social media was identified as a problem.

> *There's lots of dramas on social media, Facebook and Twitter.*

Participants identified that this was mostly because the girls have nothing to do:

> *The kids get bored and just start picking fights*
>
> *There is just nothing to do in Derby. Nothing to do and when wet season comes, there is just nothing eh. And that I think is where a lot of the stuff goes wrong.*
>
> *Yeah [the boys] they get to go like hunting or fishing even like after school hours and all, weekends and the girls like they have like Girls Academy but the people who run it don't really do much with the girls. Like they don't take them out or anything.*
>
> *And the girls don't really have much, like some of the girls who go to school here are in Banksia in Perth there, cause all they are doing is stealing.*

On occasions this was evident during the program:

> *There were times during the camp where a couple of girls became frustrated and unwilling to participate. I believe these girls became self-conscious as many of them had not played football prior to this camp. At times it was challenging to sustain morale and avoid personalities clashing but this improved as the group bonded.*

It was therefore, identified by participants that setting and enforcing ground rules from the beginning of the Game Changers camp was important:

> *I think at the start of the week we should have said, if you have a fight during the week, no one is playing until it is resolved, and this is how we resolve it. That is something I thought we could have done better, sit with the girls and say, what are the rules, what happens when we have a*

> *disagreement or a fight, what do you think we should do about it? Yes, so I thought that was probably missing.*

3.2. Aspects for improvement

On the ground delivery of the project provided various challenges for participants.

3.2.1 Role Definition

The mentors identified a lack of defined roles as challenging:

> *I found that it was you know, I wasn't really told what my role was at the start and was just going through day by day and just picking up where I could. And then being thrown in at the deep end on the last day because the coach wasn't there, and I had to try and coach them and um, that was a challenge.*
>
> *Yeah, look I think there was definitely defined roles, like the two facilitators had defined roles but everyone else kind of just picked up where they can.*

3.2.2 Tracking Better® Training

Participants who attended the Monday training session offered feedback on using the Tracking Better® tools and manual. The identified particular problems with the amount of information, both delivered in the one-day training, and in the written material.

> *I think the face to face training sessions are brilliant, it's engaging, informative and there's lots of very relevant information to learn about emotional regulation. But the written content needs improvement. I find the content and language doesn't have a structure or a framework that helps to understand how to break it down.*

Participants felt there was insufficient time to truly benefit from the training:

> *I thought the background to the project was clear and well delivered and motivations for the project were delivered and felt very placed based. I felt the training day was pretty well pitched. But there was a lot of information in there, too much. A bit of extra time for the manual would be better.*
>
> *Because we were rushed, using the tracking tools, it was a little bit um, it was a lot to get your head around. We didn't really get enough time to practice, and to talk with each other about how we scored each other and stuff like that.*
>
> *There were multiple smaller concepts that you had to get an understanding of, and then the team work and stuff like that we were looking at problem solving, team work, motivation, you know there was a lot so how do we make this real for the girls by really immersing ourselves in it as practitioners.*

A couple of participants felt that dividing the Tracking Better® and Tracking Better® at Football would have been beneficial.

> *I would have done two sessions. One for the mentors and the Tracking Better® at Football stuff, and I would do a separate session for the more generic Tracking Better® stuff.*
>
> *It was just a bit much in one day. I think the only other way around it would be to keep it in the Tracking Better® at Football kind of concept over two days and give us some more practice opportunities.*

3.2.3 Tracking Better® Resources

Some participants found the Tracking Better® resources were confusing, not well defined or culturally irrelevant:

> *I think there needs to be a framework and a logical flow, ie. contents, sections, summaries, session plans and more practical information and less 'novelty' terms used that make it hard to make sense of quickly ie. "flo-mode" and "OMG". There also needs to be a documented practical workshop element if it is to be used with young people. The stress chart is too complex and also doesn't have any information on how to use it.*

> *I think the resources themselves, like the posters for Tracking Better® are pretty busy, some of the stickers have words that clearly orientate you to where to put them on the page, so for me, when I try to think about how to use the Tracking Better® tools specifically with some of my families, I like, I sort of find it a little bit hard to know, even though they are colour coded and stuff I find it a little bit hard to know you know, which one is the rev-up and which one is the rev-down and then what relates to which part of the maps as well.*

> *I think there was only one lot of stickers that didn't have words on them. I personally, think there needed to be more cultural stuff in there. There was lots of visual stuff like the animals. I can understand it working for Australia. They* [the Derby girls] *didn't know what a Tasmanian Devil was or the nature of it. Like everyone knows what a kangaroo is or an emu. I think they would be adaptable for Derby and generally, to the Kimberley itself.*

Interviewer: So, the visual learning and the animal pictures; do you think that had an effect on either, how well the girls engaged or how much they were able to take away?

> *Not really, because it was well explained, but that is necessary. They would have to be explained to be able for them to get it. They couldn't just pick it up and say oh yeah, I understand this and how it relates to what I am feeling. So sitting down and explaining, including showing video's was quite lengthy and if they* [the pictures] *were more for the area they probably wouldn't have to go through all of that. It was difficult for them to grasp it, and once they had taught or learnt they got it but they went a long way around to do that.*

Participants discussed language and definitions:

> *Tracking Better® works very well as a training session for service providers – however I don't think it is in a practical format yet. I don't believe the resources and manuals are at a point that people working at grass roots would feel confident to pick up the resources after the training and be able to use it in their work. I also don't think Tracking Better® is practical enough to implement with young people yet, there needs to be activities and workshops built into the package that are more practical and less theoretical.*

> *Language like "stinking thinking" and "survival mode" or "focus muscle" all make sense when spoken about at the training but if you were to pick up the workbook and try to deliver to a young person, there is no explanations of these terms or teaching points to help you explain it.*

> *Maybe if there were some definitions, you know, what does foggy thinking mean, you know maybe if there was a little manual written up which gave us some definitions and helps with you know, how you describe that to a child or a young person, how do you describe foggy thinking, how do you describe racy thoughts.*

3.2.4 Cultural, community and family inclusion

One participant spoke of dual advantages for non-Aboriginal and Aboriginal staff:

> *You know, on the whole I think it is a great project for the Kimberley. The other two staff members here are both Aboriginal staff members who work with domestic violence, one with men and one with children and this stuff was so relevant to their work and for them it was broken down in a way they could understand and articulate and so then for us to have a shared language together, it was something a little bit unexpected I guess and very valuable.*

Another participant was more critical about the inclusion of the community in the consultation process, development and delivery of the project. In their view:

> *It wasn't something like a bottom-up approach. It was top down. It was we have this program and we are going to deliver it here, it wasn't like community members saying, we have this issue, what can we do to try and work it out and what is the best way of doing this. If it does go on to something bigger and better, and I really hope it does, that these issues get taken into consideration, especially cultural aspects of the project.*

Another participant provided some explanation for this:

> *During the 12-week period of time that the working group meetings were taking place, there was only a few people who could make all of the meetings regularly. From my conversations and experience, this reflects the under-resourced and over-worked nature of the youth sector here which we did try to plan for as we knew this would be inevitable. This meant making decisions and plans without comprehensive community input but at different times this was a necessity.*

The inclusion of families and communities in the project were also of concern. Recognising the geographical challenges, a participant said:

> *I think because there was a game in Derby, a game in Looma and a game in Broome it was hard. But it would have been good to have it advertised or a note sent home saying they were going to play and inviting their parents and family members to come would have been nice.*

Another participant said:

> *I also think the parents of the girls could have been invited to the first day, when all the service providers and the community came together – they [parents] should have got a special invite. Then they know what's going on – that their child will be involved in this program.*

3.3. What worked

Football, as a vehicle for learning self-regulatory skills and emotion management was seen as beneficial for the girls:

> *As a pilot program I think it went very well. Engagement was very positive which I think spoke to how well football was as an effective engagement tool and the engagement work and careful selection of the girls by the school.*
>
> *Game Changers fostered a positive and fun environment where they worked collaboratively.*
>
> *The benefits of playing team sport were clearly demonstrated during the camp.*

Even when they had not participated in something like this previously, participants noted:

> *Some girls were completely out of their comfort zone but gained confidence as they progressed.*

Relationships benefitted:

> *Through football we believe new friendships were formed and girls were able to exhibit their new learned skills in order to cope under pressure and enhance their performance.*

Importantly, these results both aligned with the conceptual framework and aims of the project.

3.3.1 Tracking Better® at Football

The Tracking Better® at Football tools were found to be useful, both during the Game Changers camp and for the girls future self-management strategies:

> *I think that a number of girls were able to grasp the main concepts and have hopefully taken away a better understanding of stress, when they feel stressed, what kind of stress they feel and how to manage that stress.*
>
> *Out of all of this I think they would have taken away a better understanding of how we get stressed and what the different types of stress and body responses are. I think we could have improved on teaching practical ways of calming they can use every day.*
>
> *The girls actually engaged with it [the manual], or used it as follow on you know, when things got out of hand, they were able to refer back to it. Still now we are able to go back to it.*

Visual Aids, games and making the lanyards were also identified as beneficial:

> *The girls were more actively engaged during the visual and practical elements of the camp. Sitting for long periods of time was challenging for a few of the girls.*
>
> *There were some things we did like Lanyards which just helped to calm down to.*

3.3.2 Mentors

Mentors made a difference for staff and the girls who participated in the Game Changers camp:

> *We had three mentors during the week. They were there during the day throughout the week and they were quite helpful and really got involved.*
>
> *It made a big difference having mentors there. I think it cuts through any tension.*

One mentor said:

> *I enjoyed being with the girls from the whole week and building that rapport with them as well.*

3.3.3 Visual Aids and Games

> *We talk about how to be calm when playing sport and how to hold your anger in … they used animals as like feelings and like that and they have like this emu and that one is like basically an example of how people run around an oval, like how much energy they use and that.*

Interviewer: So, did you find the pictures were good for you to put together with a feeling?

> *Yeah, it's like a good way to remember the feelings and action.*

One yarning session participant saw the cards as a learning tool saying that, *"they learnt what animal they were".*

Games provided a source of hope for future improvement in the Game Changers camp participants self-regulatory skills and gave participants a chance to experience the skills practically.

> *When we did that crossing the river … a couple of squares and they had to get from one side to the other. We had them lying down, bringing their heartrate down and then getting up and running. So we broke them up into two teams and put them through things where they had to work together and a bit of stress, they got time stress and they got to work with each other and that can be frustrating and once they put into place some of those skills that they learned, like stuff like when you are calm you are better at it and if you work together you are better at it. That was something I thought we could build into future things, rather than like you say, sitting in a classroom getting frustrated. Or acting it out and feeling it physically and emotionally.*

3.4. The Future

The project was a welcome future idea for the Kimberley *"whether it is a longer camp, or a longer-term program, a one day a week"*.

The mentors in the project said:

> *I reckon* [Tracking Better®] *could be delivered over the term once a week. Yeah cause it's a lot to hit them hard once a week, there is a lot of information. They could do it like Tuesday, Thursday every fortnight or something. Down at the school. Most of the girls will be going to school yep. Being at school and being in the classroom all the time is frustrating you know, they just sitting there in one place they get up start walking out of the class*
>
> *Yeah and if they make it interesting enough, I reckon they could get the other girls to come back to school you know huh? I reckon what they need is more activities.*
>
> *Make it kind of like football training and you could do this kind of training as well.*

Mentors were flagged for potential engagement in classrooms:

> *Yeah so I reckon that would be a way, get mentors in the class like local mob, so getting classes like that that tell them like how stress-less and like what the stress signs are and stuff like that, and how to like how to handle their stress yeah.*

Participants were also keen to see opportunities for the girls to broaden their experience:

> *You know, how young the girls are, I reckon like a bigger place to get them to experience like other girls, like say going to Kununurra and see other girls. Somewhere that's a bit special, yes, even like Hedland or Karratha you know; or even Darwin, you know experience playing with other people from another place you know.*

Providing lasting memories was also important to participants:

> *It would be nice for the girls to participate in another football game and also receive a DVD or photo book, so they continue to remember the camp and the skills they learnt.*
>
> *The girls would have really appreciated keeping their football shirt at the end of the camp and it would have been a great memento.*
>
> *We also think a resource book containing the Tracking Better® strategy should be developed as this can be used in all schools and the camp can be delivered to age appropriate students anywhere within Australia.*

3.4.1 Positive Outcomes

Game Changers, with the Tracking Better® curriculum, was an important initiative and well received by all participants as demonstrated by the full participation of the girls over the week:

> *Seeing the girls grow as individuals and as a team throughout the week, the excitement and enthusiasm from the girls. Seeing the 3 young mentors grow in confidence and start learning about emotional regulation. Spending time working together on a positive project with the members of working group who came on the camp – often we are working together on crisis situations/ negative circumstances. Seeing the girls engaged in something they love (football) and having the opportunity to do it.*
>
> *Game Changers encompasses such important skills for these teenagers which can assist them in their everyday life and during times when they experience significant pressure and anxiety.*
>
> *It was wonderful to see a diverse group of girls slowly bonding and working together as a team.*
>
> *As the week progressed, we could see the girls motivating and supporting one another.*
>
> *I think the girls would have taken away a new sporting confidence, perhaps some new friends they didn't have before and improved relationships with those they weren't getting along with. New understandings about services available that can help them as well as new relationships with workers in these services.*

There was full participation over the week.

> *We were particularly concerned that girls would not commit to the full week and numbers would decrease as the camp progressed. The girls clearly enjoyed the camp as each and every member attended the four full days. It also sparked an interest with girls who were not selected as other students asked to join the program throughout the week.*
>
> *Game Changers provided a model which inspired the girls to demonstrate leadership skills, improved confidence, commitment and motivation, respect to others, the importance of listening to your body and recognising the signs when you're overwhelmed and under pressure.*

Skills learned on the Game Changers camp translated to the classroom

> *I know from speaking to the school representatives that there have been really positive (measurable) improvements by some of the girls who were involved – ie. number of behavioural incidents within a day. They also spoke about one girl who was using the fight/ flight language from the program after getting into an altercation at school.*

4. Discussion

The girls from Derby and surrounding communities who participated in the Game Changers camp have come from families where multiple layers of cumulative trauma have occurred, and as a result they are girls who are socially isolated, already have or are at risk of mental health problems, are disengaged or at risk of disengaging from their education, are at risk of contact with the law and will need support and prosocial interventions like what the Tracking Better® at Football program has to offer. They have lower self-regulation abilities which impedes their capacity to self-regulate their behaviour and emotions and respond to stressful situations. The Game Changers camp using the Tracking Better® at Football tools offered them an opportunity to participate in an activity which gave them insight into themselves, skills to recognise and associate their thoughts and feelings and giving them increased strategies for coping. It engaged the girls in a fun way, which assisted them to learn skills in self-regulation, learn ways to support, understand the importance of supporting each other and how to accomplish this and to develop skills for working together as a team.

Game Changers is a new program, and as such it is important to evaluate the benefits and learn from the challenges presented in running a program such as this in a remote community. All stakeholders identified a huge need for dedicated and sustained programs for girls in Derby. The evaluation found that developing initiatives such as the Game Changers project are vital to address the complex and difficult lives of the young people. Addressing interpersonal and community violence, disengagement from school, problems with the use of social media which resulted from boredom was viewed as essential to address the social and emotional wellbeing needs of youth in the Kimberley. Results from the evaluation suggest that, overall the pilot was a very worthwhile initiative, however there were several areas which could improve future delivery of the program.

The aim of the pilot project to engage at-risk girls across the full four days using a variety of visual tools to introduce skills which can be transferred to practices in their daily lives and build their sense of hope and self-efficacy. The participants attended every day, learning these skills through something they really enjoyed doing, playing football.

Participants who attended the Monday training session offered feedback on using the Tracking Better® tools and manual. They identified that there was a large amount of information, both delivered in the one-day training, and in the written material, and one day was not sufficient to truly understand and benefit from the program. A future version would benefit from more careful layering of skill building and targeting the teaching method to the educational age of the participants, such as careful integration of educational theory followed by reinforcing activities to emphasize the learning. Participants also suggested that resources be more culturally relevant for the Kimberley.

For the girls, the four day Game Changers camp was positive, however behaviour management was at times problematic, and so setting ground rules at the beginning of the program is important for future delivery of the program. For professionals and particularly the peer mentors assisting at the Game Changers camp, more clearly defined roles will assist them to feel more secure in their role and encourage other peers to be involved and be role models in the community. Finally, the inclusion of broader family and community members would greatly benefit, both the project and broader development in community healing and wellbeing.

The evaluation found, however that the benefits for the girls far outweighed the challenges. Despite the complexity of their lives the girls were engaged and attended for the week and gained valuable skills and self-confidence. Their relationships improved, and they gained skills in self-management and self-control which were apparent not only during the Game Changers camp but translated in the following weeks in the classroom. Significant to this success of the program were the programs mentors. Overall, the Game Changers pilot project provided hope for future improvement in the self-regulatory skills of youth and was a welcome future initiative for addressing the many problems which confront youth living in communities in the Kimberley.

There is much potential for running programs of this type again in Derby or any of the surrounding communities in the Kimberley region. Programs which focus on prosocial activity, building youth resilience and providing an opportunity to build up self-regulatory and other skills potentially build social inclusion and community relationships: hallmarks of community recovery. Furthermore, it increases the possibility for building self-regulatory skills such as controlling impulsivity, which has recently been considered a significant factor in tragic suicides of youth in the Kimberley, including Derby. Exploring the current levels of social capital and social networks which exist in the communities for these youth is important. Their families and kinship networks, schools or other education facilities, contact with members of professional organisations from health and mental health, justice or youth services and many other formal or informal aspects of their networks should be given much more attention than it currently is as an important part of keeping children safe at all times.

Prosocial activities which also have an educational component such as the Tracking Better® at Football curriculum would be very worthwhile investment for a number of reasons. Firstly the benefits for the youth. Secondly, by involving their families and the wider community in these kinds of activities, there is potential for the education of multiple protective adults for these young people, who can then assist with reinforcing the strategies and skills outside of the program. This potentially enables community members with opportunities for healing across the generations. By supporting communities to host these types of prosocial activity, there is potential to provide an environment where children, youth and communities can participate in something they care about, where they can be safely challenged and can safely challenge their own thoughts and feelings, achieve a stronger sense of personal worth, and stronger sense of community belonging and provide hope and meaning for the future.

Important next steps include consulting with communities about the prospects of trialling the project in communities, supporting the ongoing evaluation, including consultation to examine which outcomes are considered most meaningful for different communities and different members within a community. Future evaluations should consider long term sustainability of the program, including development of training models for program facilitators, evaluation of costs and benefits of program delivery, and the development of an implementation framework to support scale-up of the program while maintaining its fidelity.

5. Future recommendations

5.1. Community Consultation

- Future developments of the project should ensure involvement of community in its development and delivery and in defining meaningful and measurable outcomes for evaluation
- Particular attention should be given to the involvement of the girl's parents and families and look at opportunities to have shared activities.

5.2. The Game Changers Camp

- The pilot be expanded to a number of trial sites in remote, regional and urban communities
- Identify and set enforceable ground rules at the beginning of the Game Changers camp

5.3. Training

- Tracking Better® training be held over a longer period of time with regular opportunities for practice.
- Tracking Better® generic tools and Tracking Better® at Football be delivered as two separate programs.
- Ensure mentors are engaged in any future delivery of the project with clearly defined roles and tasks so they feel secure in their role.
- Training participants be provided with the manual prior to the training
- Training curriculum be broken down into foundation skills that can be built on in a sequential order once mastered.
- Clearly define specific roles for the professionals and volunteers for the duration of the Game Changers camp
- Future program work should consider the development of a training module for program facilitators and an implementation framework.

5.4. Materials and Tools

- Develop definitional material
- Consider the way games can be implemented in the delivery of self-regulatory strategies
- Provide reward/memory material for participants
- Consult with communities on culturally relevant visual material

5.5. The Future

- Evaluating the economic costs and benefits of program delivery
- Consider the implementation of mentoring projects for self-regulation in the classroom
- Consider the regular delivery of the Tracking Better® Football skills in the classroom and sports training
- Consider future Game Changers football camps in surrounding districts to increase social skills and opportunities for social inclusion
- Plan carnivals and events decided by the community which carry young people through times when they risk being bored and losing momentum on what they learn particular during school holidays.

Appendices

Appendix A: Game Changers Football Camp Program: 23-27 July 2018

Day 0: Volunteers and Community Working Party Training

Tracking Better® Curriculum:

Early Warning Signs of Stress

Stress Triggers and Survival Mode

Tools to Calm Down

Day 1: Pre-season training

Planned Tracking Better® Curriculum:

Early Warning Signs of My Stress (Activity 1 in Manual)

My 5 Safe People (at home and on camp) (Activity 10 in Manual)

OMG, how do I calm down (Focus Muscle) (Activity 11 in Manual)

Day 2: Away Match (Looma)

Planned Tracking Better® Curriculum:

My Triggers (Survival Mode) (Activity 2 in Manual)

My Stinking Thinking – I only see huge problems (Survival Muscle) (Activity 3 in Manual)

My Eagle Eye “Yes But…” and can see the positive (Survival Muscle) (Activity 4 in Manual)

Out of Survival Mode and into Flow (how does it feel different?) (Survival Muscle + Focus Muscle) (Activity 5 in Manual)

Day 3: Home Match

Planned Tracking Better® Curriculum:

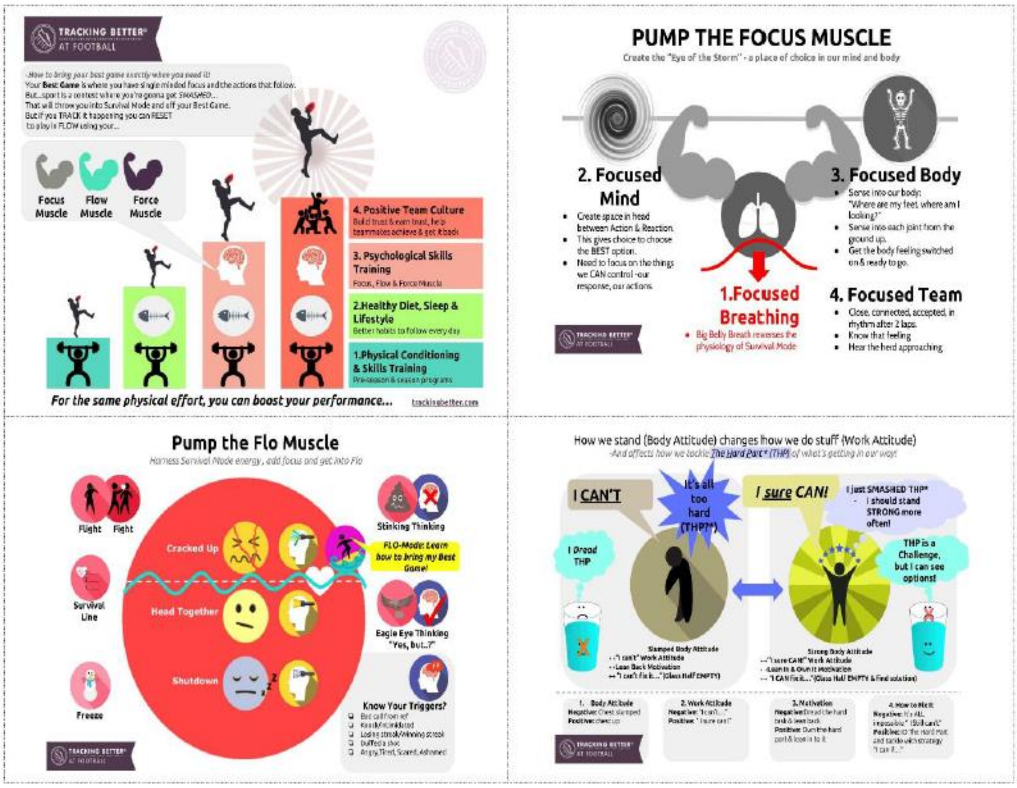
OMG, how do I calm down (Sensory Speed Dating) (Activity 11 in Manual)

Day 4: Away Match (Broome)

Planned Tracking Better® Curriculum

Appendix B Infographic: Tracking Better® at Football

Tracking Better®at Footy Infographics



-How to bring your best game exactly when you need it!
Your **Best Game** is where you have single minded focus and the actions that follow.
But...sport is a contest where you're gonna get *SMASHED*...
That will throw you into Survival Mode and off your Best Game.
But if you TRACK it happening you can RESET
to play in FLOW using your...

4. Positive Team Culture Build trust & earn trust, help teammates achieve & get it back

3. Psychological Skills Training Focus, Flow & Force Muscle

2.Healthy Diet, Sleep & Lifestyle Better habits to follow every day

1.Physical Conditioning & Skills Training Pre-season & season programs

For the same physical effort, you can boost your performance... trackingbetter.com

PUMP THE FOCUS MUSCLE

Create the "Eye of the Storm" - a place of choice in our mind and body

2. Focused Mind
- Create space in head between Action & Reaction.
- This gives choice to choose the BEST option.
- Need to focus on the things we CAN control -our response, our actions.

1.Focused Breathing
- Big Belly Breath reverses the physiology of Survival Mode

3. Focused Body
- Sense into our body: "Where are my feet, where am I looking?"
- Sense into each joint from the ground up.
- Get the body feeling switched on & ready to go.

4. Focused Team
- Close, connected, accepted, in rhythm after 2 laps.
- Know that feeling
- Hear the herd approaching

Pump the Flo Muscle

Harness Survival Mode energy, add focus and get into Flo

Know Your Triggers?
- ☐ Bad call from ref
- ☐ Knock/intimidated
- ☐ Losing streak/winning streak
- ☐ Duffed a shot
- ☐ Angry, Tired, Scared, Ashamed

How we stand (Body Attitude) changes how we do stuff (Work Attitude)

-And affects how we tackle The Hard Part (THP) of what's getting in our way!*

Slumped Body Attitude
→"I can't" Work Attitude
→Lean Back Motivation
→"I can't fix it..."(Glass Half EMPTY)

Strong Body Attitude
→"I sure CAN!" Work Attitude
→Lean In & Own It Motivation
→"I CAN fix it..."(Glass Half EMPTY & Find solution)

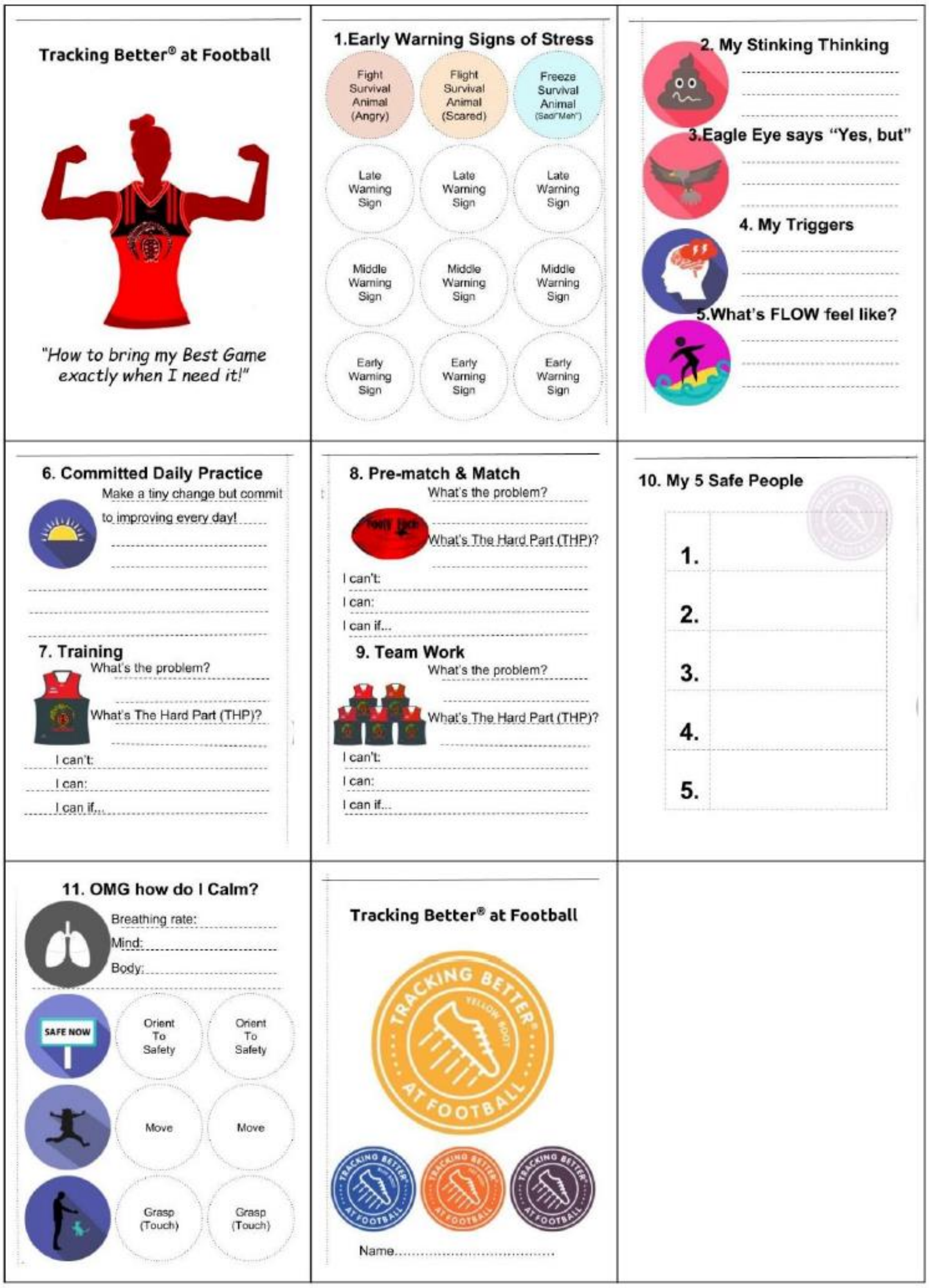
1. Body Attitude
Negative: Chest slumped
Positive: chest up

2. Work Attitude
Negative: "I can't..."
Positive: "I sure can!"

3. Motivation
Negative: Dread the hard task & lean back
Positive: Own the hard part & lean in to it

4. How to fix it
Negative: It's ALL impossible" (Still can't)
Positive: ID the Hard Part and tackle with strategy "I can if..."

Appendix C: Lanyards



Tracking Better® at Football

"How to bring my Best Game exactly when I need it!"

1.Early Warning Signs of Stress

Fight Survival Animal (Angry)

Flight Survival Animal (Scared)

Freeze Survival Animal (Sad/"Meh")

Late Warning Sign · Late Warning Sign · Late Warning Sign

Middle Warning Sign · Middle Warning Sign · Middle Warning Sign

Early Warning Sign · Early Warning Sign · Early Warning Sign

2. My Stinking Thinking

3.Eagle Eye says "Yes, but"

4. My Triggers

5.What's FLOW feel like?

6. Committed Daily Practice

Make a tiny change but commit to improving every day!

7. Training

What's the problem?

What's The Hard Part (THP)?

I can't:

I can:

I can if...

8. Pre-match & Match

What's the problem?

What's The Hard Part (THP)?

I can't:

I can:

I can if...

9. Team Work

What's the problem?

What's The Hard Part (THP)?

I can't:

I can:

I can if...

10. My 5 Safe People

1.

2.

3.

4.

5.

11. OMG how do I Calm?

Breathing rate:

Mind:

Body:

Orient To Safety · Orient To Safety

Move · Move

Grasp (Touch) · Grasp (Touch)

Tracking Better® at Football

Name.......................................

References

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. Qualitative Research, 1(3), 385-405.

Creswell, J.W. (2012). Qualitative inquiry and research design: Choosing among five approaches. Thousand Oaks, CA: Sage.

Eime, R. M., Young, J. A., Harvey, J. T., Charity, M. J., & Payne, W. R. (2013). A systematic review of the psychological and social benefits of participation in sport for children and adolescents: informing development of a conceptual model of health through sport. *International Journal of Behavioral Nutrition and Physical Activity*, 10(98). DOI: 10.1186/1479-5868-10-135

Kinniburgh, Kristine Jentoft, Margaret Blaustein, Joseph Spinazzola, and Bessel A. Van der Kolk. (2017). Attachment, Self-Regulation, and Competency: A Comprehensive Intervention Framework for Children with Complex Trauma." *Psychiatric Annals* 35 (5) 424–30.

Malvaso, C. G., Delfabbro, P. H., & Day, A. (2017). The child protection and juvenile justice nexus in Australia: A longitudinal examination of the relationship between maltreatment and offending. *Child Abuse & Neglect*, 64, 32-46.

Ralph, N., Hamaguchi, K., & Cox, M. (2006). Transgenerational trauma, suicide and healing from sexual abuse in the Kimberly Region, Australia. *Indigenous Wellbeing*, 4(2), 118-136. Retrieved from: http://www.pimatisiwin.com/uploads/386689234.pdf

Stronach, M., Maxwell, H., & Taylor, T. (2015). 'Sistas' and Aunties: sport, physical activity, and Indigenous Australian women. *Annals of Leisure Research*, 19(1), 7-26.

Western Australian Government. (2019) *Inquest into the deaths of: Thirteen Children and Young Persons in The Kimberley Region,* Perth: WA Government. Retrieved from: https://www.coronerscourt.wa.gov.au/_files/inquest-2019/13-Children-and-Young-Persons-in-the-Kimberley-Region-Finding.pdf