

Aboriginal Participatory Action Research: Learnings from The Bigiswun Kid (adolescent) Project



Lauren J. Rice^{a,d,*1}, Emily Carter^{b,1}, Emma Bear^b, Mudge Bedford^c, Cheyenne Carter^b, Jadnah Davies^b, Nikkita Rice^c, Sue Thomas^b, Fergus Wells^b, Elizabeth J. Elliott^{a,d}

^aThe University of Sydney, Faculty of Medicine and Health, Specialty of Child and Adolescent Health, Sydney, New South Wales, Australia

^bMarninwarntikura Women's Resource Centre, Fitzroy Crossing, Western Australia, Australia

^cMarra Worra Worra Aboriginal Corporation, Fitzroy Crossing, Western Australia, Australia

^dSydney Children's Hospitals Network, Kids Research, Sydney, New South Wales, Australia

Abstract

Purpose The Marninwarntikura Women's Resource Centre (MWRC) is an Aboriginal community-controlled organisation located in the remote Fitzroy Valley of Western Australia. At the request of Aboriginal community members, the MWRC partnered with the University of Sydney to conduct the Bigiswun Kid (Kimberley Kriol for adolescents) Project to understand and improve the health and wellbeing of young people living in the Fitzroy Valley. An Aboriginal participatory action research (APAR) approach guided the research design. This paper discusses the experience of implementing the APAR approach.

Methods How the elements of the APAR approach were incorporated into the Bigiswun Kid Project are described and three key implementation components are detailed: Aboriginal leadership and governance; community consultation; and Aboriginal researchers/community navigators.

Main findings The benefits of implementing the APAR approach included empowering the participants and communities, emphasising research in action and promoting knowledge translation. Five lessons from using this approach are also discussed.

Principal conclusions The APAR approach empowered young people and community members to actively participate in the study, guiding the focus, design and tangible outcomes. The approach ensured that

*Corresponding author.

E-mail address: lauren.rice@sydney.edu.au (L.J. Rice).

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knowledge translation began while the research was conducted, to provide immediate and long-term outcomes for young people.

Keywords: Australian Aboriginal; Indigenous; Social and emotional wellbeing; Mental health; Adolescence; Aboriginal participatory action research

Highlights

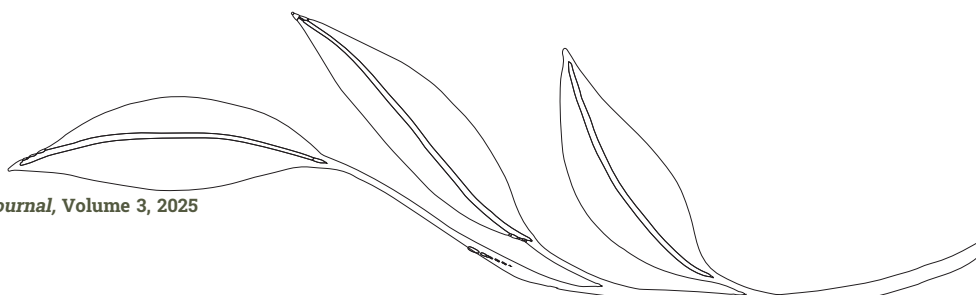
- Research methodology can influence the nature and quality of the research findings and the likelihood that the research will lead to meaningful change. The Aboriginal participatory action research (APAR) approach helps foster Aboriginal participant engagement at all stages of the research and ensures that knowledge translation is embedded in the research design.
- From the APAR approach, it was learned that:
 1. A community-driven, bottom-up approach enabled a place-based design and increased community engagement.
 2. A coordinated support model is needed to foster a holistic notion of health and wellbeing.
 3. Two-way research and service delivery respects privacy and culture and promotes two-way learning and service design.
 4. Non-Indigenous researchers and staff best developed the ability to be culturally responsive when they lived in the region and worked directly alongside Aboriginal staff.
 5. Staff working in remote Aboriginal communities must come with an open mind, listen deeply and reflect often to minimise their preconceptions and the impact of their lived experiences on how they perceive and interact in the community.

Introduction

The Fitzroy Valley is in the central Kimberley of Western Australia (WA) and covers a 400 km diameter of ancient, diverse and protected landscape with great cultural significance ([RiverOfLife et al. 2020](#)). The region includes 32 very remote Aboriginal communities and Fitzroy Crossing town. Approximately 4,500 people live in the Fitzroy Valley, of whom 80% are Aboriginal and belong to five principal language groups: Bunuba, Gooniyandi and Nykina are river people, and Walmajarri and Wangkatjungka are desert people ([Figure 1](#)). Kimberley Kriol is the primary language spoken in the region today ([Morphy 2010](#)). The Fitzroy Valley communities are rich in Aboriginal culture and have sophisticated protective kinship systems and

strong connections to the land ([Oscar 2018](#); [RiverOfLife et al. 2020](#); [Tulich et al. 2020](#)).

European settlement and colonial policies continue to threaten people's way of life, autonomy and self-determination in the Fitzroy Valley ([Thorburn 2013](#)). The intergenerational effects of colonisation persist and cannot be underestimated. Despite this, Aboriginal people from the Fitzroy Valley have worked hard to protect their way of life. In 2008, senior Aboriginal women from the Fitzroy Valley declared that their communities were in crisis, with 50 deaths in as many weeks, mostly alcohol-related and including 13 suicides ([Fitzpatrick et al. 2017c](#)). These women acted by successfully lobbying the WA liquor licensing board



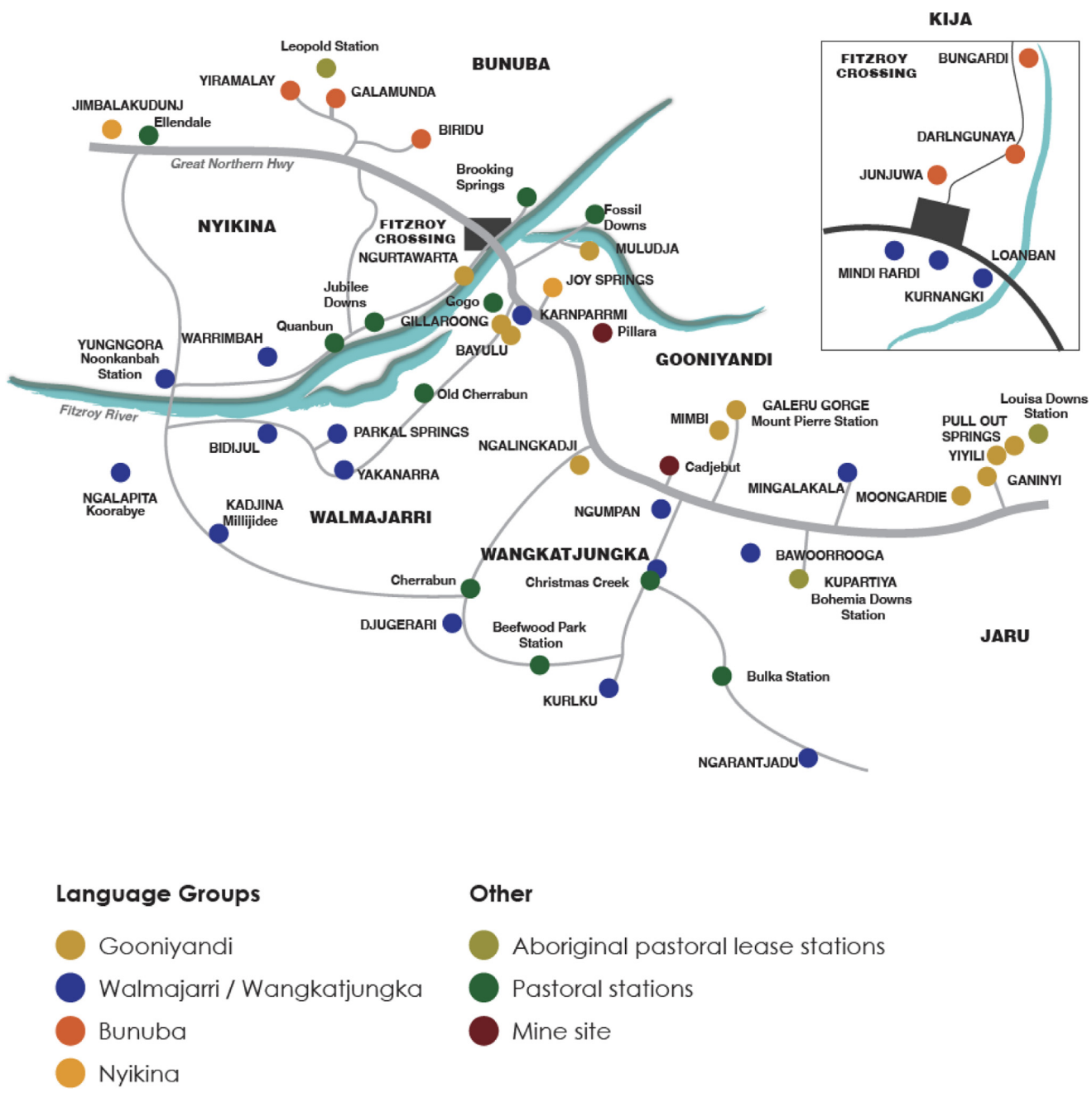


Figure 1: Map of the Fitzroy Valley.

for restrictions on the takeaway sale of full-strength alcohol (Elliott et al. 2012). Once alcohol restrictions were in place, the grandmothers requested that

attention be turned to their grandchildren, who they noticed were displaying behaviours and developmental delay that they had not seen in

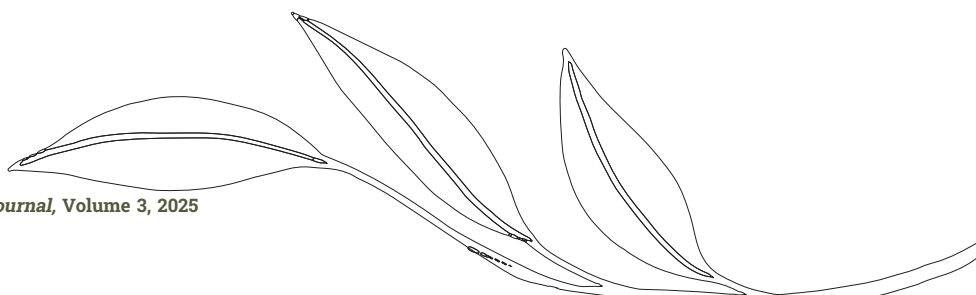


previous generations and which they questioned might be associated with the increased levels of alcohol dependence ([Fitzpatrick et al. 2017c](#)). Two Aboriginal community-controlled organisations (ACCOs) in Fitzroy Crossing – Marninwarntikura Women's Resource Centre (MWRC) and Nindilingarri Cultural Health Service – partnered with clinicians and researchers from The University of Sydney (USYD) and George Institute for Global Health to conduct the Lililwan (Kimberley Kriol for 'little ones') Project to identify the impact that alcohol use in pregnancy was having on children, including on the prevalence of foetal alcohol spectrum disorder (FASD) ([Fitzpatrick et al. 2012](#); [Fitzpatrick et al. 2017c](#)).

In 2010, all children aged seven to eight years living in the Fitzroy Valley and their parents were invited to participate in the Lililwan Project. Of all 134 eligible children and their families, 127 (95%) participated. The participation rate was high because this project was initiated and led by the Aboriginal community, and senior women from the Valley went to each family to explain what they were doing and why. Of the 127 children who participated, 90% had experienced significant early life trauma by the time they turned seven years old, 55% had prenatal alcohol exposure and 19% met diagnostic criteria for FASD ([Fitzpatrick et al. 2015a](#); [Fitzpatrick et al. 2015b](#); [Fitzpatrick et al. 2017b](#); [Lange et al. 2017](#)). This does not mean that FASD only exists in the Fitzroy Valley or more commonly in the Fitzroy Valley than elsewhere; it is because the brave women from the Valley were the first nationally to acknowledge and address the issue.

The Lililwan Project provided both short-term and long-term positive benefits at various levels ([Pickard et al. 2025](#)). Some short-term benefits included that all children received comprehensive multidisciplinary health and neurodevelopmental assessments during

the project, including formal ear/hearing and eye/vision assessments. Parents were invited to discuss their child's health or wellbeing concerns with the paediatrician and allied health professionals. Study clinicians opportunistically treated children for acute conditions such as asthma and skin infections during the research whenever possible and otherwise referred children to the appropriate services. Over 400 formal health referrals were made, including to health and mental health specialists, but there were concerns that services would not have the capacity to deal with the many children with complex health needs. Each child received a management plan, including results of assessments and clear recommendations for parents, health and education services about how to support the child's health and development ([Fitzpatrick et al. 2012](#)). At the long-term and local levels, ACCOs like the MWRC used the findings to secure funding to establish the Baya Gawiy Early Childhood Centre and Child-Parent Centre, the Marulu Team to support individuals and families living with FASD, and the Jandu Yani U ('For All Families') Parenting Program ([Butler et al. 2019](#)). Study findings, distributed through film and community feedback, helped to raise awareness about FASD (locally, nationally and internationally), including the United Nations Forum for Indigenous Issues ([Pickard et al. 2025](#)). A reduction in alcohol use during pregnancy was also documented in the Fitzroy Valley ([Symons et al. 2020](#)). Findings from the Lililwan Project were referenced in Inquiries and Royal Commissions ([Commonwealth of Australia 2011](#); [House of Representatives Standing Committee on Social Policy and Legal Affairs 2011](#); [Royal Commission into the Violence 2022](#); [Western Australia Legislative Assembly 2021](#)), helped secure a national strategic action plan for FASD (2018–28) ([Commonwealth of Australia 2018](#)), and influenced progressive governments to provide over \$100 million in funding to address FASD



(Australian Government Department of Health and Aged Care 2018).

In 2018, some senior Aboriginal women were concerned about the lack of government investment in support and services for children with complex health needs. They were worried that some of the Lililwan cohort did not receive the support they needed and struggled in adolescence. These concerns were reflected in Coroner Fogliani's 2019 inquest into the death by suicide of 13 children in the Kimberley; the report's first six recommendations related to better services and support for children with FASD (Fogliani 2019). The 2018 Banksia Hill study, in which 36% of children in juvenile detention in WA met diagnostic criteria for FASD, heightened community concerns (Bower et al. 2018). To better understand these concerns, leaders from the MWRC invited researchers from USYD to work with them to follow up the Lililwan cohort 10 years after the original study. The MWRC called this the Bigiswun Kid (Kimberley Kriol for an adolescent) Project.

The Bigiswun Kid Project was conducted as part of a long-term partnership between community leaders Ms June Oscar AO and Ms Emily Carter, past and current Chief Executive Officers (CEOs) of the MWRC, and Prof. Elizabeth Elliott from USYD, which has continued since the Lililwan Project began in 2009 and resulted in several subsequent research projects and other initiatives to ensure knowledge translation (Pickard et al. 2025). The primary aim of the Bigiswun Kid Project was to improve services that protect and promote the health and wellbeing of young people living in the Fitzroy Valley. Details about the Bigiswun Kid Research Project's aims and methods can be found in the protocol paper (Rice et al. 2022).

Non-Indigenous researchers from USYD (EE, LJR) recognised the privilege of being invited to work in partnership with the MWRC leadership team (EC, ST,

JD, MH) and senior women of the Fitzroy Valley communities. The MWRC and USYD partners spent 18 months consulting with the Fitzroy Valley community, seeking consent and discussing how best to conduct the research. Lessons were taken from previous research collaborations involving some Bigiswun Kid Project investigators – for example, the Lililwan (Fitzpatrick et al. 2012), Jandu Yani U (Andersson et al. 2019), Picture Talk (Fitzpatrick et al. 2017a; Fitzpatrick et al. 2019) and Health Services projects (Dossetor et al. 2021; Dossetor et al. 2017; Dossetor et al. 2019) – and the existing literature. An Aboriginal participatory action research (APAR) approach guided the research design (Dudgeon et al. 2020).

Western research often creates a power imbalance between researchers and study participants. The knowledge gained from Western research is not typically translated during research projects; rather, it is hoped that the findings will have an impact after the research. Participatory action research (PAR) is an approach that aims to empower individual and community participants, to level the power imbalance between them and researchers, and to promote knowledge translation activities during the research. Participatory action research 'tries to be a genuinely democratic or non-coercive process, whereby those to be helped determine the purposes and outcomes of their own inquiry' (Wadsworth 1998). It emphasises a reflective practice of action during the research and is influenced by a strong understanding of the history, cultural and local context of the place where the research is undertaken (Baum et al. 2006; Dudgeon et al. 2020; Tsey et al. 2007). The PAR approach is increasingly being incorporated into research conducted with Aboriginal and Torres Strait Islander communities in Australia (Dudgeon et al. 2020; Tsey et al. 2007). According to Dudgeon et al., APAR extends beyond the Western model of PAR to include a



‘critically self-reflexive Indigenous research method’ that can accommodate Indigenous knowledge systems and highlights the principles of Indigenous self-determination, empowerment and cultural recognition ([Dudgeon et al. 2020](#) p.18).

Therefore, this paper describes:

1. How an Aboriginal community-based participatory research action approach was embedded in the Bigiswun Kid Project (methods)
2. Key learnings from implementing an APAR approach and providing support to young people during the Bigiswun Kid Project (results and discussion).

Methods

The published protocol outlines the Bigiswun Kid Project methods ([Rice et al. 2022](#)). This paper describes how the key elements of the APAR process described by [Dudgeon et al. \(2020\)](#) were incorporated into the Project ([Table 1](#)) and specific components of the APAR implementation. This study received approval from the Kimberley Aboriginal Health Planning Forum Research Subcommittee, the Western Australian Aboriginal Health Ethics Committee, and the Western Australian Country Health Services Human Ethics Committee.

Critical components of Aboriginal participatory action research in the Bigiswun Kid Project

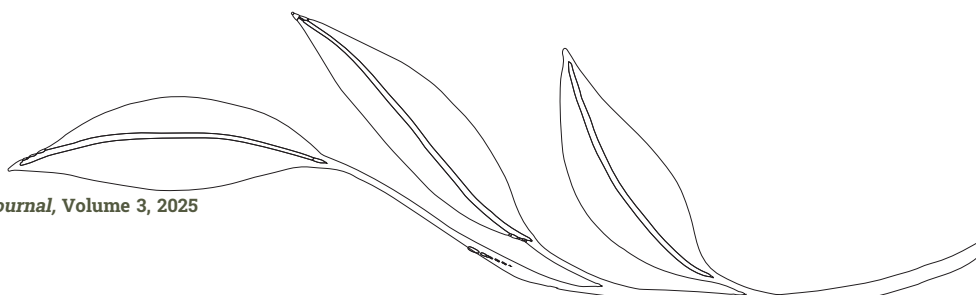
Aboriginal leadership and governance at all levels

The Project was initiated and led by senior women from the Fitzroy Valley and is a collaboration between the MWRC (led by CEO Ms Emily Carter) and clinicians and researchers from USYD. The roles and expectations of partners were outlined in a memorandum of understanding and a research agreement before data collection began. Consistent with the UN Declaration on the Rights of Indigenous

Peoples, these documents note that the MWRC owns the intellectual property gained from the research. This upholds the right for Indigenous data sovereignty, defined as ‘the right of Indigenous peoples to govern the collection, ownership and application of data about Indigenous communities, peoples, lands, and resources’ ([Gawaian et al. 2019](#)). Individual raw data are securely and electronically stored at USYD to ensure privacy and confidentiality. The Bigiswun Kid Project leadership team includes two local Aboriginal investigators (EC, JD) and three non-Indigenous researchers (EE, ST, LR). The four senior Aboriginal women on the MWRC board formed the community advisory board ([Figure 2](#)). The board was consulted approximately every three months. Eleven additional community members were employed as community navigators for individual communities or clusters of communities and trained in research methods. Throughout the project they ensured that the conducted research was culturally appropriate, provided guidance and expertise, provided advice on language, and led camps and workshops in their community. Day-to-day guidance from these 11 community members proved invaluable in ensuring the cultural safety of and engagement and support from individual communities. The community navigator role is discussed in more detail below.

Community consultation

A comprehensive 18-month community consultation was conducted before commencing the research, to determine: whether the community wanted this study; if they did want it, how they would like it conducted; what questions they would like answered; and what outcomes they wanted from the research. Seventy people were consulted, of whom 50 were Aboriginal, including: senior leaders from communities and ACCOs ($n = 10$); young people from the Fitzroy Valley



Main elements of the APAR process

How they were incorporated into the Bigiswun Kid Project

Indigenous leadership and governance and the establishment of local Indigenous community reference groups

This project was initiated and led by MWRC, an ACCO. EC, the CEO of MWRC, was a chief investigator of the research project. The MWRC board, which is made up of four Aboriginal women, formed the project advisory group and were updated at least every three months. The study also continually consulted and partnered with senior Aboriginal women, leaders of other local ACCOs, young people and their parents throughout the project.

The involvement of Aboriginal co-researchers in supporting communities to collectively identify risk and protective factors

Two local Aboriginal people, male (MB) and female (EB), were employed full-time as researchers, community navigators for non-Indigenous staff and youth mentors. An additional 11 local Aboriginal people, mostly senior Aboriginal women, were employed to provide information for, and support to, specific communities.

The enactment of a research process that respected Indigenous people as experts by experience of their own mental health, their families and communities

Continuous community consultation: Extensive and continuous consultation guided the research aims, methodology and the support provided during the research. The Bigiswun Kid Project team continually reflected on community input and refined the research and support activities accordingly.
Interview design and development: The concepts measured in the interviews were identified through formal consultation with community members, families, young people and local services. The measures and the wording of each question were reviewed, modified (if needed) and decided on by five local Aboriginal people, including EC, JD and MB.
Support trialled: A range of support offered to young people during the research process was trialled. The nature of this support and how it was delivered were identified by the participants (young people and their families) and delivered by the Aboriginal youth mentors. Some of the participants (young people and their parents) were also employed to design and co-lead this support.

Localised knowledge generation

The Bigiswun Kid Project aimed to identify prenatal, early childhood and adolescent protective and risk factors to positive and adverse adolescent outcomes for young people in the Fitzroy Valley, including SEWB. The research also captured what young people feel they need to thrive in adulthood. The research did not try to examine the young people's knowledge or understanding of Western mental health concepts. Rather, the interviews aimed to understand what young people perceived as the primary risk and protective factors impacting their wellbeing and what support and services they needed and how the support should look. The Bigiswun Kid Project findings will allow the community to promote protective factors and improve outcomes for the next generation. MWRC are also using the Bigiswun Kid Project's findings to inform the design of the support and services that young people said they need to thrive in adulthood.

Community level feedback and dissemination

The Bigiswun Kid Project data are fed to MWRC and the wider community as soon as possible to ensure that they can be used to inform service improvement and design. Preliminary analyses of the key issues facing young people and the support they need were conducted once data collection reached 25% and 50% and these findings were used to inform the support provided during the research. For example, the high rate of mental health issues being reported was quickly noticed, so it was ensured that the support focused on lifting young people up and helping them to feel good. These findings were also reported to relevant policymakers, such as the WA Mental Health Commission and local mental health services. Formal data analysis of the complete dataset is under way and the findings will continue to be fed back to the wellbeing service established as part of the research, as well as through workshops, camps and summaries posted/emailed to participants as requested at the consent process and through formal meetings with relevant local services and policymakers.

The enactment of the NHMRC Indigenous core values

A project values and ethics statement was developed prior to commencing the research to ensure that the project protocol aligned with the six values outlined in the Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: Guidelines for researchers and stakeholders 2018.

The implementation of nine guiding principles of social and emotional wellbeing

The nine guiding principles of social and emotional wellbeing were considered throughout the design, implementation and interpretation of the Bigiswun Kid Project research and when designing and implementing the support provided to young people during the research. For example, the research questions aimed to recognise the strengths and cultural connections of the young people, as well as the racism, environmental adversity and social disadvantages that may impact the young people's health and wellbeing.

Abbreviations: ACCO, Aboriginal community-controlled organisations; APAR, Aboriginal participatory action research; CEO, chief executive officer; MWRC, Marninwarntikura Women's Resource Centre.

Table 1: How the Bigiswun Kid Project incorporated the Aboriginal participatory action research components, as outlined by [Dudgeon et al. \(2020\)](#)

($n = 17$) and their parents/carers ($n = 30$); and representatives from relevant government services ($n = 13$) (e.g. Departments of Health, Education, Police, Justice and the National Disability Insurance Agency) ([Rice et al. 2022](#)).

Key messages from consultation with senior Aboriginal leaders were:

1. Any research conducted in the Fitzroy Valley must directly and immediately benefit participants.



Figure 2: The Bigiswun Kid Project Advisory, Leadership and Project Teams. MWRC, Marninwarntikura Women's Resource Centre; USYD, University of Sydney.

Community leaders did not want us to ask young people what support they needed and then have them wait for two to three years for action (following data collection, analysis, dissemination and advocacy for funding and support).

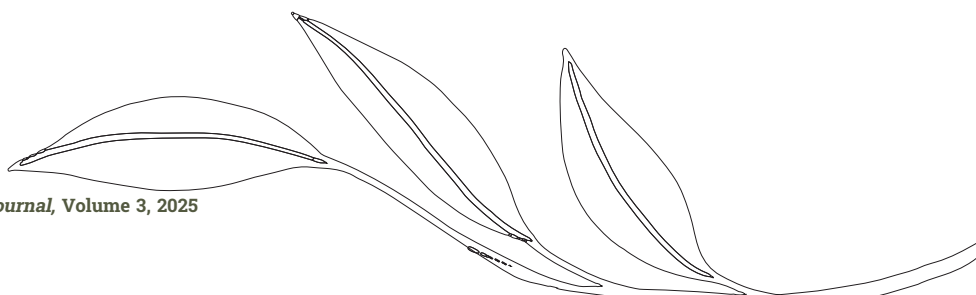
2. *The research team must live in the community to understand the culture and function of the community.* A strength of the Fitzroy Valley is that it is rich in cultural knowledge and history. Much of this is not written down, but it nevertheless plays a significant role in the day-to-day lives of communities. Continuing cultural knowledge and traditional activities through generations means that some social norms and customs are different in the Fitzroy Valley compared with other parts of Australia. These customs take time to learn but are vital to properly engage with community members. The Fitzroy Valley also experiences extreme social and economic disadvantages and barriers to accessing services. For example, a particular service might appear available to an outsider because funding has been allocated, but the service may not be operating or accessible to all. The disparity

between funding for, and availability of, services and support can only be understood through experience. High staff turnover and short-term funding mean frequent service availability changes. For these reasons, senior community members felt that researchers who aim to understand the communities' issues and needs must spend a significant amount of time living in and experiencing life in the community.

Key messages from consultation with young people and their parents were:

1. *The parents of young people wanted us to employ local Aboriginal people, whom the young people respected and got along with, as mentors on the project.* The mentors could help engage young people and support them through the research but also help connect them to the support they needed during the interviews. For cultural reasons and to ensure that the young people felt comfortable, there had to be at least one male and one female mentor.
2. *The young people wanted more opportunities and activities, such as spending time on Country, going to the river or local springs, playing sports, and participating in music, art, or nurture/pamper nights.* Like their parents, they wanted to share these activities with their peers and be supported by Aboriginal mentors.

Based on this feedback, the leadership team decided on three additional research components (Figure 3). The first component was to follow up with the Lililwan cohort to identify the support needed to improve the health and wellbeing of young people. The second was to provide direct and immediate



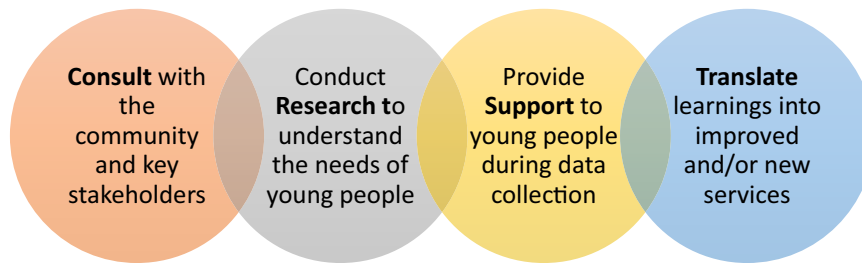


Figure 3: Components of the Bigiswun Kid Project.

support to benefit young people during the data collection phase. This support was to be identified by parents and young people and provided by local Aboriginal people employed as mentors, as described below. The third was to enhance existing services and create new services to improve the health and wellbeing of young people in the Fitzroy Valley. Based on the consultation, it was decided that a senior research team member should live in the Fitzroy Valley for the duration of the research; LR, a research fellow, lived and worked on the Bigiswun Kid Project in the Fitzroy Valley for three and half years (2019–22).

Community consultation continued throughout the project's life. Key stakeholders such as senior Aboriginal community members, parents, young people and relevant services were provided with regular check-ins and updates and invited to provide feedback and guidance. The consultation will continue as the data are analysed and written up to ensure that the community guides the specific questions posed and the interpretation of the results.

Aboriginal researchers, young adult mentors and community navigators

The project employed two local Aboriginal people (male MB and female EB), both as researchers and

youth mentors, and another 11 community navigators for specific communities.

Aboriginal researchers and youth mentors

Like the Kimberley Empowerment, Leadership and Healing Project (Dudgeon 2012), the Bigiswun Kid Project team included local Aboriginal people as researchers to ensure that local knowledge and lived experience of community members were considered in everything that was done and that local understanding of the context informed how data were captured and interpreted (Dudgeon et al. 2020).

The male and female researchers/youth mentors were employed full-time. They undertook research training and worked alongside non-Indigenous researchers with input into all aspects of the community research, including initial consultation with communities and services, study design, seeking consent from individual participants and community organisations, and conducting interviews and data collection. They also acted as mentors and directly and immediately supported young people during the two-year data collection phase by providing practical support, such as helping young people navigate existing services, taking them on Country, helping them seek employment and achieve other goals.



While deciding on the interview questions and types of support that young people should receive during the research, the Aboriginal researchers/mentors recognised the challenges and potential burden this work could have on their own wellbeing, such as the impact of listening to young people talk about their mental health concerns and early life trauma. The mentors also felt that some of the support the young people might need was unavailable in the Fitzroy Valley. They suggested that assistance from people with experience in providing support and navigating non-Indigenous services would help them build the skills to better support young people and navigate complex processes. Furthermore, when the interview questions were piloted, some young people said that they would feel more comfortable if they were interviewed by someone outside the Fitzroy Valley who they did not know; however, they said that they wanted someone relatively young with whom they felt they could relate.

Aboriginal community navigators

It was learned from the Lililwan Project that additional community navigators from specific language groups, communities or clusters of communities would be needed to help ground the research in each community. The MWRC CEO and Aboriginal researchers identified 11 local Aboriginal people from the five language groups who were casually employed as community navigators; these were usually respected senior women known for supporting their communities to access support and services. The community navigators guided the team about implementing the study and support in their communities, helped the research team engage with young people and their families, and informed the team of relevant community-specific information (e.g. if a person was in sorry business, required additional support, etc.). All Aboriginal researchers/community

navigators provided contextual information during data collection to ensure that narratives collected during interviews were not misinterpreted or distorted by Western views ([Madison 2008](#)).

Non-local researchers/youth mentors

Based on feedback from Aboriginal researchers and young people, one male (FW) and one female (NR) non-Indigenous person were employed. These non-Indigenous staff were relatively young (in their mid-to-late 20s), so they were relatable to the young people and had experience as mentors and navigating government services.

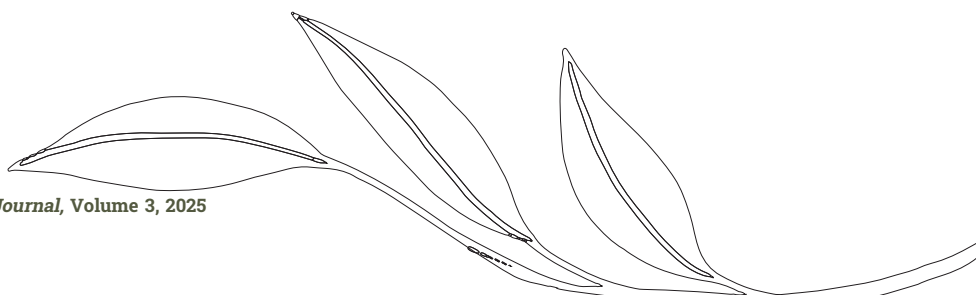
Results

Some benefits and lessons from using the APAR approach are now described and discussed in relation to existing research.

Research in action

The authors of The National Empowerment Program ([Dudgeon et al. 2014](#); [Dudgeon et al. 2017](#)) note that: *PAR is not just research, which is hoped will be followed by action. It is action, which is researched, changed and re-researched within the research process by participants* ([Dudgeon et al. 2020](#), p. 21).

The Bigiswun Kid team informed the young people about the research interview and the support available during data collection. To avoid coercion, it was made clear that they could access the support without participating in the interview. The nature of the support was driven by what young people and their parents identified during the consultation and evolved throughout the project as the interviews identified additional support required. The most common support young people requested was assistance in spending time on Country, accessing a health, mental health or sexual health service, applying for work or tertiary education, and applying for Centrelink (social





The most common support provided during the research	Number of people supported
On Country activities/camps	140
Health, mental health or sexual health services	65
Child development workshops	60
Transport (ID or licence)	60
Register birth, birth certificates	53
Bank card, superannuation, Tax File Number, Medicare card	52
Women's art therapy	50
Education and/or employment	45
Applying for housing	30
Adapting the gatekeeper suicide response training for parents	20
Centrelink	14
Supported work program	10

Table 2: Support provided to young people during the Bigiswun Kid Project

security payments) or a driver's licence. The Aboriginal and non-Indigenous mentors and non-Indigenous research fellow walked alongside the young people to access this support, which is outlined in [Table 2](#).

The consultation and interviews asked the young people about the support they might need to thrive in adulthood and how they would like this support to look. Providing support ensured that the research project immediately benefited the community, and the benefits responded to the needs and interests of the young people. Both of these responsibilities are outlined under the Australian Institute of Aboriginal and Torres Strait Islander Studies Principles for Conducting Research in Aboriginal Communities ([Australian Institute of Aboriginal and Torres Strait Islander Studies \(AIATSIS\) 2020](#)).

Employing Aboriginal people as mentors to support young people and giving mentors the help they need to succeed fits with the responsibility of engagement and collaboration, ensuring, where possible, that Aboriginal people have a right to full participation and collaboration in research projects and processes

([AIATSIS 2020](#)). Having Aboriginal people employed on the project as mentors and co-researchers also fits with item 13 of the CONSIDER statement checklist, as it ensured that the research supported developing and maintaining Aboriginal capacity. Walking alongside young people to access existing services helped provide the Bigiswun Kid team with valuable insight into the barriers and facilitators that young people experienced. The team were able to use this information to help inform local services and, where possible, make changes. Having this project embedded into the MWRC, an existing local ACCO ([Haynes et al. 2022](#); [West et al. 2012](#)), meant that the team had the community and leadership support to help them work with existing services to break down some barriers.

Knowledge translation

In addition to providing support during the research project, a knowledge translation plan was developed to ensure that the research led to improvements in existing services or, where necessary, helped establish new support and services. Forty-seven young people and their parents identified the seven knowledge translation goals during an initial 18-month consultation before the project commenced, and these were discussed and verified with a larger sample size ($n = 94$) in the interviews with parents and young people. These goals are outlined in [Tables 3 to 5](#), along with the knowledge translation activities undertaken during data collection and the steps taken to ensure that the benefits and translation continued past the research.

Critical lessons from providing support in the Bigiswun Kid Project

The Bigiswun Kid Project team (Aboriginal and non-Aboriginal researchers and mentors) learned much through observation and feedback while supporting young people and their families during the data collection process and through a collaborative process





Knowledge translation activities: social and emotional wellbeing support		
What young people said they need to thrive in adulthood	Short-term translation provided to young people and/or their families during the research	Steps taken to ensure long-term knowledge translation beyond the research
2. A culturally appropriate social and emotional wellbeing service	1. The study partnered with a clinical psychologist to run 10-week workshops (one in town and one with a remote community) with young people and their parents to learn what social and emotional wellbeing meant to young people and how they would like the support provided. 2. The study partnered with an art therapist to run weekly art therapy workshops for 12 months with young women to trial some of the social and emotional wellbeing support identified from the above workshops. 3. The study walked alongside young people who required formal mental health support, to help them navigate and access existing mental health services. 4. The study helped young people and their families co-lead on Country activities, as spending time on Country is one of the primary coping mechanisms used to manage negative emotions. 5. Through the Bigiswun Kid interviews, the young people self-reported high rates of mental health concerns as well as high rates of early life and often complex trauma.	The study repeatedly presented these findings, the lessons learned from the workshops and other activities to relevant policymakers throughout the research project. It was through this advocacy that MWRC was invited to apply for and secured funding from the Western Australia Mental Health Commission to formally pilot a young adult SEWB service.
3. Suicide prevention workshops for community members	The MWRC and USYD partnered with the Fitzroy Valley District High School psychologists and 10 senior Aboriginal women to modify the gatekeeper suicide prevention training that was designed for professionals to make it accessible to families in the Fitzroy Valley community. It then partnered with a collection of four communities to pilot the training and discuss how the communities can lead their activities to raise awareness about how to support young people who feel suicidal. The approach that the communities wanted fit well with the approach used in the Kimberley Empowerment, Leadership and Healing Project and National Empowerment Programs.	The lessons learned from this trial were written into a report that will be used to inform the potential expansion of the SEWB service to also include suicide and other mental health support workshops. The findings were also given to the school and the community to provide them with tangible strategies they can use to support young people.

Abbreviations: MWRC, Marninwarntikura Women’s Resource Centre; SEWB, social and emotional wellbeing; USYD, the University of Sydney.

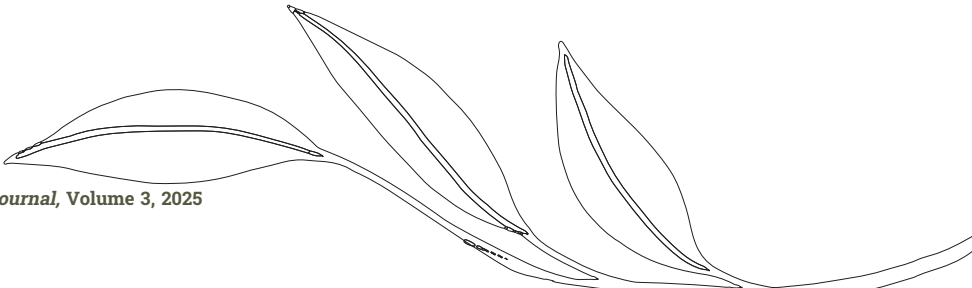
Table 3: Immediate and long-term social and emotional wellbeing knowledge translation activities

of reflection and discussion after reviewing the data collected and while providing support. Some of these critical lessons are discussed below. The Bigiswun Kid Project team identified the first three lessons, and senior community members identified the remaining two. The Bigiswun Kid Project leadership team reviewed and added to the lesson.

Lesson 1: A community-driven, bottom-up approach enabled a place-based service/support design and ensured community engagement

During consultation, community members and service providers highlighted the importance of ‘place-based’ designed support and services. During these discussions, people often spoke about the differences between towns in the Kimberley, for example: Broome,

Fitzroy Crossing and Derby in the West Kimberley. While implementing the Bigiswun Kid Project in the Fitzroy Valley, it was learned that this need for place-based design also applies to remote Aboriginal communities often clustered together. Each of the 32 Aboriginal communities that make up the Fitzroy Valley is unique with its own demography, resources and geographical strengths and needs. For example, communities near Fitzroy Crossing town typically access health services from the town-based hospital, whereas communities located 100+ km away from town access health services through a range of services (e.g., the Royal Flying Doctor Service, drive-in drive-out government or private services and community-based nurses). These differences mean



Knowledge translation activities: practical support

What young people said they needed to thrive in adulthood	Short-term translation provided to young people and/or their families during the research	Steps taken to ensure long-term knowledge translation beyond the research
1. Supported work programs	Most young people wanted to work but the available jobs required work experience. Young people wanted entry-level jobs that offer a trauma-informed supported work environment that helped them build the confidence and experience needed to enter the formal workforce. 1. The study walked alongside young people to seek employment (going to the employment agency, writing a resume, practising for interviews). 2. The study helped 10 young people obtain employment at external organisations/services. 3. We created a piloted supported work program at MWRC where we employed 9 young people in various roles within the organisation and scaffolded roles and the level of support to allow the young people to succeed, and build their skills, experience and confidence. Most of these young people went on to find full-time employment in external services after the research.	From the activities completed in the research, it was learned that there is a need for local organisations/ services/businesses to offer supported work programs. However, it is difficult for employers to do this with limited funding and resources. The Bigiswun Kid Project findings were used to help MWRC apply for and secure a National Indigenous Australians Agency grant to consult with local organisations and design a supported work program that can then be trialled with employers in the Fitzroy Valley to see whether a supported work program helps young people obtain and retain employment.
4. Housing	1. The study helped >30 young people sign up for housing, either a house in their community or through the WA Department of Communities housing to help ensure the true need for housing is reflected in the current housing applications. Many more young people intended to apply once they received the identification needed to make the application. 2. The senior research team notified every policymaker of the impact over-crowded housing and homelessness are having on young people, their families and services in the Fitzroy Valley. They reminded policymakers that even if housing was not directly part of their portfolio, housing is impacting their priorities, as homelessness affects all aspects of a person's life.	Unfortunately, it is not felt that the study has managed to progress far with the housing shortage and so will need to continue to strongly advocate for more housing to be built across the Fitzroy Valley to address the high levels of homelessness.
5. Assistance in obtaining a driver's licence	Young people wanted a driver's licence, most often to secure employment. 1. The study walked alongside 60 young people to help them access a driver's licence and identified a range of barriers. For example, to obtain a driver's licence, you need five forms of identification (ID), including a birth certificate. Most young people did not have any form of ID and, in some instances, neither did their parents. Many communities do not have phone reception, most young people do not have a phone, few people have cars and there is no public transport. Accessing services is even more complex if you do not know the ever-changing processes. 2. The study worked with the Department of Transport (DoT) to change some of their policies and procedures to make applying for a driver's licence more accessible for young people in the Fitzroy Valley and successfully advocated for more locally based support.	Some of the changes made following the advocacy: • The DoT worked with the team to develop a flyer with pictures to make it easier for people to understand what ID is required. • The DoT allowed all young people to use the pen-and-paper theory test, as this version had been adapted to have better readability than the online test. • The DoT increased how often they travelled out to the Fitzroy Valley and surrounding communities and advocated to increase the number of visits by a representative from Births, Deaths and Marriages to increase access to birth certificates. • The DoT provided funding to a local ACCO to employ someone full-time to provide driving lessons to the community. The staff trained that person in how best to work with young people in the region. • The DoT allowed a support person to sit in the back of the car for the driving either for cultural reasons (e.g. male instructor, female participant) or as a support person.

Abbreviations: ACCO, Aboriginal community-controlled organisation; MWRC, Marninwarntikura Women's Resource Centre.

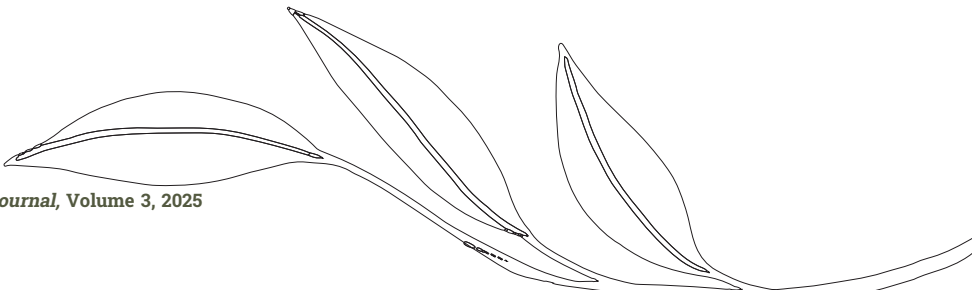
Table 4: Immediate and long-term practical support knowledge translation activities



Knowledge translation activities: disability support		
What young people said they needed to thrive in adulthood	Short-term translation provided to young people and/or their families during the research	Steps taken to ensure long-term knowledge translation beyond the research
6. Access to disability support	The NDIS was rolled out in the Fitzroy Valley in late 2020. Funding was received from the NDIA to consult with the Fitzroy Valley to determine how to improve the lives of people with disability, with a focus on the NDIS roll-out. 1. Interviews were conducted with 15 people with disability and 20 carers. 2. 13 key stakeholders were formally interviewed and further consultation was conducted with an additional 30; these included staff working at local disability services, senior staff at ACCOs and government services, and NDIA representatives. 3. The study walked alongside 20 people to navigate the NDIS process from their first appointment with an NDIA staff member to accessing services. From these activities, we wrote a report which we presented to the Minister of the NDIS, the Hon Linda Reynolds CSC.	As a result of this work, the senior Bigiswun Kid Project research team were invited to present to: 1. The Joint Standing Committee on the NDIS Inquiry into Independent Assessments; and The Royal Disability Commission. These presentations resulted in direct contact with senior state and federal representatives from the NDIA, who invited the team to be a part of an advisory group to inform the drafting of the NDIS policies for remote communities.
7. Workshops and resources for people working in the community about how to effectively talk about disabilities in remote Aboriginal communities	During the Bigiswun Kid Project consultation, we learned that many people working in the Fitzroy Valley, including staff working at the local health services, had not heard of FASD. During the interviews, Bigiswun Kid Project interviews parents who reported health professionals not understanding the needs of their child with FASD. By walking alongside several young people with FASD to access the health service, it was realised that there are many barriers these young people face. Through this work, a lack of identification and diagnosis of cognitive impairment, due to FASD or other causes, was also identified, which meant that many young adults with a cognitive disability were often left to manage health issues on their own and as a result often minor health concerns (e.g. an infected cut) would end up severe (e.g. having a finger amputated). Through both these activities as well as the above-mentioned NDIS Project activities, the Bigiswun Kid Project team identified key differences between how disability is perceived and discussed by Western-based health and disability services and how disability is perceived and discussed by community members. It is believed that this difference relates to cultural differences and the fact that there is no direct translation of the Western term disability in Aboriginal cultures in the region.	The USYD research team worked with the MWRC to apply for and secure an NDIS information, linkages and capacity building grant. The grant targeted projects that aimed to increase access to mainstream health services for people with disability. This grant is being used to conduct interviews with senior Aboriginal community members who have experience working with people with disability, to better understand how the community would like disability discussed by services. The study team will also interview health professionals to further understand the facilitators and barriers for people with disability accessing health services. The knowledge gained from the interviews will be used to develop resources for health professionals about how best to talk about disability in the Fitzroy Valley, as well as workshops with community members about the types of support and services available for people with disability (e.g. occupational therapy, speech therapy, etc).
Abbreviations: ACCO, Aboriginal community-controlled organisation; FASD, foetal alcohol spectrum disorder; MWRC, Marninwarntikura Women’s Resource Centre; NDIA, National Disability Insurance Agency; NDIS, National Disability Insurance Scheme; USYD, University of Sydney.		
Table 5: Immediate and long-term disability support knowledge translation activities		

that the types of services and how they are delivered significantly differ across communities. By systematically asking young people, their parents and key stakeholders in each community what services they need and how they should be delivered, their specific community structure and needs were

identified and incorporated into the type of support offered. This bottom-up approach also promoted buy-in from community members, including local leaders, increased community engagement, and ensured that the support was efficiently and effectively delivered. This approach was used for





every support, whether weekly art therapy workshops, in-community baby brain training, one-on-one coordinated access to services or on Country camps. Consistent with the current experience, previous research has shown that bottom-up informed services ensure place-based designs (Tiwari et al. 2018).

Lesson 2. A coordinated support model is needed to foster a holistic notion of health and wellbeing

The support provided to young people during the Bigiswun Kid Project data collection was predominately funded by research grants and designed to be an iterative learning experience. It allowed staff to modify how they delivered support based on the young people's feedback. Through this process and regular consultation with existing services, it became apparent that a significant barrier for young people to accessing services in remote regions is that the services are divided based on a Western framework that does not fit with the holistic way that health and wellbeing are viewed in Aboriginal culture (Dudgeon et al. 2014). For example, if a young person wants to get a job, they go to the employment service, where staff provide them with a list of available jobs. Almost all jobs require a driver's licence. To obtain a driver's licence, a young person needs to apply for five forms of ID, which require applying for a birth certificate from Births, Deaths and Marriages (who only visit the community twice a year), applying for a debit card from a bank (the closest is two hours away); applying for a Medicare Card remotely; and contacting two government services for letters confirming their identity (e.g., Police, Centrelink or Child Protection if they've had contact with these services). Understanding these processes is confusing, and navigating each application is challenging. Similar barriers exist for accessing other services, like applying for Centrelink payments, housing, or

health services for ongoing or chronic health conditions.

It was found that one of the most common forms of support that young people requested was someone to walk alongside them to navigate these processes, advocate where necessary, and role model how to engage with each service. This coordinated support helped young people achieve their goals while allowing them to develop the skills and confidence needed to access services independently. Walking alongside young people to navigate the services they needed to achieve their goals helped build rapport and gain trust. It also offered opportunities for them to talk about other and often more serious issues they wanted to address (e.g., domestic violence, homelessness or mental health concerns).

Below are a few anecdotal reports of the strengths the young people identified in the coordinated support model. The young people liked that:

1. The Bigiswun Kid team was a one-stop shop where they could go for any concerns and not feel like they had gone to the wrong place
2. They only had to tell their story once
3. The team helped break down barriers that could arise across multiple services (e.g. English as a second language, literacy concerns, shyness, family complexities, illness or mental illness)
4. The team scaffolded the level of support provided based on the young person's needs and would not push them into something with which they did not feel comfortable (e.g. forcing them to engage independently with a service before they felt ready).

Lesson 3: Two-way research/services respect privacy and promote two-way learning and capacity building

During the community consultation process, community members, parents and young people



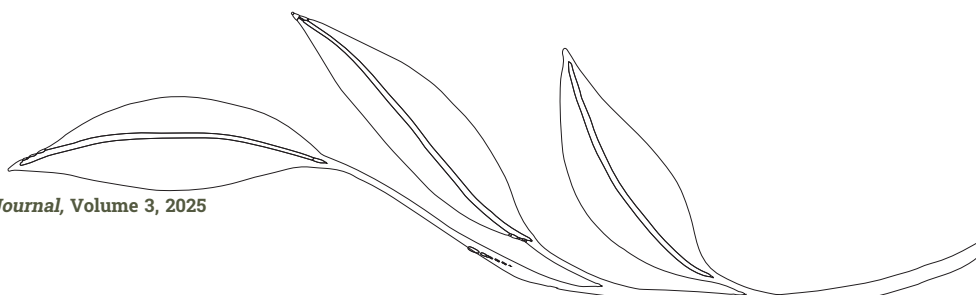
discussed balancing cultural safety with privacy. It was noted that employing local Aboriginal people to collect data and provide support was essential for identifying and appropriately engaging young people in a way that made them feel culturally comfortable and safe. However, as noted earlier, the young people wanted to be given a choice about who would support them through data collection: a local Aboriginal person known to them or someone not from the Fitzroy Valley. Some young people felt more comfortable discussing personal information with someone they did not know, as this provided a greater sense of confidentiality and privacy. During the consultation, some young people said that they would prefer a non-Indigenous person from outside the Fitzroy Valley. The Aboriginal researchers/mentors (MB, EB) who supported the young people believed that this is because non-local, non-Indigenous people feel more foreign and distant than non-local Aboriginal people, and this distance offered a greater sense of privacy. So, both local Aboriginal and non-local, non-Indigenous researchers/youth mentors were employed.

This model enabled the principle of two-way learning to be followed to encourage cross-cultural understanding and sensitivity. Aboriginal researchers/mentors brokered all initial interactions between non-Indigenous researchers and community members and ensured that non-Indigenous researchers always followed cultural protocol, as discussed more below. The Aboriginal staff lived almost exclusively in the Kimberley, providing them with extensive local and cultural knowledge. They all also had first-hand experience supporting young people and people with disability. However, living in the Kimberley meant that they had limited opportunities to access disability, mental health, social and emotional wellbeing, and other

youth-focused services. By working alongside the non-local researchers/mentors, they were able to build their knowledge and capacity in delivering youth-centred, disability and social and emotional wellbeing type support and to learn how to navigate a range of government services. They also developed their capacity as researchers and advocates for young people in their community.

By working together, the team identified differences in Western services and Aboriginal ways of knowing, being and doing that sometimes acted as barriers to service access for young people. For example, as outlined in the section on knowledge translation ([Table 5](#)), some young people needed support accessing disability services. The team identified a stark difference in how disability is perceived and discussed by local Aboriginal community members and Western service providers. By having Aboriginal and non-Indigenous staff working together, the Bigiswun team could identify and discuss differences in Western and Aboriginal worldviews and use this shared knowledge to develop a common language and strategies that helped young people and their families more comfortably engage with Western services. Funding was also sourced from the National Disability Insurance Agency to develop resources to better inform the local Western disability and health services in how best to discuss disability with Aboriginal people in the Fitzroy Valley.

It is not believed that this is the only model that would work in remote Aboriginal communities. Providing local Aboriginal people with more opportunities to visit existing services outside the region would be another way to gain experience with various services and build capacity. Confidentiality and privacy are important to Aboriginal people, and possibly even more so in remote Aboriginal communities where everyone is





known to each other. While having the option to be interviewed by a non-Indigenous researcher/mentor helped ensure privacy in this project, other strategies could be used to maintain privacy and confidentiality. For example, some participants completed the interview independently using a tablet. The young people were informed that the data were saved on a cloud with an ID number and that no one they knew could access this information. There are also services that employ non-local Aboriginal people to provide drive-in and drive-out support, and these staff have built great rapport and relationships with local people who feel comfortable speaking to them about personal concerns.

Lesson 4. Non-Indigenous researchers and staff best developed the ability to be culturally responsive when they lived in the region and worked directly alongside Aboriginal staff

‘If you don’t go to sleep here and wake up here, you do not understand what life is like for our people’ – senior Aboriginal leader from the Fitzroy Valley.

The Fitzroy Valley community is rich in Aboriginal traditions and has the highest population of Aboriginal people in the Kimberley (Morphy 2010). The rich culture, continued language and connection to land are strengths and protective factors for young people in the Fitzroy Valley. However, these factors also mean that non-Indigenous staff working in the region have much to learn to succeed, be culturally competent and provide culturally safe services. Given their extensive experience providing services and conducting research, the MWRC leadership team knew that non-Indigenous staff working in the region would need local Aboriginal staff working alongside them.

In the Bigiswun Kid Project, three non-Indigenous staff moved to the Fitzroy Valley and lived there for

one (mentor, FW), two (mentor, NR) and three (research fellow, LJR) years during the research. Through first-hand experiences, they developed skills of cultural responsiveness, reflexivity and humility that go beyond what can be taught during a one- or two-day cultural competency workshop. Such workshops can help provide an overview of the local social and historical context and some cultural knowledge. However, it was only when the non-Indigenous staff were working alongside Aboriginal staff (EC, EB, MB, CC, JD, MH and the 11 community navigators) in communities for a prolonged period – watching how they interacted, asking questions and receiving continual feedback – that they began to develop the knowledge required to respectfully interact with community members. It was learned that non-Indigenous staff who work alongside Aboriginal people and take the time when they first arrive to sit back, listen, watch and learn have the greatest success in engaging with the community. The observation that cultural responsiveness needs to be developed over time through immersion and ongoing daily guidance by Aboriginal people (e.g. cultural mentors) aligns with the experience of others working with Aboriginal and Torres Strait Islander groups in Australia (Abbott et al. 2014; Burgess 2019; Currie 2022; Curtis et al. 2019; Irving et al. 2017).

According to Currie et al. (2022), there is a continuum of cultural proficiency which begins with cultural ignorance and moves through cultural knowledge, cultural awareness, cultural values and attitudes, cultural sensitivity, and cultural competency and proficiency. In this model, cultural competency is more than just knowing about cultural differences – it is achieved when a culture’s attitudes and behaviours are reinforced by how support and services are delivered to promote cross-cultural collegiality and collaboration in local organisations/services fields





(Currie 2022). Cultural proficiency moves beyond that to include the ability of staff and organisations/ services to recognise cultural differences and respond effectively and affirmingly and is a continual process (Currie 2022). However, the term cultural safety is favoured over cultural proficiency/competency to emphasise the need to be culturally responsive and provide culturally safe environments, services or research projects (Curtis et al. 2019).

From experience, having Aboriginal people working alongside non-Indigenous staff in remote Aboriginal communities promotes cultural responsiveness. It eventually allows non-Indigenous staff to be on the cultural proficiency journey. When Aboriginal staff cannot work daily alongside non-Indigenous staff, cultural mentors should be employed and accessible to non-Indigenous staff. For such support to be made available for organisations and services in remote Aboriginal communities, funders must recognise and value Aboriginal people's cultural expertise and provide sufficient funds to allow local Aboriginal people to be employed as cultural mentors/ community navigators. In line with this experience, there is good evidence that cultural competency is essential for delivering safe and effective services and conducting research in remote Aboriginal communities (Liaw et al. 2011; Burgess and Harwood 2021).

Lesson 5: Researchers and other staff working in remote Aboriginal communities must come with an open mind, listen deeply and reflect often to minimise their preconceptions and impact of lived experiences on how they perceive and interact in the community

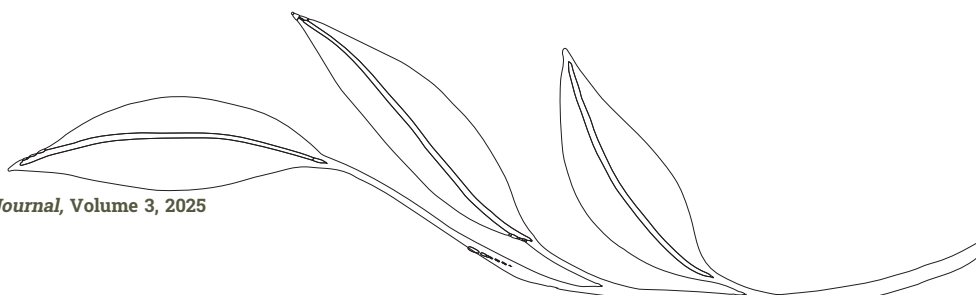
'So often non-Indigenous people come to consult with our communities, they hear, but they do not listen' – senior Aboriginal leader from the Fitzroy Valley.

For a consultation with Aboriginal community members to be effective, non-Indigenous people must

reserve their views of what they think Aboriginal people need so that they can be informed and guided by the community. Aboriginal knowledge and worldviews must be privileged so that change can come from within the community and not from outsiders (Haynes et al. 2022; West et al. 2012). Experience of the need for non-Indigenous people to go into remote Aboriginal communities open-minded and ready to listen deeply aligns with Dadirri, a concept from the Ngan'gikurunggurr and Ngen'giwumirri languages of the Aboriginal peoples of the Daly River region (Northern Territory, Australia) and shared by Miriam-Rose Ungunmerr-Baumann. Dadirri is a traditional way of healing that authors have used to help describe an Aboriginal research methodology. It is defined as *culturally informed philosophy and behaviour(s)... an Aboriginal concept which refers to a deep contemplative process of 'listening to one another in reciprocal relationships'*. This methodology encourages deep listening and reflection and requires an openness that ensures what is heard is directly interpreted as intended with an awareness of one's own bias. Dadirri also emphasises the importance of non-Indigenous staff building relationships with Aboriginal community members before community members feel comfortable working alongside them, and this also fits with the current experience. People in the Fitzroy Valley hold their culture and community close to their chests for good reason: to preserve and protect. Being welcomed in or shown around a community or taught about culture is a gift earned through building trust and developing genuine relationships with community members over time.

Discussion

This article describes how an APAR approach was implemented in a community-led youth wellbeing research project conducted in remote Aboriginal





communities in the Fitzroy Valley. In this project, the most critical components of the approach were Aboriginal governance and leadership at all levels, a comprehensive community consultation process, and the guidance of Aboriginal researchers, mentors and community navigators. Using an APAR approach ensured that the research included tangible community-identified and led support for young people both during and after the research.

As identified in other Aboriginal and Torres Strait Islander research (Bull 2010; McKnight et al. 2024; Milroy et al. 2022; Williams et al. 2024; Wilson 2020), it was learned that a comprehensive and ongoing community consultation process was essential for ensuring that the research was community-led at all stages (e.g. research design, data collection, analysis and write-up). Community consultation allowed the research team, including those from the community, to develop or strengthen relationships with community members and key stakeholders. Relationships have been defined as the core of Aboriginal and Torres Strait Islander research, as they align with Aboriginal values and help promote accountability (Wilson 2020). The Aboriginal and non-Indigenous researchers, mentors and cultural navigators in the Bigiswun Kid Project built strong and authentic bonds by working closely as a team, respecting each other's knowledge and experience. The team also worked to build relationships with key stakeholders, most importantly the young people and their families, senior community members and other services, including partnering or supporting other local service providers' activities wherever possible. The importance of centring relationships is consistent with the National Health and Medical Research Council's Core Values for Ethical Conduct in research with Aboriginal and Torres Strait Islander peoples and communities (NHMRC 2018).

The findings closely align with those of the Moorditj Moort Boodja (Solid Family and Country) on the ground community relational framework for Aboriginal research engagement (Williams et al. 2024). This framework was developed by the authors of the Next Generation Aboriginal Youth Wellbeing Cohort Study and was based on research conducted in Perth and country towns south of Perth. The framework outlines culturally secure strategies for engaging young people in research. The same strategies were found to be crucial for engaging young people in remote communities in the Fitzroy Valley. For example, the Next Generation Aboriginal Youth Wellbeing Cohort Study authors also discussed the importance of involving Aboriginal people at all levels of the research (governance, leadership, research conduct and youth mentors), ensuring cultural safety by adhering to cultural protocols, capacity building of Aboriginal researchers, focusing on reciprocity and relationships, and working respectfully across generations (senior community members, parents and young people) (Williams et al. 2024).

The current findings also align with those identified in the Transforming Indigenous Mental Health and Wellbeing Project (Milroy et al. 2022). Most notably, the authors articulated the importance of not fast-tracking research. The Bigiswun Kid Project consultation and data collection took four years, which included a six-month pause due to COVID-19. Time was crucial for developing strong relationships and following a community-led iterative process, where the research, particularly the support provided to youth, evolved following genuine discussions. Funding bodies must allow adequate time and grant funding to enable meaningful consultation in research with Aboriginal and Torres Strait Islander peoples. Having time in the region also ensured the non-Indigenous staff could immerse themselves in





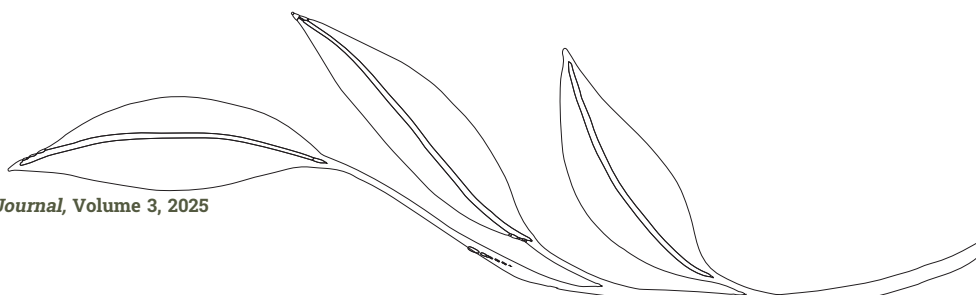
the community to develop a strong appreciation of the culture and gain insight into the young people's way of life.

Strengths and limitations

Many of the project's strengths are described throughout the paper. Some of these include the research being community-initiated and led, including Aboriginal people at all levels, and built on a long-term partnership between MWRC and USYD. The Bigiswun Kid Project also met all criteria included in the Aboriginal and Torres Strait Islander Quality Appraisal Tool; see [Pickard et al. \(2025\)](#) for details. A difficulty and limitation of the research was the lack of appropriate and validated measures available for conducting research with young people in remote Aboriginal communities. During consultation, it was learned that although some senior Aboriginal people and parents preferred yarning, as is often noted in the literature, the young people participating in this research preferred multiple-choice responses with the ability to add qualitative details if desired. The young people said that talking about themselves could be 'hard' or make them feel 'shame'. They liked how multiple-choice responses had sensitive answers written there, so they did not have to say them (they could point), and multiple-choice responses removed the pressure of coming up with answers. During the consultation and questionnaire trials, it was learned that multiple-choice responses also helped improve people's understanding of the question, particularly people who spoke English as a second language or had a neurodevelopmental disorder. However, few multiple-choice questionnaires have been designed or validated for young people in remote Aboriginal communities. If available, they were preferred and selected by the Aboriginal researchers, such as the Strong Souls Inventory. On reflection, had funding permitted, it would have been preferable to develop

and validate a place-based questionnaire that best captured the lives of the young people in this region. It is promising to see a recent increase in protocols for developing Aboriginal and Torres Strait Islander measures.

Another limitation is that the interview topics could not be revised or added to once data collection had begun, due to the delay this would take with ethics approvals and having to re-interview people. Although an extensive community consultation was conducted before data collection, it was noticed that more topics arose (e.g. nature and benefits of living within a kinship system, facilitators and barriers to participating in cultural activities and more details about environmental health) once a quarter of the interviews had been conducted. The systematic data collection did not allow an iterative process; however, the support provided to young people was iterative, and this continued to be modified and improved with feedback. Staff kept detailed notes on these topics while supporting young people so that the qualitative information they provided could provide context for interpreting the quantitative data. In line with recommendations from Aboriginal research leaders ([Dudgeon et al. 2023](#); [Milroy et al. 2024](#); [Wright et al. 2023](#)), it is anticipated that the APAR approach will be more frequently adopted in future research. As such, ethics committees may consider strategies for allowing more iterative research processes. Finally, while not a limitation, something that became apparent early during the consultation was that few community members were interested in pursuing a research career and formal research-focused education. Instead, the Aboriginal researchers/mentors on the project were interested in developing skills needed to support young people and people with disability. Therefore, the type of capacity building offered to the team was adapted to focus on upskilling





them to become mentors for young people and people with disability. It is believed that this is an important learning that may be useful for future research projects and highlights the importance of being responsive to community needs.

Conclusion

The overarching aim of the Bigiswun Kid Project was to identify adolescents' needs and build knowledge to inform services to improve the health and wellbeing of adolescents in remote Aboriginal communities. By adopting an APAR approach, it was decided through community consultation that this aim would be best achieved over three components. First, parents and young people were interviewed to identify how best to improve the health and wellbeing of young people in the region. The interviews directly asked what support is needed for young people in the Fitzroy Valley, particularly as they transition out of school, and how they would like the support to be delivered. The interviews also asked about the young people's health and wellbeing. These latter data will be combined with information collected in the Lililwan Project to identify prenatal, early childhood and adolescent predictors of adolescent health and wellbeing. The interview findings will help services to decide what programs and support they can implement or enhance to help young people thrive. The second component was to provide direct and immediate support to benefit young people during the data collection. Providing this support ensured that the young people felt heard in the interviews by allowing them to see their response put into immediate action. Consistent with the APAR approach, this component also ensured that research in action was taking place and that the young people were actively involved in the research by deciding what support would be provided and how it should be delivered. Finally, by supporting young people in accessing services, the research team could identify

and experience some of the facilitators and barriers that young people face in accessing support and services, and the barriers and facilitators that services face in implementing support in this very remote region. The project's third component was to enhance existing services and create new ones to improve the health and wellbeing of young people. This component, which includes the project's knowledge translation process, is ongoing as data are analysed and used to inform services. However, one example is that the Bigiswun Kid Project leadership team used preliminary findings from component one and the support designs developed in component two to help the MWRC secure government funding to evolve the research support into an ongoing social and emotional wellbeing service for young people. Together, these three components exemplify how incorporating the APAR approach into research strengthens community ownership and involvement and ensures meaningful immediate and long-term benefits are embedded in research design.

Author contributions

E. Carter, L. Rice, E. Elliott, J. Davies and S. Thomas conceived and led the Bigiswun Kid Project. L. Rice, M. Bedford, E. Bear, N. Rice, C. Carter and F. Wella formed the Bigiswun Kid Project team, conducting interviews with young people and their parents and supporting them. L. Rice drafted the manuscript with input from all authors. All authors approved the final version.

Data sharing

Marninwarntikura Women's Resource Centre, on behalf of the Fitzroy Valley community, is the custodian of the data collected in the community (interviews, education and health records). The data are stored at the University of Sydney for security and confidentiality reasons. The information collected in the community may be used in future research.





Requests to access the data can be made to Dr Lauren Rice (lauren.rice@sydney.edu.au) or to Prof. Elizabeth Elliott (Elizabeth.elliott@health.nsw.gov.au).

Declaration of interests

The authors have no conflict of interest to declare.

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Author biographies

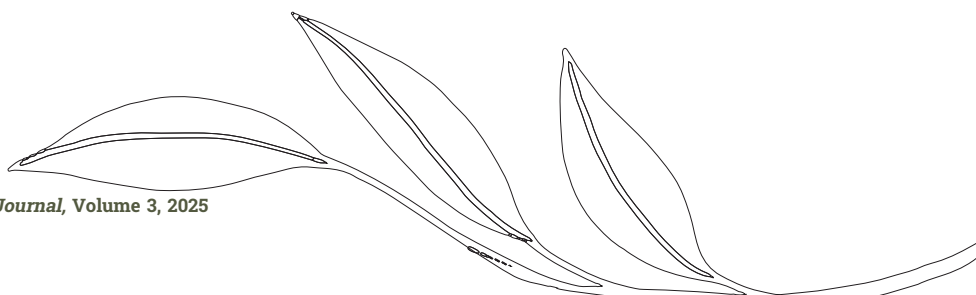
Lauren Rice is a non-Indigenous research fellow living on Yawuru and Bunuba Country. She has 6 years of experience working collaboratively with Indigenous communities. Lauren is a member of the Bigiswun Kid Project Leadership Team and spent three years living and working in the Fitzroy Valley for the Bigiswun Kid Project. She coordinated all aspects of the research.

Emily Carter is a Gooniyandi and Kija woman from Fitzroy Crossing in remote Western Australia and the

CEO of Marninwarntikura Women's Resource Centre (MWRC). Emily is passionate about creating equity and opportunity for everyone. She strongly advocates for government services and Aboriginal community-controlled organisations to work together toward the systemic change needed to ensure that Aboriginal people have the quality of life they deserve. Emily led the Bigiswun Kid Project leadership team and oversaw all aspects of the research, focusing on the work conducted in the Fitzroy Valley (consultation, design, data collection, advocacy and support provided during the study).

Emma Bear is a Gooniyandi and Ngarinyin woman from the Kimberley region of Western Australia. She was a co-researcher, community navigator and youth mentor on the Bigiswun Kid Project Team and is the author of a children's book. Emma was responsible for consulting with senior community members, designing project activities and materials to ensure they were culturally appropriate and place-based, conducting interviews with parents and young people, providing support to young people during the research, and guiding and mentoring the non-Indigenous research staff working in the Fitzroy Valley.

Mudge Bedford is a Bunuba man born and raised in the Fitzroy Valley. He was a co-researcher, community navigator and youth mentor on the Bigiswun Kid Project team. He is passionate about helping shape the next generation of young men and increasing access to disability support in his community. Mudge was responsible for consulting with senior community members, designing project activities and materials to ensure they were culturally appropriate and place-based, conducting interviews with parents and young people, providing support to





young people during the research, and guiding and mentoring the non-Indigenous research staff working in the Fitzroy Valley.

Cheyenne Carter is a Gooniyandi, Kija, Butchella and Jagera woman. As a young Aboriginal woman from the Fitzroy Valley, she provided valuable insight and direction to the research design. She was also responsible for conducting interviews and supporting young people.

Jadnah Davies is a Gooniyandi, Kija and Waanyi woman. She is the Marulu Manager at Marninwarntikura Women's Resource Centre and was a researcher on the original Lililwan Project and all subsequent research projects. Jadnah is one of the women who identified the need for the Bigiswun Kid Project to follow up with the Lililwan Project cohort to determine whether they received the support needed in childhood and adolescence. She helped inform the project design and guided and mentored the non-Indigenous staff.

Nikkita Rice is a non-Indigenous project coordinator who lives on Bunuba Country in the Fitzroy Valley. She spent two years working on the Bigiswun Kid Project, coordinating the day-to-day research activities, providing support to the Bigiswun Kid Project Team and conducting interviews with the young women. Nikkita is now supporting an Aboriginal community-controlled organisation in implementing the National Disability Insurance Scheme in the region.

Sue Thomas is a non-Indigenous educator and the Strategic Priority Lead at Marninwarntikura Women's Resource Centre. She is a member of the Bigiswun Kid Project Leadership Team and oversaw all aspects of the research, focusing on supporting staff on the ground, helping build connections with stakeholders and guiding the team.

Fergus Wells is a non-Indigenous social worker living in Bunuba Country in the Fitzroy Valley. He spent one year working on the Bigiswun Kid Project, conducting interviews and supporting the young men. Following the project's completion, Fergus remained in the community as a social worker on the Bigiswun Kid Social and Emotional Wellbeing Service.

Elizabeth Elliott is a non-Indigenous professor of paediatrics with 15 years of experience working collaboratively with Aboriginal community-controlled organisations from the Fitzroy Valley. Elizabeth led the original Lililwan Project and, with JD and Marmingee Hand, conceived the Bigiswun Kid Project. She is a leadership team member and oversees all aspects of the research.

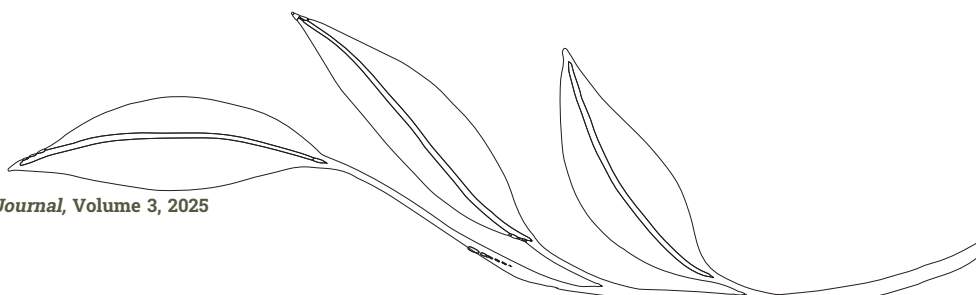
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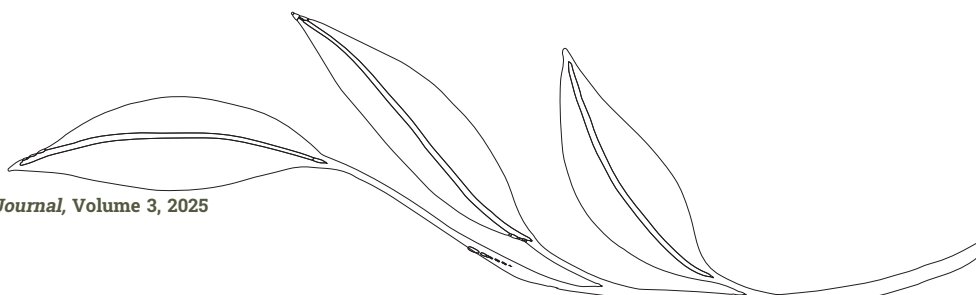
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