



# 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

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## 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

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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 yarn-ing process, more often than not, yarn-ing 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 yarn-ing and research topic yarn-ing, 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 yarn-ing. Collaborative yarn-ing expands the opportunity for sharing information, through exploring other topics which lead to new understandings (Bessarab & Ng'andu, 2010). Therapeutic yarn-ing 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, yarn-ing 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 yarn-ing 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 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. 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 yarn-ing, 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 non-threatening 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.

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## Supplemental Material

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