**‘That thing in his head’: Aboriginal and Non-Aboriginal Australian caregiver responses to neurodevelopmental disability diagnoses**

**Authors:**

Sharynne L. Hamilton[1,2]

Sarah Maslen[3]

Rochelle Watkins[1]

Katherine Conigrave[4]

Jacinta Freeman[1]

Melissa O’Donnell[1,2]

Raewyn C. Mutch[1,2]

Carol Bower[1,2]

[1] Telethon Kids Institute, The University of Western Australia, Perth, WA, Australia

[2] School of Paediatrics and Child Health, The University of Western Australia, Perth, WA, Australia

[3] Faculty of Business, Government and Law, University of Canberra, Canberra, Australia

[4] Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

**Abstract**

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

**Word Count: 7978**

## Introduction

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

The social aspects of diagnosis have long been of interest to sociologists, though relatively little attention has been paid to the ways in which different social groups engage with diagnostic processes. Gendered aspects of diagnosis have received some attention, particularly via analysis of gender-specific conditions. Studies of women's engagements with endometriosis diagnoses have emphasised contestation of medical expertise (Whelan 2007; Young, Fisher and Kirkman 2019). The significance of masculinities to men's discourses

about mental health diagnoses have also been subject to inquiry (Johnson *et al.* 2012), demonstrating that men are more reluctant than women to seek a diagnosis for a mental health condition (Zimmerman, Morrison and Heimberg 2015). Understanding diagnosis in relation to aging has also been examined, particularly in cases such as Alzheimer's and dementia, revealing the importance of listening to both caregivers and patients about their experiences of receiving a diagnosis regardless of cognitive condition (Brossard and Carpentier 2012; Schrag *et al.* 2018).

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

Studies of how different cultural groups respond to diagnoses are in their nascent stages. How health and illness is understood in the context of global Indigenous[1] cultures,

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

particularly where these cultures have endured centuries of colonial oppression, has been the subject of inquiry in a range of scholarly areas, including anthropology, medicine, and post-colonial studies (Wandji, 2019). Comprised mostly of deficit focused, Western-centred assumptions of Indigenous health and illness, these works have been extensively criticised for their lack of regard to Indigenous voices and knowledge systems (Chandler, 2012; Sherwood, 2013). Despite the well-established benefits of privileging Indigenous voices in health and illness research (Bessarab and Ng'andu, 2010; Sherwood, 2013), examination of the potential for shame and stigma to affect access to diagnostic services, or how a diagnosis is received, are largely absent in the context of Indigenous populations (Ayunerak et al., 2014).

This article begins to address this research gap through a comparative analysis of how caregivers from Aboriginal and non-Aboriginal Australian backgrounds respond to receiving a diagnosis of FASD or neurodevelopmental impairments for their child. These caregivers participated in a first-of-its-kind Australian study which was undertaken to establish the prevalence of Fetal Alcohol Spectrum Disorder (FASD) among youth sentenced to detention in (name of centre) between 2015 and 2017 (Author). FASD is a lifelong, preventable brain injury caused by alcohol exposure during pregnancy and those affected can have a myriad of secondary problems including trouble with the law (Fast and Conry 2004). Individuals with neurodevelopmental impairments (regardless of prenatal alcohol consumption) can have memory and attention problems, difficulty with language and communication, they are suggestible and prone to impulsivity (McLachlan *et al*. 2014). Of the 99 youth who underwent full assessments in the prevalence study, 74% were Aboriginal and half were from remote or regional WA. Thirty-six percent of participants were diagnosed with FASD and 89% were diagnosed with at least one severe neurodevelopmental impairment (Author). In addition to providing important information about the prevalence of FASD, this study has

opened a unique opportunity to explore cultural needs and understandings about receiving a diagnosis and diagnostic resources.

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

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

Shame is also significant in how Aboriginal caregivers receive a diagnosis of FASD in the context of intergenerational drinking.

**Background**

There is a paucity of literature exploring the way that caregivers receive a diagnosis for neurodevelopmental disabilities such as FASD. North American studies have found caregivers typically reported high satisfaction with FASD diagnostic processes and outcomes (Astley 2014). Other studies have captured how receiving a diagnosis can have dual consequences, with birth mothers experiencing grief, guilt and regret, and simultaneously feeling validated and relieved to have answers to their child's difficulties (Sanders and Buck 2010). Caregivers have also expressed concern about the uncertainty of their child's future in the absence of community support as they age (Murphy *et al.* 2007). For mothers who have children with disabilities, advocacy for their child(ren) is a much greater need, and is required more frequently, and over a much longer period of time (Blum 2015; Landsman, 2010; Doak et al. 2019) than for other children.

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

The broader literature on caregivers posits that social and biomedical explanations of diagnosis are interwoven narratives, and that network and resource mobilisation are preferred to medical intervention (Blaxter 2004; Malacrida 2004; Riessman 2008; Ryan and Runswick Cole, 2008). These narratives can produce collective understandings and connections which can assist caregivers, particularly where diagnosis is for less visible conditions such as neurodevelopmental disabilities (Blum 2015; Garro and Yarris 2009; Malacrida 2001). For mothers who have children with disabilities, advocacy for their child(ren) is a much greater need, and is required more frequently, and over a much longer period of time (Blum 2015; Landsman 2010; Doak et al. 2019) than for other children. A deeper understanding of the social and biomedical nature of the diagnosis can help parents and carers in this task.

It is important to explore what diagnostic processes mean for patients and their care networks to alleviate diagnostic uncertainty and ambivalence (Malacrida 2004). Without a diagnosis, caregivers can also be excluded from access to interventions, education, and support (Ennis-Cole, Durodoye and Harris 2013). This has been shown the case for Aboriginal children, particularly if they are geographically remote (Long 2015).

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

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

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

## Methods

### *Participants*

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

The researchers were aware of the need to minimise the harm that caregivers may have experienced. Some of these interviews were attended by the qualitative researcher in

company with the Research Officer because of the rapport that had already been built between them. In two interviews, both researchers were present for the entirety. The remainder were undertaken by the lead qualitative researcher. Remote and regional interviews were set up in community, with the assistance of youth justice personnel who worked with the families.

***Data Collection***

Data were collected using 'yarning' (Bessarab and Ng'andu 2010). Having a 'yarn' is embedded in the language of Australian Aboriginal people and is an 'Indigenous cultural form of conversation' (Bessarab and Ng'andu 2010 p. 37). Yarning creates relationships and governs responsibility and although yarning data can seem superfluous or irrelevant, it often reveals rich, insightful and valuable contexts (Bessarab and Ng'andu 2010). The qualitative researcher was an Aboriginal woman, making yarning culturally safe and aligned with the cultural values of Aboriginal people. It was also considered to be appropriate for non-Aboriginal participants in the study (for more details on the yarning method, see Author). It is important to note that while two Aboriginal fathers participated in this research, there were barriers to how much these participants could share with a female researcher, and so we focus on female caregivers in our analysis.

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

Prior to the yarn, participants were advised that the purpose of yarning was to get thoughts about receiving feedback about the results of their young person's diagnostic

assessments and to explore their thoughts on the diagnostic reports. With verbal consent, interviews were voice recorded and transcribed verbatim. Immediately following the yarn, the researcher recorded reflective field notes.

***Data Analysis***

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

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

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

In preparing the vignettes, the data from all 17 participants were re-analysed through an interpretivist lens which acknowledges participant realities are socially constructed and changeable, and agreed within cultures, social setting and relationships (e.g. Denzin and Lincoln 2003). From this process, five participants were selected based cultural background, depth of available data, children's diagnosis and transcripts reflecting diverse of views of the

diagnostic process. This allowed for a rich amount of data which reflects the stories of all participants in the qualitative study. All names are pseudonyms. Small details, such as immaterial but potentially identifying elements of examples, and reference to specific personnel and institutions, demographics and contextual information have been changed to protect participant identities. The vignettes were reviewed by members of the research team to ensure no story was identifiable.

**Vignettes**

***Phyllis and Peter***

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

When discussing whether Phyllis was surprised by the diagnosis she said:

> No, not really. I went to the school a lot because the kids were always in trouble, but school never tried to teach him special ways. Just saw them as naughty. Just put on band aids at school.

For Phyllis, diagnosis provided a way to explain the behaviour and combat the stigma Peter experienced:

> He is not an asshole like plenty of people think. It is because of that thing in his brain [FASD] … I send Peter to tell the other one to come home. Peter has forgotten what he is doing by the time he finds his brother, so neither of them get home and then they both end up getting into trouble. I want her [daughter's] other kids assessed you know, because she drank heavily, and they are still quite young, and they are running amok already.

Justice personnel assisted Phyllis with understanding and translating the contents of the diagnostic report. Diagnosis was useful in that it helped get assistance for Peter:

> I gave the report for [social services personnel] and Peter, he's been able to get help for disability. It much easier than for him remembering to go for job thing.

Phyllis liked the visual strategies that were provided as part of the diagnostic report. Relaying a story of how she sends Peter to the shop, she explained:

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

The diagnosis also helped Phyllis recognise FASD in another family member:

> I think my son has it [FASD]. He has been in and out of prisons ... I drank a lot, but I didn't know you know.

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

> I am so mad with her but then I did it to [drink alcohol during pregnancy] and she was the same.

***Katie and Kieran***

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

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

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

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

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

Katie spoke of the usefulness of the diagnosis and diagnostic report in securing access to services:

> I think it was good for him to have the assessments so he can receive proper supports and understanding as to why he thinks way he does and does the things he does.

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

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

The diagnostic report had been shared with a service provider and was also being used to plan for Kieran's release:

> We have drawn up schedules to make sure he does what he needs to do. It will be hard for him so things like Medicare and Disability Services will be supporting him too when he gets out.

When asked if she would share the diagnostic report with these services, Katie said she would "share it with anyone who would listen".

***Jill and Jasper***

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

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

might get into trouble. The fact that he can't focus, well this [diagnosis] kind of explains it.

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

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

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

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

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

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

***Suzie and Samuel***

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

Suzie felt positive about Samuel's participation in the assessments because it provided some insights into his behaviour that she was previously unaware of. She had wondered why Samuel had tended to play with much younger children. "That 'this thing in his head' (FASD) explains this", she said. However, Suzie had difficulties engaging with the diagnostic report:

> It [the diagnostic report] was hard cause the 'whitefulla speakin', I understand I ask [justice personnel] to tell me. Having it said simple helped me.

Suzie liked the strategies and ideas around using visual aids detailed in the diagnostic report to assist Samuel to remember things:

> I stuck picture on the door that said 'NO GROG' [alcohol] … he stopped, well at least in the house.

There was a sense of pride and achievement as Suzie spoke of how local community leaders had praised the initiative:

> They took photo to show other mob round ya know.

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

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

Suzie commented that Samuel was different to many other children in the community, but not due to FASD:

> He isn't like other Aboriginal kids. He doesn't like sport and doesn't play sport. This is the 'weirdness' he has, not that he can't do school good.

Suzie then asked the researcher: 'Can he go through lore [traditional customs related to emerging adulthood]?' The researcher encouraged Suzie to discuss this with community Elders.

***Sandra and Seb***

Sandra is an Aboriginal mum of 5 children. Sandra cares for her children full time and lives with her family in a small town in regional WA. Sandra's 17-year-old son, Seb, was diagnosed with FASD in the prevalence study. At the time of the interview Seb had been released and was living with Sandra.

Sandra was visibly upset by her son's diagnosis. Crying, she said:

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

Sandra also described confusion. Being the mother of a number of children, she was unsure why some of her children would be affected and not others:

> I don't really understand why Seb has many problems when [name, another child], well she is bright, finished school and works and is a good kid and I drank more with her, a lot more.

Sandra also discussed an older incarcerated child, wanting to know how he could be assessed:

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

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

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

**Discussion**

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

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

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

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

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

The participants all viewed the strategies provided in their diagnostic report as useful. However there were observable patterns to how they were engaged with. Aboriginal participants, Suzie and Phyllis, were particularly interested in visual strategies, in keeping with previous findings on the dominance of visual cultures among Aboriginal Australians

including in respect to healthcare (Thomas *et al.* 2019; Pewewardy 2002; Hickey and Wilson, 2017; Hughes, More and Williams 2004). They both reported successfully using visual strategies to assist their children. In Suzie's case, local community leaders identified this potential for this to help others, further evidence of the understanding of diagnosis within a community context (Potter *et al.* 2018). Jill and Katie did not speak of visual strategies to the same degree, although the two non-Aboriginal young people had not yet been released so their caregivers had not yet had a chance to implement strategies.

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

There was also observable cultural patterning in how caregivers envisioned their children's needs being met following the diagnosis. As reflected in Phyllis's (Aboriginal) and Jill's (non-Aboriginal) accounts, experiences of struggling to access appropriate support for their child prior to a diagnosis were common and crossed cultural lines. Following the diagnosis, the non-Aboriginal caregivers envisioned more institutional assistance. Katie focused on Kieran's potential engagement with services, while Jill came back to the lack of

assistance for Jasper, both discussing negotiating multiple systems for assistance (Blum 2015; Garro & Yarris 2009; Landsman, 2010; Malacrida 2001; Johnson *et al.* 2012; Ryan and Runswick Cole, 2008). This perspective is in keeping with sociologies of diagnosis that emphasize how a diagnosis from a practitioner controls access to care (De Swaan 1989; Whelan 2007).

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

Where there is potential for self-blame by caregivers for their children's conditions, such as in the case of FASD, shame responses to diagnosis are of particular concern (Olsvold, Aarseth, and Bondevik 2019; Zimmerman, Morrison, and Heimberg 2015). Sandra's preference to not know that Seb had FASD suggests that she recognised the potential for stigma and messages of parental incompetence from diagnosis and anticipated negative labelling (Francis 2012). Similarly, Phyllis's discussion of alcohol use during her own pregnancy reflects the intergenerational shame which can be experienced by Aboriginal people at the interface of traditional and contemporary culture (Morgan, Slade and Morgan

1997). Such experiences of shame from receiving a diagnosis has the potential to affect taking up diagnostic support (McNally and Lathan 2009).

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

**Conclusion**

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

Further exploration of the cultural patterning of receipt of a diagnosis and provision of diagnostic resources could valuably inform future sociology of diagnosis scholarship. For cultural reasons, our article only reports on the experiences of female caregivers. A focus on the distinct experiences of male caregivers warrants further investigation. Moreover, how

different cultures receive diagnoses and how diagnoses relate to individual or community understandings of health and wellbeing is currently under-investigated.

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

**Bibliography**

Astley, S. (2014) Twenty years of patient surveys confirm a FASD 4-digit-code interdisciplinary diagnosis afforded substantial access to interventions that met patients' needs. *Journal of Population Therapeutics and Clinical Pharmacology*, 21.1, e81–e105.

Attride-Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, 1, 3, 385-405.

Ayunerak, P., Alstrom, D., Moses, C., Charlie, J. and Rasmus, S.M. (2014) Yup'ik Culture and Context in Southwest Alaska: Community Member Perspectives of Tradition, Social Change, and Prevention. *American Journal of Community Psychology*, 54.1-2, 91-99.

Bessarab, D. & Ng'andu, B. (2010). Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies*, 3, 1, 37-50.

Blagg, H., Tulich, T. and Bush, Z. (2015) Diversionary pathways for Indigenous youth with FASD in Western Australia: decolonising alternatives, *Alternative Law Journal*, 40, 4, 257-260.

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

Blum, L. (2015) *Raising generation Rx. Mothering Kids with Invisible Disabilities in an Age of Inequality*. New York, London: New York University Press.

Brossard, B. and Carpentier, N. (2016) To what extent does diagnosis matter? Dementia diagnosis, trouble interpretation and caregiving network dynamics. *Sociology of Health & Illness*, 39, 4, 566-580.

Chamberlain, K., Reid, N., Warner, J., Shelton, D. and Dawe, S. (2017) A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. *Research in Developmental Disability*, 63, 99–106.

Corrigan, P., Lara J., Shah, B., Mitchell, K., Simmes, D. and Jones, K, (2017) The public stigma of birth mothers of children with fetal alcohol spectrum disorders. *Alcohol Clinical Experiment Research*, 41, 1166–1173.

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

De Swaan, A. (1989) The reluctant imperialism of the medical profession. *Social Science and Medicine*, 28, 11, 1165–70.

Denzin, N. K. and Lincoln. Y.S. (2003) *The SAGE handbook of qualitative research. 2nd ed.* Thousand Oaks: SAGE Publication.

Doak, J., Katsikitis,. M., Webster, H. and Wood, A. (2019) A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families. *Research in Developmental Disabilities*, 93, *e*103428.

Ennis-Cole, D., Durodoye, B. and Harris, H. (2013) The Impact of Culture on Autism Diagnosis and Treatment: Considerations for Counselors and Other Professionals, *The Family Journal*, 21, 3, 279–287.

Fast, D., and Conry, J. (2004) The challenge of fetal alcohol syndrome in the criminal legal system, *Addiction Biology*, 9, 2, 161-166.

Fogarty, W., Lovell, M., Langenberg, J. and Heron, M. (2018) *Deficit Discourse and Strengths-based Approaches: Changing the Narrative of Aboriginal and Torres Strait Islander Health and Wellbeing*. Melbourne: The Lowitja Institute.

Francis, A. (2012) Stigma in an era of medicalisation and anxious parenting: how proximity and culpability shape middle-class parents' experiences of disgrace. *Sociology of Health & Illness*, 34, 6, 927–942.

Gardner, J. and Williams, C. (2015) Corporal diagnostic work and diagnostic spaces: clinicians' use of space and bodies during diagnosis. *Sociology of Health & Illness*, 37, 5, 765–781.

Garro, L. and Yarris, K. (2009) "A Massive Long Way: Interconnecting Histories, a Special Child, ADHD, and Everyday Family Life, *Culture, Medicine and Psychiatry*, 33, 559-609.

Gill, VT., Pomerantz, A. and Denvir, P. (2010) Pre-emptive resistance: patients' participation in diagnostic sense-making activities. *Sociology of Health & Illness*, 32, 1, 1–20.

Heneker, K.J., Zizzo, G., Awata, M. and Goodwin-Smith., I. (2017) *Engaging Culturally and Linguistically Diverse Communities in the National Disability Insurance Scheme*. Adelaide: Australian Centre for Community Services Research, Flinders University, Adelaide.

Hickey, H. and Wilson, D. L. (2017). Whānau Hauā: Reframing Disability From an Indigenous Perspective. *Mai Journal*, 6, 1, 82-94.

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

Johnson, J. L., Oliffe, J. L., Kelly, M. T., Galdas, P. and Ogrodniczuk, J. S. (2012) Men's discourses of help-seeking in the context of men's depression, *Sociology of Health & Illness,* 34, 345-361.

Jutel, A. (2009) Sociology of diagnosis: a preliminary review*, Sociology of Health & Illness*, 31, 2, 278-99.

Jutel, A. (2019) Diagnosis: a critical social reflection in the genomic era, Ciência & Saúde Coletiva, 24, 10, 3619–3626.

Landsman G. H. (2009) *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*. New York: Routledge.

Liu, G. (2005) Best Practices: Developing Cross-Cultural Competence from a Chinese perspective. In Stone, J.H. (ed) *Culture & Disability: Providing Culturally Competent Services.* Thousand Oaks, California: Sage, pp 65-85.

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

Malacrida, C. (2001) Motherhood, Resistance and Attention Deficit Disorder: Strategies and Limits, *Canadian Review of Sociology*, 38, 2, 141-165.

Malacrida, C. (2004) Medicalization, ambivalence and social control: mothers' descriptions of educators and ADD/ADHD, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8,1, 61-80.

Magana, S., Lopez, K., Aguinaga, A. and Morton, H. (2013) Access to Diagnosis and Treatment Services Among Latino Children With Autism Spectrum Disorders. *Intellectual and Developmental Disabilities,* 51, 3, 141-153.

McLachlan, K., Roesch, R., Viljoen, J. and Douglas, K. (2014) Evaluating the Psycholegal Abilities of Young Offenders With Fetal Alcohol Spectrum Disorder, *Law and Human Behavior*, 38, 10-22.

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

Morgan, D., Slade, M., & Morgan, C. (1997). Aboriginal philosophy and its impact on health care outcomes, *Australian and New Zealand Journal of Public Health*, 21, 6, 597-601.

Murphy, N. A., Christian, B., Caplin, D. A., and Young, P. C. (2007) The health of caregivers for children with disabilities: caregiver perspectives, *Child Care Health and Development*, 33, 2, 180–187.

Nettleton, S. and Jutel, A. (2011) Towards a sociology of Diagnosis: Reflections and opportunities, *Social Science & Medicine*, 73, 793- 800.

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

Olsvold, A., Aarseth, A, and Bondevik, H. (2019) 'I think my son is a wonderful chap': working-class and middle-class fathers' narratives of their son's ADHD diagnosis and medication. *Families, Relationships and Societies*, 8, 1, 105-120.

Pewewardy, C. (2002) Learning Styles of American Indian/Alaska Native Students: A Review of the Literature and Implications for Practice, *Journal of American Indian Education*, 41, 3, 22-56.

Popay, J., Bennett, S., Thomas, C., Williams, G., *et al.* (2003) Beyond 'beer, fags and chips'? Exploring lay understandings of social inequalities in health, *Sociology of Health and Illness*, 25, 1, 1-23.

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

Rafalovich, A. (2005) Exploring clinician uncertainty in the diagnosis and treatment of attention deficit hyperactivity disorder. *Sociology of Health & Illness*, 27, 3, 305–323.

Rasmussen, E. (2017) Balancing medical accuracy and diagnostic consequences: diagnosing medically unexplained symptoms in primary care. *Sociology of Health & Illness*, 39, 7, 1227–1241.

Rennie, E, Yunkaporta, T., and Holcombe-James, I. (2018) Privacy Versus Relatedness: Managing Device Use in Australia's Remote Aboriginal Communities. *International journal of Communication,* 12, 1291–1309.

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

Ryan, S. and Runswick-Cole, K. (2008) Repositioning mothers: mothers, disabled children and disability studies, *Disability & Society*, 23:3, 199-210.

Sanders, A. and Buck, G. (2010) A long journey: biological and non-biological parents' Experiences raising children with FASD, *Journal of Population Therapy and Clinical Pharmacology,* 17, 2, Summer 2010:e308-e322.

Schrag, A., Modi, S., Hotham, S., Merritt, R., Khan, K., & Graham, L. (2018) Patient experiences of receiving a diagnosis of Parkinson's disease, *Journal of Neurology*, 265, 5, 1151–1157.

Sherwood J. (2013) Colonisation – It's bad for your health: The context of Aboriginal health, *Contemporary Nurse,* 46,1, 28-40.

Thomas, C., Novy, C., Gifford, W., Grandpierre, V., *et al.* (2019) Exploring the Intersections of Storytelling and Visual Arts: Indigenous Peoples' Experiences of Cancer, *Storytelling, Self, Society Special Issue: Storytelling for Health,* 15, 1, 71-91.

Turowetz, J. and Maynard, D. (2019) Documenting diagnosis: testing, labelling, and the production of medical records in an autism clinic. *Sociology of Health & Illness*. 41, 6, 1023–1039.

Velarde, R. (2018) Indigenous Perspectives of Disability, *Disability Studies Quarterly*, 38, 4. Available at http://dsq-sds.org/article/view/6114/5134.

Vicary, D. and Westerman, T. (2004) 'That's just the way he is': some implications of Aboriginal mental health beliefs, *Advanced Mental Health* 3, 1-9.

Wandji, D. (2019) Rethinking the time and space of resilience beyond the West: an example of the post-colonial border, *Resilience*, 7, 3, 288-303.

Whelan, E. (2007) ''No one agrees except for those of us who have it'': endometriosis patients as an epistemological community, *Sociology of Health & Illness*, 29, 7, 957–982.

Young, J., Fisher, K. and Kirkman, M. (2019) Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis. *Feminism & Psychology*. Online. Available at https://doi.org/10.1177/0959353519826170

Zarhin, D. (2015) Contesting medicalisation, doubting the diagnosis: patients' ambivalence towards the diagnosis of Obstructive Sleep Apnoea. *Sociology of Health & Illness*, 37, 5, 715–730.

Zimmerman, J., Morrison, A. and Heimberg, R. (2015) Social anxiety, submissiveness, and shame in men and women: A moderated mediation analysis, *British Journal of Clinical Psychology*, 54, 1–15.