



Exploring the Experience of Service User's Following Attendance at a Student Led Interprofessional Neurodevelopmental Clinic

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ABSTRACT

Background: The aim of the current study was to understand service user's experiences at a recently established student led interprofessional neurodevelopmental clinic for children and adolescents with suspected or confirmed prenatal alcohol exposure.

Method: Semi structured interviews were completed at 3 months post clinic attendance with 10 service users: eight parents/careers and two youth workers/case managers. Interview data were analyzed thematically using NVivo12.

Results: Four main themes were identified: (1) Clinic attendance seen as a positive event; (2) Validation, clarification, and relief, but also challenges post assessment, (3); Need for further support and importance of advocacy; and (4) Drawing on lived experience for future service improvements.

Conclusions: The current study demonstrated that service users reported benefits from tailored services delivered by student practitioners that were validating, supportive, and holistic. Findings from the current study can inform the development and implementation of future innovative service delivery models for individuals with suspected or confirmed prenatal alcohol exposure.

Keywords: Intellectual disability; Foetal alcohol spectrum disorder; Prenatal alcohol exposure; Lived experience; Interprofessional disability training; Australia

INTRODUCTION

Prenatal alcohol exposure is recognized as one of the leading causes of preventable birth defects and long term neurodevelopmental challenges in Western countries. Fetal Alcohol Spectrum Disorder (FASD) is a term that encompasses the range of impacts that can occur following prenatal alcohol exposure, including a broad array of cognitive, psychological, behavioral, emotional, and adaptive impairments. The extent

and impact of these impairments, in conjunction with a lack of societal and clinical awareness regarding prenatal alcohol exposure, can make FASD particularly difficult to identify. Indeed, FASD has been described as an under recognized, under diagnosed, and under estimated condition in many countries, including Australia. The impacts of prenatal alcohol exposure and FASD can result in significant costs to the individual, their family, and society. Difficulties with executive function, learning and memory, cognition, speech and

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language, adaptive function, and social skills, can put individuals with FASD at risk for a range of secondary conditions. These secondary conditions can include disrupted school experiences, social difficulties, unemployment, and difficulty living independently, making those with FASD a particularly vulnerable population. Additionally, caregivers can experience negative impacts such as increased levels of stress and reduced quality of life. There are currently no accurate estimates of the prevalence of FASD in the general Australian population. An international systematic review and meta analysis estimates the global prevalence of FASD among young people in the general population to be approximately 7.7 per 1000. Early identification of FASD is essential to improving outcomes for children and their families. However, delays obtaining a formal diagnosis and feeling unsupported by health professionals are reported as ongoing challenges by families. Many children remain undiagnosed due to numerous factors, including lack of knowledge and training of health care professionals, perceived stigma or discomfort of health professionals, and lack of funding to support a comprehensive, multi disciplinary diagnostic assessment. Research suggests that misdiagnosis is common, as children with FASD initially present with referrals for investigations of other neurodevelopmental and behavioral disorders, such as Attention Deficit Hyperactivity Disorder (ADHD) or conduct disorder. This highlights the importance of well defined assessment processes, but also a particular urgency for research to explore the lived experience of the assessment process, to increase the likelihood of positive outcomes. Awareness regarding the impact of prenatal alcohol exposure is increasing in Australia and the release of the Australian guide to the diagnosis of FASD in 2016 provided clinicians with a structured process to undertake an assessment and provide a diagnosis of FASD where appropriate. Formal assessment is recommended from a multi disciplinary team and requires assessment across three areas: (1) Prenatal alcohol exposure; (2) Sentinel facial features (3) Neurodevelopmental functioning (*i.e.*, assessment of brain structure/neurology, cognition, motor skills, language, attention, memory, executive functioning, academic abilities, affect regulation, and adaptive/social behavior, whereby impairment in three or more of these areas is required for diagnosis). The Australian guide provides two diagnostic outcomes: (1) FASD with three sentinel facial features; and (2) FASD with less than three sentinel facial features. There are a growing number of services in Australia that provide assessments in accordance with the Australian guide to the diagnosis of FASD. However, limited research has explored the lived experiences of service users, specifically in the Australian context. To the author's knowledge, only two Australian studies have investigated caregiver experiences of the assessment process. In both studies, caregivers reported a positive assessment experience with high levels of satisfaction and empowerment after having attended the services. Furthermore, all caregivers reported that the assessment provided them with validation and diagnostic clarification regarding their child's challenges, and a better understanding of their child's abilities and needs. However, caregivers continued to report ongoing difficulties regardless of

diagnosis, due to barriers to support, restricted service availability, and a lack of societal knowledge regarding FASD. To the authors knowledge, no previous research has examined the experience of other service users who may be involved in accessing FASD related supports, including youth workers, case managers, and young people themselves. Incorporating input from a wider variety of key stakeholders may shed more light on strengths and challenges of current service provision. Whilst FASD related service provision is increasing in Australia, given the high prevalence of the condition it is difficult for the available services to meet the required community demand, with significant waiting lists ensuing. One mechanism to improve accessibility for under served populations is to provide student led services, where students take the primary responsibility for providing the service as part of their clinical training, under the guidance of supervising staff. Simpson and Long define student led as "a health care delivery program in which students take primary responsibility for logistics and operational management of the clinic capable of prescribing disease specific treatment to patients". According to the World Health Organization, interprofessional student assisted clinics provide improved workplace practices and productivity, improved workplace morale, healthier communities, and lead to improved quality of care. The aim of the current study was to understand the experiences of service users at a novel student led interprofessional clinic. Specifically, to gain an understanding of how service users experienced the assessment process at the new clinical service, whether there were aspects of the assessment process that were helpful or unhelpful and to provide insights regarding any ongoing challenges families and young people may experience following attendance at the clinic [1-4].

MATERIALS AND METHODS

Clinic Model

The interprofessional neurodevelopmental clinic was established through a collaboration between (redacted for blind peer review) and (redacted for blind peer review) to provide a clinical service for children and adolescents with suspected prenatal alcohol exposure and their families, involving pediatricians, occupational therapists, and psychologists. The purpose of this clinic was to provide assessments that could consider FASD as one possible outcome and provide a detailed profile of each child's functioning to assist with referrals to ongoing services, intervention planning, and caregivers understanding of their child's capabilities. The clinic served as an Interprofessional Education (IPE) opportunity for allied health student trainees (*i.e.*, occupational therapy and psychology students). The clinic was designed to align with students university placement schedules, which was undertaken as a 10 weeks placement block. The numbers of students involved in each placement block varied (*e.g.*, from 2 to 4 per discipline), depending on student and staff availability. Six psychology students and sixteen occupational therapy students were involved in the clinic during the study period (*i.e.*, November 2019-September 2020). Two pediatric registrars (*i.e.*, general

pediatric advanced trainees) were involved in the clinic in 2019; however, due to a lack of availability were not involved in 2020. The students were supervised by university staff, including a registered clinical psychologist (redacted for blind peer review), an occupational therapist (redacted for blind peer review), and a consultant pediatrician also worked as part of the interprofessional clinic team (redacted for blind peer review). The clinic assessment process was informed by the Australian guide for the diagnosis of FASD and utilised the University of Washington 4 digit diagnostic code for research purposes. The assessment process was also informed by a clinic co design project, which involved interviews with

caregivers of children with FASD who had attended other diagnostic services, (redacted for blind peer review) staff, and (redacted for blind peer review) (citation redacted for blind peer review, in preparation). Importantly, caregivers and staff who participated in the co-design study stressed the importance of taking a holistic approach in designing and providing the service, which was both services user centered and strengths based. The assessment process involved four components (**Table 1**).

Table 1: Description of the assessment process.

Components	Process
Intake	A comprehensive intake with the service user, liaison with child protection services (if the patient was in care of the state), health care providers and other stakeholders, and detailed review of all available medical, developmental, and educational records. This included collection of history of prenatal history (<i>i.e.</i> , prenatal alcohol and other exposures) and postnatal adverse events.
Holistic therapeutic assessment	<p>Individualised service user goal setting using developmentally appropriate tools (e.g., Adolescent Goal Setting tools, CAPE/PAC or purpose-built card sorting tasks for younger children).</p> <p>Assessment of neurodevelopmental domains as per Australian Guide. This included a combination of standardised direct and indirect assessment tools and structured clinical observations of functional activities, individualised to service user developmental age, needs and interests.</p> <p>Assessment of sleep, eating, sensory needs, and physical health to provide a comprehensive understanding of the child.</p> <p>Assessment key FASD physical features (<i>i.e.</i>, growth deficiency; dysmorphology).</p> <p>Various sensory and behavioural support strategies were trialed, tested, with feedback, and individualised resources provided.</p> <p>Occurred over three days, once per week (approximately 10 am-2 pm).</p> <p>With support from clinic supervisors, students worked together in interprofessional pairs to plan and deliver the assessment using a family centered approach. An individualized assessment plan was developed for each service user for each day of the assessment.</p>
Case conference	Interprofessional case conference (approximately one hour per child/adolescent) with all staff and students.
Feedback	<p>Individual child/adolescent strengths-based feedback session. Individualized resources were created for each child/adolescent.</p> <p>Service user feedback session, which provided an overview of the assessment results and individualised resources and supports.</p> <p>Other key stakeholder feedback session (e.g., child safety, school).</p> <p>Provision of two comprehensive reports. One strengths-based family report and one report to support access to the NDIS.</p>

Note: CAPE: Children's Assessment of Participation and Enjoyment; PAC: Preferences for Activities of Children; NDIS: National Disability Insurance Scheme (*i.e.*, the mechanism in Australia whereby individuals with disabilities can access a range of individualized supports).

Design

A qualitative descriptive design was utilised to understand service user's experiences of the assessment process. The philosophical underpinnings of qualitative descriptive design include:

- An inductive process.
- Recognition regarding the subjectivity of participant and the researcher experiences.
- A design that allows for researchers to develop an understanding of and describe the phenomenon.
- Active participation by researchers in the research process.
- An emic stance.
- Data collection in the natural setting of the participants who experience the phenomenon.

Sampling and Recruitment

As the study focused on service user's experience of their attendance for an assessment at the student led clinic,

consecutive sampling was utilised to recruit all service users of the clinic (including careers, parents, youth workers, and case managers) who attended from November 2019 to September 2020. Service users during the study period received information about the research and were invited to participate. Service users were then contacted *via* phone, 3 months post attendance at the clinic. All service users contacted agreed to participate. The final sample included 10 participants, including eight parents/careers and two youth workers/case managers (Table 2). The diversity in caregiver type (e.g., biological mother, youth worker) is typical for children with suspected prenatal alcohol exposure/FASD who often experience heterogeneity in care arrangements. Thus, the study sample reflected participant characteristics highly relevant to the phenomenon of interest. Project sample size recommendations for qualitative interview studies published by Terry, Hayfield, Clarke and Braun were also adhered to. The aims do not involve comparison between career types, but rather the collective experience of attending the clinic, thus the sample diversity should not impact the results.

Table 2: Demographic characteristics of service users.

P No.	Gender	Relationship to child	Child age	Child gender	Primary diagnostic outcome
1	Female	Case manager	13	Male	FASD with <3 sentinel facial features
2	Female	Step grandparent	10	Female	ADHD
3	Female	Grandparent	15	Female	FASD with <3 sentinel facial features
4	Female	Grandparent	7	Male	ADHD
5	Female	Foster carer	15	Male	FASD with <3 sentinel facial features
6	Female	Foster carer	10	Female	FASD with <3 sentinel facial features
7	Male	Youth worker	12	Female	Intellectual disability
8	Female	Adoptive parent	9	Female	FASD with <3 sentinel facial features
9	Female	Biological parent	13	Female	FASD with <3 sentinel facial features
10	Female	Stepparent	14	Male	FASD with <3 sentinel facial features

FASD: Fetal Alcohol Spectrum Disorder; ADHD: Attention Deficit Hyperactivity Disorder; P: Participant.

Data Collection

Data collection was undertaken using a semi structured interview schedule that included two additional questions (a total of 25 questions) for service users who received an FASD diagnosis during the assessment process (e.g., How was it getting an FASD diagnosis for your child?). Interviews commenced with broad questions (e.g., How do you think child name found attending the clinic? and included questions on topics about clinician communication, the assessment process, their child's experience, reports, resources, the impact of receiving an FASD diagnosis (where relevant) and impacts following termination of services. Questions regarding further support for families and young people were also included to aid in future development and improvement of the clinic. Interviews were arranged at the participant's convenience. Ten interviews were completed *via* phone, and one was completed face to face. Interview duration ranged from approximately 10 minutes to 70 minutes. Interviews were audio recorded and transcribed verbatim by (redacted for blind peer review) and (redacted for blind peer review). No one else was present besides the participant and researcher during the interviews.

Data Analysis

Interview transcripts were analysed by (redacted for peer review) using reflexive Thematic Analysis (TA), a method for identifying, analyzing, and reporting patterns within qualitative data. Reflexive TA is well aligned with the theoretical underpinnings of qualitative descriptive design, as this approach utilizes the researcher's knowledge as a resource to produce a rich analysis of both the explicit and implicit derived from the data. Given the inductive nature of qualitative descriptive design, the aims of the study, and the researcher's involvement in the subject matter and research process, reflexive TA was chosen as more suitable over "codebook TA" or "Coder reliability TA". Themes were not pre conceived, and more emphasis was placed on the importance of the researcher's reflexive engagement with the data, active participation, and emic stance. Six phase procedure guided the analysis of transcripts utilizing the aforementioned principles of reflexive TA in the context of a qualitative descriptive approach; immersion in the data, reading, reflecting, questioning, imagining, wondering, writing, retreating, returning. The first step included data familiarization, whereby each transcript was read multiple times. The second step was coding the data for interesting features using QSR software product. The third step included collating and mapping codes into potential themes; as there were no redeveloped codebooks, the coding process was integral to theme development. Codes were conceptualized as "analytic units", each capturing facets of the data to comprise each theme. The fourth step included reviewing the themes and interpreting their meaning to facilitate rich and multi dimensional expressions of how lived experience,

barriers/challenges, societal stigma, and family dynamics interacted with the FASD assessment process. The fifth step involved refining these multi faceted themes, developing complexity, generating clear definitions, and naming. The sixth and final step was the reporting of the results. The concept of information power, an alternative to data saturation, was utilised. Information power indicates that the more information the sample holds, relevant for the actual study, the lower the number of participants needed. Information power is determined by (a) Aim of the study, (b) Sample specificity, (c) Use of established theory, (d) Quality of dialogue, and (e) Analysis strategy. The current study included specific aims, the participants were highly specific to the aims, the study was grounded in established theory related to the lived experience of FASD, and the interview dialogue was robust with high relevance to the research questions. Based on these considerations, the current sample was considered to generate sufficient information power and specificity of experiences and knowledge among participants [5-8].

Ethical Considerations

Ethical approval was obtained from (redacted for blind peer review) Ethics Committee (2019000170/HREC/18/QCHQ/46648) and (redacted for blind peer review) (HREC/18/QCHQ/46648). Written and verbal consent to participate and permission to audio record the interviews was obtained from each service user and re confirmed prior to commencement of the interviews. At commencement of the interviews, participants were provided with a brief summary of the project and advised that the first author (redacted for blind peer review) was completing the research as a requirement of her studies. Anonymity during analysis was ensured by assigning a code to identify recordings and removing any identifying information. Audio recordings were erased after transcription, and transcripts were stored in password protected files on (redacted for blind peer review's) research data management storage system.

Researcher Characteristics

Redacted for blind peer review was a female provisional psychologist completing her master of psychology (counseling) degree with an interest in assessment procedures for the diagnosis of FASD and improving outcomes for those with lived experience of FASD? Prior to the project, (redacted for blind peer review) had approximately 6 months of practical experience administering neuropsychological assessments to children and adolescents with prenatal alcohol exposure. The first author was known to three participants, having been the clinician involved in the assessment process for these service users. Therefore, to reduce bias of reporting from participants being interviewed by their assessing clinician, interviews for these three participants were undertaken and transcribed by another author (redacted for blind peer review), also female with

previous experience in undertaking qualitative research. Neither of the researchers who completed the interviews had pre existing relationships with the service users [9-11].

RESULTS

Four themes were identified in the qualitative analysis:

- Clinic attendance seen as a positive event.
- Validation, clarification, and relief, but also challenges post assessment.
- Need for further support and importance of advocacy.

- Drawing on lived experience for future service improvements.

Table 3 provides an overview of these four themes with associated sub themes and example quotations. The term ‘service users’ has been used when an experience and/or perception was noted by all participants. The terms ‘parent/career’, ‘parent/career and support worker’ have also been used when reporting results, to assist with context.

Table 3: Themes (bolded), sub themes, and example quotations.

Theme	Example quotations
Clinic attendance seen as a positive event	“It was a much warmer a process than what I was expecting. It was a much friendlier process... The whole thing was great. It really worked out very well. It was easy to schedule around work” (P9).
Positive, responsive, gentle, interactions with staff/students	“Everything was really well done. From my side, everyone was really friendly, which is what you want in that circumstance. I want my child to feel safe and be able to get the most out of doing this so it can produce the best results at the end of it. I really felt that that staff really do that, because they do go that step further to really make sure that they (child) feel comfortable” (P10).
Family centered/developmentally appropriate care memorable for children	“I think that a lot of that empowerment has come from (student name). They haven’t made her feel like she has a disability, they made her feel like this is you and you can rock it” (P9).
Assessment process appreciated when thorough and comprehensive	“The experience was very good, very accurate, and very attentive, they knew what they were doing, there was little confusion between what was happening...the reporting and the questioning was done very thoroughly and covered a lot of stuff and they listened and understood what I was explaining” (P5).
Validation, clarification, and relief, but also challenges post-assessment	“The few problems that were identified and the potential ways of dealing with it, whilst they might be small things, in our family they make a big impact” (P10).
Diagnostic clarification provided direction for future	“You get no support not knowing, that’s what we find. Not knowing, you don’t get any support...so, it just helps everybody to have that better understanding” (P6).
Redefined expectations of child and child’s capacity	“Yes, flexibility is key I think if you have a child with FASD. They’re not going to be able to do things the way my older sons have... (Child name) is going to be different. I have to take the blinkers off with her and think outside the square. Luckily, I have been able to do that” (P9).
Validation as a neutralizer of service user discomfort	“...they (staff/students) were really supportive of (child name), they were really supportive of me, especially in the last session, I think it was (student name) that I sat with...The student was really supporting and saying that it was ok to feel the way I was... The student reassured me that it is ok and that a lot of people are in the same boat. And even to hear that has given me a whole new, it is ok, I am not the only one feeling this” (P8).
Sense of relief experienced from diagnostic outcome	“Well like I said we have known for a long time that there is something there. One psychologist did suggest that it was FASD or Autism. But the paediatrician did not want to acknowledge that at the time. That was about four years ago. To finally get a diagnosis and a better understanding was a relief. It was peace of mind. For everybody.” (P6)
Permanency of diagnosis and future implications	“Because of the permanency, and the intellectual disability diagnosis, it’s that permanency; it’s sort of like...a level of hopelessness that you feel” (P5).

Need for further support and importance of advocacy

“If you were to ask me three years ago before we got a diagnosis for the boys, I would have. I was waiting for someone to fix it, but in that time, I learned that I am the only one who can fix it and I am the only one who can advocate. You know training and education is what people need” (P4).

Persistent behavioral challenges, tricky to manage in current support climate

“But on the weekend if you let the ropes go a little bit, we have a doorway that has holes after a few meltdowns, so we are sort of at a bit of a crisis point at the moment with all of the kids so yeah, it’s a bit of a challenge at the moment” (P5).

Parent/career burnout difficult to avoid

“For us, I felt like we went to the brink of being stretched as a family and what we could cope with” (P10).

“It has taken so long to get this far and then you think things are going ahead and then you re two steps backward and you have to wait and wait and wait” (P1).

Numerous services accessed, little help

“We have been to so many different places and they were like you don’t know what you’re talking about, you’re not a professional, and you just walk out of there thinking well that was a bloody waste of time” (P1).

Service users more likely to get other children assessed following attendance

“Now we want to get our 16 years old daughter assessments” (P6).

Drawing on lived experience for future service improvements.

“Even some counselling from someone who knows. Not from a counsellor who hasn’t been through it. But someone who has been through it and has sat where I have sat. That’s something we want more than anything” (P9).

“A much warmer a process than what I was expecting”: Clinic attendance seen as a positive ‘event’.

The first theme that was generated described how service users experienced their attendance at the clinic as a positive ‘event’ or series of events characterized by positive interactions with staff and students who communicated well, were polite, friendly, organized, and helpful. The ‘event’ was made memorable by specific factors, including the way students and staff tended to the needs of both careers and children, including any cognitive, behavioral, or emotional challenges the child or young person presented with during the assessment process. An important facet of this theme was service user’s emphasis on how their children were treated. Within this theme emerged a disconnect between service users expectations of what the clinic would be like, and their experience, informed by previously accessed services that did not approach their child from an FASD lens. Another factor that contributed to experiencing the assessment process as a positive event was the comprehensive and holistic nature of the assessment. Parents/careers and support workers reported that children enjoyed interacting with staff and students and the practitioners family centered and developmentally appropriate approaches were noted as being particularly helpful. Another memorable factor for participants included the feedback session, which was described as particularly useful in understanding the needs of the child or young person, and the impact of their unique neurocognitive profile on aspects of daily functioning. One important point regarding service user’s experience of the clinic was that they could apply the results of the assessment process in a tangible way. For example, the reports provided following the assessment had been used to apply for support through the

Australian Government’s National Disability Insurance Scheme (NDIS) or to acquire other additional school based or therapeutic supports, while the resources were used to help teachers, family, and other supports understand more about the young person who had been diagnosed.

“It just helps everybody to have that better understanding”: Validation, clarification, and relief, but also challenges post assessment.

The second theme generated described participant’s experience of benefits post assessment and clarity on challenges unique to FASD. Having diagnostic clarification was seen by service users as beneficial and provided direction in their pursuit of further supports. A pertinent facet of this theme included the perspective shift that diagnostic clarification and further information about FASD (*i.e.*, neurological impacts, intra-individual variability, and clarification of “defiant” behavior) provided. Specifically, redefined expectations, a better understanding of the child or young person’s capacity, and ultimately a better understanding of how they could help meet the needs of the child in their care. Another pertinent aspect of this theme included service user’s experience of having their concerns finally heard by health practitioners and their concerns validated as real and substantial. Service users described a sense of relief following the assessment process as it appeared to signify as a “movement in the right direction.” Although service users largely reported benefits post assessment, novel challenges were also described. Specifically, service users described the “permanency” of an FASD diagnosis, and the long term intervention needed to support the children in their care was at times overwhelming. A nuanced challenge included the emotions that may surface due to stigma associated with FASD. The biological parent/

career interviewed described her experience with feelings of guilt and shame prior to attending the service. This participant mentioned that guilt and shame had initially delayed the commencement of her child's assessment, as they had deliberated due to worry and fear of stigmatization. Notably, the participant described how attending the clinic had been helpful in assisting to alleviate guilt and shame, which they reported helped their confidence in advocating for their child's needs. However, this participant also mentioned that while a diagnosis of FASD would be helpful in acquiring services for their child, a level of acceptance would be necessary to help cope with the impact of the past. Another challenge identified by service users included a phenomenon of "post clarity overwhelm." For example, concerns regarding implementing the recommendations provided in the report, challenges in acquiring post assessment support services, the ongoing difficulties experienced at home, and the impact of problem behavior on their families. Although parents/careers appreciated the number and variation of supports recommended, many reported not knowing "where to start." This theme indicated that while the clinic provided helpful answers, this information now prefaced new challenges service users would have to adapt to. Parents/careers and support workers expressed that during their attendance at the clinic they would have appreciated the opportunity to learn and discuss how to employ practical strategies. More than half of service users expressed that having intervention services available at the clinic following assessment would have been beneficial.

"The young people can't do it on their own": Need for further support and importance of advocacy.

The following theme describes service user's narratives around support, feeling supported, and desire for advocacy following the assessment. The majority of participants described the child in their care as having either emotional, behavioral, and/or cognitive difficulties that interfered with functioning at home or school. Parents and careers also described an element of burnout in the context of the child or adolescents presenting concerns, the minimal support they had access to, and the numerous services they had accessed in the past. In the context of accessing numerous previous supports, service users reported receiving either little help or having a negative experience with previous services. Parents and careers described the experience of feeling overwhelmed, and it was frequently discussed how they had significant challenges accessing appropriate supports with schools, child protection services, and NDIS. All those caring for children in out of home care reported difficulty in their interactions with child protection services, and the experience of feeling restricted in the supports they could access. Service users also described the sense of having to initiate and lead conversations with stakeholders in order to see progress; the need for healthcare services to be educated and informed; and desire to educate others regarding the impact of neurodevelopmental disorders, including FASD. Finally, parents, careers and support workers also reported either referring others or additional children in their care to engage in the assessment process offered by the clinic.

"Even some counseling from someone who knows": Drawing on lived experience for future service improvements.

The fourth major theme generated described how service users utilised their experience at the clinic to make valuable suggestions regarding how the service could be improved for families in the future. Most commonly, service users noted the value in further therapeutic opportunities being provided by the clinic, particularly psychological interventions, behavioral therapy, occupational therapy, coordinated support work (e.g., social work, NDIS management), and support for parents and careers. Parents/careers reported the desire for the clinic to host caregiver forums that may function as a support network for families to connect, debrief, or discuss concerns. Parents/careers also suggested that peer support for biological mothers may be helpful to provide prior to, during, and after the assessment process [12-15].

DISCUSSION

The aim of the current study was to understand service user's experiences of the assessment process at a novel student led interprofessional clinic. This included gaining an understanding of how service users experienced the assessment process at the new clinical service, whether there were aspects of the process that were helpful or unhelpful, and to provide insight regarding any ongoing challenges following clinic attendance. The qualitative analysis generated four themes from the information provided by service users (1) Clinic attendance seen as a positive event; (2) Validation, clarification, and relief, but also challenges post-assessment; (3) Need for further support and importance of advocacy; and (4) Drawing on lived experience for future service improvements. The first theme presented within the results described an overall beneficial experience reported by service users attending the clinic. Service users described welcoming and reassuring interactions and specific aspects of the assessment process as helpful, including strengths-based practice, multi disciplinary assessment, the feedback session, informative resources following feedback, and comprehensive reports. The unique clinic design helped service users identify the assessment process as memorable event in the timeline of their journey, rather than just an appointment. The two previous Australian studies also noted consistent findings regarding patient satisfaction with their services. An important point to consider is that service users in the current study did not perceive that service provision by student practitioners negatively impacted the quality of the service. Although to the author's knowledge this is the first research study to explore student led provision of FASD related services, research in the provision of other types of student led clinics has reported similar results. For example, numerous studies have indicated that service users of student led clinics generally report high levels of satisfaction and the perception that their needs were well attended to and thoroughly addressed. For example found that patients of a student medical clinic reported the provision of specialist care, and the collaborative approach between staff and students as particularly helpful to their care. The second theme indicated that while service users experienced benefits following their attendance at the clinic, unique challenges emerged from the outcomes. Consistent with both previous

Australian qualitative studies regarding carers' lived experience of an FASD specialist clinic a primary benefit for many participants was noted as the diagnostic clarification. Previous research has indicated that diagnostic clarification can provide an avenue for future support, better access to early intervention, and access to targeted funding for specific supports. Research stipulates that for careers, diagnostic clarification can be important in understanding the reason for the child's behavioral challenges. Consistent with previous research, having a better understanding of their child's functioning increased both service users' confidence in requesting support from stakeholders, and their perceived control in reducing problematic behaviors. Service users in the current study also reported increased knowledge regarding misconceptions associated with FASD, particularly related to their child's behavior (*i.e.*, won't versus can't). These findings are supported who found that gaining a diagnosis of FASD enabled service users to be more empathic towards their child's difficulties, as they could then separate FASD behaviors from what was previously perceived as defiant behaviors. A particularly important finding was that service users expressed feeling validated that their concerns were attended to, legitimized, and supported. research noted similar themes, in that service users felt validated by the diagnostic process often after a long history of searching for answers from other health professionals. This highlights the importance of professionals in acknowledging career efforts, providing encouragement, and empowering service users through recognition of their knowledge regarding the realities of raising a child with FASD. The third theme described how for service users, the emotional and behavioral challenges associated with FASD is persistent stressors of which the full extent society is not privy to: they cannot be "cured." A narrative of how support, advocacy, and understanding are needed to neutralize the day to day difficulties that result from caring for someone with FASD. This was consistent with research finding that regardless of diagnosis, children experienced ongoing challenges at home and school. This theme was also consistent with research that indicated significant career burnout in those caring for children with neurological conditions, including FASD. The current study found that the cognitive, emotional, and behavioral concerns of children resulted in the need for ongoing supports across multiple contexts. Previous studies have commonly found that careers experience unavailability of resources, difficulty qualifying for services, and poor implementation of services when support is received. Furthermore, consistent with previous research, parents and careers in the current study reported that in the absence of support they experienced further perpetuation of family stress. Supported by previous research, service users in the current study described having limited therapeutic supports and challenging past encounters with professionals. Furthermore, service users expressed difficulty and lack of progress in their interactions with key stakeholders (*i.e.*, NDIS, schools, child protection services). Service users who had involvement with child protection services described their efforts in communicating with and acquiring services from stakeholders as particularly exhausting and causing additional stress. Previous literature

stipulates that additional pressure may be placed on careers of children with FASD due to a lack of societal knowledge regarding FASD, which requires careers to be their child's advocate across multiple settings. Whitehurst found careers of children with FASD reported their experience as continual advocacy on behalf of their child in the struggle for support, consistently referring to the 'battle' they endured to receive the support, services, and the diagnosis that their children needed. Consequently, lack of appropriate services has been found in the literature to leave parents, careers, or individuals feeling desperate, isolated, and with no one to turn to for support. The experience of service users in the current study was consistent with literature appraising the lack of knowledge of FASD throughout multiple systems as contributing to multi level barriers preventing successful. The fourth theme indicated that service users were able to provide valuable insights regarding changes that the clinic could incorporate to help improve service user experiences in the future. Integrating patient and family member needs, wants, and preferences in healthcare is of utmost importance to ensure that service design is centered on what consumers see as a priority. The insights gained in the current study through the consideration of a more comprehensive and diverse range of stakeholder perspectives may contribute to better understanding and addressing current challenges that service users face. This form of collaborative service improvement may be particularly useful in the further development and ongoing refinement of the interprofessional student led clinic [16-18].

CONCLUSION

The current study explored service users' lived experience of attending a novel student led interprofessional assessment clinic. Results highlighted the importance of listening to service users to capture the complexity of their lived experience and how this information can be utilized to improve service design and delivery in the future. Overall, the current study demonstrated the potential role student led assessment clinics can play in contributing to service provision for under served groups in our community. However, increased support and advocacy opportunities are still required for service users, both throughout the assessment process and post clinic attendance.

LIMITATIONS

Firstly, the size and diversity of the sample may have impacted the results. The clinic was only recently established at the time of data collection; thus, the sample was limited to participants who had accessed the service from its commencement date in 2019. As consecutive sampling was utilised to maximize participant numbers, future larger scale research could incorporate alternative purposive sampling strategies, such as maximum variation sampling, to facilitate comparative data analysis according to participant characteristics (e.g., caregiver type). Although the sample size is comparable to that of previous Australian research, it would

also be worthwhile for future studies to explore a wider range of service users. For instance, only one service user was a biological parent, only one parent/career was male, and within the sample there was little cultural diversity. Future research could examine in further detail the experiences of both biological mothers and fathers of diverse cultural backgrounds to further elucidate specific services needs and potential barriers (*i.e.*, stigma, shame) that may limit access to and participation in services. Future research, where possible, could also include secondary parents/careers and explore the experiences of children and young people themselves of accessing assessment services. Future research could also benefit from combining qualitative and quantitative data to explore experiences in the context of child and adolescent characteristics (e.g., diagnostic outcomes, neurodevelopmental profile, unique strengths, gender, age, caregiver status).

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