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RESEARCH ARTICLE



Exploring the experience of service users following attendance at a student-led interprofessional neurodevelopmental clinic

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ABSTRACT

Purpose: The aim of the current study was to understand service users' 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/caregivers and two youth workers/case managers. Interview data were analysed thematically using NVivo12.

Results: Four main themes were developed: (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 experiences 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.

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> IMPLICATIONS FOR REHABILITATION


- People with fetal alcohol spectrum disorder (FASD) can experience a range of neurocognitive impairments that impact their day-to-day living.
- Access to assessment, early diagnosis, and appropriate supports are important protective factors associated with improved outcomes for individuals with FASD.
- Results highlighted the benefits to rehabilitation professionals of listening to service users to understand the complexity of their lived experiences, including how this information can be used to improve service design and delivery.
- Results also highlighted the potential role of incorporating student-led clinics within models of healthcare and rehabilitation service delivery.
- Utilising student-led clinics can help to increase access to specialised services for underserved groups in our community, combat shortages in the health workforce, reduce burden on the public health system, and educate the future of rehabilitation professionals.

Introduction

Prenatal alcohol exposure is recognised as one of the leading causes of preventable developmental disability 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, behavioural, emotional, and adaptive impairments [1–3]. The extent and severity of these impairments, in conjunction with a lack of societal and clinical awareness regarding prenatal alcohol exposure, can make FASD difficult to identify. Indeed, FASD has been described as an under-recognised, under-diagnosed, and under-estimated condition in many countries, including Australia [4].

The impacts of prenatal alcohol exposure and FASD can result in significant costs to the individual, their family, and society [5,6]. Difficulties with executive function, learning and memory, cognition, speech and language, adaptive function, and social skills [7], 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 [8]. Additionally, caregivers can experience negative impacts such as increased levels of stress and reduced quality of life [9–11]. There are currently no accurate estimates of the prevalence of FASD in the general Australian population [12]. An international systematic review and meta-analysis

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estimates the global prevalence of FASD among young people in the general population to be approximately 7.7 per 1000 [13].

Early identification of FASD is essential to improving outcomes for children and their families [14,15]. However, delays obtaining a formal diagnosis and feeling unsupported by health professionals are reported as ongoing challenges by families [16–18]. 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 [19,20]. Research suggests that misdiagnosis is common, as children with FASD initially present with referrals for investigations of other neurodevelopmental and behavioural disorders, such as attention deficit-hyperactivity disorder (ADHD) or conduct disorder [21]. Additionally, an FASD diagnosis is more likely to be missed or misdiagnosed among children in out-of-home care, who constitute a population at high risk for FASD [22–24]. As a result, early identification and appropriate support is inaccessible for many children, leading to missed opportunities in improving developmental trajectories and longer-term outcomes. Identification and diagnosis of FASD before the age of six has been shown to be a protective factor against secondary conditions [25]. This highlights the importance of exploring novel ways to increase access to FASD-related services.

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 [8] 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 (i.e., small palpebral fissures, thin upper lip, and smooth philtrum); and (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 behaviour, 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 [8].

There are a growing number of services in Australia that provide assessments in accordance with the Australian Guide to the Diagnosis of FASD [8]. However, limited research has explored the lived experiences of service users, specifically in the Australian context. To the authors' knowledge, only two Australian studies have investigated caregiver experiences of the assessment process [14,26]. 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 healthcare (e.g., occupational therapy, psychology, speech pathology) as part of their clinical training, under the guidance of supervising staff [27]. Simpson and Long [28] 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." Students are responsible for planning and providing clinical activities, including assessment and diagnosis, treatment planning, and intervention. For healthcare providers, there are several benefits of incorporating student-led clinics into models of service delivery, including increased capacity for assessments and treatments, in-depth health teaching, and holistic and integrated care [27]. Research exploring the patient experience of student-led service provision has demonstrated satisfaction with the quality of healthcare received [29–33]. For example, participation in a student-led occupational therapy clinic indicated a positive effect on activity-based goals, physical, cognitive, health, and psychosocial outcomes of patients with acquired brain injury [33].

Therefore, the establishment of a student-led clinic that could provide assessments to consider FASD as one possible outcome is an option worth exploring. 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.

Method

Clinic model

The interprofessional neurodevelopmental clinic was established through a collaboration between The University of Queensland and Children's Health Queensland to provide a clinical service for children and adolescents with suspected prenatal alcohol exposure and their families, involving paediatricians, occupational therapists, and psychologists. The purpose of the 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 carers' understanding of their child's capabilities. The clinic served as an interprofessional education (IPE) opportunity for allied health students (i.e., occupational therapy and psychology students). The clinic was designed to align with students' university placement schedules, which was undertaken as a 10-week placement block. Week 1 of the placement was student orientation, Weeks 2–4 were client assessment, Weeks 5–6 diagnostic formulation (including interprofessional case discussions) and commencement of report writing, Week 7 client feedback sessions, and Weeks 8–10 completion of reports. The students were supervised by university staff, including a clinical psychologist (NR), occupational therapist (MM), and a consultant paediatrician (KL) who also worked as part of the interprofessional clinic team. The assessment process involved four components (Table 1). Students were responsible for both administrative and clinical components of the intake, assessment process, case conference, and feedback session. Administrative tasks included contacting clients and organising client appointments, liaising with centre staff, managing client

Table 1. Description of the assessment process.

Components	Process
1. 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.e., prenatal alcohol and other exposures) and postnatal adverse events.
2. Holistic therapeutic assessment	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). 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. Assessment of sleep, eating, sensory needs, and physical health to provide a comprehensive understanding of the child. Medical assessment key FASD physical features (i.e., growth deficiency; dysmorphology), assessment of physical health and genetic testing. Various sensory and behavioural support strategies were trialled, tested, with feedback, and individualised resources provided. Occurred over three days, once per week (approximately 10am–2pm). With support from clinic supervisors, students worked together in interprofessional pairs to plan and deliver the assessment using a family-centred approach. An individualised assessment plan was developed for each service user for each day of the assessment.
3. Case conference	Interprofessional case conference (approximately one hour per child/adolescent) with all staff and students.
4. Feedback	Individual child/adolescent strengths-based feedback session. Individualised resources were created for each child/adolescent. Service user feedback session, which provided an overview of the assessment results and individualised resources and supports. Other key stakeholder feedback session (e.g., child safety, school). Provision of two comprehensive reports. One strengths-based family report and one report to support access to the NDIS.

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 individualised supports).

files, creating resources, and completing session plans, progress notes, reports, and IP reflections. Students were also responsible for completing information gathering and triaging, clinical interviews, standardised and observational assessment, and delivering the results of the assessment during the feedback session (see [Supplemental File 1](#) for additional information). Each student worked within the scope of their discipline collaboratively within their IP team, completing most tasks independently with supervisor consultation as per placement requirements. 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 paediatric registrars (i.e., general paediatric advanced trainees) were involved in the clinic in 2019; however, due to a lack of availability were not involved in 2020.

The clinic assessment process was informed by the Australian Guide to the Diagnosis of FASD [8] and utilised the University of Washington 4-Digit Diagnostic Code [34] 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, University of Queensland staff, and Children's Health Queensland (Garavelis et al., Under Review [35]). 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 service user-centred and strengths-based.

Design

A qualitative descriptive design [36] was utilised to understand service users' experiences of the assessment process. The philosophical underpinnings of qualitative descriptive design include: (1) an inductive process; (2) recognition regarding the subjectivity of participant and the researcher experiences; (3) a design that allows for researchers to develop an understanding of and describe the phenomenon; (4) active participation by researchers in the research process; (5) an emic stance; and (6) data collection in the natural setting of the participants who experience the phenomenon [37].

Sampling and recruitment

As the study focused on service users' 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 carers, 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 (Table 2), including eight parents/carers and two youth workers/case managers. 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 [23,38,39]. 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 [40,p.22] were also adhered to. The aims do not involve comparison between carer type, but rather the collective experience of attending the clinic, thus the sample diversity does not impact the results.

Data collection

Data collection was undertaken using a semi-structured interview schedule (Supplemental File 2) 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 participants' convenience. Nine interviews were completed via

Table 2. Demographic characteristics of service users.

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

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

phone, and one was completed face-to-face. Interview duration ranged from approximately 10 min to 70 min. Interviews were audio recorded and transcribed verbatim by KG and NH. No one else was present besides the participant and researcher during the interviews.

Data analysis

Interview transcripts were analysed by KG using reflexive thematic analysis (TA), a method for identifying, analysing, and reporting patterns within qualitative data [41–45]. Reflexive TA is well aligned with the theoretical underpinnings of qualitative descriptive design, as this approach utilises the researcher's knowledge as a resource to produce a rich analysis of both the explicit and implicit derived from the data [41,43,44]. 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. Braun and Clarke's [45] six-phase procedure guided the analysis of transcripts utilising 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 familiarisation, whereby each transcript was read multiple times. The second step was coding the data for interesting features using QSR software product NVivo 12.0 (released in March 2018) starting with relatively broad codes. The third step included collating and mapping codes into potential themes. Codes were given more detail and conceptualised as "analytic units" [41], 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, including allowing time for additional insights to develop. Themes were not always related to a core concept with a singular meaning but to a central idea that could contain multiple different facets (e.g., "permanency of diagnosis and future implications"). The sixth and final step was the reporting of the results.

Rigour

To ensure the quality of the current study, the analysis utilised the 15-point checklist criteria by Braun and Clarke [42, pg.269] for quality TA, with reference to Braun and Clarke's [41] list of evaluation questions that identify best practices related to reflexive TA. Each step of the data analysis (including coding, theme development, and the write-up) was conducted by KG. In reflexive TA, the use of one coder is not considered detrimental to the quality or reliability of the results [41–43]. Steps 5 and 6 were completed by KG in collaboration with NR, an experienced supervisor and co-researcher, and NH, an experienced co-researcher. NR reviewed the coding process, data coding, and building of themes through reading and fortnightly discussion during the analytic process, including reviews of the initial write ups. Additionally, NH reviewed write-ups of the themes, and contributed to their complexity, refinement, and naming. Accordingly, the authors worked together to maintain the quality and rigor of the analysis [46] and develop the final overarching themes. The results were presented to the remaining authors to further contribute to theme development and reflexivity.

Other steps were also taken to demonstrate quality [41,42,46], including over 6 months of prolonged engagement and persistent observation within the context of the subject matter prior, providing a thick description that included a range of detailed information from participants and detailed information regarding the clinic model and setting, transparency about methods, investing significant time into the analysis, keeping a paper trail of archived files, and by maintaining a reflexivity journal to keep notes and self-examine during the coding process, development of themes, and interpretation of themes. Researcher characteristics and ethical considerations have also been made transparent within the methods section.

The concept of information power, an alternative to data saturation, was utilised [47]. Information power indicates that the more information the sample holds, relevant for the actual study, the lower the number of participants needed [47]. 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 [47]. 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.

Ethical considerations

Ethical approval was obtained from The University of Queensland Human Research Ethics Committee (2019000170/HREC/18/QCHQ/46648) and Children's Health Queensland Human Research Ethics Committee (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 KG 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 The University of Queensland's research data management storage system.

Researcher characteristics

KG was a female provisional psychologist completing her Master of Psychology (Counselling) 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, KG 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 NH, 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.

Results

Four themes were generated from the qualitative analysis: (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. 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/caregiver', 'parent/caregiver and support worker' have also been used when reporting results, to assist with context.

"A much warmer process than what I was expecting": clinic attendance seen as a positive 'event'

The first theme generated described how service users experienced their attendance at the clinic as a positive 'event' or series of events characterised by positive interactions with staff and students who communicated well, were polite, friendly, organised, and helpful. The 'event' was made memorable by specific factors, including the way students and staff tended to the needs of both caregivers and children, including any cognitive, behavioural, or emotional challenges the child or young person presented with during the assessment process. An important facet of this theme was service users' emphasis on how their children were treated:

She [child] loves [assessor]... [assessor] knows how to interact with her very well. All the staff did, and because they interact on a level that she could get... because of her language delays and inability to attend. (P5)

What contributed to experiencing the assessment process as a positive event was the comprehensive, holistic, and person-centred nature of the assessment. Parents/caregivers and support workers reported that children enjoyed interacting with staff and students and the practitioners' family-centred and developmentally appropriate approaches were noted as being particularly helpful:

When it was sort of played out on charts, and like the different green zones or red zones for the day he was feeling, and a chart done with illustrations showing different things. That was very good, I think, because he could understand all that and contribute to that. (P2)

An interesting feature of this theme included the interwoven narrative of 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:

I had one paediatrician tell me that the problem was in the home and that they would need to send someone in, like family network. So, I was really sceptical in the beginning. But even from the first moment, they reassured me, straight away. Which was a lot, because walking in, the way I was feeling, walking into that it would have taken a lot to make me feel reassured. (P8)

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 users' experiences of the clinic was that they could apply the results of the assessment process in a tangible way.

It was helpful because now when somebody comes out regarding (child), we often pull that bag out and we go through some of those pamphlets and paperwork they provided us with. So, it just helps everybody to have that better understanding. (P6)

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 providers understand more about the young person.

"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 aspect of this theme included service users' experiences of having their concerns finally heard by health practitioners and their concerns validated as real and substantial.

They were people that just listened, and um believed what you said, instead of just thinking oh you're an idiot of a mother who can't control your child. Like they really just noticed everything and listened... they listened, they took everything on board, it's the only place I have been that I felt I was getting somewhere. (P1)

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 centred/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).
Feedback, reports, and resources were helpful	"The reporting at the end of the assessment was extremely thorough and in a level of being easily understood. It was written to meet both medical and lay person needs as well as NDIS etc. so I think it was very extensive the reports that they had done. They put all the assessments in one document, which is really important because you have several assessments over so many different disciplines and they're all thorough documents whereas now it is one document that gives a complete picture so that was very important to be able to now have" (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 neutraliser 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 behavioural 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/caregiver 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).
Numerous services accessed, little help	"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).
Service users more likely to get other children assessed following attendance	"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).
Drawing on lived experience for future service improvements.	"Now we want to get our 16-year-old daughter assessments" (P6).
	"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).

Service users described a sense of relief following the assessment, as the process led to movement in the desired direction. Another 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" behaviour) provided. Specifically, redefined expectations, a better understanding of the child or young person's capacity.

It's spurred me on, you know finding out more about him...what he can and can't do, and that assists me with moving forward with different things. (P2)

She thought she was dumb, so now she understands why she doesn't know as much as she would like to. (P4)

Ultimately, diagnostic clarification helped participants better understand how to meet the needs of and communicate to the child in their care. Although service users largely reported benefits

post-assessment, 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.

Because of the permanency...it's that permanency, it's sort of like a level of hopelessness that you feel. (P5)

A nuanced challenge included the emotions that may surface due to stigma associated with FASD. The biological parent/caregiver 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 stigmatisation.

Every visit that I made, I felt more inclined to be open about it. I wasn't going to be made to feel like the awful biological mother who drank...I never was made to feel like the villain or the criminal. (P9)

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 behaviour on their families. Although parents/caregivers appreciated the number and variation of supports recommended, many reported not knowing "where to start."

As a mother, what do I do first? What is the most important thing for her, there are a lot of recommendations, and you get a bit lost—like I don't know where to start. This is new to me. (P9)

This theme indicated that while the clinic provided helpful answers, this information now prefaced new challenges service users would have to adapt to. Parents/caregivers 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.

I would be wanting strategies to equip [child] with—being able to control of emotions, managing anxiety, because it does take over [child's] life. (P10)

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 users' 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, behavioural, and/or cognitive difficulties that interfered with functioning at home or school. Parents and caregivers also described an element of burnout in the context of the child or adolescents' presenting concerns, the minimal support they currently had access to, and the numerous services they had tried 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.

They could see that I was having to deal with so much, you know what I mean. I had a lot to do, and that takes energy for me to do all this. I get very tired naturally having to retell [child's] history to everybody. I get very tired and it drains me...People have spoken to me, put their bill in for their time, and that's come out of the plan and nothing has been done for [child]. (P2)

Parents and caregivers 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.

...we are very limited especially because Child Safety are the guardians, so they are the "parent" figures as they keep pointing out. Even at the NDIS meeting the CSO [Child Safety Officer] constantly reminded the lady that everything had to go through her. So, if the lady talked to me directly, she was very quickly put into place and reminded that they were Children's Services' children. (P6)

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, caregivers 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 counselling 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, behavioural therapy, occupational therapy, coordinated support work (e.g., social work, NDIS management), and support for parents and carers.

If you could just send out information on ADHD or ADD. Yeah, or if there are any... conferences...you know training things or any talks about ADHD. (P3)

Parents/caregivers 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/caregivers also suggested that peer support for biological mothers may be helpful to provide prior to, during, and after the assessment process.

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. (P9)

Discussion

The aim of the current study was to understand service users' 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, regardless of diagnostic outcome. 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 [14,26], although not student-led. An important point to consider is that service users in the current study did not share any views that indicated the quality of their service had been negatively impacted by student involvement. Although to the authors' 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. Numerous studies have indicated that service users of student-led clinics report high levels of satisfaction and perceive that their needs were well attended to and thoroughly addressed [29–33,48–50]. This finding is consistent across various service-user populations and type of health services offered by the student-led clinics. For example, in Carrigan et al. [49], parents' satisfaction of a family-centred paediatric student occupational therapy clinic was related to the personal qualities (e.g., communication skills, rapport) of the student practitioners, verbal feedback following sessions, sufficient time to have their concerns heard, and parent-friendly reports that identified their children's strengths and difficulties. Furthermore, Sargison et al. [50] found that patients who attended student-led speech and occupational therapy services in Aboriginal and Torres Strait Islander early childhood settings reported positive impressions of the students, valued the students' assistance, and put particular emphasis on the importance of the students' efforts to connect with families, learn about their family contexts, and gradually build relationships with their children.

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 caregivers' lived experiences of an FASD specialist clinic [14,26], a primary benefit for many participants was noted as the diagnostic clarification. Previous research [14,51–55] indicated that diagnostic clarification can provide an avenue for future support, better access to early intervention, and access to targeted funding for specific supports. Diagnostic clarification can be important in understanding the reason for the child's behavioural challenges [14,17,53] and 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 behaviours [26,53]. Service users in the current study also reported increased knowledge regarding misconceptions associated with FASD, particularly related to their child's behaviour (i.e., won't versus can't). These findings were supported by Doak et al. [26], who found that a diagnosis of FASD enabled service users to be more empathic towards their child's difficulties, as they could then separate FASD behaviours from what was previously perceived as defiant behaviours. Participants who did not receive an FASD diagnosis in the current study did not discuss feelings associated with diagnostic clarification, although they did still discuss the helpfulness of understanding their child's neurodevelopmental profile following the feedback.

A particularly important finding was that service users expressed feeling validated that their concerns were attended to, legitimised, and supported. Chamberlain et al's [14] 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 caregiver efforts, providing encouragement, and empowering service users through recognition of their knowledge regarding the realities of raising a child with FASD [e.g., 53,54].

The third theme described how for service users, the emotional and behavioural challenges associated with FASD are persistent stressors of which the other people in their support network and wider community do not always understand. A narrative of how support, advocacy, and understanding is needed to neutralise the day-to-day difficulties that result from caring for someone with FASD was described by parents and caregivers in the current study. This was in line with Doak et al's [26] research finding that regardless of diagnosis, children experienced ongoing challenges at home and school. This theme was also consistent with Rowbottom's [55] research that indicated significant caregiver burnout for those caring for children with neurological conditions, including FASD. The current study found that the cognitive, emotional, and behavioural concerns of children resulted in the need for ongoing supports across multiple contexts. Previous studies have commonly found that caregivers experience unavailability of resources, difficulty qualifying for services, and poor implementation of services when support is received [e.g., 16,17]. Furthermore, consistent with previous research [e.g., 56], parents and caregivers in the current study reported that in the absence of support they experienced further perpetuation of family stress.

Supported by previous research [14,16,18], 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). Service users who had involvement with child protection 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 caregivers of children with FASD due to a lack of societal knowledge regarding FASD, which requires caregivers to be their child's advocate across multiple settings [17,40]. Whitehurst [18] found caregivers 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 services, and the diagnosis that their children needed [18]. Consequently, lack of appropriate services has been found in the literature to leave parents, caregivers, and individuals with FASD 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 outcomes [17,18].

The fourth theme indicated that service users were able to provide valuable insights regarding changes that the clinic could incorporate to help improve 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 centred on what consumers see as a priority [57]. 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.

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 maximise 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 caregiver 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 caregivers and explore the experiences of children and young people themselves of accessing assessment services. Furthermore, this clinic is one of the few in the state for children aged 11 to 17 years, and thus the sample included predominantly adolescents rather than younger children. Future research could also investigate caregivers with children of a more diverse age range. 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). Lastly, future research could also explore student experiences in the context of their placement to enhance learning opportunities in conjunction with the interprofessional nature of the experience for students and service users.

Conclusion

The current study explored service users' lived experiences 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 experiences and how this information can be utilised 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.

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