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“People talk about FASD diagnosis but barely any young people are asked about it”: Diagnosis perspectives and disability identity in adolescents with FASD

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ABSTRACT

Purpose: Young people with Fetal Alcohol Spectrum Disorder (FASD) are underrepresented in research and in public/professional discourse around the diagnosis and the impact of this disability. This study explores adolescents’ views about their self and disability identity, and knowledge and attitude towards the FASD diagnosis.
Method: Eight adolescents aged 12–19 years with an FASD diagnosis and in education, participated in this study. Data were collected online using Photovoice methodology and analysed using Interpretative Phenomenological Analysis.
Results: Adolescents expressed positive views of their FASD diagnosis in terms of its salience for self-understanding. They provided biological and causal explanations of FASD but there were no attributes of blame or shame towards biological parents. Adolescents primarily self-identified with personality traits and interests/hobbies but acknowledged FASD as part of their identity. As the adolescents developed their disability identity, parents and peers played different roles in the provision of information, support, and disclosure of the diagnosis.
Conclusion: The views expressed by adolescents with FASD about the value and impact of the FASD diagnosis, and the disability identity process, were similar to other groups of young people with different neurodevelopmental and physical conditions. Self-understanding and advocacy relating to diagnosis and disability during adolescence can enhance wellbeing, access to supports and a positive self-identity. Professionals across different services can play a proactive role to develop the positive disability identity of adolescents with FASD.

1. Introduction

Fetal alcohol spectrum disorder (FASD) is a diagnostic term, neurodevelopmental condition and disability caused by prenatal alcohol exposure with a wide-ranging impact on individuals’ biological, cognitive, social, and adaptive functioning (Harding et al., 2022). FASD is characterised as a multifaceted and often “hidden” disability (Flannigan et al., 2021), which encompasses a broad co-occurrence of neurodevelopmental differences, physical health conditions and varied functioning in areas of cognition, academic attainment, attention, executive functioning, adaptive and social skills, and mental health (McLachlan et al., 2023). FASD encompasses several earlier diagnostic terms (Fetal Alcohol Syndrome and Alcohol Related Neurodevelopmental Disorder) and its spectrum is recognised with or without sentinel facial features (Scottish Intercollegiate Guidelines Network, (SIGN), 2018).

The heterogeneity of FASD as a neurodevelopmental condition and disability is important to acknowledge (Harding et al., 2022). From a theoretical perspective, the impact and value of a diagnosis, and what it means to have this disability, may be best understood through a conceptual framework which recognises the range of interactive systems in which adolescents with FASD develop. This study is therefore framed by the bio-psychosocial model of disability as understood in the International Classification of Functioning of Health and Disability (World Health Organisation (WHO), 2001). This model proposes that a disability can arise from the interaction between the individual with a health condition, their activities and functioning and the nature of their environment. This framework also promotes disability rights, diagnostic practice and wider relevance to multi-disciplinary practice. Research into FASD diagnostic experiences has primarily focused on caregiver views (Chamberlain et al., 2017; Hayes et al., 2023) and highlights that these views need to be considered by health professionals’ during

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assessment and diagnostic reporting for young people and their families (SIGN, 2018). However, research into the diagnostic views of young people with FASD themselves is very limited as is the research of FASD exploring the identity of young people[1] with FASD (Eodanable et al., 2024). This study explores the underrepresented views of young people with FASD in the United Kingdom (UK) regarding the diagnosis of FASD and their perceptions of their self-identity and disability identity during adolescence.

1.1. *Current issues with the FASD diagnosis: Prevalence; practice and stigma*

There are low referral and diagnostic rates of FASD internationally (Burd and Popova, 2019) and in the UK (SIGN, 2018). This is contrary to the high levels of alcohol harm in the UK, confirmed in hospital episodes for women aged 15–44 years (Morleo et al., 2011) and significant levels of alcohol exposure in pregnancy (Abernethy et al., 2018). The first UK case ascertainment study with children aged 5–12 years (n = 177) estimated a minimum prevalence rate of 1.8 % for FASD, increasing to 3.6 % for possible FASD, where FASD was suspected but prenatal alcohol exposure (PAE) history was unknown (McCarthy et al., 2021). The varied profile of FASD in individuals (McLachlan et al., 2023) and the limited prenatal alcohol histories available to professionals can impact clinical practice in referral, assessment, and diagnosis, which ultimately affects the diagnostic rates of FASD (Mattson et al., 2019).

Studies with health professionals suggest that under-reporting and low diagnostic rates of FASD could be attributed to limited knowledge, a lack of guidance, and a stigmatising view of the FASD diagnosis (Howlett et al., 2019; Mukherjee et al., 2015). Health professionals' ethical discussions have often debated this as a diagnosis with limited value or impact for individuals with FASD (Helgesson et al., 2018).There are also stigmatising attitudes and discourse about FASD, amongst health professionals and the public, which can include the assumption of a trajectory of negative life experiences for individuals with FASD, and views of guilt and shame held towards biological mothers (Aspler et al., 2022;Bell et al., 2016; Corrigan et al., 2019, Domeij et al., 2018; Wilson et al. 2023). Canadian research with health and justice professionals indicates that the FASD diagnosis can act as "a road map and currency" potentially facilitating access and entitlement to support for individuals and families and should not be construed as a destination (Dunbar Winsor, 2021: p11). However, research practice has little direct engagement with individuals with FASD about their views of its meaning and impact as a diagnosis (Reid et al., 2022) or about the lived experience of young people with FASD, their priorities for support or their experiences of FASD as a disability (Eodanable et al., 2024).

1.2. *Parent and professional views on the value and impact of FASD diagnosis*

Knowledge about the impact of the FASD diagnosis has been mainly derived from research with parents/caregivers (SIGN, 2018). Parental support to access FASD assessment and interventions is often necessary for individuals during childhood, adolescence and adulthood, which can mediate outcomes and impact for individuals and families.

Clear advantages and value are attributed to the FASD diagnosis in terms of a parent's understanding of their child's needs following diagnosis (Salmon, 2008, Sanders & Buck, 2010; Chamberlain et al., 2017). The diagnostic value of FASD aids parenting and enables access to support (Lange et al., 2018). Potential disadvantages of a FASD diagnosis have been raised in terms of stigmatisation for the child and biological mother (Salmon & Buetow, 2012; Michaud & Temple, 2013) and an attribution of blame from professionals and blame experienced in families (Mukherjee et al., 2015). Recent literature reviews of diagnostic assessment experiences reveal parents' mixed emotions upon receipt of a diagnosis but equally validation of concerns being addressed, feeling empowered and valuing strength-based feedback (Chamberlain, et al., 2017; Hayes et al., 2023; Wilson et al., 2023).

A Canadian study with adults with FASD (age 18–45) outlined the positive impact and practicalities of the FASD diagnosis received in adulthood, in terms of increased disability income, access to services and its value for self-understanding (Temple et al., 2021). The diagnosis encouraged personal reflection which in turn enabled confidence to ask for supports and increased self-acceptance. Feelings of relief were mainly associated with receipt of the FASD diagnosis and for some there was an ambivalence, but it was not considered a negative impact (Temple et al., 2021). Reliance on parental support still continues from adolescence into adulthood despite neurodivergent individuals desire for independence (Brenna et al., 2017; Kenny et al., 2024).

It is still unclear what the views of adolescents and young adults are about the impact of FASD and the extent to which a diagnosis can enable further independence and better life outcomes. However, a review of the consequences of diagnostic labels for individuals with physical health and other psychological diagnoses including other neurodevelopmental conditions by Sims et al. (2021) indicates both positive and negative impact across a number of areas: *psychosocial impact (*on identity and stigma); *support; future planning*; *behaviour* (adaptations); and *treatment expectations.* The development of independence and informing transitions into adulthood is a particular focus for adolescents with FASD (Brenna et al., 2017), underscoring the importance of research with this age group.

1.3. *Engaging adolescents' views on the impact and value of the FASD diagnosis*

Further research on individuals' perspectives of the impact of the FASD diagnosis in terms of views, support and identity in adolescence could inform support for individual's self-understanding, and self-advocacy and enable healthy outcomes as they move towards adulthood (Joly et al., 2022). Existing research with young people has been limited in the number and location of studies (Skorka et al., 2020, 2022; Wilson et al., 2023). Early exploratory research by Stade et al. (2011) in Canada, and by Salmon and Buetow (2012) in New Zealand studied the lived experiences of individuals with FASD (6–18 and 14–37-year-olds respectively). The dominant theme of 'feeling different' emerged in participants' views in Stade et al.'s study (2011) and the impact of the disability was included in both studies. Only in the study by Stade et al. (2011) did a few young people discuss the unfairness of the aetiology of FASD, whereby they recognised that they had to live with the consequences of prenatal alcohol exposure (PAE). However, these studies covered a wide age range and focused on an exploration of the broad effect of FASD. As such, there is an ongoing research gap to explore what a FASD diagnosis means to adolescents alongside the realities of FASD as a disability. The significance of a diagnosis is more than "just" a label but can be viewed as a psychosocial process for the individual to consider the impact of a disability and how they manage their world (Mueller, 2019, 2021; Sims et al., 2021). Wilson et al. (2023) indicated that individuals with FASD have an awareness of their disability, but research with accessible research methodology and participatory approaches can enhance insights about the lived experience and experience of disability with adolescents with FASD (Eodanable et al., 2024).

1.4. *Self and disability identity formation in adolescence*

Adolescence is a distinct period for individual physical, social and cognitive changes that impact self and identity formation (Erikson, 1968; Tajfel & Turner, 1979). Life events or transitions can induce changes in adolescents' identity but the nature of the daily experiences

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[1] Young people is a term used to express the stage of adolescence. Usually from 12 to 18 years old and aligns with secondary school stage of education in the UK.

in the context of home and education, and supportive relationships with parents and peers contribute to a more coherent identity (Branje, 2022). The intersection of racial, ethnic, and sexual identities has been more frequently researched in adolescence in comparison to disability (Forber-Pratt et al., 2021).

Disability identity is a sense of self that includes a person's own view of their disability, and their relationship with the disability community (Dunn & Burcaw, 2013). It can shape how a person can view themselves, their body, and interactions with others (Forber-Pratt et al., 2017). Disability can be understood as part of one's individual and social identity, which can enable self-advocacy and community engagement (Smith & Mueller, 2021).A review of disability identity models by Palm-Leis (2023) highlights the lack of consensus across social identity, ecological and crip theories but highlights the contribution of disability identity theory to explore individual meaning as well as clinical, educational and societal relevance (Kreider et al., 2019). Disability identity theories are often derived from social identity theory, highlighting how one's identity is developed through alignment with social groups (Tajfel & Turner, 1979). Two such social identity theory-derived disability identity models were developed by Gibson (2006) and Forber-Pratt et al. (2020). Gibson's three-stage model (2006) was first published for clinical use with individuals with disabilities. The first phase – "passive awareness" – usually relates to childhood, where a child may not self-identify a distinct awareness of disability, due to their individual, family and environmental context, and a high level of dependency on adults. The second phase- realisation- may occur in adolescence and early adulthood, where the individual's more independent interactions in their environment can lead to greater self-realisation, potentially negative feelings and comparisons of self to peers. The last phase –acceptance- described an individual's acceptance of a disability, where the individual adult actively seeks to manage their broader world and is part of a broader disability community. Forber- Pratt et al. (2017) critiqued Gibson's model for its lack of focus on a group/community identity. However, Forber-Pratt et al.'s starting point is the acceptance status, whereby the individual and family understand and accept a disability and is less illuminative of the process of formation before acceptance in adolescence.

Intrapersonal and interpersonal identity formation in adolescence comprises rapid changes in this period, coupled with intersectionality with other identities which can lead to a more coherent identity into adulthood. This process is complex and heterogenous and should be explored at a microlevel , to understand how individuals reflect and form their identity (intrapersonal) in addition to the context of their lives and relationships (Branje, 2022). In this study, Gibson's model was applied as a framework to understand disability identity development, because it focuses on the childhood-adolescent period, and allows for such a microlevel perspective. This model has been previously criticised for not expanding on identity development beyond the point of acceptance or acknowledging potential interactions with a disability community. (Forber-Pratt et al, 2017). However, Gibson et al. (2018) clarified that fluidity between stages and emotions should be expected and that intersectionality of other identities must also be acknowledged. The clinical and educational relevance of this model has also been demonstrated in clinical application (Gibson, 2006) and research with students with visual impairment and neurodivergent college students (Gibson et al., 2018; Schmulsky et al., 2021). The intrapersonal aspect of adolescents with FASD's disability identity has not previously been explored, which is relevant in light of the lack of disability representation in school environments and curricula, and the variation of disability community experiences for this age group (Mueller, 2019).

The identity of adolescents and young adults with disability is not solely defined by their disability and can be part of multiple identities contributing to a positive identity (Rodriquez et al., 2023). Research with young adults with intellectual disabilities from the Special Olympics U.S. Youth Ambassador Program contradicts assumptions of negative labels of disability and associated stigma as the young people also valued a positive disability identity shaped by social connections, opportunities and community engagement (ibid). Participatory approaches in research using creative research methods like Photovoice (removed for peer review), audio diaries and group and individual interviews (Rodriquez et al, 2023) seek to undertake research *with* individuals and communities rather *on* individuals so that the voice and experiences can be authentically explored and shared respectfully. In addition, community-based participatory research through the mechanism of an advisory board can provide a connection between researchers and the FASD community (Dunbar Winsor et al., 2022) so that knowledge, design and dissemination can be more accurate and enhance impact. Such approaches have the potential to allow for a nuanced exploration of disability identity in FASD.

1.5. *This study*

To the authors' knowledge, there are no disability identity studies regarding FASD. It is also clear that there are few studies with adolescents with FASD about their views on the meaning and impact of their diagnosis and how it relates to their identity and disability identity. Research in this area could potentially benefit the discourse surrounding the FASD diagnosis and as Reid et al. (2022) asserts, could inform understanding of individuals' needs and supports during and post diagnostic assessment. This community-engaged photovoice study, therefore, informed by the bio-psychosocial model of disability (World Health Organisation, 2001) and theoretical lens of Gibson's (2006; Gibson et al., 2018) model of disability identity formation sought to explore two research questions:

1. What are the knowledge and attitudes of young people with FASD towards their FASD diagnosis?
2. To what extent does FASD impact the identity of young people with FASD (including disability identity)?

2. Material and methods

2.1. *Participants*

Eight young people aged 12–19 years (6 males: 2 females) participated. Participants are described at group rather than individual level, to ensure confidentiality. Six attended secondary school, and two attended college. Seven of the eight participants attended alternate education provision ("special school" or "mainstream school with a unit"). The inclusion criteria were young people aged 12–19 years who were: aware of their FASD diagnosis; in education; and living in the UK. The age range aligns with the beginning of secondary school to post-school transition in the UK and allowed for exploration of identity development across adolescence. Diversity in care experience was represented as some participants were adopted (n=4), in foster care (n=2) and one individual lived with their biological mother. The participants were identified as white British and residing in the UK (Scotland, England, and Northern Ireland).

2.2. *Materials*

A parent/carer questionnaire (see supplementary materials) was developed to gather data on the young person's diagnostic process and co-occurring diagnoses and their sources of information about FASD (Table 1). There was wide variation in age of diagnosis and length of the assessment process. The paediatrician was cited most frequently as the "referrer" and the geneticist as the "assessor" of the young people. Co-occurrence with physical, mental health, and other neurodivergent conditions was reported.

The Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q: Mckenzie et al., 2012) was administered by the lead author with the young people, with parents in attendance. The CAIDS-Q

Table 1
Parent questionnaire of child's FASD diagnostic process and outcome.

Individual age of diagnosis	
Age of FASD diagnosis:	Range: 4 months to 12 years old
Length of assessment time (time between referral to diagnostic outcome):	Range: A few weeks to 4 years
Diagnostic outcome and process	**Number of participants (N = 8)**
Diagnostic outcome:	
Fetal Alcohol Syndrome	6
Alcohol related ND Disorder	2
Co-occurring diagnoses and conditions:	
ADHD	3
Autism	1
Epilepsy	1
Physical health conditions	3
Mental health conditions	1
Who referred:	
Paediatrician	5
Parent	2
Social Worker	1
Who diagnosed:	
Geneticist	4
Paediatrician	2
FASD clinic	1
Don't know	1
Parental source(s) of FASD information:	
Self-directed learning	6
Online Information	5
Online support groups	3
Foster carer training	2
Health professionals	2
Young Person's source(s) of information:	
Parent	8
Social Work	1
Health professional	1
Peer support group	1
Social media	1

is a 7-item screening tool to identify children and adolescents aged 6–18 years who may have an intellectual disability. In the sample, two young people were identified as being likely to have intellectual disability.

2.3. Procedure

Ethical approval and sponsorship were obtained from the University of Edinburgh. As part of a participatory approach due to the research team's positionality and reflexivity, a community advisory group provided consultation on the research design/tools and supported recruitment and dissemination. The group comprised five adult representatives from the Fetal Alcohol Advisory and Support Team, FASD Hub Scotland, an NHS (National Health Service) Consultant Associate Specialist and two adults with FASD.

Participants were recruited via social media, and with the support of the advisory group. Families were emailed the participant information sheet, consent form and parent questionnaire. Written consent was obtained from all participants in addition to parents for young people below the age of 16 years. Introductory meetings were arranged online using the platform of Microsoft Teams with both parent and child in attendance. At this the researcher introduced themselves to the young person and allowed an opportunity to outline the research and discuss any questions they had.

A photovoice method was used and framed within a participatory and interpretative phenomenological analysis approach (Smith et al., 2009) so that experiences and meaning could be explored with individuals and an opportunity was provided for young people to advocate for themselves. Photovoice is a visual research method based on photos taken by participants devised by Wang and Burris (1997), which can be an accessible method for researching adults' experiences of health and disability, as well as mental health with adolescents (MacDonald et al., 2019; Stephens et al., 2023). It has previously been used to research different experiences of young people with FASD (Brenna et al., 2017; Eodanable et al., 2024; Skorka et al., 2020). The photovoice procedure in the present study was iterative and sequential in the present study featured six phases (Fig. 1). Further details about the participatory approach of this Photovoice method and study are reported elsewhere (Eodanable et al., 2024). The first interview (Phase 1) included questions about home, school and community activities consistent with the environmental contexts salient to adolescents as identified by Forber-Pratt et al. (2021). The interview concluded with questions on what the adolescents understood about the term FASD (*What does FASD mean to you?*) (See supplementary materials). In Phase 2, the young people met as a group online. The first author outlined the research process and the group discussed topics and ethics for photo-taking. During Phase 3, the young people were provided with three broad topics to guide their photo taking: *Who/what is important to you; Who/what helps you; and Challenges and how I deal with them.* Each young person was asked to take and then select 5–10 photos per topic to send to the first author: a total of 125 photos and 6 vector images were submitted. In Phase 4, each participant was interviewed individually, whereby the first author displayed the individuals' photos on a Powerpoint display according to the three topics as provided by the participant. The first author modified a SHOWed format of questions (Pavlopoulou and Dimitriou, 2020) (Table 2) to use for the interview (Eodanable et al., 2024). Phases 5 and 6 were online group sessions with similar use of Powerpoint to display photos and tools of Google Jamboard to display their categorisation. Phase 5 was a session to analyse their photos as a group, which then provided an opportunity to consider whether and how the group wanted to share these photos publicly (Phase 6). In addition to the advisory group, the young people's role was specified as co-researchers, and participatory approaches were included across the procedure: individual choice of taking and selection of photos in phases; dissemination plan and activities directed by the young people.

3. Data analysis

Interpretative Phenomenological Analysis (Smith et al., 2009) is an idiographic approach for inquiry and analysis (Lyons and Cole, 2021) and was applied to individual interview data from Phases 1 and 4. Interviews were video recorded and transcribed by the first author. The first author engaged in phases of reading individual hard copy transcripts to identify and record linguistic, semantic, and conceptual comments. As per Smith et al's. (2009) commitment to idiographic study, analysis also followed these steps; close reading and notetaking for each individual account so that initial themes relate to individual accounts and then refining themes (subordinate) to capture individuality and convergence across all transcripts. The final aspect is the authors' interpretation between the meaning made by the participants and researchers and the narration of this. At this point, the superordinate themes were refined. The research team engaged in discussion of a selection of transcripts throughout each phase and in person meetings. This contributed to the organisation of themes and checking of researcher positionality in relation to subordinate and superordinate theme development.

The biopsychosocial model (WHO, 2001) informed analysis with reference to the embodiment, language, identity and experiences of the disability of FASD. Gibson's (1996) model was used to provide a theoretical framework to explore if, when and how young people's identity development appeared to align with the model's three phases of disability identity formation. See Fig. 1, which displays a master table of themes for the group and includes Gibson's phases as subordinate themes in the third theme.

The young people conducted a group analysis of their photos and co-developed a dissemination plan (Phases 5 and 6) with a subsequent photo display with the first author. The young people choose to develop a photo display using SWAY, which was published on a FASD

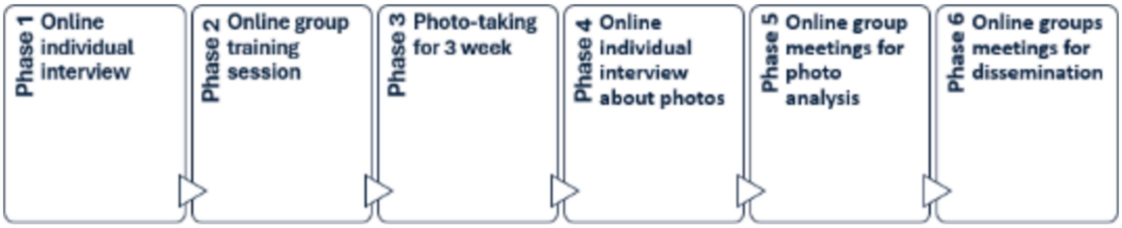

Fig. 1. Six phases of online photovoice with young people with FASD.

Table 2
SHOWed questions for individual interviews with photos (Phase 4) (removed for anonymous peer review).

S	What do your eyes **S**ee in this picture? (Tell me what is in the photos?)
H	What is **H**appening in the picture you have taken? (What is the story behind this photo?)
O	How does this photo relate to y**O**ur life as a young person with FASD? (What does this photo show about your life as a person with FASD?)
W	**W**hat is it that creates this problem/strength in your life?
E	How could this photo **E**ducate (teach) others about the lives of young people with FASD?
D	What can we **Do** about it? (What can adults – like researchers, parents, teachers do to make your experiences better at home, in school or in the community?)

community webpage. This is reported elsewhere (Eodanable et al., 2024).

3.1. Research team and reflexivity

Within the authorship team, there is educational, professional, and academic research experience of FASD and other neurodevelopmental conditions, and experience of working with neurodivergent young people, their families, and schools. No one on the team is disabled. It is recognised that the identity and experience of the authorship team will inevitably have influenced the data collection, analysis and interpretation of the data. Therefore, the first author pursed participatory approaches through the advisory group and with young people and engaged in journaling during the research team's meetings to support discussion of the analysis and interpretation of data.

4. Results

Three key themes and the subordinate themes are reported here (See Table 3: *Understanding the FASD diagnosis; Important factors for self-identity in adolescents with FASD; and Disability identity process.* The remaining two themes arising from the analysis are reported in (reference removed for anonymous peer review).

Table 3
Themes from interview data using IPA.

Superordinate themes	Subordinate themes
1. Understanding the FASD diagnosis	• Explanations and feelings about FASD • Purpose of the FASD diagnosis • Adults' role in FASD information
2. Important factors for self-identity in adolescents with FASD "*Me being me*"	• Adolescents' self-perception • Nurturing relationships provided by family • Distinct experiences with "friends" and peers
3. Disability identity process (Gibson, 2006)	• Early awareness of disability • Realisation of disability identity • Acceptance of disability identity

4.1. Understanding the FASD diagnosis

4.1.1. Explanations and feelings about FASD

Adolescents in this study constructed biological and causal explanations of FASD using clear and objective language. They also identified a range of feelings relating to their experiences of FASD as a disability. The language they used in all interviews was factual and concise stating a cause (prenatal alcohol exposure) and a biological explanation (brain works differently causing an impact to their functioning). References to biological parents (*my mum*) were again factually stated in relation to their prenatal alcohol exposure (PAE). Whilst the YP were aware that PAE should be avoided, they did not make derogatory comments or attribute feelings of shame or blame specifically towards their biological parents.

> *Curly Sue*[2]*: It's like FASD is mmm, what is it called a disability like some people have—like where some of your brain cells don't work properly. Someone, the person that was carrying you when you were a baby, was pregnant, was drinking.*
> *Chloe: My mum she was drinking when she had me. People shouldn't be drinking when you are having a baby or before you know that you're going to have a baby.*
> *Chris: You don't drink alcohol – pregnant people – they get the baby inside they get drunk. …because my mum drinks wine- drunk wine. Not this one, the other one (refers to his biological mum).*

The participants' views about FASD as a diagnosis revealed a range of emotions but there was a clear self-focus rather than a focus towards others:

> *Drummer Boy: My feelings are a bit sometimes; my feelings are like get worried or sad or happy – It's about the FASD.*

The emotions related to the individual's navigation of the impact of FASD and their understanding of this diagnosis. The young people shared a view of neurodiversity through the existence of natural human variation and difference, and again none stated maternal blame. The variation of the impact of this disability was explored in the third theme relating to disability identity process. One participant, James mentioned the word shame but attempted to dissociate FASD from shame.

> *Curly Sue: It doesn't really mean that much to me because everyone's got, everyone's different. And it's just life.*
> *Max: Just think everyone should accept it and I don't think it changed anything about me.*
> *James: There's no need to be ashamed of expressing or you know explaining… (FASD) I was okay about it…So what it is it's basically say like my tummy mummy when she was pregnant and she would have beer and wine and when she was drinking that's when me and my brother were, you know, when she was pregnant and that would have affected us. Yeah 'cause of the alcohol in the beer and wine she was drinking so that us unique and special.*

Explanations of FASD indicated an understanding of its cause. At this

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[2] Young people were offered to choose pseudonyms to represent their identity and quotes.

age, the young people in this study focused on their own feelings rather than attributing shame/blame towards biological parents. They acknowledged different emotions in relation to the impact and understanding of FASD.

4.1.2. *Purpose of the FASD diagnosis*

Each young person identified a purpose to having an FASD diagnosis. The FASD diagnosis had a subjective value for the young people, as they viewed it as more than a simple label or categorisation imposed by others.

> *Drummer Boy: It means a lot to me… because all the social, social workers help me with my mum.*

A FASD diagnosis enabled understanding and support by adults and peers around the young people. James also considered that the FASD diagnosis enabled him to discuss it with peers, which would be helpful in improving his self-acceptance and reducing his sense of isolation.

> *James: – (I want to) speak to others – It would be helpful yes so that I know that I'm not the only one.*

A few young people noted from their understanding of the FASD diagnosis, that information about alcohol use in pregnancy should be shared with peers. Chloe expressed a preventative message about alcohol use, peer pressure and risks associated around pregnancy and FASD.

> *Chloe: You shouldn't have a drink at all or even get pregnant at all. You might get peer pressured into having a drink or having a baby and you really don't want to do neither of them.*

Throughout the interviews, young people expressed their views of value concerning the FASD diagnosis in terms of improving self and public understanding of FASD, but one participant (Jack) highlighted that the views of young people with FASD are rarely sought.

> *Jack: Everyone talks about the FASD diagnosis but barely any young people are asked about it.*

When discussing the FASD diagnosis, the young people articulated a clear view and purpose to the FASD diagnosis for them as individuals and for society more broadly. For these young people, FASD was more than a diagnostic label, but a means to facilitate better understanding of the impact of FASD for the individual, family, peers, and professionals and in turn access support.

4.1.3. *Adults' role in FASD information*

All young people identified their mum/foster mum as a key source of information on FASD. Parents facilitated FASD conversations:

> *Max: Mum talks to me about it now and then and sometimes my dad.*
> *Chris: My mummy knows about it.*
> *James: My mum (told me)- we were at home, so we were, in the living room. No one else spoke it and I would go and ask my mum.*
> *Sean: I heard about FASD when I came to live here.*

Parent-led conversations provided young people with a clear explanation, almost like a script, of FASD and the young people conveyed a sense of openness in interviews when sharing these conversations. The example of Curly Sue's conversation with her foster parent was accessible to her level of understanding and in turn enabled her to have a 'script' about FASD.

> *Curly Sue: They were just saying like – Oh my mum was drinking when she had me, yeah, and some of my brain cells don't work properly. Right, I think that's all they told me though. They said it like so I would understand if you know what I mean.*

There was little recollection of professional discussion of FASD with individuals in different settings, but especially in school. There was also uncertainty about which professionals knew about their diagnosis:

> *Chris: I don't know if they (teachers) know about any of it (FASD)… I don't know.*

Parents were seen to be a reliable source of FASD information for young people throughout adolescence. These conversations enabled the development of a script that the young people used to explain FASD. Reports of parent conversations contrasted to the lack conversations about FASD with professionals.

4.2. *Important factors for self-identity in adolescents' with FASD: "Me being me"*

4.2.1. *Adolescents' self-perception*

Adolescents' self-identity was generally constructed in terms of personality traits and/or by their activities. Many of these activities were facilitated by parents. Notably, FASD did not feature prominently as part of the identities they described. The self-descriptions also illustrate the young people's individuality:

> *Drummer Boy: I mean like a comedian. Because I always tell jokes… I would describe myself a responsible citizen and I'm a helping person.*
> *Curly Sue: I'm a good swimmer – yeah (Smiles) because I've won lots of races – I won lots of medals……. I can be loud sometimes and like happy.*
> *Chloe: Sunny, smiley, fun to be around. And too chatty!*
> *Max: Probably funny and into ice hockey cause I always talk about ice hockey…I'm very active.*
> *Jack: I can be impulsive and sometimes a bit rowdy and crazy. I'm sassy, loud, and kind and creative but quite selfish. I'd say quite a selfish person.*
> *James: Daft… Me being me. Kind and energetic. …. Special and unique.*
> *Sean: I think I am funny because I say funny jokes……. I'm special.*

There was a wide range of physical and creative activities discussed by the young people. Academic self-identities were not discussed by the sample. However, for Curly Sue and Max, achievement and ability in their lives were framed positively by sport: their participation was meaningful and in turn contributed to a self-identity centred around sports.

> *Curly Sue: It's disability swimming… I'm the only girl that does it… So, I'm better at sports than school… I'm getting better at reading but I'm good at swimming.*

In general, young people expressed positive self-identities, reflecting their personalities and interests.

4.2.2. *Nurturing relationships provided by family*

Young people described their parents/carers as being the most significant adults in their lives, providing information about FASD, help with organisation, and emotional support. This provided a supportive and nurturing familial context in which to develop their individual identities. The permanence, reliability and care in the relationships enabled a sense of belonging and increased opportunities for the young people to explore their identity.

Love, acceptance, connection and belonging in the relationships were clearly expressed.

> *Drummer Boy: Mum says nothing is impossible in her own life and mine.*
> *Jack: I see my life – a great life. I see a lucky person, surrounded by love.*
> *James: I like spending time with my mum and dad because I love them very much.*
> *Sean: I got a nanny and grandad. I got some friends. I got a dad and mum, I got a brother… I'm happy.*
> *Chloe: Because your mum or anyone else is going to be there if you need them.*

Some of the young people realised that while they were capable, they deferred to their parents to do things for them. Jack was aware of his mum's role as his advocate. The descriptors of *big* and *fights* indicates the weight of this parental involvement perceived by the young person.

> *Jack: So, my mum is quite a big- she basically fights all my corners and stuff like that. I don't think I would be able to apply for uni by myself.*

Pets also had a key role for some young people in the provision of predictable emotional support and belonging in their lives.

> *Curly Sue: Your dog is always there for you- you know they can't talk they act like it… They are always going to be there unless like they passed away… Because the dogs are my family.*

Two young people commented on their care experiences with regard to transitions between placements and contact with their biological parent and siblings. The discussions featured little reference to their biological parents to conflicting emotions about contact with their biological parents and siblings.

Reliance and emotional attachment are significant to these young people's lives. Clear identification of their place in the family unit and sense of belonging were evident. They valued the love and acceptance of their families, but a few also contended with additional emotions concerning their biological family. The nature of adult support enabled young people's participation in activities beyond school, in turn developing interests they participated in and confidently identified with.

4.2.3. Distinct experiences with "friends" and peers

All the young people named and discussed friends in the school/college context, but a distinction arose in their understanding of friendships and experiences with peers. In a school setting, young people's experiences ranged from negative experiences of name-calling and social isolation to supportive experiences. Reciprocal and authentic friendship with mostly non-disabled peers impacted their enjoyment and participation in activities and how they viewed themselves.

> *Drummer Boy: Like when somebody like makes fun of me when like I get like hit by a ball or something. They always make fun of me. …I feel a bit like. I don't feel good and just don't like it when people make fun of me.*

When Drummer Boy was asked about the nature of his friendship, he did not see his friends out of school and did not know where they lived. Loneliness was not frequently discussed by individuals except for James.

> *James: I can get very upset and lonely because I don't have very many friends. So, I don't cause it's mainly because I don't have the same sense of humour as them and I just struggle socially to get along with people.*

For most participants, out with school, activities could be categorised as parent-led, gaming, or individual activities. Gaming was popular for online socialisation.

> *Drummer Boy: I only go out with my mum and dog.*
> *Chris: With being bored at home, I like the Switch which I can play on it.*
> *Drummer Boy: I like to Minecraft every single day. I like to play with my sister and my cousins.*

Most activities were also arranged by parents; only two young people mentioned self-organised activities with friends. Across the sample, most were dependent on adult support to organise and supervise their activities.

> *Chloe: (At college) We go to the* movies, *we go bowling and we go to eat at some restaurants – yeah, we've got another support worker, another adult that come out with us* — *the adult is always with us.*

For a few young people in this study, the reciprocal nature of friendships was recalled in the planning of activities, shared enjoyment, and a positive impact on their wellbeing both in and out of school.

> *Curly Sue: And then I've got my group (at school) – really, we just carry on. Have a laugh, have a good laugh and at my caravan I only get to see my friends.*
> *Max: The thing that I think is important to me. There are my mates… cause feel I can tell them anything and I'm always with them*
> *Sean: I play football with my friends in the street.*

The young people as a group expressed a clear interest in social opportunities. Friendship was viewed as desirable and increased a sense of belonging in comparison to peer interactions that were sometimes negative and induced a sense of isolation. Friendship was distinct to peer interactions as reciprocal friendship enhanced wellbeing, shared interests and provided meaningful experiences. Social relationships may enable the young people to develop their sense of their own identity, in relation to other individuals and social groupings. Reciprocal friendships also enhanced the identification of personality traits that the young person identified. *4.3 Disability identity process*.

All the young people were aware of their FASD diagnosis, and their discussion mirrored key aspects of Gibson's distinct phases of disability identity formation (Gibson, 2006; Gibson et al. 2018). However, whilst the young people's experiences did align with Gibson's first phase, Gibson's term for it ('passive awareness') did not accurately capture the young people's agency and voice. We therefore renamed this phase as "early awareness of disability" Across all phases, there was variability amongst individuals' views that was not fixed to a specific age or to those identified as likely to have intellectual disability. Some interviews reflected on different thoughts and experiences that precipitated a time of transition into the next phase and the distinct experience of disclosure. Participants' disability identity 'journey' was framed by a range of emotions, and while some participant's discussion aligned with only one phase, for others it was fluid as they appeared to be transitioning between phases.

4.2.4. Early awareness of disability

In the first phase of awareness, Gibson, (2006) proposed there is a little reference of how disability directly relates to a young person's recognition of this regarding their own identity. In these interviews, the term disability was introduced by young people but was construed as something experienced by "others" or as a physical phenomenon.

Sean was the youngest participant and explained the causation of FASD and named some difficulties encountered in the context of home and school. Curly Sue also stated her understanding of FASD was limited and reported an awareness of differences between people.

> Sean*: I got difficult days with my brain and all that stuff… I'm special. I can't think of any more else.*
> *Curly Sue: I do like a group and it's about FASD and like the first time we were doing it; they were really explaining what FASD is….I would say I don't know like a lot.*

The term disability was characterised by brief descriptions or references to physical disability in Curly Sue and Drummer Boy's interviews. A wider understanding of the different types of disability or invisible disability were not acknowledged.

> *Curly Sue: It's like FASD is mmm what is it called a disability that like some people have… I would say it's part of me and it's a disability as well… Like when people have like a disability… it's like you got something like one arm.*
> *Drummer Boy: (Use of visual prompt with teachers) You can show them when you need help or to get something or if like someone's like in a wheelchair or they're like short…*

Common to all young people whose discussion aligned with this phase, they found it difficult to generalise from their perspective of what FASD meant for them to what it could mean for other adolescents with FASD.

> *Curly Sue: Well, some people might not like it (FASD), but other people might?*
> *Sean: I don't know that one…*

For these young people, some differences and difficulties of FASD were named, but they did not relate these to their own identity and expressed a neutral emotional perspective of how FASD related to them.

4.2.5. Realisation of disability identity

In this phase of realisation, there is an emerging understanding by young people about how they view their disability in relation to themselves, peers and to other young people with the same disability (Gibson, 2006). Conflicting feelings are typical at this phase and indeed some young people with FASD in this study expressed a range and intensity of emotions. Strong emotions were raised in Drummer Boy and Max's interviews.

> *Drummer Boy: I wouldn't tell them [peers] anything because it's, I just don't want them in my business.*

Max expressed a range of views about his FASD, some of which may have appeared contradictory – both that it had minimal impact on him and was not a key aspect of his identity, but also that it was stressful to discuss. This perspective may have related to his experiences of the specific times when adults chose to discuss it:

> *Max: … I like to forget that …uhm I have it (FASD) so it's not a big deal… Normally people talk about it when, like my actions come into place or different things at school. But I don't like talking about it, so they think they can fix me……. It's just when people talk about it all the time. And you already know you have it. You have already accepted it, it just, it kinds of makes you more stressed about it.*

James did suggest that others can make assumptions about FASD and that talking with a peer with FASD could reduce his sense of isolation.

> *James: There's an awful lot of hard challenges and it's not all easy as people think it is… It would be helpful (to speak to other people) yes so that I know I'm not the only one.*

For some of these young people, the phase of disability identity realisation was reflected in their varied emotions and experiences with peers they meet across different contexts.

4.2.6. Acceptance of disability identity

In the phase of acceptance, Gibson (2006) notes that individuals can move from a negative to more positive view of themselves, identifying with disability advocacy and seeking to engage into the broader world and experiences. Again, it is noted that it is not assumed that each individual will progress in a linear manner and may return to an earlier phase. Chloe and Jack, who happened to be the two eldest participants and in college, shared their view of FASD as a disability and highlighted their experiences of disclosing FASD to their peers and their views of self-acceptance.

> *Jack: Yeah: It's definitely a disability 'cause you know you're not able to do certain things that neurotypical people would be able to do. But I also think it's a blessing in some ways because I think completely different from some of my friends and I wouldn't want to be any other way.*

The disclosures of FASD were primarily with school/college peers and were framed with emotions. Disclosure was reflected upon as a positive and transformative experience for these young people. Chloe powerfully verbalised this experience when she *"said it out loud."*.

> Chloe*: I actually told someone on my skills group about FASD… And then I started crying… Yeah, she was quite supportive when I started crying about it. And then it was quite good to realise, I just told someone about it… I was crying when I was saying it… but then I was quite relieved and happy when I just said it… I said it out loud to someone else. So, they would understand it as well as me.*

The disclosure of FASD encompassed a space and time where the young person directly identified with FASD and realised its impact for them and others in their lives.

> *Jack: Sometimes I feel like it's just not necessary, when in fact it is necessary. Sometimes I am embarrassed by it (FASD)… But when you start growing up and you start like oh my God, I'm still struggling… it's accepting that it's all about FASD, and that how it affects a person individually and that other teens probably struggle with that exact issue.*

Jack also expanded on the wellbeing that can accompany the self-acceptance of the FASD diagnosis.

> *Jack: Not a lot of people think that when you get diagnosed, it would be a big change, but it does change the way you like act and like the way you think about stuff. Subconsciously you're like easier on yourself for certain things you can't do, whereas before you would have been harder on yourself.*

In the discussion that aligned with acceptance, self-understanding was noted through the individuals' personal insight into how FASD impacted them and that it contributed to positive a self−acceptance for the individuals. Disclosure of the FASD diagnosis to peers was reflected on and felt to be, at times, necessary and positive.

5. Discussion

This is the first study in the UK that has engaged with the views of young people with FASD to contribute to a broader understanding and discourse of the FASD diagnosis, and disability identity formation. The young people provided a clear insight into their understanding of FASD in terms of a diagnosis and its causation through prenatal alcohol exposure. Their perspectives and attitudes individually and as a group did not attribute blame or shame to biological parents and significantly, they assigned a purpose to the FASD diagnosis. The young people's self-identities reflected a broad spectrum of interests and activities, which were primarily facilitated through parental support. Receipt and self-understanding of the FASD diagnosis did not dominate the individuals' self-identity. Young people discussed the variety of roles that parents and peers played as their disability identity developed. The young people expressed both a strength-focused perspective and an acknowledgement of the challenges they had faced, aligning with Gibson's (2006) phases and transitions between the phases in disability identity formation.

During the study, the young people articulated factual accounts of PAE as a biological and causal explanation. Significantly, whilst they did speak objectively about PAE as a cause of their FASD as a disability and diagnosis, they did not discuss shame/blame towards biological parents. This was the case with all participants in this study, and this finding highlights the contrast between the views of young people with the sometimes negative and stigmatising assumptions surrounding this diagnosis held by health professionals (Murkherjee et al., 2015; Howlett et al., 2018). These young people discussed FASD beyond the narrow perspective of a diagnostic label, aligning with Mueller's (2019) view that the receipt of a diagnostic label engenders an important psychosocial process for the individual. The meaning-making and emotions surrounding FASD described by the young people related to legitimacy of their needs, self-understanding, and identity. Although there are negative aspects to the distinct aetiology of FASD, the deeper exploration facilitated through this study's Photovoice methods revealed that the young people with FASD expressed ***both*** positive and negative views of psychosocial impact, support, future planning, and behaviour. Despite diagnostic tensions surrounding FASD, this study's findings can add to Sims et al.'s (2021) review of diagnostic labelling in other physical health and psychological diagnoses, which found that positive and negative impact can be assigned to diagnostic labels. FASD has a distinct aetiology which was acknowledged by the young people, but the impact of FASD as a diagnosis can offer a value for the individual.

In this study, FASD was not definitive of the young people's whole identity but was one component of it. The young people discussed their self-identity in terms of their personality traits and interests, and in relation to their pets, family, and friendships. The creation of a unique self-identity in terms of personality and interests was previously outlined in Skorka et al.'s (2020) research with young people with FASD.

The findings from the present study underline the range of relationships and activities in different contexts that can also contribute to a more coherent and positive identity in a young person (Branje, 2022). Adolescents with disabilities are more likely to engage in informal activities with families instead of peers, and opportunities for out of school activities tend to be more limited (Tonkin et al., 2014). The parental role also provided organisation and planning for adolescents to enable participation in activities, which adds to the recognition of parents' high level of support as "conductors" as indicated in research with autistic adolescents by Kenny et al. (2024: p10). Access to community and leisure activities and authentic friendships are important components of meaningful engagement and identity development for adolescents and need to be mediated in different ways (Willis et al., 2017; Kenny et al., 2024). Authentic friendships in this study could be seen in the reciprocal and shared experience of friendships with peers that did not centre on disability or diagnosis but focused on fun, wellbeing, and shared interests and activities. This contributed to a positive self-identity and sense of inclusion. Additionally, the findings suggest that a FASD diagnosis does not appear to consume a young person's self-identity in a deficit-orientated manner. In turn, it could be suggested that assessment and diagnosis of FASD will therefore not necessarily diminish the development of a positive self/disability identity.

Disability identity formation is considered a heterogenous and complex process which encompasses specific disabilities as distinct entities but that the individual's journey is comparable to other disabilities (Forber-Pratt et al., 2021). Whilst the suggestion of developmental progression within Gibson's stage model can be difficult to apply to neurodevelopmental conditions, because of the heterogeneity of symptoms, the study with adolescents with FASD adds to Gibson's model of disability identity (2006; Gibson et al, 2018) and notably it highlights the comparability of disability identity formation in FASD to that in other disabilities. Previous research by Forber- Pratt (2021) has indicated the role of relationships and connections to peers with and without disabilities can vary for adolescents There can be a shared experience with peers with disabilities, whereas non-disabled friends may not consider a disability as a significant part of an individual's identity. In this study, the individuals' experiences included disclosure to non-disabled peers about their diagnosis and disability as an important event that appeared to occur as part of their acceptance of their disability identity. This is consistent with disclosure in adults with invisible disabilities where active disclosure was categorised as confessional, pragmatic and validating, and something which helped to shape disability identity formation (Evans, 2019). Disclosure for autistic individuals (Thompson-Hodgetts et al., 2020) can vary from positive assumption of benefits held by professionals and adults, in comparison to the concern of stigma felt by autistic individuals. It is not our assumption that disclosure of an FASD diagnosis to peers is required, but it is important to reflect on the positive outcome of this disclosure for these young people's perception of acceptance.

The young people in this study identified that parents instigated conversations and provided information about FASD. The role and impact of parents providing information and scripts for young people was displayed in the individuals' internalisation of scripts. Conversely the findings also highlighted the young people's experience that there was little explicit professional recognition or use of the term FASD across school or clinic settings. This finding also adds to Mueller's (2021) suggestion that disability is not sufficiently represented or integrated in educational curricula, staffing or environments despite the central context of education in adolescence. The young people felt that this lack of discussion suggested insufficient knowledge by professionals about FASD. Forber-Pratt et al.'s research (2021) highlighted adolescent perceptions of feeling isolated or incapable due to their disability not being supported fully in an educational context. In this study, young people with FASD identified the strengths and challenges of FASD in a manner which aligned with a strength-based neurodiversity perspective and emerging disability identity. With the recent shift in research and in clinical and educational practice towards the neurodiversity paradigm, Harding et al. (2022) recommend that FASD and neurodiversity need to be both valued as entities, to shift the deficit-based perspective and promote a broader understanding of the impact and strengths of individuals with FASD. Nevertheless, if young people and families cannot access assessment and diagnosis of FASD, it does not allow for the value and impact of this diagnosis to be realised.

6. Limitations

This study adds to the understanding of views of diagnosis and disability identity formation in adolescents with FASD and in doing so, foregrounds their perspectives in research. However, whilst online data collection can increase the accessibility of research participation and enable participation across a wide geographic area, it can vary in comparison to in-person accounts due to differences in research relationships and context. The extent of participation and insight provided by the young people was notable throughout the study. However, there may be bias in the sample of young people with FASD who volunteered for this study, as young people who find their diagnostic journey particularly challenging may not wish to recount these experiences and accordingly may choose not to participate. There was also limited ethnic diversity in the sample, which may be partially attributable to low diagnostic rates of neurodivergent conditions and recruitment from diverse adolescent populations (Murray and Xie, 2024). Significantly, if young people and families cannot access assessment and diagnostic outcomes in a timely manner, then there is an additional undiagnosed population whose views are not represented (Wilson et al., 2023). The inclusion of participants who self-identify as having FASD may therefore be important in future research, though this may be more relevant for adult populations. Due to schools providing a significant and often reliable component in the lives of adolescents, it would also be important to explore interventions focussing on engagement and leadership roles as suggested by Rodriguez et al (2023) specifically for young people with FASD to support positive identity, wider community connection and self-advocacy skills. Continued research with young people with FASD can also further understanding of participatory research approaches, and positive identity development and begin to reduce associated stigma of FASD.

7. Clinical and educational implications

Professional dialogue and interaction in clinical and educational contexts should promote meaningful participation with young people. The relevance of disability identity could be further considered within professional practice to enhance discussions with young people which may contribute to a positive disability identity. In terms of disability identity formation, Kreider et al. (2020: p8) identify health and educational professionals as "critical sources of anticipatory guidance for (college) students with disabilities" but this process must begin earlier and should also be considered as part of the support offered to children and adolescents with FASD.

8. Conclusion

Self-understanding and advocacy in adolescents with FASD and the significance of their disability identity is not currently well understood across clinical/educational contexts and professional interactions. School is a key context for supporting young people's disability awareness and identity (Mueller, 2019; 2021) but disability identity and representation should not be restricted to a single context as young people with FASD access multiple services from childhood into adulthood. Findings from this study highlight the process of disability identity formation for young people with FASD and emphasise that disclosure of diagnosis and the impact of this disability are important for adolescents. This study also highlights the comparability of the views of diagnosis and disability identity formation of young people with FASD to that of young people with other neurodevelopmental conditions and disabilities.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.childyouth.2024.107979.

Data availability

The data that has been used is confidential.

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