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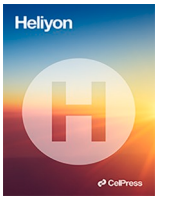

Research article

"Taking part in the project has really changed our experience as a family" investigating parents' experience of participation in a study to screen for fetal alcohol spectrum disorder

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ABSTRACT

Background: Screening children for developmental disorders presents unique ethical and methodological challenges, particularly with disorders associated with high levels of shame and stigma. Fetal alcohol spectrum disorder (FASD) is a neurodevelopmental condition resulting from prenatal alcohol exposure. The potential distress caused by informing parents that their child may have FASD has been cited as a significant barrier to conducting such studies. However, limited research has investigated the impact of screening for FASD on parents and children.

Aims: This exploratory study aimed to examine the experiences of a small sample of parents participating in an active case ascertainment prevalence study screening for FASD in Greater Manchester, UK (ADD-GM study).

Methods: Interviews were conducted with six parents, whose children aged 8–10 years, underwent screening (including three cases of FASD). Thematic analysis was performed on the collected data to identify key themes and patterns.

Results: The analysis revealed that parents perceived participation in the study as worthwhile, and their children either enjoyed or were indifferent to the process of data collection. Parents of children identified with FASD reported that although the results were surprising, they did not find the experience overly distressing.

Conclusion: The findings suggest that parents generally view participation positively and perceive limited negative impact. These insights contribute to a better understanding of the challenges and benefits associated with screening children for FASD.

1. What this paper adds

This is the first paper to report parent's experience of taking part in an active case ascertainment study looking for cases of FASD.

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Table 1
Identified condition and reason for invitation to assessment.

Pseudonym of child	Gender of child	Reason for invite	Parental Status	Identified disorder
Oliver	Male	Previously under care of LA	Adopter	FASD
Lola	Female	Parent opt in	Biological	FASD
Grace	Female	Parent opt in	Biological	ASD
Michael	Male	Under care of LA	Foster	FASD
Liam	Male	Under care of LA	Foster	ADHD
Sophia	Female	Small for age	Biological	ASD

FASD: Fetal Alcohol Spectrum Disorder; ASD: Autism Spectrum Disorder; ADHD: Attention Deficit Hyperactivity Disorder. LA: Local Authority. For further explanation of reason for invitation criteria see McCarthy et al., 2021.

Table 2
Themes.

Participation	Parent experience of data collection
	Child experience of data collection
Outcome	Receiving the report
	Impact
	Shame and stigma

The finding that parents did not find the process unduly distressing is important information to researchers, potential funding bodies and policy makers considering future screening for FASD.

2. Introduction

The term neurodevelopmental condition (NDC) covers a wide range of diagnoses all characterised by impairment or delay in the central nervous system. The total prevalence of neurodevelopmental conditions globally is unknown. Three of the most common NDC are autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and fetal alcohol spectrum disorder (FASD). ASD conditions are characterised by reduced social communication skills, repetitive behaviours or speech patterns, unusual interests, and often a learning disability [1]. ADHD conditions are characterised by reduced attention span, deficits in executive functioning and often hyperactive behaviour [1]. FASD is the name given to a range of conditions which can result from prenatal alcohol exposure. Symptoms of FASD can be similar to those attributed to both ASD and ADHD, including reduced social communication skills and hyperactivity [2,3], and screening for FASD may detect cases of other neurodevelopmental conditions.

ASD is diagnosed in an estimated 1 % of the population globally [4] with ADHD estimated to effect 7.2 % of the population globally [5]. Global prevalence of FASD is an estimated 0.77 %, with higher rates of around 2 % in Europe, where drinking in pregnancy is common [6]. In England, longitudinal studies report a prevalence of 1.7 % for ASD [7]. The UK prevalence of ADHD is widely accepted to be approximately 5 % [8,9]. The Assessing Developmental Disorders in Greater Manchester or (ADD-GM) study is the first time FASD has been screened for using the gold standard case ascertainment method in the UK and found 1.8 % of children had FASD in a small sample [10].

Screening raises ethical concerns regarding sensitivity, specificity, cost, and benefits to participants and society. Ethical considerations are further magnified when screening children, requiring assent in lieu of informed consent. A recent review examining children's experiences of taking part in research, included four studies involving children of a similar age to those involved in the ADD-GM study, suggests that children can comprehend research elements and often perceive participation as beneficial [11]. Screening for FASD and other NDCs presents additional ethical challenges due to potential stigmatization, particularly affecting individuals and parents [9,12]. Stigma, characterized by exclusion and devaluation, can hinder funding, approval, and implementation of screenings, impacting health, wellbeing, policies, and exacerbating damage caused by stigmatization [13].

Limited research exists on the experiences of parents and children in FASD prevalence studies [14]. The ADD-GM study provided the first opportunity to gather such data in a UK population, as previous studies in other countries have not published participant feedback. Qualitative interviews have explored parents' experiences of having a child diagnosed with FASD, revealing positive and validating responses to the diagnosis. Similarly, studies on screening for FASD and other conditions have shown varied reactions from parents, including relief, devastation, guilt, denial, surprise, and shock [15,16]. Consultations with parents and children taking part in the large longitudinal Millennium cohort study, which included developmental assessments and data collection involving parent and child, indicated an overall positive participation experience [17].

This paper focuses on feedback from parents following participation in the ADD-GM study, a study that aimed to determine the prevalence of FASD in the Greater Manchester area of UK. A brief outline of the structure of the study is included in Appendix 1. All parents who took part in the ADD-GM study received a report of their child's results and a cover letter which included whether a neurodevelopmental conditional was indicated, and signposting to further support. The purpose of these interviews with parents who had taken part was to gain insight into their experience of participation and receiving their child's results. Since FASD and the topic of alcohol in pregnancy is sensitive and stigmatised, we specifically aimed to find out how such sensitivity impacted on parents'

perceptions of having their children assessed for FASD.

3. Method

This qualitative study used semi structured interviews and the principles of thematic qualitative analysis.

3.1. Recruitment

Parents were invited to take part in the interviews if they and their child had taken part in the ADD-GM study and had received the report of the child's results a minimum of 1 month (but not more than 6 months) prior. (for further details on this study including the assessment process, tools used and criteria used to screen children positive, please see paper of the main study [10]. All eligible parents (N = 15) were contacted by email or telephone and asked if they would give feedback on their experiences of taking part in the study. Where a child was currently under the care of the local authority, the child's main caregiver was interviewed. All parents who expressed an interest in participating in the parent follow up interviews (n = 8) were sent further information about the study and consent form. Two of the parents did not reply and six took part.

3.2. Data collection and analysis

Semi-structured interviews were conducted by phone. Interviews were recorded (mean length of 28 min) and transcribed verbatim (by REM) with all identifiable data removed. Transcripts were subjected to thematic analysis [18] by two researchers (REM and LK) separately and results compared, and any discrepancies resolved through discussion.

The analysis was conducted in in six steps: initial familiarisation with the data, initial code development, identification and then review of potential themes which were then defined and labelled before the findings were written in a summary form with illustrative quotes [18].

3.3. Ethics

The development of the ADD- GM study, and these interviews involved individuals with lived experience of FASD and other neurodevelopmental conditions. Informed consent was obtained, and participants received study information in advance, with an opportunity to ask questions. Contact details of local relevant support organizations such as mental health charities and health and social care charities were provided after the interviews.

Ethical approval was granted by the University of Salford for the ADD-GM project (HSR1819–100 May 2019) and for this sub-study (HSR1819-100, May 2020).

4. Results

4.1. Details of participants

In this study, the term 'participants' refers to the parents who took part in these interviews, rather than the children who were participants in the wider study. All participants (n = 6) identified as female, White British, and were aged between 25 and 43 years (mean 34 years). Four parents had achieved higher level education and two had achieved fewer than four GCSEs (General Certificate of Secondary Education – a mainstream academic qualification obtained in England aged up to 16 years). Three of the participants were the child's biological mother, one was an adoptive mother, and two were foster parents. The children had been screened in the wider ADD-GM for a variety of reasons: two of the parents had opted their child into the study because of concerns over the child's development ('parent opt in'), one child had been invited due to being small for age, two children had been invited due to being under the care of the local authority (LA), and one previously under the care of the LA. Three of the parents had received reports stating that their child may have FASD, two received reports suggesting ASD, and one received a report suggesting ADHD.

4.1.1. Non-participants

Of the 15 invited to take part, nine declined. These nonparticipants were also all female, White British and born in the UK. Their child was more likely to have received a report where no neurodevelopmental condition was identified (4 of the 8 nonparticipants had no disorder outcomes). Two had reports that indicated ASD, one had a possible Learning disability and for one a specific language impairment was identified. Mean age of non-participants (where children were in the custody of their birth mother) was higher at 37yrs. Three of the eight nonparticipants had achieved higher education.

4.1.2. Participants

To preserve anonymity all names have been changed. Table 1 displays the pseudonym for each child along with their gender, reason for invitation to assessment and corresponding identified condition.

The qualitative data collected during the interviews were diverse and contained unexpected sentiments and experiences related to barriers to support, specifically in the school environment, and parent and child experiences of lockdown, during which time the interviews took place. Since themes and conclusions were too diverse to be written up in a single journal article, themes that were more

relevant to an education audience are discussed in a previously published article [19]. This current paper focuses on themes relating to participation in FASD screening research, which may be of interest to those involved in designing and conduction similar studies on sensitive topics and for the development of programmes and policy relating to developmental disorders.

Thematic analysis resulted in the following themes: participation, barriers to support, and lockdown with further subthemes (see Table 2). Participation and outcomes are the themes discussed in this paper.

4.2. Participation theme

Regarding their overall impression of the study, most participants expressed feelings of gratitude and relief in some manner. Subthemes consisted of reaction to invitation, parent experience, child experience, receiving the report and impact.

Overall parents talked about taking part in the study with warmth and positivity.

Some parents reported that the study had exceeded their expectations and that they were grateful for the opportunity to access assessment and extra information about their child.

> "I just wanted to say thank you cos taking part in the project has really changed our experience as a family." (Graces' mum)

Some parents were milder in the language use:

> "Overall erm I'm fine with everything. Erm, happy with everything, how it's been done." (Michael's mum)

None of the parents expressed regret about taking part and neither were they critical of the implementation of the study or communications with researchers.

4.3. Reaction to invitation

Notably, half of the parents who took part in the interviews had been parents who had opted their child into the study. Those opting in would have received a letter informing them the initial stage of screening had not identified any problems, but if they were concerned that their child may have a neurodevelopmental disorder, they could choose to opt in to the second phase.

Three participants had been invited into the ADD-GM study by the research team (as their child had been identified as high risk) and those parents were asked how they had felt when they had received the letter to say their child was invited to further assessment. No parents reported being upset or distressed by receiving the invitation. One parent reported concern that their child had been invited due to being in the care of the local authority:

> "I wasn't sure at first because erm with Liam being "looked after" I felt that he'd been through quite a lot already, I wasn't sure whether it was the right thing." (Liam's mum)

One parent expressed her relief at receiving the invitation letter to take part. Sophia was invited into the study due to being 'small for age' and Sophia's mum had been struggling to get school to acknowledge her daughter may have additional needs for two years at the point at which she received the letter:

> "I'd say relief on that to be honest because it was like a step forward" (Sophia's Mum)

4.4. Parent experience of data collection

Overall participants reported a positive experience of communication with the ADD-XX study researchers and the parent interview sessions. Despite the sensitive nature of some of the questions asked, no participant reported finding the parent interviews upsetting or uncomfortable. However, some parents referred to the interviews as taking a long time and struggled to find time in their schedule:

> "It was fine …. it was quite long winded." (Lola's mum)

One parent reported how some of the questionnaire screening tools had helped her to reflect on her own experience and empathise more with what life might look like from her child's point of view. In contrast, some parents doubted their own appraisal of their child's development and skills estimation; they doubted their view that their child had additional needs and were not confident about their ability to accurately report their child's symptoms and level of ability or behaviours.

> "I just feel like it's … it's hard for me to … be like sort of objective about it, 'cause there's only me at home and behaviours I'm seeing might be quite normal, but I might perceive them as being over the top" (Lola's mum)

Lola's mother went further, to be critical of the use of parent report. She felt the study relied too heavily on the answers she had given. This referred to the fact that the validated screening tools such as the Vineland Adaptive Behaviour Scale and the Children's Communication Checklist make use of parent report. However, she also acknowledged that parental input was important and that collecting data from the child would not be enough.

4.5. Child experience of data collection

All participants reported their children did not appear to have been distressed by their participation in data collection.

"… he just said that he talked, and he felt comfortable, and you'd done it in a way y'know he felt ok. (Liam's mum)

One parent expressed how happy they had been with the study process and when asked if anything could be done differently, she replied only that she would have liked her other child to take part as well. All parents noted how pleased their child was with the small 'squishy' toy reward they received at the end of the assessments. This was consistent even with a child that had need repeated saliva collection and so had multiple visits:

"He used to say, 'that lady's been again', I'd say, 'which lady?' He says, 'I forget her name the woman, woman that gave me the Squishies" (Michael's mum)

4.6. Receiving the report

All the parents interviewed had children with identified disorders. Their report would have contained this result and some basic information about the relevant condition. Although not equivalent to a clinical diagnosis, this information was only included if there was a level of confidence in the results.

To explore the accessibility of the information reported to parents, the researcher asked parents how they found reading their child's report. Though parents' prior understanding of neurological conditions varied, all participants reported that they were able to read and understand the report easily.

Participants were then asked how they felt about the information in their child's report. Many parents expressed shock on receiving their results, largely regarding the identified disorder, with a birth mother of a child found to have FASD saying:

"I was so baffled by the outcome" (Lola's mum).

One parent described the *'bittersweet'* experience of realising her daughter may have high functioning autism, and having her *'suspicion that there was something'* confirmed by screening:

"… it's been … bittersweet "(Grace's mum)

Most parents found the results reassuring, especially where there had been some disparity between parents' concerns and school reported issues. There may be some crossover with the theme 'Parents' experience of data collection', where some parents cast doubt on their ability to form judgement on their children's behaviour. It is plausible that confidence in their judgment of their child's additional needs could have been eroded if schools' opinions did not concur with their own.

"Confirmed that I'm right. *laughs* If I'm honest and that I'm not just looking for something that's not there" (Sophia's mum)

Even those who reported the shock and disbelief at the identified disorder found it reassuring to have their concerns that their child was not developing in line with other children confirmed.

"It was a huge shock really … In some ways it was … not a relief … but in some ways, it was interesting to know that in terms of testing she was coming up as y'know something." (Lola's mum)

One parent described that the report had exceeded her expectations. The report to parents was provided as an incentive for parents to take part, recognising their time and participation. Therefore, care had been taken to include explanations of technical terms and suggestions for practical actions the parent could take to support their child. We had aimed for this to be described in a supportive and easy to understand format.

There was a notable difference in the way parents talked about the disorders. When talking about ASD parents often corrected themselves if referring to it negatively as though they were aware that an ASD diagnosis should not be perceived as solely negative. This was not the case for those where FASD was the identified condition. Parents appeared reluctant to say FASD aloud. Two of the three parents referred to the condition repeatedly without directly naming it. The only parent who said FASD aloud reluctantly expressed some sadness about the result.

"… it's not … y'know it's not something that you'd want your child to have." (Oliver's mum)

This parent also expressed positive emotions about taking part in the study. This illustrates that parents may be sad about their child having FASD and at the same time happy that their condition had been identified and glad that they had taken part.

4.7. Impact

Several parents gave examples of how taking part in the study had positively impacted on the lives of their family and their child. Parents felt taking part had helped them to understand their child better and some reported that they felt more hopeful for their child's future. While one parent reported that school had put some adjustments in place as soon as they took part in the study, this was not the case for others. Parents reported the advice contained in their child's reports had been practical and useful.

Most parents found the suggested interventions and adjustments in the report useful and were able to use some of the advice at home.

"… after a recent drama I dug your report out and re looked at it and there's things I wrote down and shared" (Oliver's mum)

Some parents reported that they had made changes in how they interacted with their child at home. Including some of the recommended actions contained in their child's report.

The same parents also reported school had become more helpful after their participation in the research. Several parents felt strongly that taking part in the study had improved the outlook for their child. Reasons for this included the hope that they would be able to access support at school or referral more easily or because of the way it had affected their approach to their child's additional needs. Sophia's mum who had been struggling to have school acknowledge or support her daughter's additional needs for two years previously felt without the study her child may never have been assessed or her additional needs addressed:

> "Without what you guys have done, it would never have been done" (Sophia's mum)

4.8. Shame and stigma

Although parents did not use the words shame and stigma, it was apparent both in what was said and in what went unsaid. Universally, parents demonstrated a reluctance to name a condition, and in some cases a reluctance to pursue diagnosis. This was true for all parents but appeared especially prominent for parents where their child's results indicated FASD.

This subtheme theme was derived from non-text-based data such as context, tone, silences and leaving out words from sentences. Often participants stopped just short of naming the identified condition and trailed off whilst taking about it, tone and inflections suggested an aversion to naming the condition again, especially for FASD. This was true for both the birth parent and the adoptive parents. Most parents had not discussed the report with their child, and none had shown the results to their child. This might be because they felt the contents may be upsetting or difficult for the child to understand. It is possible that parents did not feel able or ready to discuss the results with their child and parents may have wanted to wait for an official diagnosis.

One parent described how they played down the study to their child:

> "I said it was just a study he was taking part in … cos I didn't want to …. *silence*" (Michael's Mum)

And one parent described how they had wanted to keep the report out of sight of their child to prevent them finding it by accident and reading the contents:

> "I've just put it (the report) somewhere where I was hoping she wouldn't stumble across it ….and find it." (Lola's mum)

Interestingly only one parent had discussed the information contained in the report with their child, and they explained that they had been cautious in how they had shared the identified condition.

5. Discussion

The findings of this small sample exploratory study indicate that overall parents felt taking part in a study screening for FASD had been worthwhile. Where the identified disorder was FASD, although the results were a shock and parents needed time to accept the results, they did not find it overly distressing or regret taking part. The main ADD-GM study included data collection with the parent, a process that took 2 h. Parents reported an overall positive experience of their part in data collection, despite the significant time commitment. They also felt that their children either enjoyed or were indifferent to participation in the data collection activities of the main study.

Parents' experiences of taking part in an FASD screening study is an important finding. There are many barriers to detecting FASD [20,21], and one barrier often stated is the idea that it is irresponsible, unkind, or just too difficult to give someone the news that their child's additional needs may have been cause by prenatal alcohol exposure [21]. The findings of these interviews indicate this may not always be the case. Although only one of the participants with a child identified as having FASD was a biological parent, other research has suggested correct diagnosis of FASD can be a positive experience for biological parents. While there is significant shame and stigma associated with the condition, that this does not prevent them from wanting appropriate and adequate support for their childs additional needs [16]. This would place the motivations of birth parents of individuals with FASD in line with other parents of children with additional needs.

There is evidence that early detection of neurodevelopmental conditions can prevent and reduce secondary comorbidities [12]. The findings from these interviews indicate parents are amenable to their child being screened for neurodevelopmental conditions. This indicates potential for the use of early interventions to help to mitigate the increased mental health burden in older children seen in recent years.

Parents generally expressed positive impressions of their child's experience of data collection. Child assessments were carried out by researchers with a good level of experience with children and care was taken explain the nature and reason for assessments to children in a positive non pressurised manner (see Appendix 1). The team aimed to produce reports for parents that were accessible and useful. Parent views support that this aim was achieved.

It is notable that parents were more open and positive about a potential diagnosis of ASD than FASD. Although this may be partly related to shame and stigma associated with alcohol use in general and with FASD [13], it is also likely related to the higher public awareness and acceptance of ASD, through positive representation in the media [22]. It may be useful to look at ways to raise public awareness and improve acceptance of FASD via similar methods and to increase awareness and understanding of different neurodevelopmental conditions.

5.1. Strengths and limitations

This article presents the views of a small number of parents who participated in the wider study, representing a subset of the participants. Three parents of children with FASD were interviewed, with only one being a birth parent. This small sample size and qualitative approach means these finding might not be generalizable. The lack of representation from non-participants is a recognised issue in research of this nature. Further research is needed to examine the experiences of parents in a larger sample and also to explore the motivations and experiences of those who did not participate.

It is possible that parents may have been less inclined to share negative experiences due to the same researcher conducting data collection for ADD-GM and follow-up interviews. However, the familiarity between the researcher and parents may have facilitated more open discourse and accurate interpretation during the analysis.

A second researcher conducted an independent analysis, blinded to the themes identified by the first researcher identified the same key themes I agreement with those found by the first researcher. Overall, further research is needed to address the limitations of this study, including larger sample sizes, exploration of non-participant perspectives, and the long-term impact screening for FASD.

5.2. In conclusion

Shame and stigma act as significant barriers to diagnosis, support, and improving outcomes for individuals with developmental disorders and their caregivers. Overcoming the stigma associated with alcohol use during pregnancy is crucial to increase detection rates and gather accurate prevalence data for FASD. The current underdiagnosis of FASD in the UK contributes to the lack of effective policies, diagnostic pathways, and essential services for affected individuals and their families, placing a burden on both the affected individuals, their families, and the healthcare system. These findings suggest that concerns about distressing parents and caregivers may be over-emphasized as a deterrent to screening for developmental disorders, including FASD, in primary school-age children. Addressing shame and stigma and implementing screening programs are vital steps toward improving detection, support, and outcomes for individuals with FASD.

Data statement

The interview transcriptions used in this article is not publicly available as permission from participants to enable this was not sought. Anonymized data is available on request via email from the corresponding author.

CRediT authorship contribution statement

Robyn McCarthy: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Carolyn Blackburn:** Writing – original draft, Investigation, Formal analysis. **Raja AS. Mukherjee:** Writing – review & editing, Writing – original draft, Supervision. **Clare S. Allely:** Writing – review & editing, Writing – original draft, Supervision. **Penny A. Cook:** Writing – review & editing, Writing – original draft, Supervision.

Declaration of AI and AI-assisted technologies in the writing process

AI Statement: During the preparation of this work the authors used Open AI Chat GPT to structure the abstract and make some paragraphs more succinct. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendixes

Appendix 1: Protocol from the wider ADD-GM study

ADD GM STUDY

All children in year group four and all those from year group three who were eight years old were invited to take part in initial screening on an opt out basis in three primary schools in Greater Manchester UK. For more information on the wider study see McCarthy, et al. (2021).

Step One

Screening

Height, weight, and head circumference measurements were taken, and schools were asked to provide details of children who were on the SEN register.

Exclusion

Those with genetic syndromes such as Down syndrome, post-natal brain injury and children who were unable to speak English.

Invitation

Those children who were identified as higher risk in step one were invited to take part in step two. For all other children, parents were sent a letter inviting them to opt their child in if they had concerns.

Step Two

Parent Questionnaire interviews

Researcher arranged sessions with parent either at school or at their own home, where they were supported to complete a series of questionnaires this included a maternal risk questionnaire covering sensitive topics such as alcohol consumption.

Child Assessments

Developmental assessments including the WISC V and The NEPSYII undertaken in school hours with children. Some children required further visits for saliva collection using the Oragene collection device.

Case conferences

Data was then presented to a panel of clinicians and possible or likely disorders were identified.

Individual reports

Results, accessible interpretation, and suggested interventions were compiled into reports for each child. Sent to parents with a cover letter explaining possible probable conditions were identified and advising on appropriate next steps like referral to SALT etc. Information about relevant conditions, local support groups, and national support organisations were also included with the report.

Interviewer Reads:

Do you remember when we came in to measure everyone in your class?

Well, you know how everyone has some things that they find easy and somethings that they find difficult? For example, I find art easy …. but football difficult.

Today we are going to use science to measure that. It means some of the games we play will seem easy and some will seem hard but don't worry it's meant to be like that.

Let me know if you need a break or need the toilet or a drink. It is fine for us to stop at any time.

Age-appropriate Briefing

A script was read to children at the start of the assessment session with the aim of explaining the purpose in an age-appropriate way and reduce performance anxiety or the potential to negatively impact the child's self-esteem. This was based on the researchers' previous experience of collecting data from children with additional needs.

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