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The experience of participation: Eliciting the views of children on the autism spectrum

Kate Simpson[1,2], Christine Imms[3,4], Deb Keen[1,2]

[1]Autism Centre of Excellence, School of Educational and Professional Studies, Griffith University

[2]Griffith Institute for Educational Research, Griffith University

[3]Apex Australia Chair of Neurodevelopment and Disability, University of Melbourne VCCC, Department of Paediatrics

[4]Centre for Disability and Development Research, Australian Catholic University

Implications for Rehabilitation

- Children can describe their experience of participation and identify internal and external factors that influence their participation.
- Participation is a transactional and dynamic process.
- Video provides a useful method for children to record their "in the moment" experiences.
- Children's video recordings provide a stimulus for interview discussions in both research and clinical practice.

Abstract

Purpose. Children on the autism spectrum are reported to participate less in leisure activities than their peers. Little is known about what participation means for this group and the child's voice has been largely absent, partly due to methodological limitations. To address this limitation, alternative methods of eliciting children's perspectives are needed. The aim of this study is to elicit children's views about their participation experiences using a multi-method approach, and children's feedback on the method.

Methods. Four children on the autism spectrum (9 – 13 years) used a video recording device to collect data over a 1-week period on their participation in activities. The children recorded an in-the-moment narrative to describe the activity and their in-the-moment experiences. A follow-up individualised interview was conducted, allowing children to present their unique views on their activity participation and feedback.

Results. The children's differing perspectives identified participation as a transactional and dynamic process. Involvement was described as an individual and subjective experience, with participation influenced by personal, social, and physical factors. Children viewed the research experience positively. Recording while participating "in-the-moment" was challenging.

Conclusion. The first-person perspective provided unique insights into the children's participation experiences. This approach has the potential to inform methodological practices.

Keywords. qualitative research, autism spectrum disorder, self-report, quality of life, audiovisual recording, community participation

Introduction

Children on the autism spectrum are reported to participate in fewer activities and less frequently than typically developing peers or children with other development conditions [1]. We define participation as attendance (being there) and involvement (experience while attending) in life situations; the theoretical framework for this study was the family of Participation Related Constructs (fPRC) [2]. To date, participation research has largely relied on proxy reports with parents completing standardised assessments or interviews [1,3,4]. This is problematic because participation involves not only what is observable by others (e.g. attendance at an activity) but also the subjective experience of the child's involvement in the activity [2]. Furthermore, it is important to consider participation in context. The fPRC hypothesises bidirectional relationships among a person's attendance and involvement in activities, and self-related (preferences, sense of self, activity competence) and environment/context-related factors [2]. To understand a child's participation experience requires obtaining first-person perspectives to deepen our knowledge of the relationships among constructs that support or hinder participation, defined as attendance and involvement.

There has been a move to recognise the importance of first-person accounts in research that addresses the person's life situation [5]. Despite this, there is sparse research that includes the voice of children on the autism spectrum [6]. Given that participation in life activities is viewed by the World Health Organisation [7] as important to a person's health and well-being, hearing the child's experience is central to understanding what they view as meaningful participation. A number of studies [8,9] have used self-report measures, for example, the Children's Assessment of Participation and Enjoyment (CAPE) [10]; however, the focus tends to be on the range and intensity of activity participation. There is an underlying assumption that more frequency, diversity, and intensity of activities is better, which may not be the case for individuals on the autism spectrum. Furthermore, although

enjoyment is included as an indicator of involvement, this provides a restricted view, assuming a person is only involved in activities they enjoy, which is unlikely to be the case [11]. Commonly used measures have generally been standardised on non-autistic populations, failing to take into consideration that children on the autism spectrum may view the concept of participation differently. The limited qualitative research on child participation has reported on the types of activities attended [12] rather than the child's experience of participation. The ubiquitous lack of the individual's voice in the autism research [13] may be primarily due to methodological issues [5,14]. Preece and Jordan [15] suggested that the difficulties of including individuals on the autism spectrum in research may be due to current research methods not accommodating the characteristics of autism.

Issues related to eliciting the views of children on the autism spectrum have been identified through research using semi-structured interviews. Children had difficulty understanding abstract concepts [15], recalling and discussing personal experiences [16], and identifying and expressing emotions [15], and they required additional time to process information [17]. Children's responses to questions varied from a default response of "don't know" to over-full responses or responses related to their special interest [18]. Similar issues have been reported by young adults on the autism spectrum [19], suggesting these are related to characteristics of autism rather than to the age of the participant. In addition, anxiety about the social communication experience and the unpredictability of the interview impacted on children and youth continuing in the research [20]. This suggests that traditional methods may create barriers for individuals on the autism spectrum, restricting their contribution to research topics relevant to them. Arguably the best way to find suitable methods is to have input from the individuals themselves. Research exploring innovative methods to include children on the autism spectrum is in its preliminary stages [21]. The use of photo-elicitation is an emerging practice used with children on the autism spectrum and provides the

participant with the agency to select their photos, which are then used as a stimulus for discussion [22]. Developing effective methods requires building on known effective practices, including practices from relevant fields, and combining these with knowledge of autism and evidence-supported methods (for example, visual supports [23]). Following development, methods need to be evaluated to ensure the children's voice is respected in research about them [24]. This includes offering children on the autism spectrum the opportunity to provide feedback on the methods.

The purpose of this research was to elicit the viewpoints of children on the autism spectrum about their participation experiences in activities at home and in the community and to develop and trial a research method to support the inclusion of the voice of children on the autism spectrum. Our research questions were:

1. How do children on the autism spectrum describe their experiences of participation?
2. How does a multi-media and staged approach to data gathering support the inclusion of the voice of children on the autism spectrum in research?

It is anticipated that the findings will inform methods for future research and practice that aim to elicit and hear the perspectives of children on the autism spectrum.

Method

Design

This exploratory study used multiple methods, situated within an interpretivist paradigm [25], including the collection of self-recorded videos and semi-structured interviews to generate data on the perspectives and experiences of children on the autism spectrum.

Participants

Four children (10-13 years) on the autism spectrum, living in Australia, were included. Purposive sampling involved advertising the study using social media. We sought

children on the autism spectrum aged 10-13 years with verbal communication (i.e. speech was identified by the parent as their primary mode of communication) and who had access to a video recording device. A video clip explaining the aim of the research and describing the study procedure was linked to the advertisement.

Nine caregivers provided consent for their child to be contacted; one caregiver withdrew consent due to family reasons and four children consented to be part of the research. Child demographics (pseudonym, age, gender, descriptive measures) are displayed in table 1. Two males and two females participated in this study: higher than the current male-to-female autism population ratio of 3.4:1 [26]. All children had a clinical diagnosis of autism. In addition, the parent-completed Social Communication Questionnaire (SCQ) [27] was used as a measure of autism spectrum disorder (ASD) characteristics; all participants scored above the ASD cut off score of 15 [28]. The parent-completed Scales of Independent Behaviour Revised Short Form (SIB-R Short Form) [29] was used to describe children's age-equivalent level of adaptive functioning. One child (Dylan) was reported to be functioning markedly below his chronological age and the age of the other participants. Information on race and socioeconomic status was not obtained.

Ethical clearance for this study was granted through the <removed for blind review> University Human Research Ethics Committee. Children were provided with ongoing information about what they would be asked to do at each stage of the research, and their assent was sought. Verbal information provided to children was supported by a PowerPoint presentation. An assent slide was embedded into the PowerPoint asking them to indicate "Yes" if they would like to continue, "Wait" to indicate they would like to continue the research but not now, and "No" to stop their participation. This slide was shown at the beginning and end of the initial meeting, and at the beginning and prior to the feedback component of the interview. This ongoing process of assent is appropriate when the research

occurs over time [30]. Children participating in the research project received an honorarium ($20 voucher).

<table 1 goes about here>

Procedure

During the development stage of the project we engaged a 13-year-old on the autism spectrum as a consultant who provided feedback on the content and presentation of the information and the activity recording process. He chose not to participate in the study. His recommendations and visual illustrations were incorporated into the design. Before the initial meeting and interview session, children were provided with a video outlining what would happen in each session, as audiovisual material is a useful method to provide children with information about research projects [31] and is recommended in research with individuals on the autism spectrum [21,32].

The study comprised three stages – (1) initial meeting, (2) filming, and (3) interview (see figure 1). The initial meetings and interviews were conducted by <removed for blind review> remotely, using a video conferencing platform. Children were given the choice to have a parent present during the meetings. All children except for Georgia chose to have a parent attend the initial meeting and the interview. Georgia chose to participate in the interview without her parent. Her parent consented to this and was in an adjoining room. Children participated in the initial meeting and interview from their home.

Stage 1: Initial Meeting

The purpose of the meeting was to gain child assent and to discuss the focus of the research and their role (see figure 1). Children were shown the assent slide and reminded that they could choose to stop participating in the research at any stage. Following assent, the three stages of the project were explained, that is, purpose of the first meeting, filming, and the interview. Children were told the research was interested in things they did when they

were not at school and they were being asked to film these activities. A discussion was had on the type of equipment they could use, and ethical considerations were discussed in terms of who would see the children's images and how they would be used as part of the interview. This also included a discussion on what was not ethical to include in the images (e.g., identifiable people). Children were asked about possible activities they thought they could record. This discussion was used to clarify that the children understood the activities they could and could not record. The researcher suggested they record at least two activities per day, with each video lasting approximately 2 minutes. During filming, children were asked to talk about the activity (see figure 1 – What to say). In addition, instructions were provided on how to upload videos to a private, shared, web-based repository. At the end of the session, children were asked to provide assent and to indicate when they would like to commence the filming stage of the project. The clear outline of the process involved in collecting visual images provided in this study was an important procedural step, as it is known to support children on the autism spectrum [22]. Meetings lasted 10 to 20 minutes.

<Insert figure 1 here>

Stage 2: Filming

Using their own device, children recorded activities they participated in at home or in the community across the period of one week. This included a narrative (that is, they talked while recording) describing the activity and their participation in the activity. The purpose of the filming was to capture "in-the-moment" experiences. The images and narrative were used to tailor each child's interview, and the images were used as a prompt during the interviews because visual images have been found to facilitate dialogue with children [33].

Stage 3: The Interview

A semi-structured interview protocol was developed and individualised to support each child to provide an in-depth description and explanation of the information provided in

their recordings. Individualising of interviews occurred as follows: (1) all authors reviewed the transcripts of the video narratives, (2) team discussion resulted in structured questions for each child, and (3) screen shots were taken of the children's recordings and embedded into a PowerPoint that was used in the interview. The images were used as a method to aid recall during the interview [34]. Prior to the interview the children were sent a video of the PowerPoint explaining this phase. The PowerPoint included the statements "these are the type of questions I will ask. I may ask you some more questions in the session". This provided the children with knowledge of what would happen in the session and time to prepare their responses. Providing individuals on the autism spectrum the opportunity to review interview materials in advance is considered a method of promoting participant inclusion in the research [32]. Examples of questions included:

Georgia – "You said you were very involved in these activities. Tell me what being very involved means to you?"

Chloe – "You mentioned you were really getting into it. Can you tell me a bit more about what your mean?"

Dylan – "This looks like you are in the car. What are you doing in this picture?" "Tell me about when you use the punching bag?"

Matt – "In your video you said how you loved playing video games, and you showed me your video game collection. What is it about playing video games that you love?"

Children were invited to provide feedback on the research using the Smileyometer: a 5-level scale, using emoticons ranging from "awful" to "really good" redeveloped by Read and MacFarlane [35] and co-designed by children. In addition, children were asked for their feedback on the research protocol and what they would like to see researched. Interviews lasted between 20-47 minutes.

Data Analyses

To address Research Question 1, the data analysed included the transcripts of the child's video narrative and interview. The fPRC [2], based on a critical review of existing knowledge describing participation [36], was used as an analytical framework to orientate the analysis. Initial use of a framework is viewed as a beginning point to the analysis [37]. The authors read all transcripts to be familiar with the data. An iterative, inductive process was adopted where codes were developed by the first author and then these were discussed for confirmation throughout the process. These discussions were audio recorded to provide a record of coding discussions as part of an audit trail to enhance trustworthiness [38]. Initial codes represented elements within the fPRC, for example, "activity competence", "sense of self". These were then coded depending on whether they related to the child "being at the activity" or their experience "participating in the activity". Any change in codes required returning to the transcript to ensure the new code was contextually correct. This ensures the researchers stay true to the text [39]. Detailed quotes were used throughout the coding to demonstrate transparency and soundness of the conclusions [40]. To address Research Question 2, data were summarised descriptively.

Credibility

The researchers brought diverse perspectives from a combination of allied health, education, and research backgrounds with a focus on the autism field and the phenomenon of participation. This expertise, combined with study design characteristics – child-consultant, audit trail (a record of decisions taken through the process of conducting the study), field notes and journaling, researcher triangulation, detailed descriptions of the study's implementation and participants – supports credibility of the study findings.

Results

Children provided videos of a range of different activities (8 – 12) and the duration of recordings ranged from .02 secs to 3 min 17 secs (see table 2). Three children recorded

activities within a 1-week period. Matt requested 2 weeks as he wanted to include a particular activity.

<table 2 goes about here>

The analysis generated two themes and eight subthemes focused on the children's descriptions of their experience of participation (that is, their involvement while attending the varying activities) and factors impacting on their activity participation (Research Question 1). A summary is provided of the children's experiences participating in the data collection and their responses to the research method to elicit their views (Research Question 2).

Theme 1: Involvement is an Individual and Subjective Experience

Children described their understanding and perspective of involvement and how there were *Differing Personal Perspectives of Involvement* and *Feelings Associated with Being Involved.* They identified *Fluctuating Levels and/or Focus of Involvement within an Activity* and *Factors Associated with Shift in Level and/or Focus of Involvement.* The children explained how their involvement was not always visible to others and described how others *Perceived Involvement Based on Associated Behaviours.*

Differing Personal Perspectives of Involvement

Three children described their understanding and perspective of involvement. Chloe's involvement in activities appeared to be based on her level of enjoyment and this influenced her focus on doing the activities. For example, "I really like doing it, I don't really get distracted … I really concentrate on it" (movie night). This contrasted with activities where she wasn't as involved: "I get distracted very easily" (homework). Sometimes, Chloe judged her involvement based on her perception of how others were engaged. At a family gathering she viewed herself as less involved than others, saying, "I wasn't getting into it as much as everyone else was." For Matt, being "really involved" was when his focus of attention was on the doing of the activity and he couldn't be distracted.

In contrast, Georgia determined her level of involvement based on her cognitive engagement in the activity and this was irrespective of her enjoyment of the activity. Georgia described herself as having “a very small amount of thoughts” and being fully involved was when “that’s the only thing that I think while I’m doing that”. When she was somewhat involved, she could “let my mind stray a little and think of other things”. In any activity she was always somewhat involved. This cognitive focus was also evident when the activity included a social aspect. For example, when making truffles with her family, the conversation was on the task “instead of like ‘oh how are you doing?’ it’s more of a ‘okay so I’ll roll three more truffles’”.

Feelings Associated with Being Involved

Both positive (e.g., like/enjoy) and negative (e.g., don’t enjoy/don’t like) feelings were associated with activities (table 2). Feelings tended to be identified reflectively based on a culmination of present and previous experiences of participating in the activity. Georgia expressed how when she reads a book, she goes into a different world. "I just let the words kinda [sic] wash over me”. Matt described his experience of playing computer games: “The overall feel, the relaxation, the challenge, when you get challenged and you find you do something you’ve been doing it forever on a big burst of enjoyment.” For Dylan swinging on the punching bag, it was the sensation of “getting the air in my face, like the breeze”. Feelings could also influence their non-involvement in activities. Matt identified homework as an activity he did but was not involved in because “I get really frustrated”.

During the video narratives, children attempted to identify their feelings in the moment; however, this related to elements of the activity. While playing Kelly Pool (a rotation pool game), Georgia said, “I’m feeling ... really happy. A bit cautious about the big cues”. Matt enjoyed visiting the farm, but said of the pigs, “they smell disgusting”. Chloe described how using stencils made writing her spelling words “very fun”.

Feelings experienced could change during an activity owing to contextual factors. For example, Georgia explained how she was fine doing a chore but got angry when her sister started complaining. She also described how making truffles became less enjoyable when she had the task of rolling the truffles in coconut because “it gets a bit hectic”.

Fluctuating Levels and/or Focus of Involvement within an Activity

Children described how their level of involvement or their focus of involvement in the activity could shift during their attendance. Initially Georgia described herself as “very involved” in tap dancing; however, during dance breaks she was “somewhat involved”. She would let her “brain relax” and the sound of the other dancers reminded her of her moves. For Chloe, her focus of involvement could move back and forth between concurrent activities. She said, “sometimes I'd just do the puzzle and sort of ignore the music, and sometimes I'd sort of dance to the music and stop the puzzle”.

Factors Associated with Shift in Level and/or Focus of Involvement

Children identified multiple factors that influenced their involvement in an activity. Both Chole and Georgia described shifting involvement when tired. Chloe became less involved in activities when she was tired, while Georgia would be more involved (in swimming) because it required more focus. Other personal factors included motivation to complete the activity. Chloe explained that if she wanted to go out and play after doing her homework she would “try really hard to focus”; if she didn’t, she would get easily distracted. Georgia described how she was “very involved” in washing up to avoid repeating the activity. Likewise, Matt mentioned that when walking the dog, “I’m just focussed on getting home.”

Personal and environmental factors could influence level of involvement. Chloe described how she was “really getting into it [soccer] and it was really fun” and this motivated her to try harder. This decision was also influenced by her team cheering her.

Georgia explained that when attending her sister's Scouts ceremony, her focus was on a cenotaph; however, focussing was difficult because her mother was filming around her.

Children could be involved in doing a task but could be thinking about other things, including past and future events, demonstrating how the focus of involvement can shift within a task. Chloe illustrated this when she was wrapping the present. Her involvement doing the activity was a culmination of past (shopping), present (wrapping the present), and anticipated involvement (upcoming birthday party).

> One of the activities I like doing is shopping for presents and that's what we did this afternoon. My friend A. is having a birthday party tomorrow at [bowling facility] … I think it's going to be really fun because lots of my friends are going to be there. She likes [brand] so I bought her this diary with pens and clips and that, and pencils and, also I bought myself this – it's nice and squishy – cause I loooove squishies … it's going to be really fun. I'm just wrapping the present now and I'm going to make a card for her and I'm going to get really involved with bowling. I like to do my best doing that and karaoke as well, it's going to be really fun.

In the interview, Chloe was asked what she was thinking about when wrapping the present. "I think most of it was in what was going to happen at the party, because I was excited, and it was my first one for the year … but a little bit was in doing the present and the card."

Perceived Involvement Based on Associated Behaviours

After watching her recorded videos, Georgia was surprised that her involvement was not obvious. She commented: "But most of the time you can't see that I'm involved, but if you were to ask me 'what are you thinking at the moment?' that [activity] would be one of the first thoughts that I said". She did think her family would be able to observe the small signs that indicated she was really involved based on their knowledge of her. However, this was not always the case: "But sometimes they don't understand that I'm involved, and they

interrupt me". For Matt, he felt his father could tell his level of involvement by his ability to disengage from the activity. In one example, he was not able to get out of the car until the activity (computer game) ended; in another game he could be interrupted "cause he's [father] not disturbing me that much I'll just do what he says and go back to the game". In contrast, Chloe was not sure if others would be able to tell if she was really involved in an activity, but she did think her mum could tell by her distracted behaviour when she was *not* involved in an activity.

Theme 2. Personal, Social, and Physical Factors Influenced Activity Participation

Personal

Children's choice of whether they participated or not in an activity was influenced by their emotional state and feelings associated with the activity, activity competence, and extrinsic motivation. Dylan told how his mood influenced his choice of activities. For example, he chose school work, cleaning, or jobs, when he was in the "green zone" (i.e., "when I am happy"); climbing when he was feeling "really angry and sort of hyper"; the punching bag to calm himself; and playing slime when he wanted to prepare himself for the day. Chloe described how she used music to calm herself: "like I sing along with it and sometimes dance, and it calms me" and she said this was more effective than watching the screen. But when she was "grumpy tired" she wouldn't choose those things. Playing a video was an activity Matt identified as calming. However, Matt's response to computer and video games was complex. He described the games as addictive, "I've put 68 hours into it, so you can see I'm pretty …hooked," and playing the games was not always calming: this depended on the type of game he played. For example, as he described the experience: "it's like you hate it and you really just want to stop playing … basically really addicting because you do just want to complete the level and you keep on playing and raging and raging".

Children identified activity competence as influencing participation. Matt's awareness of his physical abilities influenced his choice of activity. He described taking the dog for a walk as a "cool walk" but walking around the double lake "that would be horrible, hurt my legs like heck". He also listed a range of activities, "Scouts, tennis, rugby, soccer, basketball, netball, volleyball, pretty much all the sports", as activities he didn't participate in "cause [sic] they really hurt my legs". For Dylan, the challenge of playing strategy games on the iPad influenced his choice of this activity: "It's like an infinite game … because there's so much stuff to do, so you can't get bored".

Extrinsic motivation influenced some activity choices. Matt went to karate every week because he was "wanting to get a black belt" and he collected Pokémon cards because he wanted to get the full collection. Part of Matt's enjoyment in collecting Pokémon cards was the anticipation of getting the weekly pack: "it's really exciting waiting for a week to get your package and praying it will be a good pack, not a bad pack". In contrast, Georgia identified two activities (cleaning the toilet and washing up) she didn't enjoy but participated in because of a monetary reward.

Contextual Social Elements Associated with Participation

Activity selection was also influenced by social elements. For example, Chloe described how she now plays different activities because she plays with different people. When playing with their siblings, Dylan and Matt selected activities that accommodated their siblings' ability. Dylan played wrestling games as his brother liked to play rough and Matt would play computer games suited to his brother's ability, because he's "pretty much just amateur". Matt also participated in activities in preparation for future social involvement. For example, he recorded the activity of going to the game shop to purchase a controller, so he could play a computer game with his brother. The avoidance of social partners was also associated with activities: Georgia would play a card game when she "needed a bit of alone

time". Likewise, when Dylan needed a break from his brother, he played with his friend's dog.

Social factors also influenced children's decisions to comply with participating in activities they may or may not view as enjoyable. Georgia said she attended swimming, an activity she sometimes enjoyed and sometimes didn't, because her parents had enrolled her in the class. Chloe participated in cleaning up, an activity she didn't want to do and didn't like, because "Mum said I have to".

Over time, some social activities had developed into routines which were valued by the children. Chloe identified bedtime book reading with her mother and the family weekly movie night as regular activities she enjoyed. Family cooking activities were viewed by Georgia as "special activities". The timing of Matt's video recording coincided with strawberry picking season which was associated with the annual school Strawberry Festival.

Contextual Physical Elements Influenced Children's Participation

Physical elements, such as space and devices, could influence children's choices about how or where their participation occurred. Georgia created a space for reading and Dylan told how he would have his snack under a blanket because it gave him "a sense of, a safe vibe". For the video, Matt chose to change the route he walked the dog because he didn't want to show a certain area in the video, saying, "It's really disgusting". Physical devices also influenced children's choices. Although Georgia could read off her iPad, she preferred reading with a book. Chloe liked doing her science project on her laptop and Matt described how the device selected influenced his gaming performance. He explained that he was better on the computer screen compared to the iPad because of the size of the screen and "I'm better with my forefinger than I am with my thumb".

Participating in the Data Collection

Participating in the research required children to adopt a dual role: a participant (i.e., doing the activity) and a researcher (i.e., recording their experience). Children used different methods to negotiate these roles. For some activities, Georgia and Dylan provided footage of themselves doing the activity and discussed the activity in the interview. Another method involved a discussion before or after a demonstration of the activity. For example, Chloe said, "I can do my feet" and then demonstrated using the hula hoop. Children also audio-recorded while doing the activity. To manage the doing and the reporting, Matt played an easier level on his video game; however, he found the dual role for this activity challenging and commented, "I really knew too, it was dodgy". He also found external factors could challenge his dual role. This was evident when he was walking the dog: "Sorry person (mumble) see. Stop it … Stop it doggy. As you can see, I'm trying my hardest to keep … Don't even think about it doggy."

At times, children adopted the role of a reporter, being aware their videos would be viewed by the researcher: Georgia demonstrated how to play clock patience and Chloe shared her science project, "That's my Mars planet, and I've hyperlinked that". Matt also selected activities to share. He showed his Pokémon and game collection, identified and commented on the farm animals, and shared his pleasure visiting the swans: "I find it pure adorable, do you? Hopefully you do."

Using the Smileyometer, three children rated the experience as "really good" and one as "good". The children found the pre-session videos helpful and, in the case of the interview, they allowed them time to think about the questions. Georgia and Chloe commented that they liked having the "choice" (assent) and Georgia suggested this could be included more frequently. She explained:

> There's a lot of times when I'll be halfway through a chat and I'll think "I just want to stop this now, I don't want to do this". But that's not what I thought through this. It's just I'm thinking of others.

Matt commented that he liked the filming and found this fun. Chloe liked that they were asked to video the activities rather than to talk to someone about the activities. Chloe was the only child who provided a suggestion for future research, requesting research on friendships and why it is so hard for kids to make friends.

Discussion

This study aimed to improve our understanding of participation in activities from the first-person perspective of children on the autism spectrum. The methods of videoing participation in self-selected activities and the follow-up interview were effective in eliciting the viewpoint of children (10-13 years) with a range of capacities. Children's descriptions of participation highlighted the subjective and dynamic nature of involvement, the complexity of interpreting participation in activities, and the interconnections between personal and external factors on participation.

Participation as a Transactional Process

The results of this study support previous research indicating that multiple factors are associated with participation [41]. Furthermore, participation may be influenced by psychosocial and environmental factors and the interactions among these factors. This aligns with conceptual frameworks of participation put forth by Imms et al. [2] and Maciver et al. [42]. This transactional relationship was evident throughout the children's discussions and can be seen in the example provided by Georgia that highlights the importance of considering the interactions between factors when measuring participation. On a participation scale, Georgia would have rated herself as attending (weekly) and very involved in household chores such as cleaning the toilet. Her choice to do the activity was influenced by extrinsic

motivation (pay), and her involvement was influenced by doing the job well to avoid having to redo the task. Despite being very involved, Georgia did not see this activity as preferred or enjoyable; however, she did identify less preferred activities: "Well I prefer it to eating a whole tub of chilli powder". Thus, Georgia's involvement in toilet cleaning can be seen as her method of coping or complying with choices (or preferences) of others for her participation. This challenges previous findings on participation in children on the autism spectrum that focus on participation as an isolated outcome (e.g., counting the number of activities, frequency of attending, involvement, or enjoyment of particular activities) [3,8] by highlighting that a deep understanding of participation requires exploration of the relationships among the constructs of self, environment, and participation.

Involvement is Nuanced

The children's voices provided in-depth knowledge of their participation experiences which may be absent from a standardised measure. Participation scales commonly assess participation on video and computer games as a single item. This single item arguably fails to capture the specific idiosyncrasies associated with differing gaming genres and the child's unique perspective. Much has been written about the addictive nature of video and computer games and associated problematic behaviour [43]. This was identified by Matt, in reference to video games with levels. In contrast, Matt described playing other types of games as calming. Both Matt and Dylan discussed the enjoyment and the sense of achievement experienced in playing games. This highlights the importance of understanding individuals' experiences when modifying participation patterns.

The Methods Effectively Elicited Voice

This study procedure informs methodological practices for conducting first-person research with children on the autism spectrum and contributes to the limited research investigating novel research approaches to better support the voice of people on the spectrum

[6]. The use of video allowed children to record in-the-moment experiences. Video data can give the researcher access to the child's world as well as aiding recall of the event [44]. To the authors' knowledge, there are no guidelines for the inclusion of children on the autism spectrum in research; however, the procedure used aligns with ASSPIRE practice-based guidelines for including autistic adults [32] and supports researcher recommendations [45]. In particular, the ongoing assent process and the provision of recordings explaining each stage of the research procedure provided an accessible informed consent process; a child consult during project development further ensured materials were accessible; the children were provided with the interview guide in advance; although not required, emoticons were incorporated into Dylan's interview presentation to assist with responses; and multiple modes of data collection were used (video recordings and interviews). Children had agency to select activities they viewed as meaningful and the video provided them the opportunity to capture the in-the-moment experience. Consistent with previous research [46], this multi-method approach to data generation elicited in-depth understandings of children's perspectives.

Limitations and Future Directions

Children, at times, had trouble managing the dual task of recording these moments when physically or mentally involved in the activity (e.g., Georgia dancing, Matt playing video games). This challenge of reporting in-the-moment experiences has been identified in previous research [47]. Although the children found creative solutions for addressing this issue (e.g., having another person record, playing an easier video game), exploring ways to capture children's lived experiences has the potential to provide insights into their participation.

Children were asked to record two to five short video clips across the day but were not asked to report on frequency and/or duration of the activities. This may have resulted in children providing disproportionately novel events (e.g., weekly classes). For example,

parents have reported that their children frequently participate and were very involved in watching television [3,48]. This activity was only identified by Chloe and was part of a special family routine. Extending the capture of activities across the day, and providing more specific instructions on activities to record, would provide a broader understanding of factors that influence participation in a more generalised context. While that approach may broaden the range of experiences children report on, allowing children to choose activities in this study likely elicited activities that held meaning for them.

Including only four children in this study may have limited the diversity of experiences about the methods used (Aim 2), but it was enough to demonstrate their usefulness for the research purpose and the acceptability of them to the children. The use of the SIB-R provided a description of the children's functional ability. Dylan's functional ability was 9 years below his chronological age; despite this, he was able to complete the task. His parent commented on his desire to do the filming by himself, and this may account for the short duration of his videos and the limited narrative during the filming. However, he was able to explain his perspective during the interview. The method also demonstrated that these children, who all had verbal skills, could provide perspectives and language about participation involvement (Aim 1) that might be used for setting goals or intervention directions. As with any small size study, caution must be taken in interpreting the findings as there may be other factors (e.g., socioeconomic, cultural, or geographical factors) that impact on children's participation experiences and their engagement with the methods used in this study.

The time required for preparation of study materials in collaboration with a child-consultant, and individualising of the children's interviews after receiving the interviews, was valuable and needs to be factored into future research. The combination of materials and methods used was effective, but the children did require adult support to collect some of the

videos and to upload them. The extent to which the perceived time commitment (parent and child) impacted on recruitment is an area for future consideration.

Conclusion

Participation, which includes both attending and being involved in activities, is a dynamic transactional process influenced by individual and external factors. Recognising these factors is important when measuring children's participation. Children on the autism spectrum with a range of capacities were competent self-reporters in identifying these factors and provided an understanding of the subjective experience of their participation. This study identified important considerations for eliciting and including the child's voice in research.

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Declaration of Interest

The authors report no conflicts of interest.

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Figure 1

Research Protocol Stages

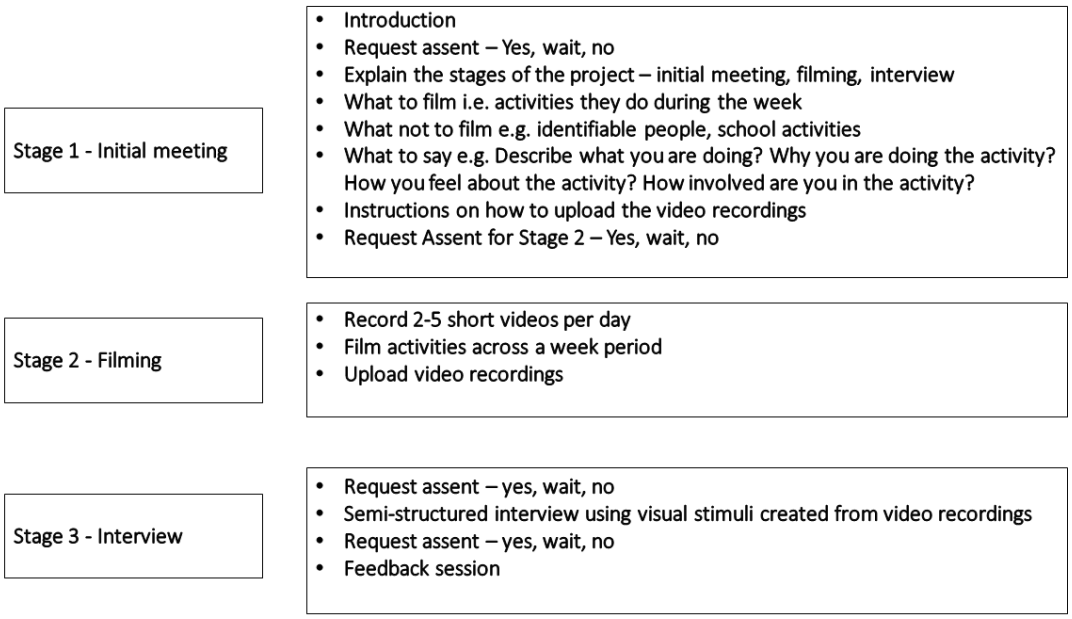

Table 1

Age, Gender, and Descriptive Measures of Participants

Name	Age	Gender	SCQ	SIB-R (age equivalent)
Georgia	11yrs 10mths	F	20	12yrs 9mths
Chloe	10yrs 8mths	F	22	10yrs 9mths
Matt	11yrs 11mths	M	24	9yrs 2mths
Dylan	12yrs 1mth	M	22	3yrs 0mths

Note. Socioeconomic data were not recorded.

Table 2

Activities Recorded or Described, and Associated Feelings

Name	Number of images uploaded (duration range)	Activities filmed or described (feelings associated with doing the activity)
Georgia	13 recordings (16 s – 1 min 52 s)	Reading ("like", "soothes me"), swimming[a] ("enjoy most of the time"), washing up[a] ("don't enjoy"), cleaning the toilet[a], staying home alone, walking the dog ("don't enjoy", "often infuriated"), playing Kelly pool (i.e. rotation pool game), 2 x cooking ("enjoyed", "don't like touching the marshmallows"), tap dancing[a], washing clothes, playing cards ("enjoy"), attending a ceremony[a].
Chloe	12 recordings (22 s – 1 min 24 s)	Talking about Twister, doing cartwheels[a] ("really enjoy"), doing hula-hooping[a] ("like"), dancing ("very fun"), doing her homework ("sometimes I don't like it"), 2 x showing her science project, talking about soccer ("very fun", "really like"), attending movie night, listening to music, reading (bedtime), preparing for the birthday party (party and karaoke "very fun").
Matt	13 recordings (8 s – 3 min 17 s)	2 x Walking the dog (on the walk Matt would stop and look at the swans "pure adorable"), playing with the dog ("very fun"), showing his Pokémon collection, 2 x visiting the strawberry farm ("fun"), playing an iPad game, showing his video game collection, going to the game shop, showing his karate class area ("pretty

		cool"), playing a video/computer game (computer games "love/really love", "makes me feel calm"; video game "raging and raging"), visiting the chickens, visiting the pigs.
Dylan	29 recordings (.02 s -7 s)	3 x climbing, 9 x swinging on the punching bag ("calms me"), 7 x playing with siblings, 4 x sitting in the car, showing the outside area, 3 x eating, playing with slime ("calms me"), jumping.

[a]Parent filmed