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Exploring the facilitation of young children with disabilities in research about their early intervention service

Abstract

While participatory research approaches are being developed and applied within speech and language therapy practice it is not clear that all children are afforded the opportunity to participate in such activities. This study aimed to explore the involvement of young children, aged between two and four years, with developmental disabilities in the research process, focusing on early intervention disability services. Eight young children took part in this qualitative research. Clark and Moss's (2011) framework for listening was used to structure the multi-method data collection process. The design was iterative; the collection of data from each participant was followed by a review of theoretical ideas to support the emerging data. Findings suggest that the use of an asset based approach to participation in research, focusing on participants strengths through a variety of data collection tools, used by a skilled facilitator, supported by parental expertise enabled the children to be part of the data collection process. The research highlights that speech and language therapists can facilitate the inclusion of children with disabilities in research activities about their early intervention service they receive. As members of early intervention teams speech and language therapists need to promote their skills in facilitating the active engagement of children with developmental disabilities in research. Thus making their participation in early intervention research, a reality with potential to promote holistic practice.

Keywords

participation, qualitative research, early intervention team, young children, disabilities.

I Introduction

Article 3 of the United Nations Convention on the Rights of the Child established the principle that all children should enjoy the "freedom to seek, receive and impart information and ideas of all kinds"(Office of the United Nations High Commissioner for Human Rights, 1989). Nevertheless, children, including those with developmental disabilities, were virtually excluded as active participants in the research process and were rarely asked to tell their own stories (Grover, 2004). While, the National Federation of Voluntary Bodies (2008) states that the presumption should be of capacity rather than incapacity when involving a person with disabilities in a research process, children with disabilities may experience a double disadvantage because they are young and they have a disability (Dickins, 2004). Gallacher and Gallagher (2008) argue that it is not sufficient to carry out research *on* or *about* children and that it is no longer enough to simply reposition children as subjects – rather than objects – of research. Researchers must research *for* and *with* children and engage them as participants in the research process (Punch, 2002). It is recognized that children have different experiences and knowledge to adults (Christensen and James, 2008; James and Prout, 1997) and that we cannot rely on adult proxies to give valid accounts of children's experiences (Beresford, 1997; Markham and Dean, 2006; Markham et al., 2009). Hence, participation of children in research is essential, supporting the view of children as competent social actors, with their own agency and voice, acknowledging children as experts of their childhood (Carter, 2009).

By promoting and facilitating children's participation in research we are advancing childhood research, adding to research generally (Tisdall, 2012) and responding to our ethical responsibility to explore ways to make children's participation a reality (Merrick, 2011). In this article, the authors share the results of a research study, which explored the involvement of young children with developmental disabilities in research through the application of a variety of tools. We argue that the SLT as a member of an early intervention (EI) team has a unique role and skill set to facilitate children with disabilities to participate together with their parents, in research.

1 Involving Children with Disabilities in Research

Research is gradually emerging involving school-aged children with speech, language and communication needs (SLCN), (Lyons et al., 2013; Markham, 2011; Merrick and Roulstone, 2011) and young children with SLCN (Press et al., 2011; Roulstone et al., 2013). Although, leading researchers in the field promote the facilitation of children with disabilities in research (Franklin and Sloper, 2006; Sloper and Beresford, 2006; Tisdall, 2012; Whitehurst, 2006), there is a scarcity of research involving young children and school aged children with developmental disabilities. Within the field of disabilities, research is also developing to facilitate the participation of school-aged children with disabilities (Beresford et al., 2004; Mitchell and Sloper, 2011; Porter et al., 2011) with one research study involving young children with developmental disabilities (Paige-Smith and Rix, 2011). Rabiee et al. (2005) suggest that the exclusion of children with developmental disabilities, in research, may be related to the lack of appropriate data collection methods to facilitate their inclusion. In studies to date, multiple data sources have been used to record and represent the children's everyday lives, including Baby Cam (Press et al., 2011), observations, interviews and

KiddyCam (Roulstone et al., 2013), narrative observations and photographs of daily events (Paige-Smith and Rix, 2011). Research including young children with developmental disabilities is warranted both internationally and in the country where the research took place. Research focussing on data collection methods to support their inclusion is necessary to progress this agenda forward.

Dickins (2004) recognises that listening to and consulting with young disabled children, with complex needs, requires the listener to use communication techniques and interpretation skills. Participation of a heterogeneous group of young children with developmental disabilities requires the researcher to use an open and flexible approach in the use of different research tools to aid communication (Franklin and Sloper, 2009; Kelly, 2007; Mitchell and Sloper, 2011; Paige-Smith and Rix, 2011). Although we cannot rely on adult proxy reports of children's experiences alone (Markham et al., 2009), it is important to recognize that parents are adept interpreters of their child's signals (Press et al., 2011) and that the skills of speakers and listeners influence successful communication (McCormack et al., 2010). In family centred practices, the family is recognised as the expert on the needs of the child (Trute, 2007). Recognising parents' expertise in early intervention and responding to parents' needs and wishes is important for building relationships with parents (King et al., 1998; McWilliam et al., 1998; O'Neil and Palisano, 2000). Therefore, the roles played by the parents and the researcher, in the research process, need to be valued and supported.

2 *Context of Study*

Designed to support family patterns of interaction that best promote children's development, EI services have long-term benefits for children and their families

(Guralnick, 2005). For children with disabilities and their families, access to effective EI services, within the first five years of life, is critical to the child's development (Guralnick, 2011). Within the context of the current study, EI services for children with disabilities are provided by multidisciplinary teams to children from birth to 5 years who are experiencing significant difficulties in two or more areas of their development (Carrroll, Murphy and Sixsmith, 2013). The way that teams function varies across the country. Teams typically comprise of families, parents and children with disabilities, and a variety of professionals, including Occupational Therapists, Physiotherapists, Speech and Language Therapists (SLT), Nurses, Psychologists, Social Workers, Family Support Workers and in some teams, a Team Leader.

The country's EI services, underpinned by the bio psychosocial model, must be family centred, integrated and inclusive (Health Service Executive, 2011). The bio psychosocial model proposes that health and wellness are caused by a complex interaction of biological, psychological, and sociocultural factors. This model provides a framework for EI team interventions. The focus of integrated EI services is on the child in the context of their family and considers the influence of the family on the child's development (Dunst et al., 2007). This family-centred approach is also advocated in SLT service delivery (McLeod and Threats, 2008). An approach to intervention that is both family-centered and strengths-based helps families feel more confident and comfortable in supporting their children's development (Wilcox, 2001). The American Speech-Language-Hearing Association (ASHA) (2008) highlight that EI services should be 'developmentally supportive and promote children's participation in their natural environments' (p.3). For children with disabilities, participation in these activities is dependent on their skills within communication, motor, social and emotional developmental domains (Wilcox and Woods, 2011).

Blackman (2003) emphasises the key role played by families as a success factor of interventions. The Health Service (2011) stress that services must be accountable, evidence based and evaluate outcomes. Facilitating a level of independent participation is an important outcome for children receiving EI (Wilcox and Woods, 2011). In keeping with EI philosophy, research is shifting to focus on enhancing young children's participation and notably their communicative participation (Ragavendra, 2013). Hearing the voice of children is vital in order to understand their experiences (Department of Health and Children, 2000; Government of United Kingdom, 2014) and their voices must inform practice (Whitehurst, 2006).

3 *Aims of the Study*

This research study aimed to answer two research questions.

1. Can young children with developmental disabilities be facilitated to engage in research?
2. If so, how can their engagement in research be supported?

II **Methods**

An asset based methodological approach was used in this study. The researcher's objectives were to interact with young children with disabilities in ways that respected their particular competence (Thomas and O'Kane, 2000) and their unique and valued view of the world (Greene and Hill, 2005); to view the children as active members of their early intervention team and to add the children's voices and engage them in the research process. Initially, the researcher took a leadership role and following a process of co-construction (Mason and Urquhart, 2001), the children's interactions led the data collection activities. The researcher was a SLT by profession and at the

time of research had over 13 years clinical experience working in EI and with children with disabilities, was a sign language user and skilled in the nuances of communication facilitation. These skills included active listening, being resourceful, respectful of the child and their style of communication, open, sensitive, and flexible.

1 Participants

A purposeful sampling strategy was used to select potential child participants from two non-government organisations (NGO) who were receiving EI services. The gatekeepers, who were managers within the organisations were asked to select: children with complex needs attending an EI team, and ranging in age from 2 to 5 years. Eight children were recruited; all attended EI team services for children with developmental disabilities in their local areas. The details of each participant are outlined in Table 1. Following the selection and recruitment procedure:

1. The researcher contacted the parents of the children identified through the selection process.
2. The parent provided consent for the researcher to meet with their child for the research.
3. The child assented to participate in an interaction with the researcher. The approach to the interaction was based on the child's level of ability.

Insert Table 1 here

2 Data Collection

Clark and Moss's (2011) Framework for Listening was used to guide the data collection process because it views children as 'beings not becomings' (Quortrup et al., 1994), and listens to children's voices. The multi-method process involved interactions with each child, use of a Microsoft SenseCam (Hodges et al., 2006),

SenseCam images, pictures, Talking Mats (Murphy, 1997), and observations. Multiple interactions also allowed the needs of the child to be respected (Irwin and Johnson, 2005) and strengthened the trustworthiness of the data (Dockett and Perry, 2007). The participants were all individuals with heterogeneous experiences and diverse interests and needs. Prior to the initial interaction, the researcher and the primary caregiver had a telephone conversation, on how best to facilitate their child's participation to engage in the interaction. Each interaction involved the child, researcher and one or both parents, was audio recorded and took place in the child's home. The parents' role was one to support the child and the researcher during their interactions. Thus, supporting the view that the parent and researcher worked in partnership and also to ensure that the research was carried out to the appropriate ethical standards. The researcher engaged in active listening, and took field notes following each interview. A Total Communication approach was used, where non-verbal communication such as body language, facial expression, signing, gestures and pictures were valued as much as spoken language (Fargas-Malet et al., 2010).

At the end of the first interaction, the researcher gave the parent/s a SenseCam for the child to wear over the subsequent few days. There was one SenseCam available for the study; subsequently five children were selected, based on nearest travel distance from the researcher, to use the SenseCam. The SenseCam, developed by Microsoft Research UK, is a passive wearable camera, fitted with a wide-angle (fish-eye) lens, which results in nearly everything in front of the camera being photographed. It takes photographs automatically and the images provide a visual account of daily tasks and activities from the child's perspective. It offers a novel route to the collection of observational data. The use of the SenseCam provided the children with a means to share their lives from their perspective (Wang, 2006). The

researcher collected the camera and a record sheet (noting the date and length of time the child wore the camera) prior to the second interaction. SenseCam Image software was used to process all the SenseCam images and the images of toys, people, places, and activities from the child's world were printed. During the second interaction, with the five children who used the SenseCam, the researcher used Talking Mats (Murphy, 1997), along with the print outs of SenseCam images and other pictures based on the child's preferences. The tools were varied and reflective in accordance with the research question and the individual abilities and preferences of the children.

3 *Data Analysis*

An interpretative framework shaped the interpretation of the data (Grover, 2004). The interactions were analysed using a constant comparative approach. Transcripts were coded to identify themes directly from the interactions. The SenseCam images were analysed using content analysis in order to reduce and make sense of the volume of qualitative material (Patton, 2002). The images were grouped into events, for example, mealtimes, playtime, watching TV, people, by the researcher to form a pictorial diary of the child's experiences. This analytical method involved the researcher adopting an outsider perspective by personally interpreting the photographs, examining and describing them as thoroughly as possible. Punch (2002) suggests that the researcher needs to be critically reflective in analysing different types of data. An interpretative framework facilitated the identification of themes in the data.

4 *Rigour*

The design was iterative; the collection of data from each participant was followed by a review of theoretical ideas to support the emerging themes. In flexible designs such as this Patton (2002) advocates the use of an audit trail, therefore the researcher kept a

reflective diary which included thoughts, feelings, biases that may have influenced all aspects of the research process and attempts made to manage them (Davis et al., 2000; Driessnack, 2006). The parents were present during all interactions with their children (as a requirement of the research) and facilitated the researcher in her interactions with the children and verified the accuracy of the researcher's observations and interpretations. The second author acted as peer checker of the data, by viewing the images, which supported the trustworthiness of the data collection process and data analysis.

5 *Ethical considerations*

The research underwent two independent reviews and received full ethical approval from two University research ethics committees. The parents were fully informed of the research and knew that they had the right to withdraw their child at any stage. Their confidentiality was assured and pseudonyms were used to provide confidentiality. The researcher wanted to facilitate the participation of the children who attended the EI services in this research and allow them to have a voice and to include those for whom obstacles may make participation difficult. Stancliffe (1999) argued that when someone is unable to communicate their own views, a well-informed guess may be preferable than no information. The National Federation of Voluntary Bodies (2008) states that where children do not have the capacity to consent a guardian (usually parent) appointed must give consent. All parents provided their written consent for their child to take part in the research. The parents knew that they might be probed to give supportive evidence to statements made by their child during the interviews. However, there should also be an opportunity for the child to express assent. In accordance with (Ireland and Holloway, 1996; Scott, Wishart and Bowyer, 2006), the agreement of the children to take part in the research was also

requested. The researcher checked at the beginning of each interaction that the child was willing to participate. The age and level of ability of the child dictated how the child's own assent and participation could be achieved (Ireland and Holloway, 1996; Scott et al., 2006). The researcher looked for verbal and non-verbal signals of the child's willingness to partake or withdraw.

III Findings

The research demonstrated that the young children with disabilities could participate in the research process about their early intervention service. The children's engagement was facilitated successfully through the use of a number of strategies during the process of data collection. It emerged that a variety of data collection tools were needed, together with parent knowledge and skills and researcher knowledge and skills. The findings are reported under these headings.

1 Variety of data collection tools

The tools that supported the children in this study were the use of the SenseCam and Talking Mats. The SenseCam was used as a recorder of the child's everyday experiences and the contexts they experienced. Five children wore the SenseCam for an average of five hours over a three-day period. During the study, Child 6 did not want to wear the SenseCam around her neck, and used it as a 'handbag' and wanted to take pictures herself. Her mother responded to her communicative signals and facilitated her to wear the camera by stitching the camera to her vest. She wore the camera and communicated to her mother when she did not want to wear it and her mother responded by taking the vest off. Child 6 moved outside during the first interaction and the researcher followed the child's lead and the interaction continued outside. Thereby allowing her to be an active participant in the research process.

Child 7 wore the SenseCam during an EI therapy session and also during his EI group interventions. This provided images and observations of his interactions with his therapists and demonstrated his participation during intervention. The SenseCam images included a playdoh activity showing him rolling playdoh with his hands, then rolling playdoh with a roller and then placing a shape in the playdoh and then the final product. For Child 7, the SenseCam allowed us view his interest in the outside world with images of his pets consistently being captured on his visits outside. His siblings and his mother were also very important people in his life. For Child 8, the images showed us his interest in Thomas the Tank Engine programmes on TV.

When using Talking Mats (Murphy, 1997), the children chose the images of their world and used non-verbal expressions such as smiling or verbally commented. The child and their parent viewed them and validated their importance in the child's life. Of the five children who used the SenseCam, Talking Mats were used as a tool with three of the children when looking at the photos. Child 5 looked at the SenseCam images on the researcher's laptop and named and pointed to the ones he liked. Child 2 looked, and pointed and named the pictures.

2 *Parents' Knowledge and Skills to Support Engagement*

The child interacted with the researcher and participated in the research. The parents supported their child's interactions when it was needed, between the researcher and the child, and the parents on occasion directed the interactions.

'I am going to do music with him now. I have a few cds that get him up. There is an Irish dancing cd and he goes mad for that. (Mother of Child 1 interaction 1).

Child 5's mother showed the researcher his activities and carried out their therapy routine and involved the researcher to take turns in the Mr. Potato Head activity.

'Here are some of his routines, that's kind of a list of all the ones we've built up and then I kind of have them in pockets so we might do a song, ...we've Mr. Potato head and the new thing then is the pictures with the words. (Mother of Child 5 Interaction 1).

Parents influenced the interactions in EI by contributing knowledge about their child. The parents shared how their child interacted in EI.

'He would push away or wriggle off my lap or turn away. If he really doesn't want something done he would let you know alright (Parent of Child 1 Interaction 1)

'People who will actually play with him and sit down with him. He responds to them much more (Parent of Child 2 Interaction 1)

Within the interactions in the home it was clear that a parent influenced and effected change in their child particularly in relation to using home opportunities to include treatment goals. When an investment in structure and routine was attached to EI, it facilitated interaction.

'Looking back it was great they (professionals) really got them into the routine. It (therapy sessions) became very familiar to them. The hello song at the beginning. (Mother of Child 4 Interaction 1).

When the researcher and his mother were observing Child 5 holding on to a toy, his mother commented that *'he wouldn't have done that a year ago'* (Child 5 Interaction 1). Accordingly, involvement in EI enabled developmental progress.

'The words are coming great. The last time then she (SLT) gave me these ones (mother showed the researcher cards) with just the words and he is getting it. He has strengthened no end' (Child 4 Interaction 1)

'He is completely different (to when he was two). Even in the last 2 months he has come on (Child 1 Interaction 1).

3 Researcher Knowledge and Skills to Support Engagement

During the interactions the researcher verbalised what the child was doing and how they responded when the response was not verbal, for example, when the child signed and/or vocalised the researcher said 'signed car and said da'. This allowed for more accurate transcription of the audio recording. The researcher, being a SLT and using a Total Communication approach, could read a lot of the children's signals and signs. The researcher also asked the parents during the interactions to verify the accuracy of her interpretations of unclear signs, signals, gestures, vocalisations and words. The researcher followed the child's lead in all the interactions. During the interviews, all forms of communication were viewed as equal.

The researcher observed Child 2, during interaction 1, playing a game with marbles and he allowed the researcher to take turns and play hide and seek with them. Marbles were of interest to this child. The child's motivation also influenced activities, and the materials used made a difference. The researcher read the child's non-verbal communication to alert her as to when had how to take her next turn. The researcher and Child 1, during interaction 2, played with playdoh. The child opened the playdoh boxes, squeezed the playdoh and rolled it out into a snake. The task was completed under the direction of his mother. Also during this interaction, the researcher noted that his mother commented on good sitting, commented saying 'open', 'squeeze' and made noises to go with the activity, named colours, named

verbs 'pull', 'push', and used short phrases 'good open', 'take some out', 'lid off', 'we scoop', 'in the box', 'lid on', 's', 'small snake', 'big snake', and changed her intonation patterns and stressed different words. His mother noted that:

'You have to be patient. You have to go slowly. Face to face contact. (Child 1 Interaction 2)

All eight children involved in the study communicated non-verbally when, they did not want to take part, were no longer interested in an activity and when they were finished interacting. They interacted by moving away or turning away from the researcher, pushing a toy or pictures away, not wanting to wear the SenseCam or wanting to leave the room. The researcher responded to the children's communicative attempts by following the child's lead and either changing the activity or stopping the interview. Initially the process was researcher led, followed by a period of co construction and finally child led. The researcher adapted the data collection methods according to each child.

IV Discussion

This research demonstrated that young children with disabilities could participate in research about their EI service. The research demonstrated that, although engaging these children with developmental disabilities in the research is difficult and complex, it is possible. EI services strive for inclusion and to be accountable (Health Service Executive, 2011). This research shows that the young children involved in these services were included in adding to research about EI services. Young children with disabilities are central to EI services. The ideology of EI services is participation of all children with disabilities in their everyday activities. Within this research, the children were viewed as competent social actors and given

the opportunity to take part in research about EI. Similar to other research findings (Beresford et al, 2004; Franklin and Sloper, 2009; Kelly, 2007), a range of data collection techniques, skills and support was required to engage this heterogeneous group of young children to participate in the research. Research with children with developmental disabilities is difficult and is compounded by the complexity of impairment and by the complex variety of children. Hence, for the children in the study, their level of participation in activities varied and was dependent on their abilities and on the context of the activity, a finding similar to those found by Paige-Smith and Rix (2011). This research also found that the people, that is, parents and the researcher were key factors in the children's engagement. This study provides evidence that a multi-method process allowed the children in this study to give a picture of their skills, needs and interests, identified what motivated them, identified their capacity to make decisions and how they interacted in their home context.

Within the research, the parents played an important role in their child's participation. The children in the study were engaged in the process with the support of their parents. Firstly, the parents consented to their children being involved in the study. The parents acknowledged their child's capacity to take part (Federation of Voluntary Bodies, 2008). Secondly, the parents were a factor in the success of their child's engagement in the research process. This is similar to the opinion that parent involvement in EI is a key factor to successful intervention (Blackman, 2003). Similar to Trute's (2007) view that parents should be regarded as partners with professionals in family centred practices, the parents and the researcher were partners in the research process. The researcher perceived the parents from a position of equal expertise (Carpenter et al., 2004) and did not rely on them to act as proxies for the children (Markham et al., 2009). Rather than acting as proxies, they enabled their

child's inclusion and their participation in the research. Without the active commitment of the parents in the research process the use of the SenseCam (Hodges et al., 2006) as a tool for data collection would not have been positive. The parents provided the opportunities for their children to wear the SenseCam in their home settings. Thirdly, during the interactions with the children in their homes, the parents verified their child's communication skills, their interests and demonstrated how interventions were supported within the home context. The parents made activities available to their child and integrated therapy interventions into home activities. Thus supporting Axelsson et al. (2013) suggestion that child-focussed activities are more involving than routines. Lastly, the parents acted as interpreters when it was required, verifying the accuracy of the researcher's interpretations of their child's communicative signals. Thus supporting the reliability of the researcher's interpretations.

The data collection tools used in the study facilitated the young children to participate in the research process. At the time of the research, the SenseCam (Hodges et al., 2006) had not been previously used with young children with disabilities. This research demonstrates that it is a useful research tool to use with this heterogeneous group of children. The SenseCam facilitated auto photography, where the world inhabited by the children was captured while, at the same time, reflecting the worlds they live in (Erdner and Magnusson, 2011). The SenseCam allowed the researcher to gain a more comprehensive picture of the children's worlds obtaining data that traditional interactions could never have provided. The use of photography is supported by previous research (Press et al., 2011; Roulstone et al., 2013) and this research adds to the evidence base to include young children with disabilities. The use of Talking Mats (Murphy, 1997) also facilitated the children's engagement in the

research and provided a prop to use pictures and images taken by the SenseCam in the interactions. In order to engage these children in research activities, the researcher and the parents needed to be flexible and respond to the child's individual capabilities.

Consulting with young children with disabilities requires the listener to use communicative techniques and interpretative skills (Dickins, 2004), which can have a substantial influence on communication (McCormack et al., 2010). This research suggests that the techniques and the skills of the researcher were an integral factor in the successful engagement of the children with disabilities in this research. The researcher was a speech and language therapist, with a professional qualification in the nuances of communication facilitation (ASHA, 2008). The authors argue that the researcher was not only a competent researcher but also had clinical competence to actively engage with the children in ways that another researcher may not. The researcher's specialist expertise and experience in working with children with disabilities facilitated the interactions and allowed the interactions to flow as the researcher understood sign language and made consistent attempts to interpret the child's communicative intentions, which is supported by McCormack et al. (2010) and Dickins (2004).

An important outcome of EI for a child with a disability is independent participation (Wilcox and Woods, 2011). This independence to participate in research can be hindered by a number of factors such as communicative competence. This research provides an example of children with disabilities displaying communicative participation in research. Speech and language therapists have a role to ensure that communication is conceptualised as a skill that is central to participation across all activities and routines in EI (Wilcox and Woods, 2011). While all professionals

within EI have skills to work with these children, SLTs have clinical competencies to help interpret and report children's views (Wilcox and Woods, 2011). SLTs can facilitate children in research and support researcher colleagues, in research about EI. SLTs can help colleagues to understand how each child communicates, shows their likes and dislikes, makes choices and to interpret a child's communicative signals. This knowledge is also important for planning family-based interventions (Dunst, 2001; McWilliam, 2010). SLTs together with their EI colleagues need to consider the young children, with whom they are working, as potential research participants and need to consider ways to facilitate participation.

The strengths of the study are that it involved multiple interactions allowing the needs of the child to be respected (Irwin and Johnson, 2005) and strengthened the trustworthiness of the data (Dockett and Perry, 2007). The researcher was reflexive by considering her role as a researcher and the power relations in the research process (Davis et al., 2000; Edmond, 2006). The researcher's clinical qualifications and clinical experience together with the parents' expertise helped ensure reliability of the data. The second author also facilitated peer checking of the data adding to the rigour of the research process (Patton, 2002). However, the research could be criticized for being non standardised and that the analysis of the findings are the researcher's interpretations and may not take account the child's own insights. The study was limited by the time that was allotted to collect the data with only eight children taking part in the study, and five wearing the SenseCam. The practice of auto photography could be seen as passive participation, however in this research the photographs were used to facilitate active participation. There is opportunity to extend the use of the SenseCam to ensure that the images are representative of the child's life. The positive

outcome of the study may have also been attributable to the children's motivation and that of their parents to facilitate their child in the research.

In conclusion, the importance of facilitating research *with* children rather than *on* children is increasingly recognised and promoted. Systems can make this participation in research activities a reality through the use of; an asset based methodological approach, a variety of data collection tools, with the support of parents and an interviewer skilled in the nuances of communication facilitation. Enabling young children with disabilities to have a voice in research has the potential to positively influence the services they receive facilitating a more truly holistic approach to EI practice.

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Child	Gender	Age (yrs)	Yrs with Team	Diagnosis	Education	No. of siblings	No. of interviews	Use of Sense Cam
Child 1	Male	3	3	Down Syndrome	Mainstream preschool	3	2	No
Child 2	Male	3	3	Down Syndrome	Mainstream preschool	0	2	Yes
Child 3	Male			Physical and intellectual	Special Preschool		2	No

		4	4	disability		2		
Child 4	Male	3	3	Down Syndrome	Mainstream preschool	2	1	No
Child 5	Male	3	3	Down Syndrome	Not yet	2	2	Yes
Child 6	Female	4	3.5	Down Syndrome	Mainstream preschool	2	2	Yes
Child 7	Male	3	2.5	Down Syndrome	Not yet	2	3	Yes
Child 8	Male	2	1.5	Down Syndrome	Not yet	0	2	Yes

Table 1: Child Sample