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**Children with Down syndrome and their communication partners participating in research about communication.**

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**ABSTRACT**

Even though 2018 marked the 70th anniversary of the United Nation's Universal Declaration of Human Rights (United Nations, 1948), published research examples which include the voices of children with disabilities are few. In the United Nations Convention on the Rights of the Child (United Nations, 1989), Article 12 states that the child has a right to express an opinion and Article 13 states that the child has the right to express his/her views. Communication is a fundamental human right, it allows for independence, contributes towards self-esteem and influences an individual's identity. For those who rely on unconventional methods to communicate, this 'right' may be inaccessible due to external barriers such as attitudes or lack of awareness. Because the voices of children with intellectual disabilities have been rarely heard ~~excluded~~ we need to explore ways to make their participation a reality. There is a pressing need to include children with disabilities as participants in research and practice in order to understand their micro- and meso-systems. This paper will share an example where three children with Down syndrome participated in research to share their views. How these children were included in terms of research design, purposeful and snowball sampling and data collection methods will be shared. The discussion in this paper will contribute to the research field where children with disabilities are generally excluded. Therefore, participatory research which includes the voices of children with disabilities is vital. This paper celebrates how children shared their views in research and shares the lessons learned aiming to support further research, policy and practice.

## Introduction

Communication is an integral part of human experience. Valenzuela (1992, p.2) defines communication as “any act by which one person gives or receives from another person information about needs, desires, perceptions, knowledge, or affective states. Communication may involve conventional or unconventional signals and may occur through spoken or other modes”. Jones (2000) underlines the fundamental relationship between communicating using a conventional language and the ability to function in society and concludes that those unable to communicate ‘conventionally’ are more likely to be excluded. The reconceptualisation of childhood and disability in terms of voice, agency, competency and rights is coming to the fore with the call to recognise ‘the child as an experiencing agent, listening to their voice as a source of understanding’ (Twomey and Carroll, 2018, p.3). There is considerable evidence that individuals with intellectual disabilities (ID) face communication challenges throughout their lifetime (Crow, 1996). Individuals with ID have experienced long-term personal, social and institutional discrimination (Jones, 2000). At the centre of this discrimination, arguably, is a powerful sense of difference (Hall, 2010). This ‘difference’ is potentially created as a consequence of an ‘impairment’, i.e. a communication impairment. Successful communication is dependent on the skills of speakers and listeners (McCormack *et al.* 2010). Therefore, recognizing differences in communication abilities is integral to the shaping of a more inclusive society. Down syndrome (DS) is characterised by developmental delays in all areas of functioning, although the level of delay can vary greatly from person to person (Deckers *et al.* 2016). According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) (American Psychiatric Association, 2013), people with DS have relative strengths and challenges in relation to communication, their strengths include receptive language and non-verbal social functioning, while relative challenges are found in expressive language and intelligibility. Due to the nature of the presentation of communication abilities, the ability to effectively communicate is often restricted (Raghavendra *et al.* 2012; Guralnick *et al.* 2011; Martin *et al.* 2009). Some people with DS never fully develop speech (Sigafos *et al.* 2010). For these reasons, multiple methods of communication may be warranted (Sigafos *et al.* 2010). The imperative to promote the inclusion of individuals with communication needs has led to a range of approaches described as augmentative and alternative communication (AAC) (Beukelman and Mirenda, 2013). AAC refers to a variety of communication forms including manual signing, communication boards and sophisticated voice output devices (Branson and Demchak, 2009). The United Nations Convention on the Rights of Persons with Disability

(United Nations, 2006) explicitly states that individuals have the right to access whichever form of communication chosen including the use of AAC.

Much of the research pertaining to AAC explores the ‘effectiveness’, for instance documenting improvements in joint attention or an increase in vocabulary, rather than looking at the ‘experience’ (Romksi *et al.* 2015). It is of paramount importance that the impact of AAC interventions are measured. Furthermore, it is of equal importance to understand the experience of using AAC so that society can enable those who use AAC to meet their communication needs. Light and McNaughton (2015) recognise that despite the benefits of AAC, many individuals with communication difficulties continue to face challenges. In order to understand these ‘challenges’, the focus must be turned towards the ‘experts’, those who use AAC and their communication partners. Communication partners provide a purpose for communication and are considered integral to AAC intervention (Johnson *et al.* 2009). Kent-Walsh and McNaughton (2005) suggest two categories of communication partners: individuals with an educative/paid role (health and social care professionals) and those with a social role (family/friends). Reports on parental experience regarding AAC are growing (Marshall and Goldbart, 2008; Angelo, 2000). However, the active participation of AAC users within the research field is limited. Successful interactions between children who use AAC systems and their communication partners need to be co-constructed (Smith, 2018). Smith urges us to understand more about these interactions from the child’s perspectives.

AAC takes two main forms, aided and unaided (Roberts *et al.* 2007). Unaided methods include natural gestures such as pointing, body language, facial expressions and manual signing. Aided methods include the use of external symbol systems such as objects, pictures, graphics or alphabet boards. Much previous research pertaining to AAC has evaluated the effectiveness of specific methods (Light and McNaughton, 2015). AAC is often not the sole communication method used by an individual; an AAC system is usually combined with speech or other methods (Meuris *et al.* 2014). Key word signing (KWS; i.e. signing the key words of sentences) has been reported as the most common AAC intervention for children with DS and has been found to support and develop communication skills (Meuris *et al.* 2014). Lámh (the Irish word for hand and pronounced ‘Lawv’) is a manual key word sign system used by children and adults with ID and communication needs in Ireland (Lámh.org, 2016). There are 500 Lámh signs, which aid expression and comprehension for users (Lámh.org, 2016). The experience of AAC users has often been overlooked in research (Light and McNaughton, 2015). In order to truly understand the effectiveness of intervention, one must understand the

experience of using the system in daily life. Therefore, the focus must turn to the users of the system and their communication partners.

Including children with disabilities and key figures in their lives in research could yield rich insights into the relationships, opportunities, and barriers experienced in everyday life (Dew *et al.* 2011). Smith *et al.* (2014) suggest interviewing family members and significant others in the life of the person with the communication disorder in order to achieve a total view of communication. A family or caregiver report is also advocated by Cascella (2005) and McLean *et al.* (1996). Rini and Hindenlang (2014) suggest observations of communication in the home environment will help us learn about real life communication opportunities. Smith *et al.* (2014) recommend discussions with the school teacher as s/he understands the communication needs of the child in accessing the curriculum and creating peer relations. This research aimed to include these suggestions to explore the experiences of children who use multiple methods to communicate and to identify the factors that support and challenge successful communication for these children and their main communication partners.

## **Methodology**

This study followed an exploratory qualitative design (Patton, 2015). An exploratory design added flexibility and allowed for exploration and expansion of emerging ideas (Fitzpatrick and Kazer, 2011). Multiple qualitative case studies explored the experiences of three children who use multiple methods to communicate. Siyambalapitiya *et al.* (2019) suggest that this methodology may be useful when exploring communication disorders. Each case study explored multiple perspectives in keeping with triangulation as a primary principle of case study design (Baxter and Jack, 2008). Following ethical approval, the gatekeeper purposely selected three children for the study based on the following criteria: aged between 8-13 years old, attended primary education, lived at home, had an intellectual disability and used multiple methods to communicate. The child was the central focus of each case. Purposeful sampling is frequently used in qualitative research for selecting information-rich participants related to the phenomenon of interest (Patton, 2015). The gatekeeper subsequently contacted the parents of the three children and gave them the study information sheets in order to assist them to make an informed decision regarding their participation in the study. As the research involved children; three with an intellectual disability, additional planning and preparation during the methodological stage was necessary. In this case, the researchers created child friendly information sheets and topic guide questions with age appropriate language. The children's parents provided written consent for their child to participate. During all interactions each child gave assent to participate. A subtype of purposive sampling called snowball sampling

facilitated each child to select further participants (Patton, 2015). During the initial interview each child identified their main communication partners. Subsequently, the gatekeeper invited these communication partners to take part. In total three children and their 16 identified communication partners took part.

Data collection included 18 interviews and seven observations. Triangulation of data sources (i.e. collating data from different qualitative sources) is a way to add rigour to research and can widen or deepen the understanding of the phenomena as it is observed through multiple readings (Lewis *et al.* 2014). Participant details are outlined in table one below.

	<b>Case Study A</b>	<b>Child Study B</b>	<b>Child Study C</b>
<b>Participants</b>	Child + 6 Communication Partners	Child + 4 Communication Partners	Child + 6 Communication Partners
<b>Child Participants</b>	Mary: a 13 year old with DS and attends a special education school. Uses Lámh. Mary lives with her parents, has no siblings. Hobbies include gymnastics and the cinema	Tracy: a 10-year-old girl with DS and attends a special education school.	Ella: A nine year old girl with DS who lives at home with her parents and siblings. She attends a mainstream school.
<b>Communication Partner Participants</b>	Mother and Father (interviewed together) Teacher Speech and language therapist (SLT) Special needs assistant (SNA 1) Special needs assistant (SNA 2)	Mother Father Teacher Special Needs Assistant (SNA)	Mother and Father Older Sister (S1) aged 11 Younger Sister (S2) aged 7 Teddy (T) a stuffed animal voiced by Ella. Teacher (CT)
<b>Data Collection: Observations</b>	3 observations (1 x Classroom 2 x speech and language therapy sessions)	2 observations (1 x home 1x school)	2 observations (1 x home 1x school)
<b>Data Collection: Semi-structured interviews</b>	6 interviews	5 interviews	7 interviews

**Table 1: Participants and Data Collection (Pseudonyms are used to protect the identities of research participants).**

## *Interviews*

Individual interviews allow participants to share information that is in-depth and personal which an individual may not have wished to disclose in a group context (Yeo *et al.* 2014). Each initial interview took place with the child and their parents in their home. Prior to the interviews the children's parents shared information about their child's communication skills. During the initial interview, each child identified their contexts of communication and the people they communicate with most frequently. All three children in this study used a key word signing system called Lámh to aid their communication skills (lámh.org, 2016). Each researcher was certified in Module One of the Lámh Sign System used in Ireland for people with communication needs. Photographs and pictures were also used during interviews to support interactions.

For example in Case Study A, the researcher used cut out figures to represent people and a large drawing of a house/school to represent different settings. Mary was asked to pick a cut out figure that represented people in her life and stick each one on the drawing. Mary was asked whether the individual identified used Lámh key word signing or not. Cut out figures of non Lámh users such as her dog were also used to support trustworthiness of Mary's responses. During the second interview with Mary, the researcher used Talking Mats (Murphy, 1997), a low-tech AAC framework to support the interaction. One of Mary's SNAs was present to act as interpreter when necessary. The purpose of this interview was to learn more about Mary and to explore her use of key word signing as a communication method.

In Case Study C, use of photographs identified the main communication partners to be included in the study. Ella's parents being present during the interview process was a critical factor in the success of the child's engagement in the research process. They verified Ella's communication skills, her interests and acted as interpreters when required, verifying the accuracy of the researcher's interpretations of their child's communicative signals (Carroll and Sixsmith, 2016; Yeo *et al.* 2014). In Case Studies A and B, the researchers used Talking Mats to enhance successful communication. In Case Study C, the researcher aided data collection by interviewing the child's teddy bear which the child personified.

The researchers used semi-structured interviews with all participants as they consisted of key questions, while also allowing the researcher or the participant to deviate from the topic if a response warranted more information (Gill *et al.* 2008). When interviewing the children with ID, the researchers applied Lewis's (2002) principles of interviewing: (1) summarised information and requested a yes/no response to ensure the researchers' interpretations were reflective of the child's views, (2) each child had a familiar person present at all interviews for

interpretations if necessary and (3) the researcher used the child's methods of communication throughout.

Due to the nature of Down syndrome, the ability to effectively communicate is often restricted (Raghavendra, Olsson, Sampson, McInerney and Connell, 2012; Guralnick, Connor and Johnston, 2011; Martin, Klusek, Estigarribia, and Roberts, 2009). Different strategies were used by each researcher based on each individual participant. The researchers occasionally relied on their own assumptions when the child's speech was unintelligible, this could be viewed as a limitation because the child's views may have been misinterpreted. The researchers' knowledge as pre-registered speech and language therapists (SLTs) is important to note and their experience and knowledge may have influenced and shaped the research (Austin and Sutton, 2014).

### *Observations*

Both event sampling and time sampling were used during the observations to informally document events, behaviours and interactions in different communicative contexts (Marshall and Rossman, 2011). These observations allowed the researchers to examine complex interactions and processes that could be difficult to describe during interviews or that may be subconscious or instinctive to the participants (McNaughton-Nicholls *et al.* 2014). During the different case studies the role of researcher as participant or non-participant observer varied. In Case study A, the researcher acted as a participant observer during the first observation in a classroom setting, which allowed the researcher to be part of Mary's everyday social interactions whereas the researcher acted as a non-participant observer during the two observations of the speech and language therapy sessions. For Case study C, the researcher acted as a non-participant observer in the classroom setting, meaning the researcher did not interact with the participants although the participants knew the purpose of the researcher being in situ (Polgar and Thomas, 2013). However, in the home setting, the researcher engaged in a communicative interaction with Ella and her sisters and the researcher took field notes immediately after this interaction had ended.

### *Data Analysis*

The data from field notes, audio-recordings and observations within each case study were conjoined and analysed using thematic analysis (Braun and Clarke, 2006). Thematic analysis allows the main features of a dataset to be summarised, and gives an in-depth description of



the data (Braun and Clarke, 2006). It highlights similarities and differences across the dataset and can generate unanticipated insights not overtly seen by the researcher (Miles *et al.* 2014; Braun and Clarke 2006). Firstly, each case was analysed using thematic analysis and then the first author used cross case analysis to identify the common relationships among cases (Stake, 2006). To enhance the rigour and trustworthiness of this research, the strategies of reflexivity, member checking and multiple coding were employed. The researchers kept a reflective log alongside field notes over the course of the research. This enabled the researchers to reflect on how the data was generated and analysed. During the interview process each researcher checked with the participants that their understandings matched the participant's intended meaning.

## **Findings**

Three common themes emerged from the analysis. Theme 1: What makes communication work, Theme 2: To be Understood and Theme 3: Longing for More.

### *Theme 1: What makes communication work?*

This theme captures the importance of understanding and considering 'What makes Lámh work?'

*Willingness and Familiarity* were important. There was a sense among the participants, that individuals must be willing to learn and use the key word signing, Lámh. For Mary in Case Study A, the importance of having a 'willing' listener was central for successful communication. Her teacher gave an example of how easily communication can break down in the absence of a familiar listener, '*we have had a couple of substitutes recently in my class, they mightn't have used Lámh before.....she is trying to talk to them and then she would just leave it*' (Case Study A: Teacher).

The importance of *frequency and consistency* when using and learning key word signing was emphasised. In Case Study A, Mary's father felt that extended family members were not using KWS due to limited exposure.

### *Theme 2: To be Understood*

This theme echoed throughout the participants' accounts. Lámh was perceived as a pathway to mutual understanding as many of the participant's spoke of how Lámh supported the children

in getting their message across. Throughout the observations, it was evident that key word signing, Lámh, often repaired communication breakdown. In Case Study A, it was found that being understood could be challenging for Mary. During Mary's initial interview, the researcher observed how frustration came to light as a result of being misunderstood. Mary's attempt at informing the researcher regarding an individual in her life was captured on audio playback but misinterpreted during the interview. Mary's frustration was apparent on audio playback by her repeated 'no' in response to being misunderstood. Her frustration went unrecognised during the interview. This interview scenario depicts how, in the moment, frustration can be disguised, as the researcher nor the other individuals present realised that Mary was frustrated and also failed to interpret her communication intent correctly. Frustration as a result of being misunderstood or not being able to understand was evident throughout the data.

*'she gets quite annoyed, you feel sorry for her because she is so desperate to tell you something'* (Case Study A: SNA-1)

*'you can see her head go down, she would be frustrated and that's hard'* (Case Study A: SNA-2).

In Case Study B, Tracy's mother reported her daughter's difficulty in communicating with her peers in gymnastics, drama and at her siblings' birthday parties because these peers did not have communication difficulties themselves, they used speech as their first mode of communication and they lacked awareness and knowledge of key word signing.

### *Theme 3: Longing for More*

This theme was identified as the participants discussed how key word signing, Lámh, deserved more attention regarding awareness, resources, courses and generalisation. There was an undeniable sense of longing, whether it was from the children wanting to say more, or their parents wanting more training and better resources. While the teacher, SNAs and SLTs collectively felt that generalising Lámh was their ultimate goal, as a group there was undoubtedly a feeling of 'longing for more'.

## **Discussion**

The communication partners indicated that key word signing supported the children in their communicative endeavours. The participants appreciated key word signing and discussed how it empowered the children. Key word signing reduced communication breakdown and was seen

as a 'back up'. According to Beukelman and Mirenda (2013), the primary purpose of AAC is to facilitate communicative competence, social interaction and participation. The findings demonstrate how key word signing facilitated the children's communication allowing them to participate and socially interact in their worlds. This highlights the importance of knowledge and use of AAC in wider society to support those who use unconventional ways to communicate come out from the shadows. Ronski *et al.* (2015) reinforce how AAC is used to augment existing speech to enhance message intelligibility, providing an input mode as well as an output mode. For the communication partners in this study, key word signing facilitated the children in being understood. The desire for mutual understanding was prominent when one of the parents stated *'I want to be able to understand everything'*. However, signing is not a natural way of communicating, and findings suggest that for the participants a conscious effort was required to incorporate signing into daily life. This experience was not always easy as they revealed moments of forgetting signs, uncertainty and frustration.

Light and McNaughton (2014) revealed how an individual's communicative competence can vary depending on the partners and environments. The current findings suggest that using key word signing was restricted to particular communication partners and settings. This inevitably could impact on the children's participation and independence which may become increasingly important as they approach their teenage years. A possible reason for this may be due to particular attitudes, unawareness of AAC and the fact that key word signing such as Lámh is only used when individuals are having difficulty acquiring oral language. Thus it is used in response to a 'need' rather than a choice. A number of participants recalled prompting and encouraging the use of Lámh as supporting factors. During the observations, the researcher recorded several times the utterance *'use your sign'* which repaired communication breakdown. There is an obligation to move towards accepting Lámh as being a 'different' form of communication as highlighted by one of the parents: *'we need to inform people that there are others way to communicate, it's not just speech'*. On audio playback the researcher realised one child's communication attempts in Case Study A was unintentionally ignored and hence her comment excluded from the interview. This reinforces McCormack *et al.*'s (2010) findings that successful communication is dependent on the skills of speakers and listeners.

A fascinating development in Case Study C was the how the child Ella selected her teddy bear as a communication partner. Most interestingly, the child and 'Teddy's' reports differed. Teddy may have been used as a support for the child during her interviews. Salmon (2006) found that toys increased the child's comfort when talking to an interviewer and helped

the child to communicate emotions or experiences that might be otherwise difficult to report (Majors 2013; Salmon 2006). This toy may have brought comfort to the child in expressing her true thoughts and acted as a distraction from upsetting others (Majors, 2013). Alternatively, ‘Teddy’ could be identified as a member of the child’s family. A personified object is one that a child treats as an actual living being, giving it human characteristics (Gleason, Seabanc and Hartup, 2000). Children’s relationships with these objects do not differ from their real-life companions (Gleason and Hohmann, 2006). Imaginary companions are replications of real relationships and are created as a result of the child’s need or desire for a relationship (Gleason and Hohmann, 2006). The child may have used ‘Teddy’ to compensate for the difference between her communication abilities and those of her peers. The use of this toy allowed the researcher to delve deeper into the child’s inner thoughts and gave the child another mode to express her thoughts on the research phenomenon. For example, the child shared that teddy was the only one that understood everything she says.

Research now encourages the gathering of multiple perspectives in order to gain a holistic view of a phenomenon. A positive addition to this research was the variety of participants, children; three with DS, adults and a ‘Teddy’. The range of participants allowed for multiple experiences of multi-modal communication to be explored (Smith *et al.* 2014). Participants identified inherent qualities in each other that supported communication. Without multiple accounts, factors that promote successful communication could have been missed. This research included children, three with DS and showed that conducting research with hard to reach populations is possible. Inclusion of children with disabilities in research may take more time and preparation but it is achievable. The findings show that the input of children is valuable and without their inclusion the information gathered would lack depth.

The variety of voices in this research produces a powerful reminder that more awareness and education is needed to ensure that children who use AAC to communicate in particular key word signing such as Lámh can be included. The themes highlight the value that other methods of communicating, such as key word signing, had for the participants. However the participants wanted ‘more’. Qualitatively examining the views of the children and their communication partners established a holistic view of their communication. The value of including children with DS in research is highlighted. Even though the value of augmentative communication methods are recognised, a child’s communication partners need support to fulfil their motivation. For one of the children, her personification of her teddy allowed the researcher to gain a deeper understanding of her communication. She was able to express using

her teddy that she was aware of the ability of others to understand her. Supporting children, who may be seen as ‘hard to reach’, in sharing their views is very important.

There has been a notable reduction in disabling barriers for individuals with ID due to a more educated society, improved methods of diagnosis and the social model of disability (Hannon, 2007). The social model of disability focuses on the physical, cultural and social environments that disadvantage individuals rather than on the impairment they experience (Barnes, 2001). In a persuasive article titled ‘Including All Our Lives’, an advocate for the Disability Movement states the ‘removal of barriers is the solution to the disadvantages we experience’, capturing the importance of social change (Crow 1996, p.3).

The 70th anniversary of the United Nation’s Universal Declaration of Human Rights has arrived but to date research which includes the voices of children with disabilities is sparse. For those who rely on unconventional methods to communicate such as AAC, this ‘right’ may be inaccessible. Furthermore often leading to the voices of children with intellectual disabilities being excluded. We have a duty as researchers and practitioners to explore ways to make their participation in research a reality. This research shares an example of how qualitative case studies can include children who use unconventional methods to communicate to come out from the shadows and share their voices and be active participants in research.

## **Conclusion**

Communication is a fundamental human right, it allows for independence, contributes towards self-esteem and influences an individual’s identity. For those who rely on AAC, this ‘right’ may be inaccessible due to external barriers such as societal attitudes or lack of awareness. Society is now immersed in the wonders of technology, today more than ever before it is more acceptable to communicate via a screen rather than face to face, thus society is already embracing ‘different’ ways to communicate. When it comes to communication there should be no boundaries. Creating an inclusive society is not only a goal of policy makers but for all who seek to ensure that children, whatever their circumstance, are afforded the same life chances as their peers. There is an obligation to move towards accepting key word signing as being another form of communication. The onus is now on society to take that extra step and do ‘more’ to meet the needs of those with communication differences. Individuals with ID are generally excluded from research because professionals do not have the resources or experience to conduct interviews (Whitehurst, 2007). Therefore, the approach ‘Nothing about us without us’ (Campbell and Oliver, 1996) should be adopted claiming that research should not be done for

individuals with ID but rather with them. More awareness and education is required to inform society on how to interact and include individuals who communicate ‘differently’ in research activities. Consequently, these individuals who rely on unconventional methods to communicate such as key word signing may access a broader range of social contexts and communication partners.

## References

- American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders*, 5th Ed. Arlington: American Psychiatric Publishing
- Angelo, D. H. (2000) Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication*, 16, 37–47
- Austin, Z. and Sutton, J. (2014) Qualitative Research: Getting Started. *Canadian Journal of Hospital Pharmacy*, 67, 6, 436-440
- Barnes, C. (2002) Emancipatory disability research: Project or process? *Journal of Research in Special Educational Needs*, 2, 1, [no page numbers]
- Baxter, P. and Jack, S. (2008) Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report*, 13, 4, 554-559.
- Beukelman, D. R. and Mirenda, P. (2013) *Augmentative and Alternative Communication: Supporting children and adults with complex communication needs*, 4th Ed. Baltimore, MD: Paul Brookes
- Branson, D. and Demchak, M. (2009) The use of augmentative and alternative communication methods with infants and toddlers with disabilities: A research review. *Augmentative and Alternative Communication*, 25, 274-286
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101
- Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding Our Past Changing Our Future*. London: Routledge
- Carroll, C. and Sixsmith, J. (2016) Exploring the facilitation of young children with disabilities in research about their early intervention service. *Child Language Teaching and Therapy*, 32, 3, 313-325
- Cascella, P. W. (2005) The expressive communication strengths of adults with severe to profound intellectual disability as reported by group home staff. *Communication Disorders Quarterly*, 26, 156–163

- Crow, L. (1996) Including all of our lives: Renewing the social model of disability. *Encounters with strangers: Feminism and disability*, 206-226
- Deckers, S., Van Zaalén, Y., Stoep, J., Van Balkom, H. and Verhoeven, L. (2016) Communication performance of children with Down Syndrome: An ICF-CY based multiple case study. *Child Language Teaching and Therapy*, 32, 3, 293–311
- Dew, A., Balandin, S. and Llewellyn, G. (2011) Using a Life Course Approach to Explore How the Use of AAC Impacts on Adult Sibling Relationships. *Augmentative and Alternative Communication*, 27, 4, 245-255
- Fitzpatrick, J. and Kazer, M. (2011) *Encyclopaedia of nursing research*, 3rd Ed. New York: Springer Publications
- Gill, P., Stewart, K., Treasure, E. and Chadwick, B. (2008) Methods of data collection in qualitative research: interviews and focus groups. *BDJ*, 204, 6, 291-295
- Gleason, T. and Hohmann, L. (2006) Concepts of Real and Imaginary Friendships in Early Childhood. *Social Development*, 15, 1, 128-144
- Gleason, T., Sebanc, A. and Hartup, W. (2000) Imaginary companions of preschool children. *Developmental Psychology*, 36, 4, 419-428
- Guralnick, M., Connor, R. and Johnson, L. (2011) Peer-Related Social Competence of Young Children with Down Syndrome. *American Journal on Intellectual and Developmental Disabilities*, 116, 1, 48-64
- Hall, E. (2010) Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 54, 48-57
- Hannon, F. (2007) *Literature Review on Attitudes towards Disability*. Disability Research Series, National Disability Authority [Accessed 26 Nov. 2018 at [https://www.ucd.ie/t4cms/004801%20NDA\\_public\\_attitudes\\_disability\\_2006\\_literature\\_review.pdf](https://www.ucd.ie/t4cms/004801%20NDA_public_attitudes_disability_2006_literature_review.pdf) ]
- Johnson, H., Douglas, J., Bigby, C. and Iacono, T. (2009) Maximizing community inclusion through mainstream communication services for adults with severe disabilities. *International Journal of Speech-Language Pathology*, 11, 180-190
- Jones, M. (2000) Hope and despair at the front line. Observations on integrity and change in the human services. *International Social Work*, 43, 365-380
- Kent-Walsh, J. and McNaughton, D. (2005) Communication Partner Instruction in AAC: Present Practices and Future Directions. *Augmentative and Alternative Communication*, 21, 3, 195-204

- Lámh.Org (2016) Lámh signs Ireland | communication augmentation sign system [Accessed 22 March 2018 at <http://www.lamh.org/>]
- Lewis, A. (2002) Accessing, through research interviews, the views of children with difficulties in learning. *Support for Learning*, 17, 111-116
- Light, J. and Mcnaughton, D. (2014) Communicative Competence for Individuals who require Augmentative and Alternative Communication: A New Definition for a New Era of Communication? *Augmentative and Alternative Communication*, 30, 1, 1-18
- Light, J. and Mcnaughton, D. (2015) Designing AAC research and intervention to improve outcomes for individuals with complex communication needs. *Augmentative and Alternative Communication*, 31, 85-96
- Majors, K. (2013) Children's perceptions of their imaginary companions and the purposes they serve: An exploratory study in the United Kingdom. *Childhood*, 20, 4, 550-565.
- Marshall, J. and Goldbart, J. (2008) 'Communication is everything I think.' Parenting a child who needs Augmentative and Alternative Communication (AAC). *International Journal of Language & Communication Disorders*, 43, 1, 77-98
- Marshall, C. and Rossman, G. B. (2011) Primary Data Collection Methods Designing Qualitative Research. Los Angeles, CA: Sage
- Martin, G., Klusek, J., Estigarribia, B. and Roberts, J. (2009) Language Characteristics of Individuals with Down Syndrome. *Topics in Language Disorders*, 29, 2, 112-132
- Mclean, L., Brady, N. and Mclean, J. (1996) Reported communication abilities of individuals with severe mental retardation. *American Journal of Mental Retardation*, 100, 580-591
- Mcnaughton Nicholls, C., Mills, L. and Kotecha, M. (2014) Observation. in J. Richie, J. Lewis, C. McNaughton Nicholls and R. Ormston (Eds.) *Qualitative Research Practice: A guide for social science students and researchers*, 2nd ed. London: Sage (pp. 243-268)
- Mccormack, J., Mcleod, S., Mcallister, L. and Harrison, L. J. (2010) My speech problem, your listening problem, and my frustration: The experience of living with childhood speech impairment. *Language, Speech, and Hearing Services in Schools*, 41, 379-392
- Meuris, K., Maes, B., De Meyer, A. and Zink, I. (2014) Manual Signing in Adults with Intellectual Disability: Influence of Sign Characteristics on Functional Sign Vocabulary. *Journal of Speech Language and Hearing Research*, 57, 3, 990- 1010
- Miles, M., Huberman, A. and Saldana, J. (2014) *Qualitative Data Analysis: A Methods Sourcebook*, 3rd Ed. London: Sage
- Murphy, J. (1997) *Talking Mats: A low-tech framework to help people with severe communication difficulties express their views*, University of Stirling



- Patton, M. Q. (2015) *Qualitative Research and Evaluation Methods*, 4th Ed. Thousand Oaks: Sage
- Polgar, S. and Thomas, S. (2013) *Introduction to research in the health sciences*, 6th Ed. Edinburgh: Churchill Livingstone
- Raghavendra, P., Olsson, C., Sampson, J., Mcinerney, R. and Connell, T. (2012) School Participation and Social Networks of Children with Complex Communication Needs, Physical Disabilities, and Typically Developing Peers. *Augmentative and Alternative Communication*, 28, 1, 33-43
- Rini, D. and Hindenlang, J. (2014) Family centered practice. in R. Paul and P. Cascella (Eds) *Introduction to clinical methods in communication disorders*. Baltimore: Paul H. Brookes (pp. 329-353)
- Roberts, J., Price, J. and Malkin, C. (2007) Language and communication development in Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 1, 26-35.
- Romski, M., Sevcik, R., Barton-Hulsey, A. and Whitmore, A. (2015) Early Intervention and AAC: What a Difference 30 Years Makes. *Augmentative and Alternative Communication*, 31, 3, 181-202
- Salmon, K. (2006) Toys in clinical interviews with children: Review and implications for practice. *Clinical Psychologist*, 10, 2, 54-59.
- Sigafoos, J., O'Reilly, M. and Green, V. (2010) Communication difficulties and the promotion of communication skills. in A. Carr, G. O'Reilly, P. Noonan Walsh and J. McEvoy (Eds) *The Handbook of Intellectual Disability and Clinical Psychology Practice*. London: Routledge (pp.606-643)
- Smith, A., Romski, M., Sevcik, R., Adamson, L. and Barker, R. (2014) Parent Stress and Perceptions of Language Development: Comparing Down syndrome and Other Developmental Disabilities. *Family Relations*, 63, 1, 71-84
- Smith, M.M. (2018) Accessing the Voices of Children who use Augmentative and Alternative Communication: Merits and Perils of Co-Construction. in M. Twomey and C. Carroll (Eds) *Seen and heard: Exploring participation, engagement and voice of children with disabilities*. Peter Lang Publishers: London (pp. 171-190)
- Stake, R. E. (2006). *Multiple Case Study Analysis*. New York: The Guilford Press.
- Siyambalapitiya, S., Howe, T. and Hambly, H. (2019) Qualitative case study and its use in communication disorders research. In R. Lyons and L. Mcallister (Eds) *Qualitative research in communication disorders: An introduction for students and clinicians*. Croydon: J&R

Press (pp. 213-238)

Twomey, M. and Carroll, C. (2018) Introduction: Why voice and why now? in M. Twomey and C. Carroll (Eds) *Seen and heard: Exploring participation, engagement and voice of children with disabilities*. Peter Lang Publishers: London (pp. 1-14)

United Nations (2006) *Convention on the Rights of Person with Disabilities*. United Nations: New York.

Whitehurst, T. (2007) Liberating silent voices—perspectives of children with profound and complex learning needs on inclusion. *British Journal of Learning Disabilities*, 35, 55-61.

Yeo, A., Legard, R., Keegan, J. And Ward, K. (2014) In-depth Interviews. in J. Richie, J. Lewis, C. McNaughton Nicholls and R. Ormston (Eds) *Qualitative Research Practice: A guide for social science students and researchers*, 2nd Ed. London: Sage (pp. 177-210)

United Nations (1948) *Universal Declaration of Human Rights*. [Accessed on 26 Nov 2018 at <http://www.un.org/en/universal-declaration-human-rights/>]

United Nations (1989) *United Nations convention on the rights of the child*. Geneva, Switzerland: United Nations.