

& Society

Disability & Society



ISSN: (Print) (Online) Journal homepage: <u>https://www.tandfonline.com/loi/cdso20</u>

# A methodological reflection on investigating children's voice in qualitative research involving children with severe speech and physical impairments

# Seray Ibrahim, Asimina Vasalou, Laura Benton & Michael Clarke

**To cite this article:** Seray Ibrahim, Asimina Vasalou, Laura Benton & Michael Clarke (2022) A methodological reflection on investigating children's voice in qualitative research involving children with severe speech and physical impairments, Disability & Society, 37:1, 63-88, DOI: 10.1080/09687599.2021.1933389

To link to this article: <u>https://doi.org/10.1080/09687599.2021.1933389</u>

9	© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group	Published online: 24 Jun 2021.
	Submit your article to this journal 🛽 🖉	Article views: 1974
Q	View related articles $\square$	Uiew Crossmark data 🗹
名	Citing articles: 4 View citing articles 🛽 🖓	



OPEN ACCESS OPEN ACCESS

# A methodological reflection on investigating children's voice in qualitative research involving children with severe speech and physical impairments

Seray Ibrahim<sup>a</sup> (b), Asimina Vasalou<sup>a</sup>, Laura Benton<sup>a</sup> and Michael Clarke<sup>b</sup>

<sup>a</sup>UCL Knowledge Lab, University College London, London, UK; <sup>b</sup>Department of Language and Cognition, University College London, London, UK

#### ABSTRACT

Investigating voice in research that involves children with disabilities is highly challenging. Very few studies have problematised voice for the purposes of designing new technologies for and with children who have disabilities. We embarked on qualitative fieldwork with children who have severe speech and physical impairments with the view to motivate designers to consider new child-centred perspectives for conceptualising new communication technologies. In this article, we use reflexivity as a tool to critically examine how empowering our methodological decisions were for children with disabilities, in advancing child-centred accounts of their communication experiences. We propose four considerations that can be useful for researchers and practitioners when undertaking participatory work involving children with disabilities. These are: 1.Theoretical lenses guiding data collection, analysis and interpretation; 2. Developing credible accounts through strong and prominent ideas; 3. Children's ways of participating evidencing their voices, and; 4. Methods hindering the promotion of child centred accounts.

#### **Points of interest**

- Children with severe speech and physical impairments are rarely involved in designing new technologies for supporting communication.
- It can be challenging to study what children with severe speech and physical impairments express as important about their communication.
- This article examines the ways in which researchers made decisions about how they worked with children. We studied communication

**CONTACT** Seray Ibrahim Sibrahim@ucl.ac.uk

© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

#### **ARTICLE HISTORY**

Received 30 September 2020 Accepted 19 May 2021

#### **KEYWORDS**

Severe speech and physical impairments; disability; child's voice; technology; qualitative research; reflexivity

#### 64 👄 S. IBRAHIM

by focusing on the child during their interactions. Our goal was to understand what children expressed as important for communication.

- We found that researcher beliefs, the use of different methods, and observing children's ways of participating all influenced the findings.
- The findings identify that it is important for researchers to be clear to others about the perspectives and different data sources that influence their decisions. Some data collection methods, such as taking photos, can be less empowering for children as they can focus on how the researcher sees the situation.

#### Introduction

Children with severe speech and physical impairments interact and socialise differently compared with children who use natural verbal speech. Connected with these differences, they can experience limited opportunities for interaction, social participation and learning, and increased risk of social isolation and violence (Webster and Carter 2007; Jones et al. 2012; Fauconnier et al. 2009). In an attempt to address some of these complex issues, communication technologies, such as digital augmentative and alternative communication (AAC) devices, are designed to augment or replace natural verbal speech through the option of electronic speech generation. However, the notable underuse or abandonment of AAC device provision suggests that as well posing a range of challenges that affect their adoption (Baxter et al. 2012; Crisp, Draucker, and Cirgin Ellett 2014), they may not reflect the contemporary concerns of children who are expected to use these technologies.

Fifteen years ago, Ingunn Moser (2006) argued a need to rethink ideological claims about the promise of technology for reducing disabling barriers. By examining how disability manifested, and what role technologies and other material arrangements played in allowing people to carry out daily activities, she highlighted that new and potentially transformative technologies can reproduce asymmetries that they intend to mitigate (Moser 2006). Despite Moser's call to consider what role technologies can take in enabling or disabling access to daily activities, an overwhelming volume of technologies for children fail to mitigate the asymmetries that they are designed to address, i.e. with a linguistically oriented focus for alleviating bodily impairment. In support of this, in our prior work we identified that the majority of technology solutions for supporting communication have been informed by a restricted set of design perspectives, including the dominant, normative view that technologies alleviate bodily impairment (Ibrahim, Vasalou, and Clarke 2020).

One possible reason for the limited breadth of design perspectives on communication technologies is that children with severe speech and physical impairments are rarely involved in research. This is primarily because it can be challenging to know how to involve disabled children, resulting in views and priorities being sought via carers and professionals acting as proxies on their behalf. The implications of this are that children's voices can be masked or diluted by adult motivated learning and therapeutic goals.

Acknowledging the complexities of designing with children, yet critical of the frequent use of proxies acting on behalf of this group of children (e.g. Benton and Johnson 2015), we wanted to support new ways of thinking about the design of children's communication technology, that move beyond the deficit lens, by building on the lived experiences of communication. In doing so, we aimed to support an emancipatory agenda in participatory research by showing that methodological decisions by the researcher can be both empowering and disempowering for children with severe speech and physical impairments. Echoing Vines et al. 2013, who captured the implicit and explicit ways in which user participation occurs in the design process, we recognised a need to support a more diverse approach toward configuring how and when participation happens. We engaged in a gualitative study involving observations and creative methods, with five children who have severe speech and physical impairments, investigating communication from a multimodal social semiotic perspective (Kress 2010; Bezemer and Kress 2016). This perspective acknowledges that children can use a wide range of resources that are available to them for the purposes of meaning making (ibid.). The insights gained were communicated to designers in the form of design documentaries. Design documentaries are video stories in the form of a narrative, designed to convey multiple dimensions of people's lived experiences (Raijmakers, Gaver, and Bishay 2006). In creating these design documentaries for designers who were tasked with designing new technologies for communication, our goal was to ensure children's voices and priorities concerning their communication were heard so that designers might be motivated to reconceptualise new ways of designing communication technologies.

This paper reflects on our approach for engaging with children's voices for the purpose of informing the creation of design documentaries. We focus on voice, as very few qualitative research studies involving disabled children have critically considered children's contributions as an epistemological and methodological issue. Our findings contribute to theoretical and methodological debates in the literature, in four ways. First, we illustrate how the role of participant-researcher can give emphasis to the child's voice by listening and responding within the moment. Second, we describe how is it possible to build multidimensional understandings of the child that are informed by different methods. Third, we exemplify how children's ways of engaging with the methods can signal how they affect power dynamics in adult-child interactions, and fourth, we reflect on methods used that hinder our goal for advancing child-centred accounts. These findings inform future researchers, practitioners and policy makers who are interested in studying the views of disabled children, by identifying new considerations about how methods are used and how children's contributions are interpreted and represented.

#### Background

# Socially constructed voices: the role of social, political and historical perspectives

Researchers in childhood studies have increasingly highlighted the need to engage with children's voices, which is recognised as highly complex and fraught with challenges associated with issues of representation, diversity, authenticity (James 2007). However, while the rhetoric of 'children as competent social actors' is increasingly recognised by politicians, practitioners and popular culture, challenges remain in understanding how to listen to and act on children's voices for the purposes of informing change. These challenges are even more pronounced when listening to and interpreting the contributions of children who have disabilities and diverse ways of communicating.

Spyrou (2001) examined children's voices by investigating the sociological and political perspectives that shape how the notion of voice is constructed. In empirical research that studied Greek Cypriot children's constructions of national identity, Spyrou interviewed and observed primary age children in school settings and found that children's expressions of their identities were closely influenced by culture, tradition and nationalistic influences. For example, children talked about their identities in terms of how they were different from other communities in Cyprus. Spyrou highlighted that children's contributions were multi-layered, and to avoid stereotyping their contributions, it was important to interpret what children would say beyond face value. In subsequent work, Spyrou (2011) invited researchers to consider how relations of power, institutional and discursive contexts can be investigated in non-normative ways, for instance by attending to what children express through their silences. For Nolas, Aruldoss, and Varvantakis (2019), ethnographic study on the relationship between childhood and public life involved tuning in to understand what mattered to children involved by attending to the embodied, affective and lived experiences of children's everyday lives. Such research emphasises the importance of moving beyond voice as language to a broader set of contextual and embodied concerns, particularly in cases where children's voices are deeply nestled within social, educational and therapeutic surroundings.

Considering how epistemological positionings translated onto research practice, Mauthner and Doucet (2003) argued that in their own empirical research, amongst other factors, personal, institutional and theoretical

influences all impacted on the interpretive process. The authors argued a need for researchers to be reflexive in how they analysed accounts of other people's lives. In another example, Morris (2003) considered how theoretical models of disability impacted on researcher interpretation in qualitative research involving children who have communication impairments. Reflecting on four of their own past projects, Morris claimed that by drawing on the social model of disability, they were able to separate out concepts associated with impairment versus disability for communication. For instance, acknowledging barriers posed by children's bodily impairment, Morris identified the importance of having augmentative communication systems to hand, as well as researchers understanding about children's communication needs prior to planning methods.

#### Qualitative methods for developing credible accounts

Considering how research methods can impact on investigating voice, Connors and Stalker highlighted the benefits and difficulties that researchers faced in obtaining credible accounts when using different methods (Connors and Stalker 2007). In their empirical research, the authors used the interview method with 27 children who were disabled in different ways. They asked children questions about what they are good at; what they found difficult and what they might change in their lives. Analysing interviews using a qualitative interpretive approach, the authors identified that whilst children were able to share personal experiences, they lacked a positive language with which to talk about their differences. Based on their interview method and analysis, this led the authors to challenge whether their interpretations were credible and aligned with children's perceptions of their experiences.

Recognising the limited extent to which people with complex communication needs who use AAC participate in research, some work has focused on developing and testing creative interview methods for gaining credible views (Clark and Moss 2011; Dee-Price et al. 2021). For example, Dee-Price et al. (2021) used photo elicitation and other methods to improve access to research participation for people with complex communication access needs, highlighting advantages in using multiple methods for discovering meaning from participants. Considering the limitations of traditional methods for gaining first person accounts, some prior research has suggested that indirect methods can allow for children's participation when direct methods such as interviews and questionnaires are less appropriate (Morris 2003; Vasalou et al. 2021). For example, reflecting on methods from their past empirical projects, Morris (2003) describes indirect methods that allow for 'being with' participants through observation and by taking part in daily activities. Expanding this, Gallacher and Gallagher (2008) highlight the pitfalls of involving children through direct methods, especially when those reflect the adult researcher's agenda. Instead, they suggest that indirect methods like observation have the potential for allowing open-ended inquiry into what children's contributions might be conveying. Like in the case of Nolas, Aruldoss, and Varvantakis (2019), these studies suggest that investigating credible accounts of voice involves moving beyond what children verbally express, towards seeing what children do. This can be especially pertinent where there is a careful need to balance the researcher's agenda with the tools available to children to contribute.

Very few studies have critically investigated voice in the case of children with little or no verbal speech. Whilst there is a growing volume of qualitative research actively seeking to engage with the opinions of children and young people with disabilities (e.g. Herrero, Gasset, and Garcia 2021; Hynan, Murray, and Goldbart 2014; Rabiee, Sloper, and Beresford 2005), most have used direct questioning or methods that prompt fixed choices. One exception to this is the work of Wickenden (2011) who used ethnographic methods to investigate identity in empirical research involving nine teenagers who use communication devices. Wickenden's methodological approach highlighted the importance of selecting methods that can optimize ways of revealing and representing the unheard voices of young people who cannot talk easily (Wickenden 2011).

The studies described above suggest that beyond traditional interview methods, opportunities exist for drawing on more open-ended methods that allow for researchers to bring with them an ethical analytic and interpretive lens. Building on Mauthner and Doucet (2003), who consider interpretive ethical issues in analysing accounts of people's lives, we reflect how our theoretical, epistemological and personal influences informed our interpretations of what children expressed as important about their communication.

#### Context, motivation and goals

In the context of designing technologies for and with children, the voices of children with severe speech and physical impairments have not shaped design priorities, prior to important design decisions being made (Benton and Johnson 2015; Börjesson et al. 2015). Concerns remain about whose voice is actually heard and acted upon within the technology design process (Parsons et al. 2020). Further, as identified through childhood studies, research methods can be an impediment to children's voice by foregrounding adult driven goals. Despite this, very little research by those designing technology for disability has problematised voice, suggesting that childhood research, which has not been concerned about technology, can inform how design researchers might study voice.

Given these concerns, the goal of our research was to motivate designers to apply multiple, alternative perspectives to designing communication technologies, given both the dominant, normative view that technologies can alleviate bodily impairment, and the challenges in facilitating children-designer workshops. To achieve this goal, we turned to a narrative method, the design documentary, to generate vivid, rich accounts of children's lives, capturing their communication experiences. For this reason, it was ever more important for us to represent children's voices that would potentially convey their values and priorities about their communication. This was achieved by employing observations and creative methods over a yearlong study involving primary aged children who have severe speech and physical impairments.

The project was comprised of three main stages;

- 1. Qualitative fieldwork involving five children who used AAC; investigating the salient features of communication when children communicate in diverse ways.
- 2. Representing a child-centred account of communication by creating an example design documentary; which is a video story that conveys to designers detailed instances from children's lives with the intention of motivating design (see Ibrahim, Vasalou, and Clarke 2020).
- 3. Testing the design documentary by involving design students to consider new ways of designing technologies (ibid.).

In this article, we focus on the first stage of the project which generated data for the creation of the design documentary. We identify how children's contributions were studied and interpreted during the qualitative fieldwork study.

Within this first stage, there were three main research questions that motivated how we undertook fieldwork. These were:

- RQ.1 What are the salient characteristics of communication involving children with severe speech and physical impairments and AAC technologies?
- RQ.2 What are the salient characteristics of multimodal communication involving these children, beyond AAC use; how do children use resources available to them for meaning making?
- RQ.3 What do children appear to value based on the ways that they communicate?

The goal of this article is to critically examine how our methodological decisions impacted on engaging with children's voices when involving five children who have severe speech and physical impairments. We reflect on our methodology that encompass the plans and procedures that span data collection, analysis and interpretation.

We use reflexivity as a tool to help us to problematise and critically engage with the issue of voice. As others have done so, we define reflexivity as being concerned with the orientations that inform the generation of knowledge (Burawoy 1998; Woolgar 1988). By explicitly evaluating how our own actions impact on the generation of knowledge (Shaw 2010), we examine how our decisions impacted on how we were able to investigate voice. As suggested by Rode (2011), we examine how our interpretive process was informed by the use of theory and participant observation, that acknowledges the interpretive role of the researcher in observation.

From a theoretical stance, we were committed to investigating communication from a multimodal social semiotic perspective, recognising that communication is situated and co-constructed. This acknowledged the ways in which the school context and people all shaped how communication manifested. In line with a social constructivist and interpretivist epistemology, as a participant researcher, the first author was closely involved in the generation of data through their physical presence during fieldwork, her direct interaction with the participants and in analysis.

Having previously worked in the school as a speech and language therapist, the first author held a detailed understanding of children's day to day experiences of school life, their interests and some knowledge of their home lives. This prior knowledge was helpful for minimising obstacles, anxieties and nervousness in interacting with children who have complex communication needs (Hornof 2009). Alongside the benefits of an 'insider perspective' there were also challenges. Negotiating the dual role as clinician and researcher was problematic at times. As well as having familiarity with the children and school staff, the first author also held personal beliefs about the role of existing AAC technologies. Namely, having worked with children and existing AAC technologies for more than a decade and experienced the underuse and abandonment of existing technologies, the researcher's PhD research was primarily motivated by dissatisfaction with the opportunities that existing technologies offer children, particularly for those children who do not read or write. These challenges and others are further reflected on within the findings.

### Methodology

### Participants

Five children aged 6-9 years were recruited. To avoid emphasising children's deficits, their clinical profiles were not considered. Instead, descriptive accounts of their communication styles and assistive equipment used were presented to provide additional context for the findings (table 1). These accounts were created based on prior knowledge the clinician-researcher held about participants and supplemented through discussions with their class teachers. The sampling criteria were primary age students identified as having severe speech and physical impairments and using some form of

Name	Age	Gender	Description of communication and other assistive equipment used				
Noah	6	М	Uses 5-10 intelligible words and symbol communication system on touch screen tablet, accessed through hand swiping and support to finger point. Uses partner assisted manual wheelchair with trunk and head support.				
Maya	7	F	Uses eye-pointing to direct others to interest and looks away to indicate negation, e.g. 'I don't like it'/'no'. Uses symbol communication system on an eye gaze controlled device, mounted to her wheelchair. Uses partner assisted manual wheelchair with full head, torso, trunk and foot support. Partly enterally fed via g-tube and j-tube. Sometimes uses neck brace and oxygen to support her breathing. Has uncontrollable repetitive movements.				
Clara	7	F	Uses 5-10 intelligible words and can combine 2 manual signs or gestures but signing is unclear owing to coordination difficulties. Becomes very anxious with unexpected events and opts out by self-harming and moving away. Uses symbol communication system on a touch screen tablet with a key guard. Walks unaided but unsteadily. Sometimes uses a walking frame outdoors and wears helmet.				
Oscar	8	Μ	Uses 3-5 intelligible words and some hand gesturing/signing with right hand. Uses a symbol communication system on a touch screen tablet. Walks a few steps unaided and uses a walking frame and helmet, weaker muscles on his right side.				
Grace	9	F	Eye pointing, facial expression and tone of voice are clearest form of unaided expressive communication. Uses a symbol communication system on an eye gaze controlled device that is mounted to her wheelchair. Uses partner assisted manual wheelchair with head, torso, trunk and foot support. Likes to use her arms and fist to point to things and also has strong, uncontrollable movements.				

 Table 1. Participant profiles.

digital communication device. Applying a critical case sampling strategy (Patton 2015) we invited participants who would offer insights through their varied profiles.

#### Fieldwork and justification of methods

Fieldwork took place in a primary special educational needs school in the UK where children deemed to have receptive language skills in advance of their expressive language abilities are often assessed for and provided with AAC devices. This was the primary context where children learn how to use AAC. Fieldwork that is reported within this article took place over the course of 14 weeks between November 2016 and February 2017 and consisted of 23 visits in total.

In line with Morris (2003) and Wickenden (2011), we chose to use methods that would allow for children to participate in ways that were familiar and natural to them. At different points, we drew on both direct and indirect methods for engaging with understanding about communication, based on our set of research questions. Given our interest in technology, the first research question focused on communication involving AAC, children with severe speech and physical impairments and their peers in classroom interactions. We took an exploratory, inductive approach for investigating multimodal communication and used observations and fieldnotes to understand about how communication was achieved through and around AAC.

Addressing RQ1 highlighted the importance of attending to multimodal communication, including the use of communication devices, in adult interactions, but we were also aware that this research was set in the classroom context. Identifying that multimodal communication took a key role in communication challenged us to consider how it manifested in peer interaction, which has been underrepresented in past work. Therefore, informed by work on RQ.1, RQ.2 investigated situated communication involving children with severe speech and physical impairments and their social groups beyond formal teaching contexts and where the children's communication devices were not used. Taking a similar exploratory approach, we used observation and fieldnotes to investigate how multimodal communication manifested.

RQ.3 expanded on a different aspect of communication that is experience-centred. We were interested in finding out what children appear to value for communication. To investigate this, we drew on a number of direct and indirect creative methods used in design and observed how our five participants engaged with these methods. Our methods included: photo capturing and retelling, craft-based workshops and stakeholder involvement to support in organising our methods. This variety in methods is summarised in table 2.

#### Methods

Observations and fieldnotes across the school day allowed us to attend to the gradual unfolding of events within the school context. The data collected were video footage of class activities and field notes of class and outdoor activities. Being present within the school context meant that we could focus on how children acted, which informed our interpretations about the

Method	Generated data		
Observation	20 class-based video recordings: 10 ½ hrs		
Fieldnotes	33 field note entries relating to varied setting and activities (e.g. classroom, playground, lunchtime, assembly etc)		
Photo capturing & retelling	594 lifelogging images (automatically captured by wearable camera) captured by 'Maya' documenting children's everyday lives. 921 lifelogging images captured by 'Grace' documenting children's everyday lives. 197 class-based photos captured by researcher		
Design workshops	3 workshop sessions for each participant: 2 collage making sessions on children's likes/dislikes, 1 storyboard making session on children's interests, 1 persona editing session to verify researcher's interpretations of children's communication profiles.		
Stakeholder involvement	9 face-to-face or telephone interviews with 5 parents and 2 teachers to inform planning of other materials.		

Table 2. Summary of methods.

context and implications of children's actions whilst re-watching videos at a later date. Observations were intertwined with the researcher's interaction and dialogue with children and adults. This insider knowledge provided context around events of interest and formed part of the analysis.

Photo capturing was used to document critical moments in children's everyday lives, extending the research into the home context. Out of the five participants, two provided consent for this element of the data collection. Acknowledging the physical challenges of asking these child participants to take photos, we invited them to wear a small clip-on 'lifelogging' camera on their shirt for 24 h. The camera automatically captured images at the child's torso level, every 30 s. Over a 24-hour period, the camera recorded 594 images for one participant, and 921 images for the second participant. Following a photo capturing stage, participants, their parents and teachers were advised that we would jointly view all of the photos so that children could choose whether to delete any photos they did not want to share more widely (see Durrant et al. 2013).

Design workshops: Three design workshops were held. These were organised in groups within the classroom, involving child participants, their class peers and teaching staff. As all workshops took place in school, children were supported in their participation by teaching staff. Workshops reflected typical classroom activities and as such they were familiar to the children and involved tasks in which the children had previously demonstrated some competence in terms of their engagement. We chose two craft-based activities that centred on expressing information about what children liked and disliked generally, informing our understanding of the type of activities they participated in and were motivated by. The craft-based activities involved (i) making collages about themselves, (ii) constructing story boards about themselves and fictional characters in order to explore 'by proxy' interests expressed through characters designed by the child. A third workshop was planned at the end of the research to gain children's input on persona drafts constructed by the researcher. This was intended to ensure that the children could verify or reject the researcher's interpretations. Across all three workshops, besides the visual artefacts generated (collages, storyboards, persona drafts), children's interactions were also video recorded.

Stakeholder involvement: Whilst the involvement of parents and teachers was not the primary focus of data collection, it offered two forms of data, (i) a starting point for preparing workshop materials based on activities that adults associated with children's interests and (ii) a separate perspective to triangulate how and what children expressed about themselves in the context of the other methods. Nine face-to-face and phone interviews were held with five parents and two teachers, in addition to email correspondence with some of the parents maintained by the researcher. Furthermore, we regularly shared project updates from the fieldwork with parents and teachers. On those occasions, we invited parents and teachers to tell us about other activities that children had been involved in when we were not present (see also Boyle and Arnedillo-Sánchez 2016).

## Analysis

Our goal was to look beyond literal meanings discernible in the research toward a deeper understanding of child experience (Frauenberger, Good, and Keay-Bright 2010). We approached this through the use of video analysis and social semiotic multimodal analysis (Bezemer and Kress 2016, discussed below).

Following Stebbins' 'concatenation of theory development' in exploratory qualitative analysis (Stebbins 2001), the analysis was geared towards gradually building on theoretical insights from careful systematic examination of the video recordings.

Reflective practice was at the core of the study and strongly influenced how the different parts of the study were planned and carried out. In order to conduct reflexivity in a systematic way, we created a record of fieldwork notes after each school visit that recorded and evaluated what was happening. The authors also regularly met to look back on interactions with children and observation sessions, evaluating what this meant for the kinds of insights that were being generated, and informing discussions about follow up activities. As such, we took an inductive approach to gradually develop themes by triangulating the insights that were generated across the different methods. Based on our analysis, we identified five overarching considerations for managing ways of hearing and promoting children's voices within the design process:

- 1. Theoretical lens guiding data collection, analysis and interpretation: acknowledges both the role of theory and the researcher in shaping the theoretical lens through which the child is seen.
- Developing credible accounts through strong and prominent ideas: describes the importance of triangulation in generated child-centred accounts;
- 3. Children's ways of participating evidencing their voices: captures values emerging from forms of engagement, and;
- 4. Methods hindering the promotion of child centred accounts: considers the challenges and limits of certain methods.

# Results and discussion

## Theoretical lens guiding data collection, analysis and interpretation

During the early planning stages of the research, recursive discussions on the topic of communication theories within the research team affected how communication would be studied. We were initially interested in the affordances

of framing communication from both anthropocentric and non-anthropocentric perspectives. For this reason, in the early research design stage, we considered how different theories of communication might affect how communication was studied. For instance, we discussed what the analysis might look like when taking a human-centred, multimodal social semiotic approach (Kress 2010; Bezemer and Kress 2016) compared with a nonhuman-centred, material semiotic perspective, for example, through actor-network theory (Latour 1999; Law 2007). Each approach would offer a different perspective on children's communication by either centralising the agentive role of the child (social semiotic multimodal theory) or distributing agency amongst many parts (actor network theory). Hypothetically, deciding to embrace a non-anthropocentric perspective through actor network theory would have meant treating everything in the social and natural world as being relational, and attending equally to all kinds of actors that include humans, objects, machines and other actors (Law 2007). Instead, we decided to advance a child-centred perspective which we defined as attending to the ways that children used resources such as objects, technologies and arrangements available to them, to signal their interests. Connected with prior research that recognises power as a fundamental aspect of research relationships (Letherby 2006; Bratteteig and Wagner 2016), we undertook research that focused on how children agentively used resources for advancing their own goals. In doing so, we aimed to advance an emancipatory perspective that was empowering for the children with severe speech and physical impairments.

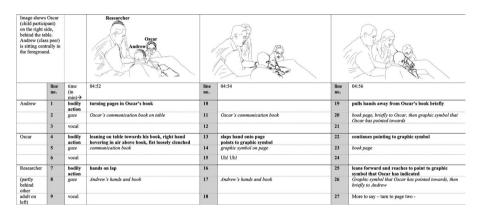
A decision was made to use multimodal social semiotics as the underlying analytic approach that cut across the entire methodology. This included decisions about data collection, analysis, interpretation and representing the findings. From a theoretical standpoint, we focused on the semiotic work carried out by the child for the purposes of meaning making (Kress 1997). Importantly, in embracing the view that children created meaning by drawing on the resources that are available to them, the analysis focused on the many different and legitimate ways that children expressed themselves, therefore rejecting the developmental view of children's 'divergent' communicative actions as delayed or disordered (Flewitt 2005).

In addition to a social semiotic perspective that predisposed us to 'see' children in a particular way, there were further choices as a researcher that were equally critical in how children were seen. For instance, this was captured through our decision to use varied conventions for transcribing video excerpts of children's interactions. Even though the findings of RQ1 and RQ2 both highlighted that all participants' actions shaped child communication as a collaborative process, the representation of children's communication required more focus to bring this to the foreground, to avoid it being masked by the large volume of adult initiations. When addressing RQ1, because the use of communication devices in interaction is typically slow, we focused transcribing longer events that captured less detail. This is illustrated in figure 1.

#### 76 👄 S. IBRAHIM

Video still	Maya (child)			Sally (adult)		
Sally: middle Maya: right side. Dark yellow highlight.	Speech (electronic speech in CAPS)	Eye gaze	Hand movements	Speech	Eye gaze	Hand movements
time direction ↓ 00:43	SPICY	To Sally	Hand wriggling continues	Not spicy, no. Yummy or yucky?	To AAC screen	Rested arm begins to lower then: Points between 2 points on screen

**Figure 1.** Transcription conveyed line drawing and adult's and child's use of speech, eye gaze and hand movements occurring simultaneously on the same line, broadly capturing events over a longer period of time.



**Figure 2.** Transcription conveyed line drawing and detailed record of bodily action, gaze and vocal actions of all parties. Simultaneous actions occur within the same column. Transcription convention used for RQ2 included more detail over a shorter period of time.

This contrasted with the work addressing RQ2, beyond communication device use, where our transcriptions focused on conveying specific detailed accounts over shorter periods. An example of this is presented in figure 2.

By deciding on this detailed view, the transcripts addressing RQ2 presented the ways that different participants simultaneously acted together. For example, in the case of Oscar, Andrew and the researcher, in figure 2, the presentation of the data reflects that all parties were collectively responsible for orchestrating the interaction; jostling for the communication book, and acting in ways to advance their own interests whilst acknowledging the moves of others.

Earlier, we drew on prior research suggesting that personal, institutional and theoretical influences all impacted on the interpretive process in qualitative research (Mauthner and Doucet 2003). Our findings reinforce this perspective, and highlight the importance of being explicit in communicating the historical and personal perspectives that inform constructions of voice. In our case, our commitment to conveying child-centred accounts of communication meant paying attention to the subtle ways that communication manifested, so that we could show how the children in our study exercised agency by communicating in multimodal ways. Beyond our theoretical commitments, additional methodological decisions were taken concerning how these findings were represented, in our case, by attending to transcription conventions. These decisions raise methodological implications for future work by showing that theoretical perspectives can impact on methodological decisions when committing to analysing, interpreting and representing data.

#### Developing credible accounts through strong and prominent ideas

According to Lincoln and Guba (1985), credibility refers to how congruent the findings are with reality, identifying credibility as a key indicator of trustworthiness in qualitative research through naturalistic inquiry. One way to achieve credibility is by evidencing the consistency between strong and prominent ideas across the methods used (Shenton 2004). This technique generated confidence about children's accounts since the communication of children with severe speech and physical impairments can be often ambiguous (Clarke and Kirton 2003).

When addressing RQ3, attempting to represent what children might value or prioritise, meant developing rich interpretations that lie beneath what children expressed over time. For example, for some children, the varied data sources contributed to building a picture about what children valued. This ranged from protecting their privacy to advancing social interactions and more.

During fieldwork, we gradually identified that one of our child participants, Oscar, valued 'involvement', through his desire to be part of social interactions with adults and children. We found that different methods revealed facets or dimensions to Oscar's desire to be involved in social life. For instance, when engaged in a collage making activity in one of our design workshops, Oscar's collage output showed that he valued social activities (e.g. supermarket shopping, going to the cinema and birthday parties). Added to this, a playground interaction helped to identified how Oscar reacted to being ignored by other children. On one occasion, the researcher chose to join Oscar outdoors during playtime, to seek insight about his relationships with other children, and to see how other people's reactions might influence Oscar's behaviours. The fieldnote that follows captured the first author's interpretation of an interaction involving Oscar and a group of children in the playground:

In the playground, he occasionally waved towards some of the mainstream school children and would then go over to greet them, attempting to join in their play. Some responded positively, letting him join in, others took a teacher role, instructing him to 'be gentle Oscar', or to 'slow down Oscar'. Others reacted more negatively, running away as if scared by him approaching them, reacting with fear in an exaggerated way.

Coupled together, these varied data sources showed the differing actions and reactions of other adults and children that could spark different behaviours. This was supplemented by a discussion with his teacher which helped us to get a sense of how others interpreted Oscar's behaviours. On one occasion, Oscar's teacher had mentioned that he enjoyed being with other children but this could sometimes be difficult. The teacher shared that Oscar was often keen to gain other people's attention in any way possible, and would sometimes seek out a reaction from others by shouting, biting or spitting. According to his teacher, whilst Oscar's actions could appear quite negative on the surface, he was desperate to interact with other children in the mainstream part of the school and did so in any way that he could. At this point, we had begun forming a view that Oscar's desire for involvement manifested in socially undesirable ways that could be misinterpreted by others as being aggressive or difficult.

Capturing these multiple perspectives across different data sources and employing reflective and rigorous techniques, revealed different layered accounts of communication and specifically, what *being involved* meant for Oscar. This allowed for drawing new interpretive conclusions that motivated new inquiries. By evaluating the kinds of knowledge that was being generated, we were able to understand what Oscar and other children expressed about their communication through studying different dimensions of children's lives. Therefore studying how children's ideas and contributions were pervasive across the different methods and data sources were empowering in foregrounding the child's voice, as it allowed for developing a stronger case for understanding credible insights about children's communication experiences.

In line with Lincoln and Guba (1985) and Shenton (2004), we attempted to identify how congruent our findings were with reality by evidencing consistency in strong and prominent ideas across the methods. However, in addition to conveying pervasive ideas across methods, different methods helped us to reach detailed understandings about complex situations by exposing different dimensions about these understandings. For the purposes of engaging with children's voices, these multifaceted dimensions were crucial in shaping our interpretations of children's experiences that were very different to our own experiences, as adult researchers.

# Children's ways of participating in the research context evidencing their voices

At an epistemic level, we accepted the view that the children who participated in our study were active contributors, rather than subjects being studied. We also recognised that the knowledge that was being generated was jointly constructed by all participants, including the researchers, and children may also express themselves differently in alternative contexts (Carter and Little 2007). As such, it was important for us to attend to how children behaved with the researcher and what children's forms of engagement might be conveying. This meant that instead of treating our methods as tools for objectively measuring reality, we anticipated that children's contributions would convey multiple understandings beyond their face value. Past research has shown that children exercise power in subtle ways in the context of research which can depend on their interactions with the researcher and the methods (Gallacher and Gallagher 2008). This can affect how children take part in research and how child voice is influenced by adult-designed agendas. For instance, in Gallacher's and Gallagher's (2008) research of primary school settings, children evidenced their assertiveness, directing interactions with the researcher by taking away their notepad and appropriating it for their own purposes. The authors suggested that spontaneous tactics motivated new insights for their research data, albeit unpredicted.

Similar to Gallacher and Gallagher (2008) who found that children's actions signalled unstated intentions, we found that children's behavioural engagements with the methods expressed their values. In one striking example of this, one of the children, Grace, used bodily action to signify her values in response to the researcher's actions. On one occasion during a cooking class session, the first author worked with Grace to make an omelette. As she attempted to physically support Grace in holding and stirring with a spoon (which was physically challenging) Grace tensed her body, turned her head to the side and pushed backwards in her standing frame, and shouted 'I do it!'. Although Grace was predominantly 'non-verbal', this phrase was one that had become intelligible to many people at the school and, as illustrated in Figure 3, was a common characteristic in her interactions with others.



Figure 3. Line drawing from video still of Grace (right) resisting physical help from the researcher (left), Grace vocalises 'I do it!'.

Despite physical challenges, Grace's frequent, physical persistence to carry out workshop activities and everyday classroom activities by herself signalled that she valued independence.

In contrast, for another participant Clara, it was protecting her privacy that motivated how she engaged with the research. Prior work that has investigated communication involving adults, children and AAC devices has suggested that power differentials can exist between adults in teaching roles and children (Ibrahim, Vasalou, and Clarke 2018). As the first author had known Clara in a separate capacity prior to undertaking the research (as her speech and language therapist), we anticipated that disclosure norms from this prior relationship had carried over, impacting on Clara's willingness to open up. Namely, more work was needed to dispel ideas about the researcher's perceived authority and goals, and that she might share information with other healthcare staff without Clara's consent. With this in mind, class-based sessions began with the researcher tentatively attempting to gauge Clara's reaction before choosing whether or not to continue. One instance of this was captured in the fieldnote entry below:

I walked over to the table where Clara was sitting and in the spirit of giving her a say about my presence, asked her if I was able to sit next to her at lunchtime to which she replied 'no' by shaking her head then pointing to the door. The teaching assistant, who was supporting her commented: 'Oh, that's not nice, [researcher] just wants to sit and join us', but Clara was adamant that I leave. I suggested that I could sit with another child but didn't push this. Clara commented (by signing) that I could come back after lunchtime, so respecting her wishes, I left the room to return in the afternoon session.

In this instance, in deciding to leave, the researcher tried to demonstrate to Clara that the power relationship was different. Namely, by practically demonstrating the reality of reconstituting the relationship. Instead of persisting in trying to persuade her with other strategies, which can be typical in adult-child therapeutic or learning sessions (e.g. Ibrahim, Vasalou, and Clarke 2018) we were sensitive that this may also sabotage any chance of gaining her trust within this new researcher role.

Clara's motivation for regulating privacy was clearly signalled through her actions. Whilst Clara had consented to be part of the study and often wanted to participate in fieldwork activities, she was also extremely cautious and sometimes anxious about how her contributions would be used. Two other instances that reflected these interpretations were whilst discussing consent and during the collage making workshop. Figure 4 illustrates a discussion about consent for recording (left) and Clara's rejection of the collage-making activity (right).

We learned that the researcher would constantly need to rethink and adjust. Given that we aimed to understand about child-centred communication



Figure 4. Clara's consent board using Talking Mats approach (Murphy 1998) and collage materials.

by attending to the ways that children used resources available to them to signal their interests, we needed to make on-the-spot decisions that advanced this goal. For both Grace and Clara, it was their ways of engaging with methods that articulated their views.

In line with previous research, our findings highlighted the value of moving beyond what children may be directly saying, towards seeing what they do (Connors and Stalker 2007; Nolas, Aruldoss, and Varvantakis 2019; Gallacher and Gallagher 2008). We found that in order to move closer towards engaging with children's voices, we needed to interrupt existing power dynamics that are common in teaching contexts, by focusing on the research relationship between the child participant and adult researcher.

#### Methods hindering the promotion of child-centred accounts

In the previous section, investigating how children engaged with methods exposed some of the ways that children exercised agency in managing power dynamics involving adults and other children. Furthermore in earlier sections, we demonstrated that through the first author's role as participant-researcher, being involved in first-hand interactions allowed for 'listening' and responding to give emphasis to the child's voice. Added to this, this first-hand experience allowed us to build a multidimensional understanding of the child, with a common narrative that was informed by different methods over time. These methodological decisions helped in revealing the child's voice by allowing for interpretations that could be traced back to first-hand interactions, thus there was a lived element to the data production.

In contrast, we found that the photo capturing method hindered this process and was instead disempowering for the children taking part. Acknowledging the physical effort involved in taking photos, children were invited to wear a small lifelogging camera that would automatically record images over a 24-hour period. However, even though the cameras offered

#### 82 👄 S. IBRAHIM

a glimpse into the home context, it also took away control from children. This lack of control manifested in two ways. First, children were unable to physically decide when to start or stop the automatic photo capturing, and second, in the absence of being physically present, the researcher needed to make assumptions about what the images might be signalling. At the outset, it was anticipated that once we had captured images of children's daily lives, these would be discussed with children in order to reconstruct the meaning of the events captured, transforming children's passive everyday activity into active engagement. However, of the two children who agreed to wear the camera (Grace and Maya), neither wanted to explore the photos automatically captured. This may have been due to the volume of photos that were generated. Conversely, had we cut down the number of photos, we would have made decisions on behalf of the child (Durrant et al. 2013). This would have been problematic, as deciding to reduce the number of photo choices could potentially have omitted important instances that children may have treated as significant. We identified that in this case, there was too much data to co-create the interpretive work with children.

In the absence of children's own accounts of their data, and in losing the insider perspective of being physically present as per other observation sessions, we faced tensions interpreting the photos in a credible way that reflected the reality of the situation that was photographed. For example, one of the images considered was of Grace sitting in her wheelchair at the edge of the living room whilst her younger brothers played and watched television on the floor on the other side of the room. The camera angle and the lack of sound/moving image, privileged a particular perspective adding distance between Grace and her brothers (Figure 5).



Figure 5. Life logging image captured of Grace at home. Grace sits in her wheelchair at the side of the room whilst her two younger brothers lie on the floor looking up at the TV.

In lacking context, however, we questioned the credibility of this interpretation and it was difficult to move past our own subjective interpretation of the activity or what the situation might be signifying. In the absence of being able to develop strong and prominent ideas across many methods (as discussed earlier), we did not feel that photo capturing via lifelogging offered credible insights about children's interests. Added to this, on an epistemological level, children were not able to actively contribute to these interpretations, which hindered our goal to investigate child-centred accounts of children's communication experiences. Given these misalignments, this method was removed from the analysis.

#### Conclusion

Prior studies that have investigated designing technologies that are intended for disabled children, have not tried to understand the relationship between the research process and voice. We know from previous work in childhood studies that it can be challenging to understand the views and priorities of children. The reasons for this include difficulties in managing social and contextual factors, as well as power dynamics between stakeholders. In these situations, reflexivity can help by providing space for evaluating if the findings reflect what the child may be intending to express through their contributions. Therefore this research used reflexivity as a tool to critically examine how empowering our methodological decisions were for the children who took part, in advancing child centred accounts of communication. We embarked on a systematic reflexive approach through fieldnotes and regular discussion with the author team to understand how our methods informed the data. By reflecting on our observations, creative methods and discussions with children and adults, we were able to adapt our approach to reflect our goal for understanding about child-centred accounts of communication.

Through our methodological reflection we identified that the researcher is vital in listening to children and representing their voice. However this is not a straightforward process, and work is needed to understand about the multiple factors that impact on how we study children's priorities and experiences. We contribute to current debates in the literature and highlight important considerations for researchers in four ways. First we acknowledge both the role of theory and the role of the researcher in shaping child-centred accounts. Second, we describe how is it possible to build multidimensional understandings of the child that are informed by triangulating different methods. Third, we show how children's ways of participating can evidence their voices, and fourth, we reflect on methods used that hinder our goal for advancing child-centred accounts.

To create holistic accounts that acknowledged the different dimensions of children's communication experiences, we drew on a variety of data

84 👄 S. IBRAHIM

sources. By triangulating these varied data sources, we aimed to produce credible accounts that highlighted both prominent ideas that were expressed across methods, and different dimensions of children's experiences. Furthermore, we identified that the relational nature between the child and researcher was central in forming knowledge. In some cases, children exercised power over researcher-child interactions, expressing more about what was important to them through how they engaged with methods. In other cases, we chose to abandon methods that limited children in contributing on their own terms. Our findings corroborate Morris (2003) who argue that non-direct methods may be appropriate in allowing for children to participate in ways that were familiar to them.

Our considerations have implications for communities outside of academia. For practitioners from education, healthcare and social care contexts, our findings offer insights for those who are looking for ways to work with disabled children to understand their views. We show that observations and creative methods, if used reflexively, offer an appropriate method to study what children might be expressing as important in their lives, beyond what is visible on a surface level. For policy makers who are tasked with reading study briefs, our study shows that for studying credible accounts, triangulation of many methods is needed. Furthermore, connected with our theoretical lens for focusing on disabled children's strengths, we suggest that policy makers should scrutinise the theoretical lens that drives researcher interpretations, since this can impact on the actions that researchers take. These insights can also be transferable to other groups of marginalised children, for instance, children with sensory and cognitive impairments, but also children whose race and/or socioeconomic situation can increase risk of marginalisation through the extent to which they too are under-researched.

As researchers, we must critically challenge how our own priorities impact on what we decide to foreground when constructing narratives about disabled children's voices. Through our study, we have problematised the issue of voice and shown how to mitigate challenges in the context of research that later informed design. This was important because given the impact that technology has on children's lives, understanding and building on the concerns of children who are expected to use these technologies is crucial for future work.

#### Funding

This work was supported by an ESRC studentship and ESRC postdoctoral fellowship awarded to the first author under Grant number ES/P000592/1. The authors would like to thank the children, families and school who agreed to take part.

#### ORCID

Seray Ibrahim (D) http://orcid.org/0000-0001-9358-6802

#### References

- Baxter, Susan, Pam Enderby, Philippa Evans, and Simon Judge. 2012. "Barriers and Facilitators to the Use of High-Technology Augmentative and Alternative Communication Devices: A Systematic Review and Qualitative Synthesis: AAC Barriers and Facilitators Review." International Journal of Language & Communication Disorders 47 (2): 115–129. doi:10.1111/j.1460-6984.2011.00090.x.
- Benton, Laura, and Hilary Johnson. 2015. "Widening Participation in Technology Design: A Review of the Involvement of Children with Special Educational Needs and Disabilities." International Journal of Child-Computer Interaction 3–4 (January): 23–40. doi:10.1016/ j.ijcci.2015.07.001.
- Bezemer, J., and Gunther R. Kress. 2016. *Multimodality, Learning and Communication: A Social Semiotic Frame*. London ; New York: Routledge, Taylor & Francis Group.
- Börjesson, Peter, Wolmet Barendregt, Eva Eriksson, and Olof Torgersson. 2015. "Designing Technology for and with Developmentally Diverse Children: A Systematic Literature Review." In Proceedings of the 14th International Conference on Interaction Design and Children, 79–88. New York: ACM Press. doi:10.1145/2771839.2771848.
- Boyle, Bryan, and Inmaculada Arnedillo-Sánchez. 2016. "Exploring the Role of Adults in Participatory Design for Children on the Autism Spectrum." In *Design, User Experience, and Usability: Design Thinking and Methods Lecture Notes in Computer Science*, 209–218. Cham: Springer. doi:10.1007/978-3-319-40409-7\_21.
- Bratteteig, Tone, and Ina Wagner. 2016. "Unpacking the Notion of Participation in Participatory Design." *Computer Supported Cooperative Work (CSCW)* 25 (6): 425–475. doi:10.1007/s10606-016-9259-4.
- Burawoy, Michael. 1998. "The Extended Case Method." *Sociological Theory* 16 (1): 4–33. doi:10.1111/0735-2751.00040.
- Carter, Stacy M., and Miles Little. 2007. "Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Methods in Qualitative Research." *Qualitative Health Research* 17 (10): 1316–1328. doi:10.1177/1049732307306927.
- Clark, Alison, and Peter Moss. 2011. *Listening to Young Children: The Mosaic Approach*. London: National Children's Bureau.
- Clarke, Michael, and Andrea Kirton. 2003. "Patterns of Interaction between Children with Physical Disabilities Using Augmentative and Alternative Communication Systems and Their Peers." *Child Language Teaching and Therapy* 19 (2): 135–151. doi:10.1191/0265659003ct248oa.
- Connors, Clare, and Kirsten Stalker. 2007. "Children's Experiences of Disability: Pointers to a Social Model of Childhood Disability." *Disability & Society* 22 (1): 19–33. doi:10.1080/09687590601056162.
- Crisp, Cheryl, Claire Burke Draucker, and Marsha L. Cirgin Ellett. 2014. "Barriers and Facilitators to children's use of speech-generating devices: a descriptive qualitative study of mothers' perspectives." *Journal for Specialists in Pediatric Nursing* 19 (3): 229–237. doi:10.1111/jspn.12074.
- Dee-Price, Betty-Jean M., Lorna Hallahan, Diane Nelson Bryen, and Joanne M. Watson. 2021. "Every Voice Counts: Exploring Communication Accessible Research Methods." *Disability & Society* 36 (2): 240–264. doi:10.1080/09687599.2020.1715924.
- Durrant, Abigail, Jonathan Hook, Roisin McNaney, Keir Williams, Thomas Smith, Mathew Kipling, Tony Stockman, and Patrick Olivier. 2013. "Design to Support Interpersonal Communication in the Special Educational Needs Classroom." In Proceedings of the 12th International Conference on Interaction Design and Children, 46–55. IDC '13. New York, NY, USA: ACM. doi:10.1145/2485760.2485778.

86 👄 S. IBRAHIM

- Fauconnier, Jérôme, Heather O. Dickinson, Eva Beckung, Marco Marcelli, Vicki McManus, Susan I. Michelsen, Jackie Parkes, et al. 2009. "Participation in Life Situations of 8-12 Year Old Children with Cerebral Palsy: Cross Sectional European Study." *BMJ* 338 (2): b1458. doi:10.1136/bmj.b1458.
- Flewitt, Rosie. 2005. "Using Multimodal Analysis to Unravel a Silent Child's Learning." Early Childhood Practice: The Journal for Multi-Professional Partnerships 7: 5–16. http://oro.open.ac.uk/2721/.
- Frauenberger, Christopher, Judith Good, and Wendy Keay-Bright. 2010. "Phenomenology, a Framework for Participatory Design." in, *187*. New York: ACM Press. doi:10.1145/1900441.1900474.
- Gallacher, L.-A., and M. Gallagher. 2008. "Methodological Immaturity in Childhood Research?: Thinking through 'Participatory Methods." *Childhood* 15 (4): 499–516. doi:10.1177/0907568208091672.
- Herrero, Pablo Rodríguez, Dolores Izuzquiza Gasset, and Andrés Cabrera Garcia. 2021. "Inclusive Education at a Spanish University: The Voice of Students with Intellectual Disability." *Disability & Society* 36 (3): 323–376. doi:10.1080/09687599.2020.1745758.
- Hornof, Anthony J. 2009. "Designing with Children with Severe Motor Impairments." In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 2177. New York: ACM Press. doi:10.1145/1518701.1519032.
- Hynan, A., J. Murray, and J. Goldbart. 2014. "Happy and Excited": Perceptions of Using Digital Technology and Social Media by Young People Who Use Augmentative and Alternative Communication." *Child Language Teaching and Therapy* 30 (2): 175–186. doi:10.1177/0265659013519258.
- Ibrahim, Seray B., Asimina Vasalou, and Michael Clarke. 2018. "Design Opportunities for AAC and Children with Severe Speech and Physical Impairments." In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems, 227:1–227:13. CHI '18. New York, NY, USA: ACM. doi:10.1145/3173574.3173801.
- Ibrahim, Seray B., Asimina Vasalou, and Michael Clarke. 2020. "Can Design Documentaries Disrupt Design for Disability?." In Proceedings of the Interaction Design and Children Conference, 96–107. IDC '20. New York, NY, USA: Association for Computing Machinery. doi:10.1145/3392063.3394403.
- James, Allison. 2007. "Giving Voice to Children's Voices: Practices and Problems, Pitfalls and Potentials." *American Anthropologist* 109 (2): 261–272. doi:10.1525/aa.2007.109.2.261.
- Jones, Lisa, Mark A. Bellis, Sara Wood, Karen Hughes, Ellie McCoy, Lindsay Eckley, Geoff Bates, Christopher Mikton, Tom Shakespeare, and Alana Officer. 2012. "Prevalence and Risk of Violence against Children with Disabilities: A Systematic Review and Meta-Analysis of Observational Studies." The Lancet 380 (9845): 899–907. doi:10.1016/S0140-6736(12)60692-8.
- Kress, Gunther R. 1997. *Before Writing: Rethinking the Paths to Literacy*. London ; New York: Routledge.
- Kress, Gunther R. 2010. *Multimodality: A Social Semiotic Approach to Contemporary Communication*. London ; New York: Routledge.
- Latour, Bruno. 1999. Pandora's Hope: Essays on the Reality of Science Studies. Cambridge: Harvard University Press.
- Law, John. 2007. 'Actor Network Theory and Material Semiotics'. http://www.heterogeneities. net/publications/Law2007ANTandMaterialSemiotics.pdf.
- Letherby, Gayle. 2006. "Emancipatory Research." In *The SAGE Dictionary of Social Research Methods*, edited by Victor Jupp. London: SAGE Publications, Ltd. http://srmo.sagepub. com/view/the-sage-dictionary-of-social-research-methods/n62.xml.
- Lincoln, Yvonna S., and Egon G. Guba. 1985. *Naturalistic Inquiry*. Beverly Hills, Calif: Sage Publications.

- Mauthner, Natasha S., and Andrea Doucet. 2003. "Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis." *Sociology* 37 (3): 413–431. doi:10.1177/00380385030373002.
- Morris, Jenny. 2003. "Including All Children: Finding out about the Experiences of Children with Communication and/or Cognitive Impairments." *Children & Society* 17 (5): 337–348. doi:10.1002/chi.754.
- Moser, Ingunn. 2006. "Disability and the Promises of Technology: Technology, Subjectivity and Embodiment within an Order of the Normal." *Information, Communication & Society* 9 (3): 373–395. doi:10.1080/13691180600751348.
- Nolas, Sevasti-Melissa, Vinnarasan Aruldoss, and Christos Varvantakis. 2019. "Learning to Listen: Exploring the Idioms of Childhood." *Sociological Research Online* 24 (3): 394–413. doi:10.1177/1360780418811972.
- Parsons, Sarah, Nicola Yuill, Judith Good, and Mark Brosnan. 2020. "Whose Agenda? Who Knows Best? Whose Voice?" Co-Creating a Technology Research Roadmap with Autism Stakeholders." *Disability & Society* 35 (2): 201–234. doi:10.1080/09687599.2019.1624152.
- Patton, Michael Quinn. 2015. "Sampling, Qualitative (Purposeful)." In *The Blackwell Encyclopedia of Sociology*, edited by George Ritzer. Oxford, UK: John Wiley & Sons, Ltd. doi:10.1002/9781405165518.wbeoss012.pub2.
- Rabiee, Parvaneh, Patricia Sloper, and Bryony Beresford. 2005. "Doing Research with Children and Young People Who Do Not Use Speech for Communication." *Children & Society* 19 (5): 385–396. doi:10.1002/chi.841.
- Raijmakers, Bas, William W. Gaver, and Jon Bishay. 2006. "Design Documentaries: Inspiring Design Research through Documentary Film." In Proceedings of the 6th Conference on Designing Interactive Systems, 229–238. DIS '06. New York, NY, USA: ACM Press. doi:10.1145/1142405.1142441.
- Rode, Jennifer A. 2011. *Reflexivity in Digital Anthropology*, 123. New York: ACM Press. doi:10.1145/1978942.1978961.
- Shaw, Rachel. 2010. "Embedding Reflexivity within Experiential Qualitative Psychology." *Qualitative Research in Psychology* 7 (3): 233–243. doi:10.1080/14780880802699092.
- Shenton, Andrew K. 2004. "Strategies for Ensuring Trustworthiness in Qualitative Research Projects." *Education for Information* 22 (2): 63–75. doi:10.3233/EFI-2004-22201.
- Spyrou, Spyros. 2001. "Being One and More than One: Greek Cypriot Children and Ethnic Identity in the Flow of Everyday Life." *disClosure: A Journal of Social Theory* 10: 8. doi:10.13023/DISCLOSURE.10.08.
- Spyrou, Spyros. 2011. "The Limits of Children's Voices: From Authenticity to Critical, Reflexive Representation." *Childhood* 18 (2): 151–165. doi:10.1177/0907568210387834.
- Stebbins, Robert A. 2001. *Exploratory Research in the Social Sciences. Qualitative Research Methods*, vol. 48. Thousand Oaks, Calif: Sage Publications.
- Vasalou, Asimina, Seray Ibrahim, Michael Clarke, and Yvonne Griffiths. 2021. "On Power and Participation: Reflections from Design with Developmentally Diverse Children." *International Journal of Child-Computer Interaction* 27 (March): 100241. doi:10.1016/ j.ijcci.2020.100241.
- Vines, John, Rachel Clarke, Peter Wright, John McCarthy, and Patrick Olivier. 2013. "Configuring Participation: On How We Involve People in Design." In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 429–438. CHI '13. New York, NY, USA: ACM. doi:10.1145/2470654.2470716.
- Webster, Amanda A., and Mark Carter. 2007. "Social Relationships and Friendships of Children with Developmental Disabilities: Implications for Inclusive Settings. A Systematic Review." Journal of Intellectual & Developmental Disability 32 (3): 200–213. doi:10.1080/13668250701549443.

- Wickenden, Mary. 2011. "Talking to Teenagers: Using Anthropological Methods to Explore Identity and the Lifeworlds of Young People Who Use AAC." *Communication Disorders Quarterly* 32 (3): 151–163. doi:10.1177/1525740109348792.
- Woolgar, Steve, ed. 1988. *Knowledge and Reflexivity: New Frontiers in the Sociology of Knowledge*. London ; Newbury Park: Sage Publications.