# 16 Do All Children Have the Right to Express Views?

## Abstract

It is now internationally accepted that children have the 'right to express views', but detailed discussion is needed of how this right can be realised in practice for children with complex communication needs. This chapter explores some of the issues that arise when attempting to discern the views of children who do not communicate primarily through verbal speech. It explores ontological, epistemological, and ethical issues which arise when working with 'differently voiced' views and considers practical strategies and technologies which may enable us to attend more effectively to children who communicate differently.

Running Head Right-hand: Do All Children Have the Right to Express Views?

Running Head Left-hand: Lauran Doak

# 16

# Do All Children Have the Right to Express Views?

## Listening to ‘Differently Voiced’ Communicators

**Lauran Doak**

## Introduction

The right of disabled and non-disabled children to express their views on matters affecting them is now well-established in international policy. The UN Convention on the Rights of Persons with Disabilities (2006) (CRPD) requires signatories to

> ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.
>
> (Art. 7)

Similar provision exists in the UN Convention on the Rights of the Child (1989) (CRC):

> States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
>
> (Art. 12)

Whilst these aspirations are laudable, the question of how this right is to be realised in practice for children with significant disability-related communication difficulties requires further examination. Is ‘disability- and age-appropriate assistance’, such as augmentative and alternative communication (AAC), a universal solution? Is the right to have one’s views taken seriously contingent upon the attainment of some notional yet poorly defined threshold of ‘age’, ‘maturity’, or ‘communicative capability’? Does such a threshold subsequently exclude the views of disabled children with the most complex communication needs? This chapter sets out to unpack these questions.

Communication needs may arise as a result of intellectual or learning disabilities, which can include difficulty with learning, recalling, spontaneously producing, sequencing or combining words, signs, or symbols. Communication needs may alternatively be associated with a physical impairment which renders speech production impossible or unclear, or with a combination of physical and intellectual impairment. It is difficult to establish the worldwide prevalence of childhood communication needs due to a lack of global epidemiological data on childhood developmental disabilities generally (Olusanya et al. 2018) as well as the diffusion of communication difficulties across diverse underlying medical diagnoses (Bunning et al. 2014; Wylie et al. 2013). The *World Report on Disability* by the World Health Organisation (WHO) and the World Bank (2011) indicates that approximately 15% of the world population (over one billion people, including children) experiences some form of disability, with 2–4% experiencing significant difficulty in functioning. We do not have specific WHO data on the prevalence of communication difficulties within these figures, although Bunning et al. (2014) estimate that 1.1–1.9% of children globally have complex communication needs. In England, unmet communication needs in childhood have been associated with social, emotional, and behavioural disorders, increased referrals to mental health, lower academic attainment, unemployment, and criminal offending (ICAN/RCSLT 2018). These findings underline the importance of ensuring that disabled children have a means to express their views.

In this chapter, I begin with a discussion of the right to express views for children I refer to as *systematic communicators*. By this I mean children and young people who are able to use any recognised formal system(s) of communication (such as speech, typing, sign language, AAC) to a level that would permit expression of views through that modality. For instance, a child in this category would be able to convey information about what they do and do not enjoy about school, and a person who had not previously met the child but was familiar with their communication system would understand the information conveyed.

I then discuss separately the expression of views for children I refer to as *idiosyncratic communicators*. This denotes children and young people who have limited or no use of any recognised formal communication system but who communicate in ways which are known to family, friends, and familiar caregivers. For example, a particular non-verbal vocalisation, gesture, or facial expression might come to be known as an expression of happiness based on repeated interactions and a sustained relationship with the child. It is acknowledged that this systematic/idiosyncratic binary is merely a heuristic device and that the reality is more complex. For instance, communicators might traverse the categories gradually over time as part of their developmental trajectory, or rapidly and temporarily due to fluctuating health or environmental factors. Further, this chapter does not presuppose an underlying cognitive developmental binary, as absence of systematic communication can result from inadequate assistive technology equipment or instruction or low expectations on the part of educators and health professionals (Bryan 2018).

Finally, this chapter explores some of the complex epistemological, ethical, and theoretical questions raised by the process of learning to attend to the views of differently voiced communicators.

# Expressing Views: Systematic Communicators

As we have seen, Article 7 of the CRPD (Children with Disabilities) refers to ‘disability- and age-appropriate assistance’ to realise the right to expression of views. Here, I argue that such assistance can be conceptualised on three levels. The immediately evident level is the material provision of assistive technology, other resources, or human assistance in the form of interpreters. A second level is cognitive scaffolding of the expression of views through resources that not only enable non-verbal expression but also support vocabulary and conceptual recall and sequencing. A third level of support is pedagogical, that is, ensuring that meaningful vocabulary pertaining to self-advocacy and expression of views is both available and taught regularly so that it forms part of a communicator’s readily usable repertoire.

## Technological Support

Some children can combine words, phrases, and sophisticated concepts with ease: their communication needs are simply for a medium other than verbal speech that will be understood by the listener. A famous example of such a communicator is the late professor Stephen Hawking, who authored books and delivered talks on theoretical physics through a speech-generating device (SGD). Examples of children and young people in this category might include a deaf child who expresses their views fluently through their national sign language, or a child with cerebral palsy who has significant physical impairment, but not learning disabilities, who communicates using an SGD controlled by eye gaze. In this case, the SGD can be based on conventional literacy skills, which allows the child to spell out words independently, although SGDs which are symbol-based can provide more support for communicators with more significant levels of learning disabilities. The difference that appropriate provision can make to systematic communicators can be life-changing, as described by SGD user Sophie Webster:

> My [SGD] has been amazing help to me, it has reduced many, many meltdowns and helps me daily whether it be asking for things from my carer on in

> a shop to telling the doctor how I'm feeling. It is amazing to be listened, heard and understood for the first time.
>
> (Webster 2016, p. 22)

In these cases, support for expressing views might seem relatively straightforward, a 'reasonable accommodation' as envisaged by Article 2 of the CRPD, achieved by providing equipment or an interpreter. What in principle appears straightforward, however, is not necessarily happening in practice. The cost of assistive technology and access to speech and language therapy can be prohibitive in the Global South (Bunning et al. 2014). More developed economies do not necessarily fare better, with UK provision of SGDs described as 'inconsistent and inequitable' (Judge et al. 2017, p. 181).

## Cognitive Scaffolding

The second level of assistance required by some systematic communicators is cognitive scaffolding of the expression of views. This is important for communicators who have difficulties not only with speech production but also with short- and/or long-term memory, vocabulary, or conceptual recall, or sequencing a narrative. An example of a resource providing this type of support is Talking Mats© (Murphy 1998), which asks communicators to physically arrange symbol cards under categories of 'like' and 'dislike'. The provision of concrete manipulatives can be a useful scaffold as it allows participants to see visual representation of the issue being discussed and facilitates the reviewing of previous answers (Bunning and Steel 2007). Stewart, Bradshaw, and Beadle-Brown (2018) further note that Talking Mats© may shift the power balance between interviewer and interviewee and subsequently produce less 'acquiescence' than a traditional interview. This is because communicators are placed in a more agentic position of actively sorting cards into categories rather than responding to an interviewer-led questioning, which may invite agreement as the cognitively easier option which will require less verbal elaboration. Other approaches which draw upon visual scaffolding of ideas include the use of video (Rojas and Sanahuja 2012), photo elicitation (Fisher 2009), and photovoice (Booth and Booth 2003). These approaches may facilitate recognition of the right to express views in a wider group of communicators. As Stewart et al. (2018, p. 2) argue, our over-reliance on research methods such as interviews has meant that the right to express views has often been denied to 'all but the most verbally able' disabled people. Whilst this literature foregrounds communication in the context of research participation, the communication approaches explored are relevant to anyone wishing to listen more attentively to disabled children, including practitioners and policymakers.

# Pedagogical Support

The third level of support is pedagogical: the provision of an SGD, signing system, or other resource will not by itself facilitate the expression of views unless relevant vocabulary is provided, taught, and used regularly. Elsewhere, I have noted the heavy representation of requesting words and transactional vocabulary ('I want a biscuit') and vocabulary associated with politeness and acquiescence ('Please, thank you') in children's classroom AAC repertoires (Doak 2018). This is echoed by the lived experience of Webster (2016):

> [A]t school [I] couldn't explain what was wrong and why I was getting upset unless it was on my symbol keyring which had basic needs on it such as toilet, drink, teachers' names, snack. It was extremely limited and meant I was unable to make friends and have any voice at school which led to hours of meltdowns and nobody ever knew why.
>
> (Webster 2016, p. 21)

The predominance of requesting and politeness-related AAC vocabulary persists into adulthood for learning-disabled people. Brewster (2007) observed in an adult residential facility an overemphasis on the 'requesting' speech function as well as the policing of vocabulary such as expletives. This, she argues, points to complex relationships between vocabulary and power: being cast primarily in the role of ‘requester’ consolidates the position of both children and adults with learning disabilities as needy, dependent, and passive recipients of services. Dreyfus (2006) describes a ‘chicken and egg’ situation: should we wait until we consider a communicator cognitively capable of expressing views before teaching the necessary vocabulary, or is the provision and teaching of such vocabulary a form of conceptual scaffolding for understanding of ‘views’ to emerge? From a Vygotskian perspective:

> The relationship of thought to word is not a thing but a process, a movement from thought to word and from word to thought . . . speech does not merely serve as the expression of developed thought. Thought is restructured as it is transformed into speech.
>
> (Vygotsky 1987, pp. 250–251)

In order for a child to self-identify as a capable expresser of views, therefore, the provision and teaching of relevant vocabulary is an essential ‘tool’ to scaffold such an understanding of self. Embedding approaches such as Talking Mats or AAC-mediated phrases such as ‘I like . . .’, ‘I don’t like . . .’, ‘I hate . . .’ into everyday home and classroom life may support capability as a confident self-advocate. The harnessing of AAC for self-determination and expression of views has been associated with better post-school outcomes and quality of life (Kleinert et al. 2010), pointing to the need to take expression of views seriously in our AAC pedagogy.

## Expressing Views: Idiosyncratic Communicators

Some children who do not use a communication ‘system’ instead develop idiosyncratic communication, such as facial expression, non-verbal vocalisation, and behaviours which are interpreted by the people who know them well. In this section, I examine four possible approaches to ‘hearing the voice’ of an idiosyncratic communicator: communication passports, wearable technology, (multimodal) observation, and proxy informants.

## Communication Passports

A ‘communication passport’ (Millar and Caldwell 1997) is a document which describes the idiosyncratic communicative behaviours of a minimally verbal person and their likely significance. This description is for the benefit of new caregivers or professionals who do not have a shared history of interacting with the person. For example, the passport might explain that a particular movement, facial expression, or vocalisation is typically an indication of distress, drawing upon the knowledge which has been accrued by the child’s closest family, friends, and carers. The document might also be supplemented with video evidence depicting behaviours and their significance (Millar and Aitken 2003). Goldbart and Caton (2010) argue that communication passports are not so much an intervention directed at the person as at their environment. This makes them congruent with the social model of disability (Oliver 1996): the aim is not to increase systematic communication but rather for interactants to become more responsive to the existing communication strategies the person already has. A range of resources are available to support the production of communication passports, including downloadable templates (CALL Scotland 2018) and books (Millar and Aitken 2003), although there is a need for further formal published evaluation of their usefulness (Goldbart and Caton 2010).

## Wearable Technology

Recent developments in wearable technology permit insight into the physiological responses of the wearer to different stimuli and environments. For instance, Vos et al. (2010) measure breathing and heart rate variables with Dreamer® technology in an attempt to study emotions of people with profound intellectual and multiple disabilities (PIMD), whilst Lyons et al. (2013)

explore the use of startle reflex modulation technique (SRM) to infer positive or negative emotional responses. Such measurements have even been used to generate BioMusic (Blain-Moraes et al. 2013), which involves the child wearing non-invasive sensors that measure a range of autonomic nervous system signals and convert them to a holistic soundscape which can be heard by others. The presence of electrodermal activity (sweat) drives the melody, skin temperature changes the musical key, blood volume pulse drives the tempo, and respiration shapes the musical articulation and phrasing. According to Blain-Moraes et al. (2013), seven out of eight caregivers reported that BioMusic had a positive impact on their interactions with their child by sensitising them to their child's subtle physiological responses. Cheung et al. (2016) further argue that BioMusic can be useful to quickly identify anxiety in autistic children. Nevertheless, both ethical and epistemological questions remain about the use of physiological measures such as BioMusic, which are explored later in the chapter.

# Participant Observation

The perspective of idiosyncratic communicators may also be explored through observation of their behaviours and responses in everyday settings. I am conscious that discussing observation gives the impression of a singular method, whereas it encompasses a proliferation of approaches with diverse underlying theoretical bases and analytical lenses. Here, I examine some studies which elucidate the perspectives of minimally verbal communicators through observation.

Observational studies more frequently make the modest claim of documenting immediate reactions or preferences to an event rather than the more expansive epistemological claim of extrapolating views. For example, Hingley-Jones (2016) reflects on the usefulness of ethnographic observation to support social workers in understanding the lived experience of adolescence for teenagers with severe learning disabilities, although she does not claim to have accessed views:

> As an adolescent with significant needs, it is not possible for Daniel to straightforwardly tell a researcher how things are for him, yet through the

> observation, elements of his personality and adolescent identity emerge, set within the web of his relationship with the people with whom he lives.
>
> (p. 124)

Maes et al. (2021) argue that observation allows researchers to attend closely to the person's behaviour in an everyday context, without depending upon the interpretations of proxy informants (discussed further in the following). Additionally, the authors note that observation which uses video recording allows researchers to repeatedly interrogate their data afterwards, facilitating deeper and more complex analytic possibilities. As an example, I have previously used fine-grained multimodal analysis to examine the communicative moves of non-verbal children with autism and learning disabilities from video observation data in a classroom context (Doak 2019). By transcribing visual data second by second in a multimodal matrix, I analysed the significance of embodied communicative moves, including eye gaze, gesture, postural and proxemic shifts, vocalisation, and object manipulation. Multimodal analysis provides a powerful analytical framework for observational data as it accords equal analytic status to all communicative modes by resisting the conventional privileging of language (Jewitt, Bezemer and O'Halloran 2016). This framework, in turn, contributes to an ontological construction of the child as 'differently voiced' (Ashby 2011) rather than non-verbal: in other words, they are still recognised as agentic meaning-makers who wish to communicate their needs, desires, preferences, aversions, and personhood. However, like Hingley-Jones's (2016) research, my study did not make the epistemological claim of extrapolating views from observed and analysed embodied behaviours.

Simmons and Watson (2018) explore the subjective lifeworld of a child with PIMD using participatory and non-participatory observations, pre-observation focus groups, and ongoing dialogue with staff and parents. Their approach is framed by phenomenology which foregrounded lived experiences of intersubjectivity (Merleau-Ponty 2002). Numerous interactions between 'Sam' and the staff and peers in his mainstream and special settings are described in detailed narrative vignettes, and their possible interpretations are subjected to ongoing negotiation with Sam's family and classroom staff. For instance, vignettes describe how Sam appeared frustrated by the special school staff prompting him to press a switch which would utter the words 'good morning', yet happy to press the switch in his mainstream school setting when supported by peers. On the basis of repeated observations, the authors consider whether the presence of non-disabled peers in his mainstream setting may place Sam in an optimum learning state: their presence 'raises bodily expectations, alertness, and primes Sam to engage with his social milieu' (Simmons and Watson 2018 p. 179). Whether or not these findings might be said to constitute Sam's views about mainstream versus specialist education is an epistemological question which is explored later.

# Proxy Informants

A further way to consider the views of idiosyncratic communicators is through a proxy informant, typically a family member, carer, or key worker who knows the person well. McVilly, Burton-Smith, and Davidson (2000) examine the correspondence between quality-of-life assessments undertaken by participants with mild learning disabilities and by proxy informants answering on behalf of the disabled person. They find a very high degree of subject/proxy concurrence, concluding that the use of proxy informants can work, providing that the proxy had 'close and regular contact' (McVilly et al. (2000) p. 19) with the disabled person. Similarly, Gordon et al. (2007) report high subject/proxy concurrence when adults with mild learning disabilities and their key workers were asked to rate depression using a standardised scale. It should be noted that, in both of these studies, the reported mild learning disabilities might indicate an ability to verbally articulate one's views on quality of life or depression and to converse on these issues with significant others in previous interactions. Such previous conversations may then contribute to the building of a shared understanding with proxy informants which may or may not exist in the case of idiosyncratic communicators with more severe learning disabilities.

Other studies have sounded a more cautious note about proxy informants. Galloway and Newman (2017) note that children identified as having attention deficit hyperactivity disorder (ADHD) perceive their quality of life more favourably than their parents do. They conclude that proxy and self-ratings ‘should not be considered interchangeable . . . rather both should be considered as unique and valuable perspectives for clinical and research purposes’ (Galloway and Newman 2017, p. 26). Others have voiced concerns that proxies may find it difficult to divest themselves of their own views and should be given space to express their own views separately from their attempts to articulate the views of the disabled person. This may help them maintain the difficult balance between ‘imaginative fusion and reflective separation’ (Clegg (2003), cited in Nind 2008). Maes et al. (2021) argue that proxy informants may be able to approximate the disabled person’s perspective more accurately in discussion of more ‘objective’ issues, such as cognitive, communicative, and motor behaviour, and less so in discussion of ‘subjective’ themes, such as emotional experiences and personal perspectives. They advise that researchers seek to validate proxy reports through behavioural observation.

## Ontological, Epistemological, and Ethical Issues

So far, this chapter has reviewed some of the possibilities for hearing the views of children who might be termed *systematic* or *idiosyncratic* communicators. In this section, I discuss some of the ontological, epistemological, and ethical issues in attending to differently voiced views.

### Ontological Issues

Ontology concerns itself with the nature of being and the kinds of entities that can be said to have existence. There are at least two ontological questions which underpin the discussion of alternatively voiced 'views'. The first is how we define the entity we are calling a 'view', and the second is what kind of child is recognised as an entity capable of possessing and expressing a 'view'. These questions are explored together here as they are deeply intertwined.

A 'view' is defined by the *Cambridge English Dictionary* as 'an opinion, belief, or idea, or a way of thinking about something'. This definition might point to a degree of abstraction and endurance which is not entirely tied to the present experience: for example, although an opinion may evolve over time, one disappointing episode of our favourite television programme is unlikely to change our overall view that it is generally worth watching. Ware (2004, p. 175) has 'serious doubts' about whether people with profound and multiple learning disabilities (PMLD) 'can be said to have views about complex conceptual issues at all' (p. 176). She questions whether data capturing immediate responses—through wearable technology or observation—equate to a view:

> A photo of a child enjoying a particular activity can[not] be equated with them expressing the view that they want to participate in that activity. Neither is photographic evidence of a child with profound and multiple learning disabilities enjoying activities in a particular school the same as the child expressing a view that they want to attend that school.
>
> (Ware 2004, p. 176)

Ware goes on to illustrate this point with the example of herself visiting the dentist: observations and measurements of physiological responses might indicate an extreme negative reaction, yet she nevertheless retains the view that visiting the dentist is a wise course of action. For this reason, she maintains, elevating behavioural and physiological responses to the status of views is ontologically 'fraught with problems' (p. 176). This position is supported by Nind (2008, p. 11), who similarly maintains that expressing a preference for something in the here and now 'is not the same as being able to express views'.

As in the CRC, both Ware and Nind conceptualise the person who is capable of forming and expressing a view as being in possession of certain prerequisite characteristics. Nind (2008, p. 11) argues:

> Views are different from reactions, they are opinions, beliefs, standpoints, notions, ideas and they require the person to be an intentional communicator rather than at a pre-intentional stage in which communicative intent is inferred by others.

Ware (2004, p. 177) further argues that many 'views' additionally require the cognitive ability to conceptualise the future:

> Having a view about something that will take place in the future, will be ongoing or is complex or abstract requires a relatively advanced level of cognitive development. In order to have a view about some future event an individual needs at the very least to be able to anticipate that event and to be able to compare it (in some way) with similar events.

Such a definition might exclude not only idiosyncratic communicators but also a tranche of the emergent-level systematic communicators who are able to use a communication system with a limited repertoire of symbols. For instance, the use of Talking Mats© to sort symbols into 'I like' and 'I don't like' categories might satisfy the test of intentionality (an intention to indicate that you like the sensory room and don't like outdoor play) yet fail to demonstrate views about the (un)desirability of future iterations of the categorised events (that you might like outdoor play better in the future with a different range of play equipment or playmates).

Ware's position has been subject to critique. Simmons and Watson (2015) argue that this position represents 'a reductionist, post-positivist perspective that denies rights to people with PMLD' (p. 55). According to their phenomenological position, the problem shared by both post-positivist and constructivist approaches is the individualism of the researcher/researched binary, whereby the researcher is an individual seeking to understand a separate individual as their object of research. In contrast, the authors seek to transcend the researcher/researched binary by foregrounding the creation of a shared space of intersubjectivity (Merleau-Ponty 2002). They make the case for a democratic relationship of knowledge co-construction:

> [This approach] focuses on voice not as singular and literal, but as something that is enacted or comes into being through relationships. Voice is a performance between Sam and his social and material world that unfolds in context. Sensitive observation and co-constructed interpretation of this performance allows Sam to talk in ways that escape objective behavioural observation schedules or constructivist 'interview' formats.
>
> (Simmons and Watson 2015, p. 63)

In terms of the related question of who may hold a view, Simmons contends that everyone has a view, irrespective of their capacity to reflect on it using symbolic communication or temporal extrapolation:

> To deny that children with PMLD have a view because . . . they have not learned to communicate using a narrow collection of symbols (e.g. pointing) strikes me as being reductionist. It overlooks the wonderful ways that we are embodied and situated in the world, and how this informs our consciousness awareness about the world . . . children with PMLD have a view on the world already, insofar as it affords a meaningful space.
>
> (Simmons, Personal Communication, 26 Jan 2021)

This understanding of view appears to have some similarity to a secondary definition offered by the *Cambridge English Dictionary* in the context of geographical viewpoints: 'what you can see from a particular place, or the ability to see from a particular place'. In other words, each person has a view upon the world based on the interaction between the material affordances of the world relative to their own embodied presence and actions in and on that world. I would argue that this is a useful way of conceptualising ‘view’, as it acknowledges that all children, including all those with PIMD, have a ‘view’ and does not require that they articulate their view through words or other shared sign systems for it to be accorded legitimacy. At the same time, the caveats offered by Ware (2004) and Nind (2008) remind us to retain a degree of self-reflexivity in our practice and to continually question whether a currently held view can and should be assumed to apply to future events.

From the previous text, we can see that there is disagreement about what constitutes a view and about whether there are cognitive and communicative prerequisites to being the kind of person who can legitimately be said to hold a view. This chapter began by noting that international convention accords the ‘right to express a view’ only to ‘the child who is capable of forming his or her own views’ (CRC, Article 12) or to express a view whose ‘weight’ may be evaluated in accordance with perceived ‘age and maturity’ (CRPD, Article 7). Whilst the removal of the requirement of capability of forming a view might be said to be a welcome step forward and indicative of developments in our thinking around disability between the older CRC and the more recent CRPD, ‘age and maturity’ in the CRPD nevertheless have potential to be used as a benchmark in their own right. For instance, Nowak, Broberg, and Starke (2020) note that professionals may cite lack of age and maturity as justifications for not implementing direct child participation in planning, decision-making, and evaluation of support. It is therefore important that we continue discussions around this conceptual uncertainty, lest we unintentionally start to accord basic convention rights only to those children who we deem to have met our poorly defined thresholds of competence.

# Epistemological Issues

*Epistemology* refers to the study of knowledge, questioning what we know, how we have come to know it, and how we justify the validity of our knowledge. This section explores claims of generating knowledge about children’s views and how sure we can be of our interpretations of such views, particularly when they have not been expressed verbally but rather extrapolated from AAC-mediated expressions of preference or opinion, observation of multimodal embodied communication, and/or measured physiological responses.

This question of how we can come to know the views of another is pertinent to many figures in the child's life, including family members, educators, healthcare professionals and therapists, social care providers, policymakers, and researchers. In the context of academic research, the interpretative role of the qualitative researcher has been problematised for decades, even in a wider context of research with verbal participants, which yields conventional spoken and transcribed interview data. For instance, Lincoln and Guba (1986) acknowledge that the researcher can reach analytic conclusions which are not shared by participants, and they propose a range of measures to maximise the credibility of qualitative research. These include member checks (also referred to as participant validation), whereby participants are invited to read and dispute researcher interpretations; triangulation (comparing findings from multiple sources or research methods); and peer debriefing (discussing interpretative and analytic processes and conclusions with an academic peer). The epistemic problem of validating researcher interpretation is therefore not particular to studies involving disabled or alternatively voiced participants, and such research should not be thought of as categorically different in the epistemological challenges presented. Similarly in a family or practice-based context, it is entirely possible to misrepresent the views of a non-disabled child with verbal speech, particularly where power relations do not enable the child to easily contest adult misinterpretation. Careful, self-reflexive practice when attending to a child's expression of views is therefore required across both research and practice.

Nevertheless, several factors may render the role of careful and reflexive interpretation more pronounced in the case of alternatively voiced communicators. Firstly, behavioural responses (whether documented through human observation or physiological measurement) may not have the nuanced affordances of spoken language to express views, opinions, and responses with precision. For instance, Brooks (2014, p. 3) notes that the emotions of anxiety and excitement have ‘remarkably similar’ physiological correlates, ‘though they have divergent effects on cognition, motivation, and performance’. This physiological approximation of emotions increases the chance of researcher interpretation which diverges from participant lived experience. Additionally, the absence of spoken language means that participant validation of emergent analysis is not feasible. Cheung et al. (2016, p. 2) reflect on this conundrum in the context of BioMusic:

> Methodologically, it is extremely challenging to develop classifiers with a population who are unable to verify their performance or communicate the ‘ground truth’. Ethically, we must be conscious of the potential challenges of assigning affective state labels to individuals who can neither confirm nor correct their accuracy.

In the case of systematic communicators who use some form of AAC, questions may also arise about the extensiveness of their AAC vocabulary repertoire and its subsequent capacity to convey their views. We might question how the epistemological question (the extent to which we believe we can come to know the views of a differently voiced child) is related to the expansiveness of the vocabulary repertoire contained in their system. For the AAC user who has conventional literacy skills and can therefore type or otherwise generate sophisticated and nuanced messages, it is not difficult to see how participant validation may be achieved through further probing and invitation to elaborate upon or clarify initial responses. However, for the child who is working at the level of sorting symbol cards into *I like/I don’t like*, there is considerable interpretative work required on the part of the listener to discern possible intended nuances, such as ‘I like chocolate, but it makes me feel sick afterwards’ or ‘I enjoy sensory massages but only for short periods of time and with certain members of staff’. AAC is therefore a useful tool in the ongoing process of exploring views, but it does not obviate the epistemological conundrums associated with idiosyncratic communicators.

I would argue that researchers, practitioners, and policymakers alike need to remain sensitised to the epistemological question of how we can come to know differently voiced views and acknowledge the epistemological limitations of selected tools for attending to views. Careful consideration should be given to how AAC, observation, proxy informants, and other methods may work together to help us build a picture of views in the context of an ongoing relationship with the child and carefully negotiated co-constructed meanings.

# Ethical Issues

Closely intertwined with ontological and ethical considerations are questions of ethics. Attempts to ascertain the views of differently voiced children may occur in the context of academic research where researcher conduct is governed by research ethics regulation from institutional committees and/or discipline-specific codes of conduct. They may also be undertaken in more general everyday settings, such as a teacher seeking to ascertain the child's views on their education provision. In the former case, the ethical standards applied to the listener may be more rigorously formalised and involve higher degrees of external scrutiny and internal researcher reflexivity than in the latter case. However, I would argue that in either context, the following ethical considerations are worthy of consideration.

Firstly, it is important to consider the deeply intersecting nature of epistemology and ethics when we are seeking to ascertain the views of another. On the one hand, as outlined previously, it is tempting to elevate a physiological response or a behavioural observation to the status of a view which is then used to guide future provision for the child. For instance, Blain-Moraes (2013, p. 162) acknowledges 'the ethical concerns of inappropriately using BioMusic to indicate more than the occurrence of a physiological change', whilst Cascio et al. (2020, p. 3) acknowledge that 'translating emotional correlates [through BioMusic] also creates potential risks such as misrepresentation, or invasion of privacy'. If such physiological data is not carefully triangulated with knowledge of the child derived from a sustained relationship with frequent interaction, it could be misleading. For example, a child's measured physiological responses to an event could be interpreted as excitement without considering the margin for interpretative error given the close correlation of physiological markers for excitement and anxiety (Brooks 2013). This child may then be repeatedly exposed to a particular therapy or approach which is anxiety-inducing. This would be an instance of harm, whether in a research or everyday context, and in the case of a non-verbal or minimally verbal user of the technology, the interpretation of the physiological data cannot be verbally verified.

Given the epistemological challenges associated with ascertaining views, it might be tempting to conclude that the most ethical course of action is to declare the task impossible. However, I would argue that this approach is potentially even more problematic on ethical grounds. The term *epistemic injustice* (Fricker 2007) refers to ways in which we may ethically wrong someone on the grounds of unwarranted assumptions about their (lack of) status as knower. One form of epistemic injustice which is particularly relevant here is testimonial injustice, where 'prejudice causes a hearer to give a deflated level of credibility to a speaker's word' (Fricker 2007, p. 1). If we disbelieve or discount someone's account of their own experiences (their epistemic subjectivity), this is the primary epistemic harm, but for disabled people in particular, it may also result in secondary epistemic harms, such as learned helplessness, a loss of trust in one's own knowledge, and the loss of ability to make decisions (Dohmen 2016).

Not only does being discounted as a valid knower have ethical ramifications on the individual level, but it can also lead to more widespread testimonial injustice in terms of neglect of the views of differently voiced communicators in academic research. In their study of representation in autism research, Russell et al. (2019) note that whilst 50% of people with autism also have learning disabilities, this group is significantly underrepresented in research. Up to 94% of all autism study participants do *not* have learning disabilities. The authors go on to note that 80% of autism studies show selection bias against people with co-occurring learning disabilities who are considered a harder-to-reach population, with many researchers expressing the view that they do not have time to devote to securing their involvement in research. They conclude that 'what we know about a condition may largely reflect groups who are easier to access' (Russell et al. (2019) p. 8). This points to epistemic injustice on a wider scale: if we attend only to the views of those who express themselves verbally and therefore are amenable to our usual toolkit of research methods, we are failing to listen to a significant tranche of disabled children. This, in my view, is a serious and pressing ethical question. Consequently, I would argue that we should not be excessively fearful of methodological innovation over the risk of misinterpretation but rather proceed cautiously with a self-reflexive stance which acknowledges the possibility of misrepresenting the person's intended communication. Of course, this epistemic injustice also has associated rights-based implications: as noted previously, the international right to express views is accorded the child deemed 'capable of forming his or her own views' (CRC, Art.12) or to express views which may be weighted 'in accordance with their age and maturity' (CRPD, Art.7). Our lack of attention to the complex ontological, epistemological, and ethical dimensions of enabling differently voiced communicators to express their view may lead us not to overinterpret their behaviour but rather to disregard *ab initio* any possibility of listening.

## Conclusion

This chapter has explored diverse ways of attending to the views and perspectives of children who are not primarily verbal communicators. It is encouraging to reflect on the ever-expanding range of established tools we have at our disposal to support, recognise, and amplify self-expression for both children who use AAC systems and children whose communication might be described as more idiosyncratic. At the same time, the CRC and CRPD appear to conceptualise this right not as universal but rather as requiring *capability* (CRC) or *age* and *maturity* (CRPD). This idea of 'qualifying' for the right to express views raises complex ontological, epistemological, and ethical questions. For instance, the question of what we understand a view to be raises questions about how (if at all) it does differ from an immediate preference or behavioural response. This, in turn, has implications for the types of children we deem in/capable of forming and expressing a view, and the cognitive prerequisites we consider necessary.

It is clear that much discussion and research are needed on the question of how to attend to the views of differently voiced children. It is important that we make explicit and challenge assumptions about who may or may not hold or express a view, in order to ensure that differently voiced children are accorded their rights under international convention. This, in turn, has ethical implications which cut across research and practice, from the individual child whose perspective on their own education, healthcare, leisure, and other areas of service provision goes unacknowledged to wider-scale neglect of differently voiced children in academic research. Whilst technological innovation is to be cautiously welcomed as a means of diversifying our methodological toolkit, it is essential to continually evaluate such developments within an ontological, epistemological, and ethical framework. This involves a great deal of self-reflexivity for both researchers and practitioners: acknowledging our pre-existing beliefs and biases about whose views are worth attention and amplification; ongoing triangulation of information pertaining to a child’s views, with acknowledgement of uncertainty, ambiguity, and contradiction; and fully considering the implications in practice of an unintended misrepresentation of views. Perhaps, as the social model of disability suggests, we would do well to focus less on disabled children’s perceived in/capacity to express views and more on our own capacity to discern alternatively voiced views which come in myriad forms.

# References

Ashby, C. E. 2011. Whose ‘voice’ is it anyway?: Giving voice and qualitative research involving individuals that type to communicate. *Disability Studies Quarterly* **31**(4).

Blain-Moraes, S., Chesser, S., Kingsnorth, S., McKeever, P. and Biddiss, E. 2013. Biomusic: A novel technology for revealing the personhood of people with profound multiple disabilities. *Augmentative and Alternative Communication* **29**(2), pp. 159–173.

Booth, T. and Booth, W. 2003. In the frame: Photovoice and mothers with learning difficulties. *Disability & Society* **18**(4), pp. 431–442.

Brewster, S. J. 2007. *Asymmetries of power and competence and implications for AAC: interaction between adults with severe learning disabilities and their care staff* (Ed. D. Thesis), Birmingham, University of Birmingham.

Brooks, A. W. 2013 Get excited: Reappraising pre-performance anxiety as excitement. *Journal of Experimental Psychology* **143**(3), p. 1144–1158.

Bryan, J. 2018. *Eye can write: A memoir of a child's silent soul emerging*. London: Bonnier Publishing.

Bunning, K., Gona, J. K., Newton, C. R. and Hartley, S. 2014. Caregiver perceptions of children who have complex communication needs following a home-based intervention using augmentative and alternative communication in rural Kenya: An intervention note. *Augmentative and Alternative Communication* **30**(4), pp. 344–356.

Bunning, K. and Steel, G. 2007. Self-concept in young adults with a learning disability from the Jewish community. *British Journal of Learning Disabilities* **35**(1), pp. 43–49.

CALL Scotland. *Personal communication passports.* [online] [Accessed on 23 November 2021] Available from: www.communicationpassports.org.uk/creating-passports/

Cambridge English Dictionary [Online] [Accessed on 19 April 2022] Available from: https://dictionary.cambridge.org/dictionary/english/view

Cascio, M. A., Teachman, G., Grond, F., Tembeck, T., Blain-Moraes, S. and Park, M., *What's at stake with Biomusic? Ethical reflections on an emerging technology.* [online] [Accessed on 26 November 2021] Available from: www.jhrehab.org/wp-content/uploads/2020/04/Cascio_JHR_Spring2020.pdf

Cheung, S., Han, E., Kushki, A., Anagnostou, E. and Biddiss, E. 2016. Biomusic: An auditory interface for detecting physiological indicators of anxiety in children. *Frontiers in Neuroscience* **10**, pp. 401.

Doak, L. 2018. *Exploring the multimodal communication and agency of children in an autism classroom* (PhD Thesis), Sheffield, Sheffield Hallam University.

Doak, L. 2019. ‘But I’d rather have raisins!’: Exploring a hybridized approach to multimodal interaction in the case of a minimally verbal child with autism. *Qualitative Research* **19**(1), pp. 30–54.

Dohmen, J. 2016. A little of her language’: Epistemic injustice and mental disability. *Res Philosophica* **93**(4), pp. 669–691.

Dreyfus, S. J. 2006. *When there is no speech: A case study of the nonverbal multimodal communication of a child with an intellectual disability* (PhD Thesis), Wollongong, University of Wollongong.

Fisher, C. A. 2009. *Photography as a communication tool for individuals with intellectual and developmental disabilities* (PhD Thesis), Missouri, University of Missouri.

Fricker, M. 2007. *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.

Galloway, H. and Newman, E. 2017. Is there a difference between child self-ratings and parent proxy-ratings of the quality of life of children with a diagnosis of attention-deficit hyperactivity disorder (ADHD)? A systematic review of the literature. *ADHD Attention Deficit and Hyperactivity Disorders* **9**(1), pp. 11–29.

Goldbart, J. and Caton, S. 2010. *Communication and people with the most complex needs: What works and why this is essential.*[online] [Accessed on 2 February 2021] Available from: http://espace.mmu.ac.uk/198309/1/Mencap%20Comms_guide_dec_10.pdf

Gordon, M. S., Shevlin, M., Tierney, K. J., Bunting, B. and Trimble, T. 2007. Correspondence between self-ratings and key-workers’ ratings of depression in adults with mild learning disabilities. *British Journal of Clinical Psychology* **46**(4), pp. 491–495.

Hingley-Jones, H. 2016. Using observation to research the experiences of teenagers with severe learning disabilities. In G. Ruch and I. Julkunen (eds.), *Relationship-based research in social work: Understanding practice research.* London: Jessica Kingsley Publishers, pp. 107–126.

ICAN/ RCSLT. 2018. *Bercow: Ten Years On. An independent review of provision for children and young people with speech, language and communication needs in England.* [online] [Accessed on 23 November 2021] Available from: www.bercow10yearson.com/

Jewitt, C., Bezemer, J. and O'Halloran, K. 2016. *Introducing multimodality*. Routledge.

Judge, S., Enderby, P., Creer, S. and John, A. 2017. Provision of powered communication AIDS in the United Kingdom. *Augmentative and Alternative Communication* **33**(3), pp. 181–187.

Kleinert, J. O., Harrison, E. M., Fisher, T. L. and Kleinert, H. L. 2010. 'I can' and 'I did'—Self-advocacy for young students with developmental disabilities. *Teaching Exceptional Children* **43**(2), pp. 16–26.

Lincoln, Y. S. and Guba, E. G. 1986. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. In D. D. Williams (ed.), *Naturalistic evaluation: New directions for program evaluation.* San Francisco: Jossey-Bass, pp. 73–84.

Lyons, G. S., Walla, P. and Arthur-Kelly, M. 2013. Towards improved ways of knowing children with profound multiple disabilities: Introducing startle reflex modulation. *Developmental Neurorehabilitation* **16**(5), pp. 340–344.

Maes, B., Nijs, S., Vandesande, S., Van Keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J., Petitpierre, G. and Van der Putten, A. 2021. Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities* **34**(1), pp. 250–262.

McVilly, K. R., Burton-Smith, R. M. and Davidson, J. A. 2000. Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual and Developmental Disability* **25**(1), pp. 19–39.

Merleau-Ponty, M. 2002. *Phenomenology of perception*. London: Routledge.

Millar, S. and Caldwell, M. 1997. *Personal communication passports.* SENSE Conference, 13 September, University of Dundee.

Millar, S. V. and Aitken, S. A. 2003. *Personal communication passports: Guidelines for good practice*. CALL Centre.

Murphy, J. 1998. Talking Mats: speech and language research in practice. *Speech and Language Therapy in Practice*. (Autumn), pp. 11–14.

Nind, M. 2008. Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. [online] [Accessed on 23 November 2021] Available from: http://eprints.ncrm.ac.uk/491/

Nowak, H. I., Broberg, M. and Starke, M. 2020. Opportunity to participate in planning and evaluation of support for children with disabilities: Parents' and professionals' perspectives. *Journal of Intellectual Disabilities* **24**(1), pp. 5–20.

Oliver, M. 1996. *Understanding disability: from theory to practice*. London: Palgrave Press.

Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N.-Y., Nair, M., Halpern, R., Kuper, H., Breinbauer, C., De Vries, P. J. and Gladstone, M. 2018. Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the global burden of disease study 2016. *The Lancet Global Health* **6**(10), pp. 1100–1121.

Rojas, S. and Sanahuja, J. M. 2012. The image as a relate: Video as a resource for listening to and giving voice to persons with learning disabilities. *British Journal of Learning Disabilities* **40**(1), pp. 31–36.

Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T. and Ford, T. 2019. Selection bias on intellectual ability in autism research: A cross-sectional review and meta-analysis. *Molecular Autism* **10**(1), pp. 1–10.

Simmons, B. 2021. *Email to Lauran Doak*, 26 January.

Simmons, B. and Watson, D. 2015. From individualism to co-construction and back again: Rethinking research methodology for children with profound and multiple learning disabilities. *Child Care in Practice* **21**(1), pp. 50–66.

Simmons, B. and Watson, D. 2018. *The PMLD Ambiguity: Articulating the life-worlds of children with profound and multiple learning disabilities*. NewYork: Routledge.

Stewart, K., Bradshaw, J. and Beadle-Brown, J. 2018. Evaluating service users' experiences using Talking Mats®. *Tizard Learning Disability Review* **23**(2), pp. 78–86.

UNICEF UK. (1989). *The United Nations convention on the rights of the child.* [Online]. [Accessed 14 December 2022]. Available from: https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_PRESS200910web.pdf?_ga=2.78590034.795419542.1582474737-1972578648.1582474737

United Nations General Assembly. 2007. *Convention on the Rights of Persons with Disabilities (24 January 2007).* [Online]. A/RES/61/106. [Accessed 14 December 2022]. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.Vos, P., De Cock, P., Petry, K., Van Den Noortgate, W. and Maes, B. 2010. What makes them feel like they do? Investigating the subjective well-being in people with severe and profound disabilities. *Research in Developmental Disabilities* **31**(6), pp. 1623–1632.

Vygotsky, L. S. 1987. *The collected works of LS Vygotsky*. New York: Plenum.

Ware, J. 2004. Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities* **32**(4), pp. 175–179.

Webster, S. 2016. My communication journey as a person with autism. *Communication Matters* **30**(3), pp. 21–22.

World Health Organization and the World Bank. 2011. *World Report on Disability.* [Online] [Accessed on 23 November 2021] Available from: www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability

Wylie, K., McAllister, L., Davidson, B. and Marshall, J. 2013. Changing practice: Implications of the world report on disability for responding to communication disability in under-served populations. *International Journal of Speech-Language Pathology* **15**(1), pp. 1–13.