The right to be heard: the missing voices of students with learning disabilities

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ABSTRACT

Set within the context of the United Nations Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child, this article interrogates the extent to which the right to be heard is afforded equally to all children and young people. It shows that despite widespread global commitment to these conventions, the voices of children and young people with learning disabilities continues to remain largely unheard. Attention is drawn to the ways in which limiting assumptions contribute to this on-going breach of rights. Research approaches that take a more inclusive approach to listening to the 'voices' of children and young people with learning disabilities are shared. These show that while the gap between policy intent and reality remains considerable, there is much that can be done to honour the right to be heard. Presuming competence, being attentive to different communication preferences, allowing time, and providing multi-modal input and response options, are each essential if the current gap between policy intent and reality is to be closed.

INTRODUCTION

> It is not difference which immobilizes us, but silence. And there are so many silences to be broken (Audre Lorde, cited in Sawicki, 1991, pp.9)

Reflecting greater acceptance of children's rights globally, the last two decades have seen wider recognition of the importance of listening to children and young people. This has been accompanied with the development of more inclusive and participatory research methods. In this article we argue that while much progress has been made, and innovative methods for accessing voice continue to be developed, the right to be heard is still not experienced equally by all. We focus primarily on one group of learners; those with learning disabilities. We highlight the missing voice of students with learning disabilities within research, and further, show that this is particularly the case for those with more significant learning or communication difficulties. Reflecting on some of the reasons underpinning this injustice, we illustrate the impact that deeply entrenched assumptions have on the right to be heard. We also present research examples that take a more inclusive approach and discuss some of the strategies they

employed. These show what can be achieved when ableist assumptions are dismantled and the right to be heard is taken seriously.

A note about terminology: The term 'disability' is often applied generically, implying a homogenous group. This fails to acknowledge the considerable differences between the capabilities of those to whom the term is applied. Similarly, labels such as ASD (autism spectrum disorder) convey little about an individual's particular strengths and challenges. In this article, we focus on those who have been diagnosed as having a degree of intellectual impairment. The terminology used in the research we cite varies across different national, institutional and policy contexts. Examples include intellectual disability (ID), learning and developmental disability (LDD), autism spectrum disorder (ASD), special education needs and disability (SEND), diverse language and cognitive abilities. In this article, for consistency, we use the terms learning disability.

THE RIGHT TO BE HEARD: THE ASPIRATION

The Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) and the Convention on the Rights of the Child (UNCRC, 1989) both emphasise that disabled children have a right to be involved in decisions that interest and affect them. As articulated in Article 4.3 of the UNCRPD, States Parties are expected to "closely consult with and actively involve persons with disabilities, including children with disabilities" in all matters affecting them. Article 7 builds on this by emphasizing the right of children with disabilities to express their views freely "and to be provided with disability and age-appropriate assistance to realize that right". This is further reinforced in Article 21 which protects the right to communicate "through all forms of communication of their choice" and through the use of "accessible formats and technologies appropriate to different kinds of disabilities". Similar expectations are laid out in the UNCRC (see for example Article 12: respect for the views of the child; Article 13: freedom of expression). These Conventions emphasise not only the right to be consulted, but also the need to consider how communication might be enabled when doing so.

As a signatory to these conventions, New Zealand has committed to upholding these rights and this is reflected in policy initiatives. Principle 3 of the New Zealand Disability Strategy 2016-2026 (2016) recognises disabled people as experts in their own lives who should be consulted on all matter affecting them while Outcome 7, Choice and Control, promises to respect "the evolving capacities of disabled children and to consider their views". Similarly, New Zealand's National Ethical Standards for Health and Disability Research (NEAC, 2019) call for research involving disabled people to recognise the social origins of disability and respond in ways that respect this context. They encourage researchers to use participatory and consultative approaches, adapt materials to meet participants' individual needs (for example, through large print or Easy Read formats), and ensure that researchers themselves are accessible and responsive to participants' needs.

THE RIGHT TO BE HEARD: THE REALITY

Given widespread support for these international conventions, as reflected in their ratification by many countries, one might well expect to find greater evidence of policy in practice through approaches that actively listen to children and young people in everyday settings and in research. On the contrary, there is a conspicuous absence of the views of children and young people with disabilities within research (Condor et al., 2016; Jacobs et al., 2018). As we demonstrate below, their voices have been either marginalised or not sought at all. Instead, the views of adult stakeholders have been prioritised over those of children and young people.

Review studies offer a useful starting point. Jacobs et al.'s (2018) review of research on the school-to-post-school transition experiences of those with significant learning disabilities found that most studies did not seek the views of students themselves but instead, relied on the accounts of parents. Similarly, a review of studies on the schooling experiences of students with ASD found that only a small number used multi-modal approaches or participatory methods to elicit the views of students themselves (Horgan et al., 2023). Again, the voices of adult stakeholders were prioritised. Here in Aotearoa New Zealand, Condor et al. (2016) found this to also be the case. They draw attention to the exclusion of disabled children from disability research.

A look at some individual studies exemplifies this on-going disempowerment and exclusion. Bruck et al.'s (2022) study, entitled, 'Transition support for students on the autistic spectrum: a multiple stakeholder perspective' focused on the views of educators, parents and paraprofessionals. In this case, 'multiple stakeholders' excluded the views of students themselves. Similarly, an article entitled 'How did autistic children, and their parents, experience school transition during the Covid-19 pandemic?' (Code, 2022) was based entirely on the views of the parents. These are just a few examples but are illustrative of a wider trend whereby the views of children and young people with learning disabilities remain absent. This is in direct contravention of their right to be consulted and listened to, as required by the UNCRPD (2006) and the UNCRC (1989).

A second concerning trend is also evident. Even when the views and experiences of those with learning disabilities are sought, there is an over-representation of those whose learning disability is less severe and those who are verbally communicative (Barr et al., 2023; Courchesne et al., 2022; Hurd et al., 2018). As noted in Fayette and Bond's (2017) systematic review of studies that specifically sought the views of learners with ASD, there is an over-representation of "participants who were able to engage in verbal discussion" (p. 349). A recent review conducted by one of the authors confirms the marginalisation of particular voices. Across the 51 studies identified on the transition to adulthood for disabled young people, 35 employed qualitative approaches. Of these, 27 incorporated the voices of disabled participants themselves, yet only six studies attempted to include young people who were low or non-verbal. In each of these, the representation was minimal, typically limited to one or two participants, and few studies described the use of adapted or inclusive methods to facilitate their participation. Most of the studies relied on standard interview or survey methods, which meant that young people with significant communication differences were rarely included. Of the five studies conducted in Aotearoa New Zealand, only two

gave voice to low-verbal participants. Instead, the literature leans heavily on the voices of parents, professionals, and verbally fluent young people. Those with the most complex communication needs appear only at the margins, if at all.

THE RIGHT TO BE HEARD: THE BARRIERS

Participant selection criteria

It appears that one contributing factor is that verbal communication is viewed as a prerequisite for participation in research. Those who communicate in other ways, for example, through sign language, symbols, and AAC (augmentative and alternative communication), are therefore excluded by default. For example the participants in a study of students with disabilities in Canadian schools, needed "sufficient English language fluency for participation in the interview process" (Reeves et al., 2020: p.617) while an investigation of learning disabled people's motivation for and participation in research, noted one limitation of their study was that "people with more intellectual disabilities" were excluded "because of communication challenges" (Frankena et al., 2018, p.946). Similarly, the selection criteria in Olcay-Gul and Vuran's (2015) analysis of the views of students with 'special needs' in Turkey meant that participants were still of the 'more able' amongst those 'special needs'. In order to participate, students required 'the ability to self-express'. It was apparent that this meant verbal communication. And in Alesech and Nayar's (2020) New Zealand research with children with special educational needs, the ability to speak English was required for all participants.

These are just a few examples but are indicative of a wider trend. We draw attention to them not to criticise the specific research endeavours. Indeed, each has something valuable to add to our understandings about those with learning disabilities. Rather, our intent is to highlight and challenge what appears to be a deeply entrenched feature of research with those with learning disabilities; namely, the privileging of the spoken word over other ways of communicating. We also question the associated assumption that those with communication difficulties are intellectually impaired to the extent that they are unable to participate meaningfully in research or have nothing of value to communicate. Selection criteria such as those illustrated above ignore the possibility of conducting an interview in a way that enables those who are non-verbal to understand and engage in research.

Davis and Watson's (2017) ethnographic work in a special school for students with multiple impairments provides a thought-provoking illustration of why it is important not to make assumptions about a child's capabilities based on their apparent limited ability to understand what is going on around them or to communicate that. They describe how it quickly became apparent to John, the field researcher, that staff at the school thought that the children in their care were incapable of thinking for themselves and would have little to share with him. Nevertheless, as John spent time in the environment and interacted with the children, he came to see that this was far from the case. In one example, a non-verbal girl guided him around the room until he realised that she was letting him know which children he had been ignoring because they were non-verbal. The authors explain that in doing so, this child had helped John to recognise his own bias in "attributing more status and time to those children who were easier to communicate with" (p.125). The extended time that John spent in the setting also

meant that he was able to learn each of their communication preferences. This then enabled the children to take an active role in 'conversations' with him. He learned, for example, that another student was a keen football follower and each Monday, had much to share with John about which teams had done well over the weekend. Up until then, staff, although aware of the student's interest in football, had underestimated his desire and ability to engage in 'conversation' and share his knowledge. The authors emphasise that it is easy to attribute a lack of 'normal' communication to a lack of cognitive understanding and they argue that adults should not assume low or non-verbal children are incompetent.

It is interesting to note that the impact of exclusionary selection criteria is not limited to research with those with learning disabilities but also extends to children more generally. Bourke and Loveridge's (2013) analysis of informed consent in research with Year 4 and Year 8 children in Aotearoa New Zealand found that staff decisions in the four participating schools circumvented the researchers' intent that all children be provided with information about the research prior to expressions of interest being sought. This was to allow the same opportunity to all children and to give them some control and agency over their involvement. Instead, unofficial selection criteria were applied by school staff. Reflecting the earlier examples, and as articulated by one principal, '*The way we selected the children was for the teachers to select children who were articulate and confident*' (p.156). While such actions may be well-intentioned, they nevertheless have an exclusionary effect.

Gatekeepers

In addition to selection criteria imposed by researchers, and as illustrated above, gatekeepers also exercise control over which children and young people participate in research. This further contributes to the exclusion of certain voices. The examples below come from one of the authors who is currently part-way through her doctoral studies. Her research aims to explore the transition experiences of learning-disabled ORS-funded school leavers, some of whom have no or limited verbal communication skills. The examples come from the recruitment phase of the research and show how gatekeeping posed a significant barrier to young people's opportunities to participate. The actions of gatekeepers could be interpreted as pragmatic or protective. However, even if the intentions were well-meaning, the effect was exclusion and a quiet but powerful silencing of voices that are already rarely heard.

Example one comes from a social enterprise that employs people with learning disabilities. When approached with information about the study, staff informed the researcher that none of their employees met the study criteria and that none would be interested in taking part. Yet the organisation's website highlighted case studies of employees who had transitioned from ORS-funded schools - individuals who clearly did fit the criteria. The researcher also had insider knowledge that confirmed this mismatch. The refusal could have reflected concerns about the additional workload of sharing research information with potential participants. We suggest that it more likely exemplifies an assumption that sharing the information, which was available in accessible formats, would be a waste of time because the young people would either not understand, not be interested, or not have anything worthwhile to contribute. Whatever the reasoning, the important point is that the decision was made for them rather than with them and by them. Decisions of this kind reflect wider discourses that

position disabled people as less capable. In doing so, they limit opportunities for their perspectives to be heard.

Families and teachers also acted as gatekeepers. Comments such as "you probably won't get much out of him" or "I can talk to you if you want" implicitly reveal underlying assumptions. Again, these comments could be interpreted as well-meaning, however, they ultimately took away the young person's opportunity to speak on their own behalf. This contravenes Articles 7 and 12 of the UNCRPD (2006) and Articles 12 and 12 of the UNCRC (1989), which affirm children's rights to express their views freely and to be provided with appropriate means to do so. These interactions resonate with Davis and Watson's (2017) description, in which adults are often positioned as the primary and sometimes only legitimate voice in the lives of disabled children and young people. Parents' hesitancy may be partly understood within the broader context of their lived experience. Many have had to emphasise their child's deficits in order to gain any support or funding (Priestley et al., 2022; Reeves et al., 2020). This means that the child's strengths and abilities are not formally recognised which over time can subconsciously shape how families and professionals perceive what a child is capable of contributing. Some families may also worry about their child experiencing difficulty or fear of wasting the researcher's time. As anyone with lived experience with someone with a learning disability will know, these responses, understandably, may suggest a preference for minimising uncertainty and holding to familiar routines, rather than stepping into the unknown of research.

It was interesting to note that gatekeepers' non-verbal cues also showed a juxtaposition of sentiments. Parents and teachers who verbally agreed to share information sometimes showed unease through scrunched faces, averted eyes, or subtle shakes 'no' of the head as they verbally agreed. Just as multimodal communication is essential for many disabled people themselves (Courchesne et al., 2022), these cues suggested the doubts and discomfort of these adults.

Gatekeeping also appeared in community spaces where inclusion might have been expected. When recruitment material was shared in an online disability advocacy forum, the responses resisted rather than welcomed participation! Some members questioned whether ORS-funded young people could meaningfully participate, while others argued that only parents or whānau should be consulted. A few went further, insisting that even with adaptations, those with complex needs would be unable to take part. For example, one contributor wrote: "Some young people with very complex needs would be unable to participate even with adaptations. Are you looking at whānau views as well for these young people?" In response, the researcher described a range of adaptations she had prepared to support communication, and with which she has experience. These included eye-gaze, AAC, Talking Mats, tactile resources, yes/no formats, and where appropriate, involvement of a support person. Even then, another group member insisted that "not all can communicate so you can't get the information you are talking about".

These statements reproduce a familiar assumption that young people with learning disabilities cannot speak for themselves. In some cases, members explicitly suggested that researchers should bypass young participants altogether and rely only on parents or carers. For example, one contributor suggested that "You need parents' or whānau views on this, as a lot can't communicate with you well enough, and whānau views are very valid". While we agree that the views of

parents/carers are important and acknowledge that parent/carer support in the interview process may be needed, these views sit uneasily alongside the principles of participation emphasised in the UNCRPD (2006) and UNCRC (1989). As Barnes (1992) illustrates only too clearly in his publication on disabling imagery, disability has a long history of oppressive and negative representation. It seems that remnants of these deeply rooted narratives continue today, even in environments that signal openness. Keeping in mind the assumption that online forums are often filled with dominant and/ or confrontational opinions, it is concerning that the young disabled people's right to speak and to be heard was so quickly questioned.

Looking across these examples, it is clear that the voices of young people with learning disabilities were restricted and their contribution potential overlooked, even amongst those that claim to advocate for inclusion. They demonstrate that the points raised earlier about limiting assumptions do not apply just to past research, or research in other jurisdictions, but are equally present in Aotearoa New Zealand today.

THE RIGHT TO BE HEARD: MOVING FORWARD

The picture we have painted so far is a disheartening one. It shows that there is still considerable progress to be made to meet our obligations under the UNCRC and UNCPD and to create opportunities to listen to all children and young people - including those with learning disabilities and those whose communication needs sit outside the verbal 'norm'. This is perhaps not surprising given that research designed to incorporate the active participation of children and young people with disabilities comes with additional considerations. Gaining access and approval from gatekeepers, addressing ethical concerns, and interpreting participant-generated data all become more complicated and time consuming, particularly in the case of young children or those with more severe learning or communication difficulties. Vincent and Benstead (2023) speculate that even when there are no cognitive or social communication barriers to consider, the perspectives of children with other disabilities, such as those with hearing and visual impairments, have been neglected within mainstream research simply due to methods not adequately taking account of their unique communication requirements. In all of these cases, research methods need to be adapted to accommodate differing cognitive capacities and communication abilities and preferences.

While the disjoint between aspiration and reality in relation to the right to be heard is significant, there are a small but growing number of researchers tackling the challenges inherent in working in this space. They have found ways of mitigating the aforementioned barriers and have developed approaches that allow formerly silenced voices to be heard. We present several examples, highlighting important commonalities. They show what can be achieved when ableist assumptions are dismantled and more inclusive approaches to accessing voice are employed.

In their research with students with special educational needs and disabilities in schools in England, Benstead et al. (2024) make a case for 'research conversations'. This referred to the final phase of a stepped-research process that incorporated a range of multi-sensory data collection tools. In this research,

learner-led tours of the school, photo-voice techniques and creation of a 'special story' were each employed as a way of circumventing the limitations of more traditional interview-type research. Notably, the children also had control over the pace and length of time they engaged in each phase of the project. The researchers concluded that a scaffolded process that offered a range of communication options allowed the students to "present their thoughts in a way that worked for them" (Benstead et al., 2024, pp.10).

Similarly, Courchesne et al. (2022) describe a protocol they developed for accessing first-person perspectives from 33 young people with autism in Canada. They describe it as a strengths-oriented approach aimed at enabling students with diverse language and cognitive abilities to share their views on a range of topics relevant to their daily lives. The protocol involved flexible use of a range of materials and communication support strategies. These accommodated different verbal, written, non-verbal and alternative communication responses. Another important element to their approach was an interview with a parent or carer prior to engaging with the young person. The purpose of this was to gain information that would enable the researchers to tailor the interview to each young person's strengths and preferences. The researchers argue that the flexibility offered by their approach resulted in richer, more detailed information than would otherwise have been gathered.

Worthy of note is that both of these examples can be viewed as aligning with Universal Design for Learning (UDL) principles; in particular, offering multiple means of representation (ways of enabling participants to understand what the researcher is asking) and by providing multiple means of action and expression (ways of enabling participants to share their thoughts and experiences). As Courchesne et al. (2022) note, the visual supports that had been prepared for their non-verbal participants, also proved to be beneficial for other (verbal) participants. Offering choice and flexibility should therefore be a given in any research.

In their exploration of the challenges faced by researchers seeking the views of young people with autism, Scott-Barrett et al. (2019) draw together the key strategies that researchers found to be successful in supporting children and young people with communication difficulties to share their views and experiences. These included seeking guidance from practitioners and parents prior to data gathering, and additionally, spending time in the young person's environment. This familiarisation, rapport building and information gathering enabled a tailored approach to subsequent data gathering. The use of visual supports and providing a range of response options were also key to robust research outcomes.

These approaches were incorporated into the research currently being undertaken by one of the authors. They enabled a more empowering experience by providing multiple means by which a participant could communicate with the researcher. For example, information sheets and consent forms were written in Easy Read format (see Australian Government, 2024). This means using plain English, keeping text short, having pictures or symbols alongside the text, keeping the font simple and large, and placing only a small amount of information on any given page. This approach ensured that participants understood the purpose and requirements of the study. Communication was further supported through a range of multimodal tools. Talking Mats allowed participants to organise and respond to questions by physically moving topic symbols (see Figure

1) while core boards provided a set of symbol-based 'core vocabulary' which allowed participants to respond by pointing to symbols on the board. Other visual supports, such as 'need a break' cards, offered a non-verbal way to pause or end the interaction (see Figure 2).

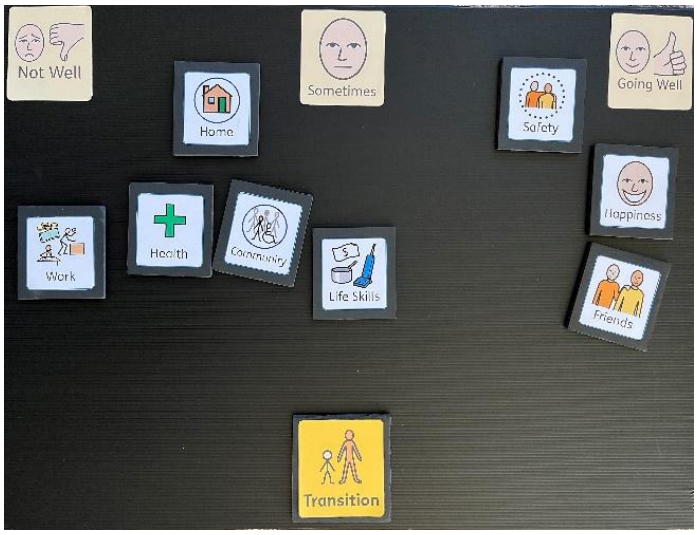

Figure 1. Talking Mat Example

Figure 2: 'Need a break'

These tools meant participants had a range of ways to communicate and could choose what suited them best at any given time. They also allowed participants some control over the pace of the interview, when to start and stop, when to move onto a different to topic, and when a break might be required. For example, one participant declined the visual supports at first, but later picked up a topic card and core board to ask the researcher a question. Having the visuals in sight meant she could choose her own moment to communicate, and the card gave her a way to start the interaction without needing to find the words or rely on eye contact. For other participants, the visual communication board provided a permanent record of topics, so nothing needed to be remembered. These tools enabled participants to offer longer and more detailed answers than what otherwise may have been the case.

These examples, and others like it, serve two important purposes. First, they help challenge limiting assumptions about children and young people whose communication abilities and preferences lie outside the 'norm'. They show us that such learners do indeed have valuable insights to share if only we provide the means to do so. Secondly, these studies also provide ideas about how we can modify traditional research tools and processes to accommodate different abilities and preferences.

CONCLUSION

In this article we wish to neither oversimplify nor minimise the challenges inherent in accessing the voices of children and young people with learning disabilities. Rather we wish to draw attention to the limiting assumptions that are often made about them and the ways in which this undermines their right to be heard. Too often, decisions are made about learning disabled children and young

people without ever asking them directly. This is not simply a missed opportunity; it is a breach of rights. Both the UNCRPD and the UNCRC are explicit that disabled children and young people must be consulted on matters affecting them, and that their views should be taken seriously. Addressing the current disjoint between policy intent and reality is also important because of what we learn from and about these students. Their perspectives are needed, alongside those of adults, for full and balanced understandings about their lives and aspirations. The insights they provide are critical to the advancement of inclusive policy and practices.

We have argued that children and young people with significant learning and communication difficulties can be active and authentic participants when researchers and practitioners take the time to develop and adopt flexible, multifaceted research methods. Offering a range of multi-modal data gathering methods that can be deployed flexibly, as well as becoming familiar with an individual's communication preferences prior to engaging in research, offer useful starting points for those considering undertaking research in this area. This requires planning ahead, presuming competence, being willing to adapt, and questioning the assumptions that can quietly exclude people. Strategies such as these not only protect communication rights but contribute to deeper understandings about needs, goals, and experiences than is otherwise the case. As New Zealand moves towards the goal of a fully inclusive, non-disabling society, we need to make sure participation rights are upheld for every child and young person, including those with diverse language and cognitive abilities. Doing so brings us closer to meeting our obligations under the UNCRC and UNCRPD, and to building an education system where all learners are included, valued, and heard.

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