
VOICES INTO ACTION: THE VOICES OF CHILDREN WITH PROFOUND AND COMPLEX LEARNING NEEDS

Introduction

This document draws on research conducted after a two-year drama project with children with profound and complex learning needs. Access the full paper for further information:

Whitehurst, T., 2007. 'Liberating silent voices – perspectives of children with profound & complex learning needs on inclusion' *British Journal of Learning Disabilities*, 35, 55–61. [doi:10.1111/j.1468-3156.2006.00405.x](https://doi.org/10.1111/j.1468-3156.2006.00405.x)

According to Whitehurst, the overall aim of this research was 'to empower students by giving the right tools to enable them to respond and influence the world'. The research aimed to enable learners with learning disabilities to share their perspectives.

Communication with learners with profound and complex learning needs depended on:

- Appropriate communication mechanisms for each learner
- Sensitive interpretations
- Power relationships in the exchange
- Attitudes established over time.

Consent and assent

Informed consent cannot always be gained from learners with profound and complex needs. However, steps can be taken to gain consent from parental and school authorities, in addition to participants' assent.

Permission and consent may be gained from some schools and organisations through channels such as an ethics committee or board of trustees. When official consent is requested, it is important to share full information about the research aims, purposes, methods and anticipated outputs. Furthermore, the researcher should use each individual participant's preferred means of communication to gain assent, explain what is involved and ask if they wish to take part.

Confidentiality and anonymity

It may not be possible to guarantee full confidentiality when working with groups of learners with profound and complex needs. However, as far as possible, views expressed

and contributed must be respected and reported authentically, ensuring that learners are anonymous and their views are presented respectfully and ethically.

Specialists and experts

Specialists and experts who know each participant well are essential to the process. They should be involved in gaining assent, determining the appropriate means of communication unique to each participant in a known environment, and interpreting responses.

These experts may be speech and language professionals or other members of education or care staff in a special school or unit. It may be necessary, or preferable, to use more than one expert for each learner. One may facilitate the communication system, another may help to conduct the interview and another may attend to issues of care, such as reducing anxiety.

The interviews should be individualised to each participant. The researcher must meet the specialist team well in advance to discuss what sort of information is to be gained from the interview, the limitations of the process and the individual participant's specific needs and interests. This will allow the specialists time to prepare images or other necessary resources and advise the researcher on any limitations, such as those of time, duration and place.

The use of photographs may enable participants to understand and respond to the questions and convey their answers. Experts familiar with each learner will know the context and extent of the learner's understanding and will help formulate the questions with appropriate images to elicit responses.

Interviews may use a combination of photographs, images, symbols and verbal communication by the person working with the participant. Communication systems, such as Makaton or Talking Mats, may also be used if participants are familiar with these.

Makaton is a unique language programme that uses symbols, signs and speech to enable people to communicate. It supports the development of essential communication skills such as attention and listening, comprehension, memory, recall and organisation of language and expression. ([What is Makaton?](#))

Talking Mats offers participants a way to indicate their preferences/responses to straightforward options, by placing a picture or symbol on a prepared 'mat' (such as 'like' or 'dislike') and allowing them to communicate a range of emotions. Specialists familiar with individual learners can enable more detailed and nuanced views to emerge, using a combination of methods.

Talking Mats is an evidence-based visual communication system, based on symbols and images, in both physical and digital versions. Talking Mats aims to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about the things that matter to them. ([Talking Mats](#))

Reliability and validity

Reliability and validity of interviews with learners with profound and complex learning needs depend on the authenticity of the process, with the involvement of experts and specialists that the individual participants trust.

It is recommended to conduct brief semi-structured interviews with the care and education specialists who work closely with the participants. Through these interviews, they can share perspectives on the participants' everyday experiences and offer knowledge and understanding of their backgrounds. This information can strengthen the data from learner interviews.

Difficulties and challenges

There are challenges in hearing the voices of those who have been silent and overlooked, but these can be addressed through careful planning and anticipation. In planning, implementation and interpretation of findings, it is vital to consider all ethical issues that may arise.

Evidence from earlier research demonstrates that learners with profound and complex difficulties have views, opinions and preferences and know what is important to them, just like other learners. It is our obligation to ensure they have the same opportunities to make their voices heard, no matter how challenging that might be.