Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have 'a voice'

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Aim: This study aimed to investigate the experiences of children and young people being educated in residential special schools, with a particular focus on how their rights and well-being were being promoted by their schools.

Method: The study was conducted using participatory research principles and aimed to develop techniques and approaches that would support the inclusion of all children.

Findings: The findings indicated that the techniques developed during this study helped to provide insight into the experiences of pupils with a wide range of special needs, and facilitated their voices. The piloting of a method that integrated ethnographic observation techniques with checklists adopted from the SCERTS framework (developed by Prizant and colleagues) provided important insights into the experiences and preferences of children with the greatest learning and communication needs, and is an approach worthy of further development.

Limitations: The study was conducted over a very short time frame, one academic term, which influenced the time available to refine techniques and work with our young researchers' group. Whilst every residential special school in England was invited to participate, the sample was based on those schools that volunteered, many with good and outstanding Ofsted ratings. Therefore, the sample may not be fully

representative of the range of experiences provided by residential special schools in England.

***Conclusions:** The development of specific techniques to facilitate an understanding of the views and experiences of children who experience significant challenges in communication is possible. The knowledge, skills and expertise of educational psychologists and other professionals can be harnessed to respond creatively to this challenge and it is important to acknowledge the reciprocal value of professional practice and research skills.*

***Key words**: Residential special school, children's voices, children's rights, participatory research techniques, research methods for use with children with special needs.*

This paper describes the development, and critical review, of a range of research and assessment techniques that were used to facilitate the voices of children and young people who were being educated in residential special schools. The study was funded by the Children's Commissioner for England and aimed to examine the experiences of these children, with a particular focus on how their well-being and rights were being promoted and facilitated by their schools. The special school population is extremely diverse and includes many potentially vulnerable children and young people. In undertaking the study, the researchers were aware that many of the participants would experience challenges in communication. A key aim of this study was to ensure that all children were able to contribute their views and have their voices heard, even for those who found verbal communication particularly challenging. A full account of the study is provided in Pellicano et al. (2014).

Protecting children's rights

The key aim of the study was to ascertain how residential special schools were protecting and promoting the requirements of the United Nations Convention on the Rights of the Child (1989). The UN Convention requires that all children should have access to an education that helps them to develop to their full potential. Furthermore, the Convention acknowledges that children and young people with special educational needs and disabilities are likely to experience significantly greater challenges in achieving this aim. The Convention provides additional support for these children through Article 23, which requires that children with disabilities have the same rights and entitlements as all children, namely to live a full and decent life in conditions that promote independence and the opportunity to participate in their community.

Of particular relevance to this study was the requirement of Article 12 of the UN Convention, which explicitly states that children have the right to participate in decision-making about their lives. It is required that all children have these rights and that adults must facilitate all young people to have their views, feelings and aspirations elicited and placed at the centre of plans for their future. This requirement was noted by Shier (2001) to be 'one of the provisions most widely violated and disregarded in almost every sphere of children's lives' (p. 108). For professionals working with children and young people with special needs, and in particular those with complex, severe, profound and multiple needs, that are accompanied by major challenges in communication, this presents a considerable challenge. Creative and innovative approaches need to be be developed to facilitate this aim. In order to explore how residential special schools were supporting their pupils to express their

views, and have them taken into account when planning for their future, it was essential to develop techniques suitable for use with very a diverse population of children and young people with a wide range of complex needs.

Despite the vulnerability of children attending residential special schools there has been a remarkable lack of research conducted with this population. This is likely to be, in part, influenced by the challenges in gaining the children's views. Some studies that have focused on this population have concluded that it was not possible to elicit the perspectives of the children with the greatest learning and communication needs, (Rabiee et al, 2006). Furthermore, there is a paucity of research evidence to inform how this might be achieved (Cavet & Sloper, 2006). The Children's Act 2004 and associated government guidance highlights the importance of actively seeking and listening to the views of pupils (The National Minimum Standards for Residential Special Schools, Department for Education, 2013). Even so there remains a dearth of methods available for use with children and young people who are nonverbal, preverbal or who have emerging language (Goldbart et al., 2014). This situation perhaps reflects the danger of adopting a traditional approach to eliciting children's views. This paper argues that professionals have the ability to draw creatively on their professional knowledge, skills and expertise to develop techniques that promote the inclusion of all pupils, and seeks to promote practice-informed evidence.

The UN Convention places a clear responsibility on adults to engage in creative and developmentally appropriate ways of facilitating children's communication. In conducting this study, the researchers were aware that they would encounter groups of children that are frequently omitted from research studies. These are children who are described as having 'complex learning needs often with co-existing needs (e.g. autism and ADHD), or profound and multiple learning difficulties' (Carpenter et al., 2011, p.

3). Within the residential special school population this is a sizeable group; studies have suggested that as many as 46% of these children and young people are reported to be unable to use speech to communicate (Pilling et al., 2007). These young people are also often believed to have little agency, ability to voice experiences or opportunity to participate in society (Simmons & Watson, 2014 p.19). It was therefore of great importance that the researchers were able to understand the experiences of these children. During this study it was critical to develop methods and approaches that would ensure that the researchers were able to gain insights into the experiences and preferences of *all* children and young people. The ability to do so is a key responsibility for educational psychologists in discharging their responsibilities under the Special Educational Needs and Disability Regulations 2014 and the Children's Act 2004. Furthermore, the study provided the opportunity to engage in the reciprocal processes of practice-informed evidence that seek to promote evidence-informed practice. The research team for this study included three educational psychologists, a consultant speech and language therapist and two specialist researchers, and provided a fertile context in which to adapt and develop creative techniques and approaches.

Ethical issues

One of the overarching aims of this research was to explore young people's own views and perspectives about being educated and living away from home in a residential special school. In order to afford these children, who varied considerably in their cognitive and language abilities, the opportunity to participate in research of this kind, a number of ethical considerations were necessary. Ethical approval was granted from the UCL Institute of Education Research Ethics Committee.

Parents/guardians of children under the age of 16 provided written informed consent

for their child to participate, with the children themselves providing assent. Young

people aged 16 years and older provided informed consent for their own participation.

There were a number of instances in which the typical procedures for securing

consent would have precluded certain young people from participation, for instance,

where parents/guardians were non-native English speakers or had learning difficulties

that influenced their understanding of the information sheet and consent forms.

Further, some young people's language or cognitive abilities meant that

understanding whether they were assenting to participate was not straightforward.

Finally, young people who were over the age of 16 years, and did not have the

capacity to consent for themselves according to the Mental Capacity Act 2005, were

necessarily excluded from the research process.

To limit the impact of these potential barriers to participation the researchers

explained the nature of the research and consequences of participation over the

telephone or face-to-face so that parents could make a truly informed decision about

their child's participation. In addition, social stories (short illustrated descriptions of a

particular situation; Gray, 2010) were sent to schools in advance of research visits,

and researchers made multiple visits to schools to help prepare the young people,

allowing them sufficient time to process what would be involved, and ensuring they

had a meaningful role in the decision to assent to participate in the study. In cases

where a child could not verbally communicate a desire to withdraw from the study, a

member of school staff who was familiar with the child was present in the room and

informed the researcher if they believed the child was no longer willing to participate.

Furthermore, a red 'stop' card was present during the data collection, and children had

been informed that they could point to the card at any time if they wanted to end their involvement.

The adjustments made to the consent process in this research project resulted in a sample of young people that was more representative of the population of those living in residential special schools than would have been possible if the standard procedures had been followed. This meant that no children or young people were excluded from the study, other than those of the over 16s who were judged not to have the capacity to consent for themselves. It is especially important in research such as this, where an express aim is to include the voices of those so often marginalised from participation in research, to take care in addressing ethical considerations that may inadvertently contribute to the continued exclusion of certain groups.

Future research with similar populations should consider the language and communication preferences of those likely to participate in their research. If these vary to a large extent, as they did in this research, we would encourage researchers to design multiple methods of securing consent availing of audio or video recorded information clips. It is important to allow enough time for researchers to become familiar with the participants before they are required to make a decision about participation. Using this additional time to create social stories with pictures and symbols to support understanding of the nature of the research, will help to ensure that participants give informed consent.

When conducting research that relates to young adults who are judged not to have the capacity to consent for themselves, a careful process of securing permission needs to be presented to the institutional review board responsible for ethical oversight of

the project. This will help to ensure the access of this group and to enable them to share their stories with researchers.

Methodology

The full study employed a mixed methodology, which included the collection of both qualitative and quantitative data. This paper focusses on the qualitative techniques employed to elicit the child's 'voice' Data were collected from children and young people, and their parents, carers, teachers, care staff and other professionals working within the schools. It was a core aim of the study that the children and young people were central to the research process and that they should contribute to the design of the study, advise on data collection techniques and the analysis of the data, and help to steer the research process. It was essential that the issues that they considered to be of greatest concern were not subsumed by those of adults. The study was guided by participatory research (PR) techniques.

Participants

83 children and young people participated in the study. The age profile ranged from 8 years 3 months to 19 years 8 months and the gender profile reflected 50 boys and 33 girls. The participants had a wide range of needs and disabilities. The child or young person's primary need, as identified by their statement of special educational needs, was used to define the profile of the study population: attention deficit hyperactivity disorder (ADHD; n=2), autism spectrum disorder (ASD; n=44), behavioural, emotional and social disorders (BESD; n=3), severe learning difficulties (SLD; n=1), epilepsy (n=3), hearing impairment (HI; n=11), moderate learning difficulties (MLD;

n=3), profound and multiple learning difficulties (PMLD; n=2), speech language and communication needs (SLCN; n=13) and visual impairment (VI; n=1). Many of these young people, however, had multiple needs.

Participatory Research

The literature that describes the uniqueness of participatory research (PR) methods accentuates the value of empowering participants in the research process. Examples of PR have shown how participants are encouraged to make decisions about, and guide the topic of research, to have control over the collection of data and to assist in the interpretation process (for example, Greig et al, 2013; Thomas & O'Kane, 1998). Applying PR methods with children with SLD and PMLD however, requires more thoughtful and deliberate consideration.

Shier (2001) refined Hart's (1992) eight rung ladder of participation, describing a five step model of participatory approaches that reflected:

- Children being listened to,

- Children being supported in expressing their views,

- Children's views being taken into account,

- Children being involved in decision making processes and

- Children sharing power and responsibility for decision making.

An adaptation of the work of Cornwall (1996) and Truman and Raine (2001) describes six degrees of participation that reflects movement from the more traditional research paradigm to a more radical approach. These levels of participation reflect:

- **co-option**, a tokenistic approach where users are represented but are not actively involved in the research;

- **compliance**, where users are assigned tasks but researchers decide the research agenda and processes;

- **consultation**, which seeks their opinions but researchers lead the analysis and research agenda;

- **co-operation**, which reflects users working alongside the researchers to determine priorities but the responsibility for the research process remains with the researchers;

- **co-learning,** which reflects a process whereby users and researchers share their knowledge to develop new and shared understandings and in partnership develop and conduct the research activity;

- **collective action**, where users set the research agenda and conduct the research without outsider involvement.

In this study the aim was to engage children and young people in working at the levels of consultation, co-operation and co-learning. This was achieved through the development of a young researchers' group. Davis, (2009) highlights the challenges of developing a 'gold standard' of participatory techniques and advocates a pragmatic approach based on what is possible within time, ethical and budgetary constraints. There were many challenges in operationalising this study, in terms of the time frame

for the study, which restricted the opportunities to build relationships with our young researchers, and to consult adequately with them when analysing the data. Furthermore, this added to the challenges in developing and piloting creative techniques to enable the full involvement of all participants. Despite these constraints, the findings indicated that the approaches developed, through co-operation and co-learning, that are described below have considerable potential for providing greater insight into the rights, entitlements, experiences and opportunities provided to our most vulnerable learners within their residential school settings.

The Young Researchers' group

From the inception of the study we developed a Young Researchers' group to advise, support, steer and report on the study. The group included children and young people aged from 13 to 19 years and reflected a wide range of special educational needs and disabilities, including: severe learning difficulties, autism, ADHD, social emotional and mental health needs, hearing impairment and the deaf, and those experiencing challenges with verbal communication. They were all attending one of two special residential school provisions. The diversity of group meant that some young researchers were more able to communicate their experiences verbally than others, but all were able to support and contribute to the research agenda. We used interpreters and key workers to support access to discussions where necessary. The Young Researchers' group advised on all stages of the study, including helping to identify key issues for investigation and advising on and piloting appropriate methodologies. They verified the themes emerging from the data and led on the development of an accessible form of the report (available here: bit.ly/1yAD9NN), and helped to

disseminate the findings at the House of Lords in December 2014. The Young
Researchers also made a short film of their experiences.

Approaches and techniques developed and employed in this study

What follows is a description of some of the approaches to data collection that were
employed in this study. The techniques were selected to be relevant to the diverse
range of needs that were to be encountered during the study, and to help elicit views
from all participants. The procedures adopted were based on the insights gained
through the professional experiences of those conducting the research.

The Graffiti Wall

Background

The Save the Children study by Fajerman et al. (2004) considered the Graffiti Wall
approach to be suitable to use with children of all ages and abilities who are able to
write, or to do so with assistance. The approach has been used in health care settings
to obtain children's views and perspectives on their treatments, (Mathers et al., 2010).

Procedure

The activity involves providing children and young people with appropriate stimulus
materials, either through verbal discussions, written materials or video prompts, to
help capture their perspectives and experiences of a particular phenomenon. The idea
is to enable them to describe both positive and negative views. Typically, the

participants are then given access to a wall, large white board, or sheet of paper, on which they can record their responses to stimulus questions about their experiences. The wall should be located in place where they can write without inhibition, and in their own time. However, the wall should be monitored regularly to ensure that it is not misused.

Adaptations

The technique was adapted during this study to involve the use of Post-It notes. Two distinct colours were used and the participants were asked to use one colour to write or draw all of the 'good things' about school and the other to record or draw the things they 'didn't like' so much. Given the diverse profile of needs in our sample the stimulus session included visual supports and prompts that were specifically tailored for each small focus group. In some cases, children and young people were accompanied by their key workers to help them to contribute their views, but most participants were able to work alone. Some children drew their responses, some wrote, others used symbol communication techniques to enable their key workers, or the research team, to record for them. The Post-It notes were then all gathered together and stuck on a wall and shared with the group to support a wider discussion.

Critical evaluation

The graffiti wall was a very popular and effective technique. Many children and young people were able to participate with minimal support from the researchers. The use of Post-It notes that were written in privacy or with 1-1 support enabled children to express their views without them being clearly attributed to an individual, and

unconstrained by the views of others in the group. The approach was readily adapted

to the diverse needs of each focus group. Participation was enthusiastic and it was

clear that all children had strong views they wished to communicate which provided a

very rich picture of the participants' experiences.

Limitations

Whilst the approach worked extremely well with a wide range of participants, those

unable to record were able to work with key workers or researchers to facilitate their

participation. The use of key workers was important for those who had challenges in

communication but, of course, it may have inhibited their ability to express negative

views if they were concerned about how these might be viewed, or if they related to

their relationship with their supporter. These issues could be managed by using the

researcher as facilitator, but this would require time to build relationships and to

develop an understanding of each young persons' communication style.

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Diamond Ranking Activity

Background

The Diamond ranking activity is a tool devised to enhance and facilitate discussion,

and has previously been used as part of a participatory research project with children

(O'Kane, 2008). Other studies have also demonstrated the versatility of the diamond

ranking activity, by adapting the approach using photographs instead of statements

(for example, Niemi et al., 2015; Woolner et al., 2010). For example, Niemi et al. (2015) gave cameras to the children and asked them to take photos of their learning activities in school, which they then evaluated with their teachers through the use of the diamond ranking activity.

Procedure

The activity is typically completed in pairs or small groups and involves the ranking of a number of statements (usually nine) in order of importance. The statements are ranked and presented in the shape of a diamond so that the statement which is considered to be the most important is at the top point of the diamond. Two statements are then placed below this and are considered to be of equal value to each other. On the third row of the diamond, three statements are chosen which represent medium significance or importance to the participants. The fourth row consists of two statements of equal value, further lessening in importance, and the final statement at the lower tip of the diamond indicates that of the least value. The worth of the task is not necessarily the final order of the statements, as there are no 'right' answers, but the process of discussion, reflection, reasoning and negotiating of the prioritisation (Clark, 2012).

Adaptation

In this study we adapted the work of O'Kane, (2008), who had elicited nine statements during interviews with looked-after children regarding making decisions about their lives. These were then used as statements in a diamond ranking activity with these children. In this study the nine statements were revised using adapted

language and the use of animated widget symbols below each statement to aid the children's understanding.

   The diamond ranking activity was conducted with pairs of young people and in individual interviews. Initially the statements were discussed to ensure that the participants understood them and considered them relevant. The process for sorting the statements, as outlined above, was then explained to the child, or pair of children. As the child sorted the statements this facilitated a discussion of the way they were ranking them and allowed each individual or pair to develop a narrative about their experiences and to articulate their views and preferences.

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Critical evaluation

This approach provided a very useful framework for facilitating children to reflect on their experiences and to develop their views about their life at school. O'Kane (2008) discusses how 'active' forms of communication, that involve completing activities, were more effective and engaging for some young people, rather than 'passive' communication techniques, such as talking in interviews. Indeed, in this study it was noted that some young people, and in particular those on the autism spectrum, felt uncomfortable being the focus of questions in an interview. However, they coped far better with this technique, which aided their reflections and enabled them to discuss their choices.

Furthermore, the diamond ranking activity reduced the power imbalance between the researcher and participants, as some young people played a very active role, either as individuals or in pairs, in determining how the task was to be completed. One pair completed the activity with minimal facilitation from the researcher. They made their own rules for completing the task and engaged in detailed discussions about each statement.

Limitations

This task requires high levels of reasoning ability, and if children are required to explain their choices it also demands quite advanced language skills. There were times when some children found it difficult to explain *why* they had chosen one statement to be more important than another. The diamond configuration is quite arbitrary, and other ways of organising the statements might be just as useful.

Techniques developed for children and young people with complex needs and limited communication skills

As noted above a key aim of study was to facilitate the views and experiences of all those pupils attending residential special schools, regardless of the severity of their communication needs or cognitive abilities. Accessing the views of this population is notoriously challenging, and according to some researchers may be of questionable reliability and validity (Cummins, 2002). Furthermore, even those researchers committed to inclusive research methodologies note the difficulties of developing appropriate research methods and interpreting data gathered from pupils with PMLD (Nind, 2013; Walmsley & Johnson, 2003). These populations often have idiosyncratic

ways of communicating and may require familiar adults to support the interpretation of their communication (Bellamy et al., 2010). The two models described below were specifically developed for, and piloted with the SLCN and PMLD populations in this study with these considerations taken into account.

School preferences cards

Background

This technique was developed to support work with children who have significant communication challenges and for those with learning difficulties. The approach is based upon a profiling tool previously used with autistic adults with additional learning disabilities to explore their sensory preferences. The Kingswood Sensory Preferences system (Brand et al, 2012) consists of 75 photographic cards, each illustrating a type of sensory experience, labelled with simple phrases (for example, a photo showing a person looking at a TV screen, labelled 'watching TV'). Users are asked to sort the cards into positive, negative and neutral categories, labelled 'like/seek' (thumbs up cartoon); 'don't like/avoid' (thumbs down image) and 'OK'.

Adaptations

To access participants' views on their residential school experiences, photo cards were prepared based on photographs taken within each child's school. This allowed the researchers to target the places, people and practices that might capture the key issues that had been identified by the Young Researchers' group. Our response categories were slightly simplified to allow a binary response, alongside the 'neutral' category (thumbs up/down image, labelled 'yes/like' and 'no/don't like' and 'OK').

We also developed a small set of cards symbolising emotions or properties to extend the initial sorting procedure. These were based on the Picture Exchange Communication System (PECS) symbols, but were selected for the transparency of their meaning to non PECS users. These were intended to allow users to add a level of explanation to some of their choices.

A range of cards was used to address each theme. For example, a photograph showing a classroom visual display of rules related to the theme 'how things are run', and an image of a school bedroom contributed to the theme 'living at school'. We produced sets of approximately 35 cards per school, but as few as 10 cards were presented to students with lower attention levels.

It has been claimed that methods for eliciting the views of students with PMLD are liable to be over-interpreted (for example, Ware, 2004). To be certain that students' responses were valid, that is related to the intended topic and not to incidental features of the image, it was critical that photographs bore a clear and direct relationship to the theme addressed. We selected images with least potential for ambiguity in interpretation, as agreed between researchers. Labels reflected school terminology (for example, 'the residential', for the after-school accommodation).

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Procedure

Participants were introduced first to the cards representing the sorting categories, with signing to support understanding of 'like', 'dislike' and 'don't mind'. Participants

were shown each photocard and asked to place it next to their choice of response category. Researchers noted any cards that received particularly positive or negative responses. These responses were queried again, and participants asked to match the photocard with one of the selection of emotion/property labels (for example, sad, bored, cold). In this way, the activity acted as a visual questionnaire tapping children and young people's school/living preferences. No expressive language and minimal receptive language was needed to respond.

Critical evaluation

Introducing photographic images reflecting aspects of the child's everyday environment was effective in capturing participants' interest and establishing common ground between researcher and participant in a short space of time. Results with participants with both PMLD and SLCN suggested that the cards were able to focus attention and communicate concepts. Expressive non-verbal response, such as excitement and smiles or silence, suggested that the exercise was meaningful to participants. The face validity of responses appeared good: for example, a PMLD school used a personal communication book to facilitate students' choice of activity throughout the day. The photograph representing this tool was well liked, though the image did not appear to be intrinsically attractive.

Interestingly, some pictures appeared to act as emotional cues. For example, a card showing the staircase leading to the residential area, labelled 'arriving in residential', aimed to explore participants' primary responses to entering the boarding environment. In spite of the cartoon characters decorating the walls, a 9-year-old participant placed this in the 'dislike' pile, choosing two negative emotion symbols.

He said: 'don't like … make me sad. Miss mummy.' In examples like this, the technique appeared to be successful in accessing authentic responses.

Limitations

The selection of pictures and captions to communicate clearly and accurately the desired concept is critical to the success of the technique, and may be time consuming. Even with this, careful consideration needs to be given to the degree of inference involved (Ware, 2004).

Since most SLCN and PMLD schools practise a form of picture communication system, many students are practised in communicating with pictures. However, in this research a small number of participants responded to the cards as sensory stimuli without representational intent. In our attempts to understand the motivations underlying participants' responses, there were some successes using emotion symbols. However, there are clear limitations in offering a small number of emotions options.

An ethnographic observation approach using SCERTS communication checklists

Background

In accessing the 'views' of children with complex needs, it is often more apt to examine their expression of preferences, as determined by their communicative behaviour, and their experiences with others within their natural environments. The *SCERTS* framework ('Social Communication, Emotional Regulation and Transactional Support', Prizant et al., 2006) is a comprehensive multidisciplinary

approach to enhancing communication and social abilities of those on the autism spectrum and with related needs. The assessment process emphasises an analysis of dynamics between the child, their natural environment, and the methods that adults were using to support them (Prizant et al., 2003). A method was designed which utilised both ethnographic methods and structured observations to capture and describe the type and nature of interactions between these children and their carers across a variety of settings and with different communication partners.

Observation Tools

Structured observation

A structured observation time sampling technique was used to capture the frequency and nature of children's spontaneous communicative behaviour and how their adult communication partners interpreted these behaviours. Particular attention was paid to the times that children made choices, expressed emotions and shared preferences and how these were responded to by adults. Furthermore, the schedule recorded the frequency of the adults' initiated interactions, the supports they used and how the children responded. It was also noted whether or not bids for interaction led to reciprocal interactions.

Adapted SCERTS Observational Checklists

Four checklists were used to capture the nature of theses adult child relationships.

- *Social Emotional Growth indicators:* This checklist consisted of 40 observable, developmentally appropriate behaviours relating to the child's joint attention,

social communication and emotional regulation behaviour under the headings: 1) happiness; 2) sense of self; 3) sense of other; 4) active learning and organisation; 5) flexibility and resilience; 6) cooperation and appropriateness of behaviour; 7) independence; and 8) social membership.

- ***Expression of Intentions and Emotions Worksheet****:* This checklist was used to record the presence of socio-communicative behaviours, for example requests for desired food, taking turns, comments on an object and expresses happiness. Whether the young person used pre-symbolic means of expression, for example, eye-gaze, facial expressions, reaching, showing, waving, or symbolic means, for example, delayed echolalia, sign language, or if a picture system was used. All of this data was documented.

- ***Interpersonal Supports (social adaptations):*** This checklist has 33 items, which describe how a child's partner modifies their own social behaviour to 1. Be responsive 2. Foster initiation 3. Respect independence 4. Set the stage for engagement 5. Provide developmental supports 6. Adjust their language and 7. Model appropriate behaviour.

- ***Learning Supports (environmental adaptations):*** This checklist has 25 items, which describe how an adult adapts the environment to 1. Structure activities for active participation 2. Provide augmentative communication support to foster development 3. Provide visual and organisational supports 4. Modify the goals, activities and learning environment

Procedure

First, information was collated about the context and the activity in which the child was participating. The structured observation schedule was then completed at 60 second intervals and supplemented by photographs, which the researcher took every 10 minutes. Finally, at the end of the activity, SCERTS checklists were completed to give an overview of communicative and regulatory behaviour used by the children and the nature of any environmental or social supports provided by the child's communicative partner that either hindered or helped the child. This process was repeated for each activity the researchers observed resulting in a series of discrete observational data depicting the sequence of a child's day.

These structured observations were combined with ethnographic methods, in which the researchers spent extended periods of time with the children and young people. This facilitated the researchers to observe their transitions from the residential setting into the school context. Furthermore, as part of this approach the researchers were involved in unstructured interactions with the young person, conversations with staff supporting the child, and engaged in activities with the child. Notes and observational data were collected throughout the day focussing on the child's activities, their environment, the nature of the support given by staff and the amount of choice they were perceived to have during the day. This additional information provided a rich picture of the child's life at school.

Table 1 shows an activity using a SCERTS approach with one child.

[TABLE 1 ABOUT HERE]

Critical evaluation

The researchers integrated ethnographic methods, observational data (observation schedule) with criterion referenced components from a research-based framework (SCERTS), creating a rich, mixed methods narrative of children's experiences. This approach enabled researchers to create a discrete evidence base of context specific information, relating to the environmental and social modifications that adults made. These were then linked to the nature and purpose of children's communicative behaviour.

Researchers were able to make some tentative judgements relating to:

- Levels of participation experienced by children across a variety of settings and with different communicative partners

- The extent to which specific environmental and social modifications either supported or hindered children in sharing their views, needs and preferences.

- How interpersonal dynamics between children and adults develop over the course of an activity.

Limitations

Collecting and analysing this information was extremely time consuming, although it is widely recognised that meaningful interactions needs both time and flexibility on the part of adults working with children with complex needs. (Williams, (2005). Using the tools also required a high level of technical expertise on the part of the observer and, because the observations were conducted by a single researcher owing to time and resource constraints, it was not at that stage possible to establish their reliability. The methods, however, were designed with multidisciplinary practice in

mind, so it would be hoped that practitioners implementing this methodology would exploit the expertise of a range of professionals working with children. The study was also only concerned with gathering information and there would have been value in sharing successful strategies with children's education and residential teams as part of an assessment of reflective learning. Similarly, researchers only looked at how children communicated their preferences and ideas in the moment; it is still unknown how teams recognise and use these systematically to inform long-term planning related to children's lives. Finally, it would have been of great interest to the researchers to extend the parameters of this study to facilitate greater levels of involvement from children's families in analysing and interpreting children's interactions with their key adults. It is hoped that all of these issues could be explored in future studies, and in the implementation of participatory approaches.

Discussion

The findings of this study provides evidence to support professionals in fulfilling their statutory obligations, to help facilitate the voices of all children, in line with the requirements of the Special Educational Needs and Disability Regulations 2014, the Children Act 2004 and in the spirit of the UN convention on the Rights of the Child. The focus of the study was pupils attending residential special schools, of whom it has been noted above that up to 46% may be unable to use speech to communicate. The techniques and approaches trialled and piloted during this study proved effective in helping to facilitate insights, perspectives and voices to many of the young people in this population. The study also helped to question a number of factors that might have

contributed to the dearth of research with this vulnerable population, and the potential reduction in their opportunities to influence their outcomes.

The findings of the study challenge the attitudes and positions of a number of authors who have concluded that it is not possible to access the views of pupils with the most complex needs, including those with SLD, PMLD, autism and SLCN (Cummins, 2002; Rabiee et al.; 2006, Ware, 2004,). Simmonds and Watson (2014) have critically observed that conventional views regarding this population often inaccurately characterised these children as 'helpless and lacking in volition and intention' and 'are largely believed to have little agency, ability to voice experiences, or opportunity to participate in society' (p.19). The current study provides evidence that by embracing a more holistic conceptualisation of how children express their views, the dated and 'paternalistic' paradigm can be questioned. Furthermore, it is considered that these restrictive attitudes may have, perhaps unwittingly, contributed to the limited research in this area (Milton et al., 2014).

Increasingly researchers working in this field have highlighted how these negative attitudes often contribute to low expectations in those working with this population, and that this serves to limit their opportunities for participation in society (Crombie et al., 2014; Sheehy & Nind, 2005). Those advocating an alternative view of this population, dispute perceptions of these young people as passively responding to their environment (Burr, 2003; Davis & Hogan, 2004) and view them as active social agents when they are adequately supported, (Nind et al, 2010). During the study it was clear that many schools are actively promoting children's voices and are developing creative techniques to do so. It is therefore necessary for professionals working with, and conducting research with this population, to embrace a more holistic conceptualisation of how children express their views.

The ethnographic observation approach using SCERTS communication checklists, piloted during this study, helped to identify patterns of communication in children with the highest needs. The data highlighted how some communication partners are better at facilitating the young person's active engagement in making choices, and expressing preferences. This was often the case where the communication partner was very familiar with the child, and was able to understand their distinct means of expression, (Ware, 2004). This finding is significant, as during the study it was clear that whilst some schools recognised the importance of building relationships so that staff could attune to the young person, and help to optimise understandings of their preferences; others were concerned about maintaining professional boundaries and deliberatively changed key workers regularly. These are important issues for professionals to consider in making recommendations about future support. In addition, the evidence about observed patterns of communication could be used to help inform educational and therapeutic support plans. Whilst this technique is at early stage in development it does show promise and would benefit from further piloting and refinement.

Other factors that may have contributed to the dearth of research with young adults in this population may relate to the challenges in securing ethical approval for studies involving those over the age of 16, who are judged not to have the capacity to consent for themselves, under the Mental Capacity Act (2005). It is important to develop robust systems for securing consent, including working with others who know the young person very well, and to support the development of materials to ensure the young person is able to indicate that they want to participate, understand what is required of them, but also have the protected right to withdraw from a study at anytime. Managing these challenges is crucial both in terms of protecting the rights

and entitlements of these young people, and in ensuring that their experiences are understood and that their interests are promoted.

In conducting the study, the research team demonstrated that participatory research approaches are readily accessed by children and young people in the residential special school population, and that pupils with a very wide range of learning and communication needs are able to contribute to the research process given adequate time, support and facilitation. It was acknowledged that to support the inclusion and participation of all young people can pose challenges, but that in the main these require the adoption of a positive attitude to participation, flexibility and creativity, and the investment of adequate time. It may also require the support and participation of those who know the children and young people best. Davis, (2009) Nind, (2013). Given these conditions very high levels of active and meaningful participation is possible. The Young Researchers' group played an active role at each stage in the research process and helped provide vital feedback to ensure that the materials developed were accessible and appropriate and that the research was focused on the most important issues for young people. They helped with the analysis of data during meetings where preliminary themes were shared, refined and agreed. The Young Researcher's also contributed to the production of an accessible version of the final report, working alongside a cartoonist to capture the key messages. The group also contributed to making a short film. It was also deemed essential that they joined the research team to present the findings of the study at the House of Lords.

The techniques developed have been described above and show promise and helped to yield valuable data. The two new approaches, School Preferences Cards and the Ethnographic Observation Approach using SCERTS Communication Checklists have

demonstrated that they have potential to promote greater insights into the views and preferences of children with the greatest needs.

Strengths and Limitations

This study was of short duration and had very limited preparation time. This factor reduced our opportunities to work extensively with our Young Researchers' group at each stage of process and limited opportunities to trial and pilot the new techniques and materials developed.

However, this study demonstrated that in drawing on professional practice skills it is possible to engage with **all** young people and to develop creative ways to gain insight into their preferences and experiences during a research study. The challenges are to invest sufficient time and to find the best approaches to facilitate this aim. Breaking down the artificial barriers between professional practice and professional research will help to ensure the smooth transfer of knowledge, skills and expertise in both domains and ensure that intentions of article 12 of the UN convention on the Rights of Children is fully operationalised.

Conclusions

This study demonstrated that in developing research techniques that are suitable to enable the inclusion of children and young people with the greatest needs, the participation of professionals skilled to work with these populations in the research process is essential. Furthermore, it highlights the importance of synthesising evidence-informed practice to support the developments of practice-informed evidence. This reciprocal process will undoubtedly enhance both of the professional domains, practice and research. Furthermore, it clearly demonstrates the importance

of professionals engaging in the research process and questions the current divide between practice and research.

Furthermore, the evidence suggests that in order for professionals to meet their current statutory requirements it is essential to move away from traditional models and views of how to elicit children's voices, and consider using observation techniques, such as the one based on SCERTS, described here to make sense of patterns of behaviour and to reflect on how these provide insight into children's preferences.

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[NOTE TO EDITOR: I HAVE SHOWN BOTH THE COLOUR ORIGINAL AND A

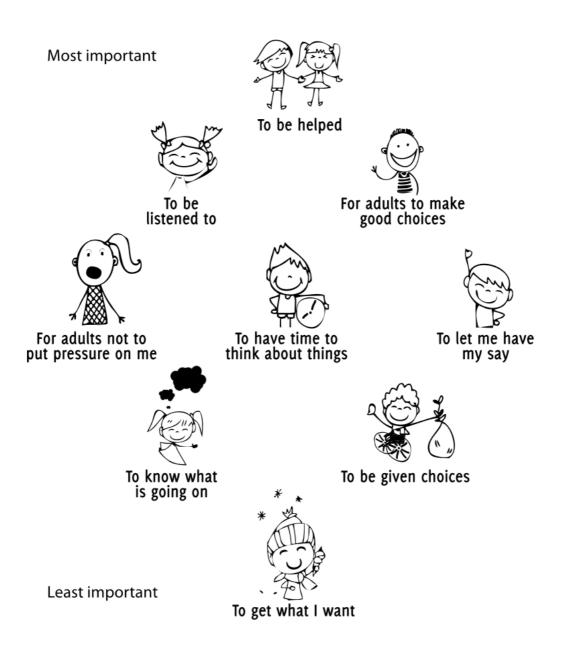GREYSCALE EXAMPLE OF IMAGE 1]

Image 1: Example of a Graffiti Wall Activity

[GRAYSCALE EXAMPLE OF IMAGE 1]

Image 1: Example of a Graffiti Wall Activity (note: the original is in full colour

Post-It notes)

Most important

To be helped

To be
listened to

For adults to make
good choices

For adults not to
put pressure on me

To have time to
think about things

To let me have
my say

To know what
is going on

To be given choices

Least important

To get what I want

[NOTE TO EDITOR: I HAVE SHOWN BOTH THE COLOUR ORIGINAL AND A

GREYSCALE EXAMPLE OF IMAGE 3]

Image 3: Example of School Preferences Activity

[GRAYSCALE EXAMPLE OF IMAGE 3]

Image 3: Example of School Preferences Activity

Table 1 Ethnographic Narrative data with associated SCERTS communication data

for Adam

Adam Activity 1		
Ethnographic Data	**SCERTS checklist**	
Narrative	**Adult's Supports**	**Adam's communication**
Adam had his own breakfast menu that had been individually designed for him with photographs of a range of food and drink. His teacher placed the pictures around him on the table and immediately as these were laid out, Adam picked a picture of cranberry juice and gave it to his Teacher. His Teacher left the table to pour the cranberry juice as he had requested and held it in front of him, with the photograph, and stated; 'Here's your cranberry juice'. Adam then tapped the visual and the juice was given directly to him. Through using this method, Adam chose toast and Nutella. While waiting for the breakfast, Adam looked at his Teacher, moving his head closer to his Teacher and looking directly into his eyes. He repeated this 5 times to which every time his Teacher would reciprocate and copy his movement, with a smile and sometimes with a nod of the head. After Adam ate his breakfast, he reached for his book, turned the page and chose cereal and toast, to which his Teacher responded that he needs to choose just one of these. To support Adam's understanding of his teacher's expectations, he held both pictures up in front of Adam and Adam chose the cereal. He was then shown pictures for options to put on his cereal – Adam chose honey.	**Uses AAC to foster development** Uses AAC to foster communication and expressive language (learning support 2.1) **Partner is responsive to child** Responds appropriately to child's signals to foster a sense of communicative competence (interpersonal support 1.3) **Uses AAC to foster development** Uses AAC to foster communication and expressive language (learning support 2.1) **Partner sets stage for engagement** Uses appropriate proximity and nonverbal behaviour to encourage interaction (interpersonal support 4.3) **Partner is responsive to child** Imitates child (interpersonal support 1.6) **Partner is responsive to child** Responds appropriately to child's signals to foster a sense of communicative competence (interpersonal support 1.3) **Uses AAC to foster development** Uses AAC to foster understanding of language and behaviour (learning support 2.2)	**Sense of Self** Makes choices when offered by partners (Mutual Regulation 2.6) **Social Membership and Friendships** Looks towards people (Joint Attention 2.1) **Sense of Self** Makes choices when offered by partners (Mutual Regulation 2.6) **Social Membership and Friendships** Looks towards **people (Joint Attention 2.1)** **Social Membership and Friendships** Engages in extended reciprocal interaction (Joint Attention 1.4) **Independence** Responds to visual cues (Symbol Use 2.6) **Independence** Makes choices when offered by partners **(**Mutual Regulation 2.6)