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Disabled children and young people
Empowered and Effective Decision Making: Consultation Report

Disabled children and young people

Making choices and participating in everyday decisions: Consultation Report

Contents

Executive summary

Empowered and Effective Decision Making is an action research project, funded by the Scottish Government, and is a partnership between Capability Scotland and the Centre for Research on Families and Relationships (CRFR), a cross-university centre based at The University of Edinburgh. The full report sets out the aims of the project, and reports on initial consultations with young people, families and professionals.

Background

▶ Empowered and effective decision-making is an action research project that aims to understand when and why disabled children and young people feel empowered to make their own decisions
▶ Phase one consulted with 17 young people age 12-16 years, 18 staff and 8 parents across four diverse schools to identify approaches and strategies that may help young people make informed and effective decisions

Decision-making contexts

▶ Young people were involved in a number of decisions including everyday decisions about washing, eating and dressing, decisions about leisure activities, their health and therapy sessions, and decisions within the school day

Decision-making strategies

▶ Communication methods were a key feature of involvement in decision making for some young people, and a range of these are described in the full report
▶ Practitioners and parents employ a number of tailored strategies to enable young people to make decisions including goal setting, feedback forms, developing key signs, and trying out communication methods for themselves
▶ Particular strategies are used with young people with autism, including establishing routine, clear systems for choices between options, and a good lead in time for new activities

What helps young people make effective decisions?

▶ Parents and practitioners having an **attitude** that young people should be involved in decision-making

▶ **Being familiar** with young people, their methods of communication, and ways of being can help with interpretation of choices

▶ A level of **expertise** amongst staff that enables young people to communicate their choices well

▶ **Good communication** networks between those who care for and support young people

▶ **Ongoing training** in communications methods and approaches

▶ Having a **high staff ratio** to enable enough time to facilitate effective decision-making

▶ Suitable **equipment** especially technology and support aids

▶ Adequate **financial resources** for the staffing and equipment

▶ Using a **diverse range of tools and strategies.**

What hinders young people making effective decisions?

▶ Cognitive ability can sometimes impair decision-making

▶ Parents being over-protective of their children in terms of what they might do

▶ Lack of awareness in society about the needs of disabled young people

▶ Young people's reticence and lack of confidence

Next steps

▶ These findings will be taken forward into phase two of the project which will work closely with a few young people to explore and expand the range of decisions they make in everyday life through action research

▶ Emergent learning gathered through the action research on what tools strategies and approaches work well will be disseminated with partners and stakeholders throughout the country

Background

Rationale

Research commissioned by the Long Term Conditions Alliance Scotland and for Scotland's Disabled Children (Scotinform, 2011[1]), has highlighted problems in relation to disabled young people's role in making decisions about their lives, and the poor outcomes faced by disabled children and young people as a result. The evidence showed that disabled children: were more negative about the levels of autonomy they had compared to the European average; were much less involved in social interaction with their peers; and had lower scores for psychological well-being. However, they did report better success in being listened to at school than in other services.

Research collated by About Families[2] in 2010 highlighted the impact parents may have on the decision making of disabled teenagers. Unpublished research by Napier University from 2009, using data from the Cerebral Palsy Register for Scotland, also supported the findings.

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1   Scotinform (2011), I want to behe same as my brothers!, LTCAS & FSDC.
2   Mountney, K. (2010), Parenting Teenagers: Relationships and Behaviour - About Families.

Research aims

Whilst there is strong evidence of the disempowerment of disabled children and young people in decision making, and the struggle that they have in getting their opinions across, there has been little attempt to establish what actually works and assists them. This current project will attempt to better understand when and why children and young people feel empowered to make their own decisions and establish parents' and practitioners' roles within this. The project will aim to identify and evaluate ways of addressing a situation that currently may prevent disabled children and young people from taking a central role in decisions about their life. The project investigates the following questions:

▶ What do disabled children and young people feel support and hinder them to make informed and effective decisions?
▶ What do parents/carers feel support and hinder their son/daughter to make informed and effective decisions, and how do they see their role in supporting their child in the process?
▶ What do practitioners feel help and hinder the young person to make informed and effective decisions, and what is their role in this?
▶ What tools, approaches and strategies work well and what does not work so well?

Research process

Literature review: The project is informed by a literature review conducted by the Centre for Research on Families and Relationships (CRFR), in order to understand the key issues, provide a framework and context for the research questions, and identify potential ways forward.

Research Phase 1: explores the research questions with a sample of young people, families and professionals, aiming to identify strategies and approaches that may help disabled children and young people to make informed and effective decisions.

Research Phase 2: some of the tools, strategies and approaches identified in Phase 1 will be trialled, their effectiveness assessed and the results shared with young people, parents and practitioners across the country.

Intended outcomes

Improving disabled children and young people's ability to make decisions can help meet the Scottish Government Performance Framework National Outcome of developing successful learners, confident individuals, effective contributors and responsible citizens. It can also help embed the GIRFEC principle that children and young people should have their views listened to and that they should be involved in decisions that affect them.

The project aims to ensure that disabled children and young people are:

▶ listened to carefully by parents and practitioners, who will hear and understand their wishes as a result of better awareness, of both the impact of their actions, and of approaches for improving consultation
▶ more appropriately involved in discussions and decisions that affect them, as a result of the identification of proven tools, approaches and strategies for achieving this
▶ better able to source, and rely upon, appropriate support as soon as possible to help them make their own decisions

Creating Smiles

Methods

Young people's participation

The project aimed to consult and work with up to 20 disabled young people, aged 12 to 16 years old, with: mild to moderate learning disabilities; severe and complex needs; physical disabilities; additional support needs; and autism. The literature had highlighted the fact that disabled children and young people are far from being a homogeneous group, but include a broad range of complexities concerning competencies, experiences and challenges (Davis and Watson 2002; VIPER 2013; Cavet and Sloper 2004). The recruitment strategy allowed for exploration of some of this diversity.

The literature review highlighted the importance of gaining opinions directly from disabled children and young people themselves, and so it was important to conduct consultations with the young people, independently of their parents, to ensure that the young people's opinions were not subsumed within their parents' opinions. A report by the World Health Organisation (2010), states that, "Far too often well-meaning adults, including policy-makers, service providers, parents and care-givers make decisions on behalf of children with intellectual disabilities without consulting about those decisions, which have a direct impact on their lives." It was also found that the views of parents were often sought over the views of their disabled children, despite the fact that children's and parents' views may differ.

The research aimed to consult with up to 20 parents and practitioners, including teachers, support workers and therapists. The literature review also drew attention to the key relationships in the young people's lives, noting that these can either enable or inhibit participation in decision making (Davis and Watson 2000;2001; Billington 2006; Murray 2001; Lightfoot and Sloper 1999). It was therefore decided that parents and practitioners, who care for and support the young people, should also be consulted, as the quality of these relationships were at the core of potential meaningful participation.

Research by Scotinform (2011) highlighted the relative success of schools in listening to, and empowering, disabled children and young people. For this reason, it was decided to begin the research process within the school environment.

Sampling

Four schools across Scotland were selected who, between them, provide an educational environment for children and young people with a broad range of disabilities:

▶ Schools 1 and 2 are specialist schools for day and residential pupils, aged five to 18 years, who have severe and complex needs
▶ School 3 provides education and supported accommodation services to children and young people with additional support needs, specialising in autism

► School 4 is a mainstream secondary school that includes young people with a disability, and also has an Additional Support Needs Unit on site, attended by young people with severe and complex needs from across the local authority
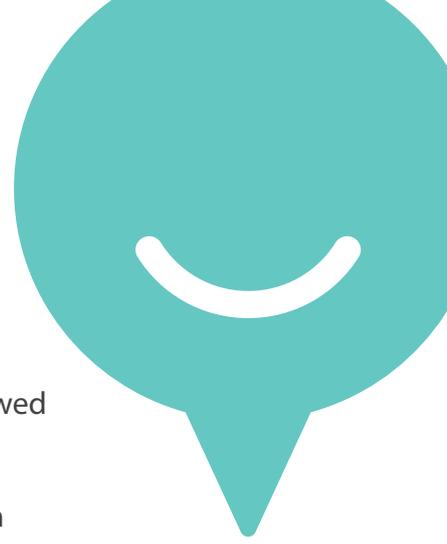
Each of the four schools selected up to five pupils to participate. Schools 1 and 2 chose the young people on the basis that they were both within the appropriate age range and were cognitively able to meaningfully participate. School 3 chose participants purely on the basis of appropriate age, regardless of their perceived ability to take part. School 4 selected participants of the appropriate age, who were registered with a disability and attended the mainstream school.

All of the young people, with one exception, were consulted individually by the researcher, during face-to-face interviews that took place at their school. One young person from School 1 was interviewed by his Speech and Language Therapist (SALT), as he was not available on the day the researcher attended his school. The young people from School 4 did not require support and were interviewed alone, as was one young person from School 2. Interviews with all other young participants, from Schools 1, 2 and 3, were facilitated by a member of staff. 17 young people were interviewed in total, with each interview lasting not more than half an hour.

Members of staff were also interviewed by the researcher, in person, at Schools 1, 2 and 3. School 4 did not arrange for contact to be made with staff: no explanation was given. The consultations with staff took place within the schools, individually or in groups of two or more, depending on what arrangements had been made by the school. Interviews typically lasted between 45 minutes and an hour.

Staff included: Teachers (N=6); Speech and Language Therapists (N=4); Occupational Therapists (N=3); one Classroom Assistant; one Physiotherapist; one Support Worker; one Residential Worker and one After School Club Leader. 18 members of staff were interviewed in total.

Eight parents took part in telephone interviews lasting between 20 minutes and an hour. School 1 was unable to provide contact details for parents within the time frame. .Schools 2, 3 and 4 provided contact details for those parents of the young people taking part who had given their consent to do so. One parent from each of these schools did not wish take part. Similarly, of those who had given consent, one parent from each school was unable to be contacted before the research deadline.

With both parents and practitioners, the researcher raised topics for discussion in the form of open-ended questions and allowed the participants to talk around those areas. This allowed issues to arise that had not previously been considered, with the researcher acting to draw attention back to the issues in question if the discussion wandered away from the focus of the research.

An outline of topics for discussion for parents and practitioners (Appendix A), as well as information and background relating to the research (Appendix B), was made available prior to all consultations. An information sheet for the young people (Appendix C) was written in the form of a simple social story, in an attempt to ensure it could be understood by everyone taking part. Due to the specialist communication needs of the young people taking part from School 1, specific questions for each young person were provided in advance (Appendix D), so that adequate preparations could be made for their involvement. Please refer to Appendix E for questions used at Schools 2, 3, and 4. Consent forms were also provided for all participants (Appendix F).

In summary, the numbers of young people, parents and practitioners taking part from each school is as follows:

	School 1	School 2	School 3	School 4	Total
Young people	3	5	5	4	17
Staff	7	6	5	0	18
Parents	0	3	3	2	8
Total	10	14	13	6	43

Discussion topics

A topic guide was developed based on the issues identified in the literature review and covered the following areas:

Contexts for decision-making

There is limited research relating to disabled children and young people's experiences within family settings (Lewis et. al 2007) or their participation in everyday decisions. For this reason, the first topic area for discussion with the young people and their parents, focused on decisions relating to their life outside school hours, including: their everyday routine (washing, dressing, etc.) and choices around buying clothes and choosing what to wear. The second topic area addressed decisions regarding how the young people spent their leisure time. Questions relating to daily decisions concerning the areas of education and health, were also addressed with the young people.

Facilitating decision-making

The importance of considering the competency of the adult to support a young person's involvement in decision-making had also been highlighted (Bilington 2006). The literature suggested that adults should be reflexive; constantly considering and challenging their own assumptions about the young people they are supporting (Davis and Watson 2000). Areas for discussion therefore also included opportunities for parents and practitioners to expand on the strategies and approaches they adopted, in relation to their role in facilitating the young people to make choices.

Consultation challenges

Consultations with the young people at the specialist Schools (1, 2, and 3) posed a number of challenges. Initially, based on the literature review, a list of 22 questions had been devised as a basis for a semi-structured interview. This was made up of five questions for each of the four topic areas of: everyday routine, leisure, education and health; with a further two questions asking what helps and hinders the young people to make decisions. Due to the range of complex disabilities catered for, it was known in advance that some of the young people taking part from Schools 1 and 2 use 'percutaneous endoscopic gastrostomy' (PEG) feeding tubes, therefore two questions relating to food choices were asked only at Schools 3 and 4 and were omitted from the original list.

Prior to consultations at Schools 1, 2 and 3 it was necessary for the researcher to meet with staff to gain information about the cognitive level of understanding and methods of communication used by those young people taking part. During these meetings, it became apparent

that the proposed list of open-ended questions would need to be revised, due to the complex and diverse range of communication requirements of the young people taking part. In each school there were different issues to be addressed, as discussed below.

School 1

At School 1, the young people taking part had both a physical and learning disability, communicating by either pointing to, or gazing at symbols. The SALTs advised: that each young person would be unable to concentrate for longer than half an hour; that only a maximum of five questions could be meaningfully answered within that time; and that it would be necessary to ask questions requiring only a 'yes' or 'no' answer ('polar' questions). It was agreed that it would therefore be appropriate for each young person to answer five questions relating to one topic area that was of interest to them. Clothes and dressing, eating and food choices, and physiotherapy sessions were therefore addressed with the three young people at this school.

With two of the young people at School 1, two SALTs facilitated: the researcher asked the questions using simple and clear language, the questions were then repeated by one SALT while the other held up the 'yes' and 'no' symbols clearly for them to select. The young people answered by shifting their gaze to the relevant symbol. The SALTs then verbally fed back the answers arrived at, asking 'so are you telling me x?' to ensure that they were not over-interpreting and that they had accurately understood their meaning. This proved important as not all responses had been correctly interpreted at the first attempt.

The third young person was interviewed by his SALT using a combination of symbols, a Talking Mat and a Pragmatic Organisation Dynamic Display. This young person is capable of some voluntary movement and responded either by pointing or by speaking single words – although it is important to note that he uses word approximations that only the SALTs are familiar with.

Consultations at School 1 were therefore highly time-intensive:

▶ in the preparation and planning of questions that had to be individually adapted
▶ in the preparation of communication tools (although this was conducted in advance by the SALTs)

▶ in coordinating the availability of the young people and their facilitators; and in the time taken to gain and double-check responses during the consultation itself

That these young people could only be asked polar questions was also a limiting factor, as was the degree of uncertainty surrounding the responses given. Expertise, knowledge and cooperation on the part of the SALTs in using the various communication tools was vital but also has implications for future research.

School 2

At School 2, each of the five young people has a physical disability and communicates using a Voice Output Communication Aid (VOCA). One also has a moderate to mild learning disability. At a meeting with the SALTs it was agreed that approximately 25 questions for each young person was appropriate during a half-hour interview. This meant that the original list of 22 questions could be used. However, having been informed of the use of VOCAs with these young people and hearing about the range of different VOCAs available, five questions were added concerning the young person's choice of VOCA as it was relevant to the topic of everyday decision making.

Up to 27 questions were posed verbally by the researcher to each of the five young people, who responded by accessing their VOCAs. Some questions were omitted and others added, in response to each young person's level of concentration, fatigue and enthusiasm. The researcher judged which questions to omit to ensure that each young person answered questions relating to every topic area.

At School 2, the interviews took longer than anticipated due to the time needed for each young person to process the question, think of their response, enter that response into their VOCA and finally hear the response being voiced. However, the use of VOCAs allowed these young people to respond to a greater number and therefore a broader range of questions than those at School 1.

School 3

At a meeting with the Head Teacher at School 3, it was made clear that five young people would be chosen purely on the basis that they fell within the appropriate age range as the Head Teacher strongly felt that young people who presented complex challenges should not be excluded from taking part. Information concerning each young person's level of understanding and method of communication was not passed to the researcher until the evening before the consultations took place. This precluded the possibility of adapting questions and preparing materials. Whilst this allowed the challenges of consulting with these young people to be directly observed and documented, informing considerations for future research, it also removed the possibility of selection bias that was deliberately present in the selection of participants at schools 1 and 2.

During the consultations, each young person was accompanied by a practitioner with whom they are comfortable and familiar. Two of the young people communicate their needs through behaviour and idiosyncratic vocalisations, but are not yet able to process and answer questions. Gaining responses from these young people was therefore not possible during this research consultation. Both of these young people communicate decisions by using objects as references: an association is built over time between an activity and an object that represents it, these young people then select the object that represents the activity they wish to engage in. Neither of these young people is able to use symbols, although this is a goal they are working towards at school and home. Further consideration needs to be given regarding how it may be possible to engage young people who use object reference as a means of communication, in future.

One young person was able to respond to polar questions, communicating 'yes' or 'no' by a thumbs-up or thumbs-down sign. This meant that only polar questions could be asked, and therefore only a couple of questions per topic area could meaningfully be included. This young person's facilitator prompted, rephrased or simplified the verbal questions posed by the researcher, as she felt necessary. This young person does have a range of symbols that he uses, however none were provided during the consultation and no explanation for this was given. Once again, this did allow the challenges of communication to be highly visible, which may have been the intention. In order to gain a wider range of responses with this young person in future, planning questions and materials (such as symbols) with the facilitator, prior to the consultation, would be beneficial.

The remaining two young people were able to verbally answer questions posed in simple, clear language. The original list of 22 questions, plus two questions relating to food choices, was therefore used, although they responded with 'I don't know' to a number of questions. One of these young people asked their facilitator, 'what do you think?' to questions he was unable to answer. It was unclear whether this was because they did not understand the question, or because they could not think of a response.

This school was highly organised in terms of timings of consultations and the researcher was given the opportunity to talk to staff and observe the young people at lunch and play. Opportunities were also provided to directly observe the challenges faced in involving young people on the autism spectrum in research. With such a complex group of young people, more information and a great deal of preparation and planning would be needed in order to engage them more fully in research in the future.

School 4

At School 4, four young people were selected by the Depute Head Teacher on the basis that they: were in the appropriate age range; had a disability and attended the mainstream school; and were not taking part in exams. While the school was unfortunately unable to provide information concerning the nature of each young person's disability within the time frame, the researcher was informed that posing questions verbally would be appropriate and that no additional materials would be necessary. During the consultations, each young person answered all of the 22 questions, plus the two questions relating to food choices, without the aid of a facilitator.

Data collection

During the consultations with the young people, the researcher noted the responses given for each question and also made observation notes – in particular regarding whether a young person was prompted by staff towards a given answer. Notes were also taken during the telephone interviews with parents. All consultations with practitioners were recorded, with their consent and on the understanding that they would later be deleted. Notes were also taken during these consultations.

Data analysis

The different categories of data were produced in the following ways:

▶ Responses to the specific questions relating to the five decision-making contexts were noted, collated and then summarised
▶ The identification of particular tools took place either through direct observation of their use, or were described by practitioners and parents. These were recorded, collated and then listed in full
▶ All strategies reported by all participants were noted and summarised
▶ Discussions relating to the approaches that help and hinder

young people to make decisions, were analysed through the process of 'open coding': identifying and categorising themes that frequently occur in the data. As this is a small-scale, exploratory study, the numbers of participants taking part is relatively low. Therefore themes were identified as occurring 'frequently' if they were raised by three or more participants. Once identified, frequently occurring themes were then organised into the categories of: approaches that help; and approaches that hinder

The results of each data category is reported in the main findings section.

Main findings

The first phase of the research reported here aimed to:

▶ explore the context of current decision-making among disabled young people
▶ identify tools, strategies and approaches that facilitate their involvement in decision-making processes

In this section, the results of the consultation process have been organised to address each of these aims in turn.

Decision-making contexts

The young people interviewed appear to be involved in a range of everyday decision making across several areas. The following represents a summary of the responses given, by those asked, to each of the five topic areas.

1. Everyday decisions

Most young people follow a routine of washing, eating and dressing on school days that fits with the needs of the family as a whole, but appears to be agreed upon by consensus. At weekends the young people have more freedom to choose when to get up, wash and dress. The young people typically go shopping with parents and siblings to buy clothes, making their own choices of what to buy and what to wear on a daily basis, with some input from siblings and/or parents. For those young people who do not use feeding tubes, decisions about what to eat are made themselves, typically choosing from the options made available to them both at home and at school.

2. Leisure

Leisure choices were again made by the young people themselves, although these were limited: both by the availability of parents and carers to support them; and by the availability and timing of appropriate activities for their age group and ability. However, the young people interviewed took part in a wide range of activities, including: swimming, bowling, race running, boccia, horse riding, music, sports clubs, scouts, and outings to concerts and the cinema.

3. Health

Many of the young people interviewed are required to participate in a number of different therapy sessions, including Physiotherapy (PT), Occupational Therapy (OT) and SALT. While young people could not choose whether or not to take part in a given therapy, there were a range of options available to

them within the therapy session itself. Practitioners reported that goals were first agreed between the therapist and young person and choices were then offered as to the type of activity undertaken to achieve these goals. For example, within a physiotherapy session young people could choose between exercising in the hydro pool, on the trampoline or on floor mats. Therapists stressed the need to offer choice and to adapt aims and methods in order to keep the young person motivated. Young people reported that they were able to choose to stop a therapy session if they were tired and to request less or more of a given therapy.

All of the young people who were asked, reported that dental appointments were made for them by their parents. However, they could request that appointments were not made during those times when favoured activities were taking place, and they reported that their requests were usually taken account of.

4. Education

Most young people at all schools follow a timetable. However, there are choices available within the school structure. For example, choosing which book to read within their level of the Oxford Learning Tree; choosing which subjects to study as they progress up the school and choosing to opt out of studying certain topics. All schools also offered a choice of meals at lunch time.

5. VOCAs

For those young people who used VOCAs, all had been involved in choosing their machine. The Scottish Centre of Technology for the Communication Impaired (SCTCI) would spend time at the school demonstrating the range of options available. The SALTs would assess the communication options and consult with each young person's PT and OT regarding positioning and muscle tone, to assess how the young person might access a given machine. Young people would then choose from the machines selected by the therapists, typically trialling one or two for a month, before making a final decision. Young people reported that they were given the option of personalising their machine, with many choosing to select its voice and colour.

On the whole, the young people said that they were happy with their lives and their current level of involvement in decision making, both at home and at school and did not express any desire for their current situation to change. All therapists stated their aim was to work towards increased independence for the young people, in communication,

in movement and in living skills. All staff stressed the importance of giving reasonable, informed choice and asserted that the more able the young person, the more freedom and choice could be given. Parents were also keen for their sons and daughters to make their own decisions, where possible. However, parents also provided the caveat that freedom and choice were tempered with their concerns for the young person's comfort and safety. Parents and practitioners both reported that providing the young people with highly motivating choices lead to the young person extending their horizons and thereby to a greater sense of general well-being.

Tools

Early in the consultation process it became clear that methods of communication were a key feature of involvement in decision making. Through interviews and observations, it soon became apparent that a wide range of communication methods was currently being employed by practitioners and parents, and that these were continually updated, customised, personalised and adapted to suit the young people's changing needs.

Some of the methods of communication being used with the young people were as follows:

▶ Pragmatic Organisation Dynamic Displays (PODDs): essentially a ring-bound folder displaying categorised symbols on each page. These are used with young people who have severe and complex needs resulting from physical and learning disabilities.
▶ My Tobii: for those who are unable to directly point to a symbol, but instead rely on eye-gaze to communicate, personalised PODDs have been uploaded onto a My Tobii computer. This can be controlled by eye tracking and is ideal for someone with limited physical movements, as the device follows the person's gaze, allowing them to select options by focusing on them.
▶ Talking Mats: symbols are categorised into sections on this specially-devised mat, and help young people to organise their ideas and express their views around particular topics.

▶ Voice Output Communications Aids (VOCAs): these allow the young person to select words or symbols and to construct whole sentences that are then voiced by the machine. There is a wide range of different types of machine and means of accessing them, and again all machines can be assessed and customised to suit individual needs. These machines are used with those young people who have a physical disability and no learning disability, or with a mild to moderate learning disability.

▶ Object reference: real objects are used to represent activities and choices with those young people on the autism spectrum who have little or no understanding of language and are not yet able to recognise symbols.

▶ Photos: these are also used to represent activities and choices with those young people on the autism spectrum who have little or no understanding of language and are not yet able to recognise symbols.

▶ Symbols: pictorial representations of activities and choices are used with those young people on the autism spectrum who have little or no understanding of language. The most common standardised symbols used are the Picture Exchange Communication System (PECS) and Boardmaker.

▶ Sign language: some basic signing is used with and by some of the young people with a range of disabilities. The most common sign systems used are Signalong and Makaton.

▶ Behaviour: those disabled young people with communication difficulties also use a range of idiosyncratic behaviour to communicate their needs, for example taking shoes and socks off to indicate they wish to stay indoors, or putting shoes on and standing by the door to demonstrate their wish to go outside.

While the researcher observed and was told about these communication tools being used with the young people, not all of these were used during the consultation process. The use of each will now be considered in turn.

PODDs

As mentioned, PODDs were used with two of the young people at School 1 and a great deal of time, expertise and knowledge is required for their construction. Every PODD is personalised for the young person, according to their vocabulary and interests; with photos of their family, friends and key workers on the appropriate pages; and the number of symbols displayed per page corresponding to each young person's ability to focus and direct their gaze.

Each PODD is continually expanded and updated in line with the young person's development and changes in their life. However, there are a number of limitations of using this method of communication during a research consultation, including: it is hugely time-consuming; the young people are not able to initiate communication; staff who are familiar with the categorisation system and each young person's available vocabulary need to be on hand to facilitate in order that it can be used efficiently and effectively; and it requires the facilitator to double-check answers, as responses are not always clear.

My Tobii

Many of the PODD's limitations are largely overcome by the My Tobii computer, which has the advantage of encouraging and enabling more spontaneous, independent communication, as well as speeding up the communication process. Unfortunately this tool was not used during these consultations, as the two young people interviewed are still learning to use this device. However, they could allow for more meaningful engagement of young people with physical and learning disabilities in future research.

Talking Mats

Talking Mats, used to interview one of the young people at School 1, is a useful tool for those with communication difficulties, that enables topics and themes to be visually organised and decisions and views to be expressed. While this low-tech device was used by a trained SALT during this research, online training courses, as well as free materials and support, may be accessed through the Talking Mats website. The use of this tool could be beneficial in future research.

VOCAs

At School 2, VOCAs proved to be a necessary and useful means of communication. However, for the young people interviewed, their VOCA is more than just a communication tool: it is their primary means of expression and therefore can be considered a key component in their support network. Many of the young people interviewed were extremely attached to their VOCA: one of the young people had given theirs a name and most had been particular about choosing its voice. When consulting young people who communicate using VOCAs, it is important to go at the young person's pace, allowing plenty of time for responses to be generated. It is also necessary to recognise that consultations may be tiring for the young people and to adjust the number of questions asked accordingly.

The use of VOCAs did allow for any question, that could be understood by the young person, to be asked, and the responses did not, for the most part, require interpretation. However, even with this communication tool, the young people were largely selecting vocabulary via symbols displayed on their VOCA's screen, and were therefore limited in their responses by the options available to them.

Object reference

For those who use object reference as a means of communicating decisions and preferences, careful thought and planning in order to develop creative methods of questioning would need to take place in order to enable meaningful involvement in the research process. Input from those who have considerable experience of using this method would be necessary, and a significant amount of time would need to be set aside to prepare adequately. This method has not been utilised so far in this study.

Photos and symbols

Aside from the young people at School 1, neither photos nor symbols were used during the consultations for this study. The young people who communicate using photos and/or symbols usually have particular sets of these that are personal to them. Again, it would therefore be necessary to take time to organise questions that take account of this, requiring input from those who are familiar with the young person and so can inform the researcher about levels of understanding and help with preparation of materials.

Sign language

While basic Signalong and Makaton, which are standardised sign languages, are used to a greater or lesser extent with the young people taking part in this study, many of the young people use idiosyncratic signs. Familiarity with the signs used by each individual young person is therefore a necessary prerequisite for their use. Again, input from those who have a good knowledge and understanding of the young people would be necessary in order for this method to be used in future research. Sign language was not used in this study.

Behaviour

During the consultations at School 3 in particular, it was both observed and reported that a young person's behaviour is sometimes a necessary means of communicating preferences and decisions for those with communication difficulties. To understand and interpret idiosyncratic communication requires intimate knowledge and experience of each young person. While some of the facilitators did interpret the young people's behaviour during consultations, such observations and interpretations were not included in the results and analysis, as their accuracy could not be guaranteed. Further consideration needs to be given as to the circumstances under which the inclusion of the interpretation of idiosyncratic behaviour would be appropriate.

Decision-making strategies

The young people, limited by the method of communication used, did not generate conversations around any topic area, but responded directly to questions asked only in very basic terms. As mentioned previously, often only polar questions could be asked. As a result of this, young people did not offer information regarding the use of strategies. At School 4, the young people's disability did not appear to act as a barrier to their ability to be involved in decision making processes, and therefore no particular strategies were being employed with this group. The following strategies were all provided by practitioners and parents from Schools 1, 2, and 3.

Given the range of disabilities experienced by the young people, a corresponding variety of strategies, appropriate to the young person's needs, were currently being used to help the disabled young people to make decisions.

Practitioners

Practitioners working with young people who have a physical disability, some of whom also have a range of learning difficulties from mild to severe, had a range of strategies to involve young people.

Involving in setting goals

Teachers, PTs, OTs and SALTs all reported involving the young people in the setting of short-term and long-term goals. Within the different therapeutic areas, goals are set with the young people, with parents often inputting via email or telephone. This is an ongoing process, with goals continually revised relative to progress.

'We learn their likes and dislikes, listen to their opinions, and use these to develop therapy sessions. We set targets at an initial screening meeting and we all discuss and agree them... Their needs change constantly, so you have to be flexible... the greatest improvements are made when we are all working together.' (OT 1)

Young people, key support staff and parents meet each year to all participate in the young person's annual review. In the time leading up to the young person leaving school, when crucial decisions need to be made concerning the young person's immediate and long-term future, consultations take place between young people, parents and practitioners every six weeks, with everyone working together to achieve the young person's wishes, as far as is possible.

Decision-making systems

Practitioners reported that there are systems in place to enable young people to express their opinions and wishes about a variety of issues that concern them. For example, Teachers and Classroom Assistants spoke about a standardised form that can be completed by the young people, in which they can raise matters that are important to them. To complement this, a Student Council has been set up, with a representative young person in every class. A young person can then give their completed form to their student representative, who will raise the issue on their behalf at the next meeting.

However, how often this system is used by the young people to influence decision-making at school, and how successful it is in that aim, was beyond the scope of this research.

Parents

A parent of a one young person (Anne) told the following anecdotes to illustrate her recommendation of the following two strategies, which she reported as having been successful for her daughter:

1. Sharing key signs:
   Anne really enjoyed her swimming lessons, but was on the verge of giving them up, due to increasing anxiety over being without her VOCA, and therefore unable to communicate, while in the pool.

This issue was resolved through teaching the swimming coach three basic gestures that she would use: one to indicate when she wanted to say 'no' to a particular request; another to let the coach know when she needed the toilet; and the third to demonstrate her decision to take a break. This strategy could be employed in other situations where the young person is unable to use their VOCA, and by other young people, in a variety of contexts, who have communication difficulties.

2. Putting yourself in their shoes:
   Anne's mum reported that all of her daughter's family and close friends had tried communicating using her daughter's VOCA for one day. Literally putting themselves in the young person's shoes, even for a couple of hours, has apparently enabled a much greater understanding of the time needed to communicate, the complexities involved in operating the machine and the frustrations that may be encountered. This strategy may be useful to raise awareness among the wider community.
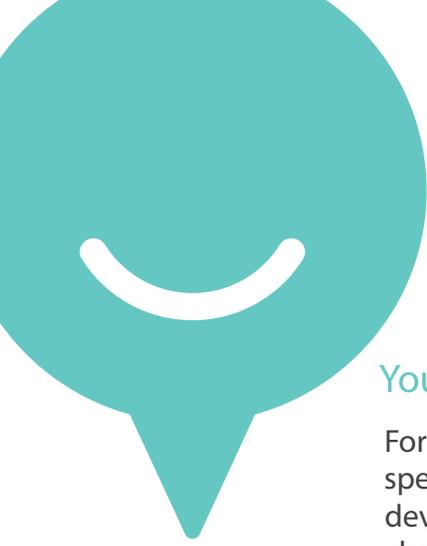
Young people with autism

For young people on the autism spectrum, strategies have been developed that address the particular challenges and difficulties that are inherent in those with this condition. The staff took part in a group consultation and together described the process they employ to enable young people to make decisions. It was interesting that parents also described a similar process, reflecting the consistency of both the challenges faced, and the strategies that work, with these young people. Strategies taken by both staff and parents, employed the following three steps.

1   Establishing routine:
People on the autism spectrum, to differing degrees, suffer from anxiety in social situations. The group of practitioners and one of the parents, therefore spoke about the importance of reducing anxiety through constructing and maintaining a consistent, familiar and predictable routine. The young people need to know what is happening now and what will happen next. At school, a structured timetable is displayed at each young person's work station, using recognisable visual aids such as symbols, photographs, or objects. One of the parents (Finn's mum) also described using a visual timetable at home, displayed always on the back of the kitchen door. This parent, like the school, uses Boardmaker to construct symbols, as this programme allows any personal symbol or photograph to be standardised to a certain size, shape, colour and font, thereby maintaining consistency. PECS is also used at school. For those young people who have a good understanding of language, sequence strips are also used at school.

2   Introducing a choice of familiar activities:
At school - Once a routine is established, flexibility and choice is then introduced. At school, each young person has a work station containing four colour-coded work trays. The young person can choose three of the four trays to work with in a given day, choosing to reject one. They are also able to decide the order in which they use them. A Golden Ticket system has also been introduced for one young person: each golden ticket allowing him to choose to opt out of a particular activity.

Time at school is typically divided between a timed work activity, followed by a leisure activity. For those using object references to communicate, a box containing three objects corresponding to three leisure activities is offered. Tony, for example, has a choice of three objects for leisure activities: a ball representing soft play; a small string of lights representing the sensory room; and ribbons

he likes to flap while running about, representing going outside. Tony will pick up the object representing his choice of activity.

Difficulty of making the transition from one activity to the next, is a common feature of those on the autism spectrum. Therefore, knowing when an activity is going to end and being given time to prepare for this, is important. For school work, visual timers – large egg timers for example – are used by the teachers to help the young people understand the length of time an activity will take, and when it is coming to an end. For leisure activities, countdowns are often used, letting the young person know that an activity will end in 10 minutes, five minutes etc.

At home - Finn's mum again described how she has attached pocket folders containing choices in the form of symbols, beneath Finn's visual timetable. She stressed that it is necessary for all choices in the folder to be doable and possible, thus allowing the young person to confidently remove symbols from their timetable, replacing them with symbols from the choosing folder.

3 Introducing new activities:
At school - Doing something that is not part of their routine, can cause anxiety for those on the autism spectrum and this can lead to distressing and challenging behaviour. To introduce new activities without raising anxiety, practitioners cited the strategy of young people observing others in a particular activity, gradually involving the young person in that activity if they show an interest. The aim is to introduce a range of experiences, that slowly become familiar to the young person, through observation. They can then make a more informed decision concerning whether or not to take part and thereby the young person's options are increased.

At home - At home Finn's mum described taking a series of photos to introduce him to a new activity. For example, she would photograph the front of their local cinema, the box office and the seating area, establishing a familiarity with the location before actually taking him to see a film. Once going to the cinema had become part of his routine choices, a new activity could then be introduced in the same way.

The importance of going at the young person's pace through all of these steps, consolidating one before going on to the next, was emphasised by all.

Approaches: what helps young p

Nine key themes

Through an analysis of the consultations with parents and practitioners the following themes were found to occur frequently:

- ▶ attitude
- ▶ familiarity
- ▶ expertise
- ▶ good communication networks
- ▶ ongoing training
- ▶ high staff ratio
- ▶ equipment
- ▶ finance
- ▶ application of a diversity of tools and strategies

Attitude

An attitude of respect and care for the young people was evident in all consultations with practitioners. Some stated explicitly that it is vital to start from the assumption that, although these disabled young people display a huge range of communication difficulties and abilities, they are all able to communicate in some way and are therefore all capable of communicating certain opinions and making certain decisions.

One classroom assistant was especially keen to make this clear at the outset saying

'It's really important for you to know that all of our young people communicate… they are all very different and there's a huge range of disabilities here, very different levels of understanding… but all of them communicate in some way, it's up to you to learn to understand them.' (CA 1)

Similarly, the SALTs interviewed at two of the schools, described their role as, **'supporting communication to the best of the young person's ability' (SALT 1)** and, **'striving to understand communication so we can support them to make decisions' (SALT 2)**.

All parents interviewed enthusiastically launched into talking about the sorts of decisions their sons or daughters made, taking for granted the assumption that they were able to do so. One parent of a son with autism did explicitly state:

'For young people like Finn it's important that everyone understands that it is always possible for them to make choices and take decisions… he certainly knows his own mind.' (Finn's mum)

Another parent of a daughter with a physical disability but no learning difficulties asserted that, **'The biggest problem she has is dealing with idiots who treat her like her an idiot' (Lily's mum)**, going on to say that people who assume she cannot understand or think for herself make her daughter extremely frustrated, as they tended to talk about her, in her presence, rather than to her, directing any questions to the parent. This is a good example of how, if one assumes communication cannot be done, one doesn't bother to try.

Familiarity

All practitioners, either explicitly or implicitly, asserted that knowledge of each young person is a key component to their involvement in decision making. Many of these young people use

idiosyncratic behaviours, vocalisations, facial expressions and gestures to communicate and this requires a degree of familiarity of each individual young person that is built up over time:

'You have to get to know the young people really well and know their expressions. Strategies are okay but there's no substitution for that.' (Teacher 1)

'Sometimes the 'yes' and 'no' is not clear, so you need a back-up and you need to know their facial expressions.' (SALT 2)

We're not visiting therapists, we're working with them every day, so you get to know how to read the non-verbal behaviour and that's really important… they make greater improvements and work harder when they're happy with what they're doing.' (PT 1)

Being familiar with a young person's likes and dislikes, level of ability and understanding, concentration span and physical needs is also necessary.

While practitioners did state the importance of building mutual relationships of trust and understanding with the young people, they mainly spoke of 'familiarity' from their perspective: as being important for a clearer interpretation of the young people's needs and wants in order to involve, engage and motivate them. Although parents did also talk about familiarity from the adult's perspective, they tended to focus more on the young person's perspective, asserting: that the more familiar the young person was with you, the

more they would feel comfortable communicating their likes and dislikes and informing you of their decisions:

'She needs to be relaxed and confident with you… she will happily tell you things, ask for things, if she knows you'll listen and she knows you.' (Anne's mum)

This is an important point, as these young people require support to carry out their decisions and so have to be able to communicate their decisions to others. It appears that in order for young people to be involved in making decisions, it is important for the adult to be familiar with the young person, and for the young person to be familiar with them.

Expertise

Many of the practitioners mentioned the importance of expertise in the staff team. This theme often arose in relation to their reliance on each other's knowledge when faced with challenging situations:

'You need people around you who know what they're doing... you have to be able to rely on everyone having a good understanding of their own practice area.' (OT 2)

'There's a lot of expertise here in the staff team, and that's really important when you feel someone isn't making the progress they should, because you've always got someone to ask who might have some answers.' (Teacher 2)

Most, perhaps for reasons of modesty or because it is taken for granted, did not mention their own expertise.

This theme also recurred in the interviews with parents, mostly in relation to the expertise of staff at their daughter's or son's school, which they were both impressed by and grateful for:

'The Speech Therapist works with her on using her voice and she is brilliant... she always knows the right thing to do and it always works.' (Mary's mum)

'The school tries new things with him, they can do that because they know the right way to go about it and then they show us how to do it at home.' (Mel's mum)

Good communication networks

Good relationships and ongoing communication between those who care and support the young people, was another recurring theme among practitioners. Holding regular formal and informal consultations, within and between the different practice disciplines, to discuss the young people's development, achievements and difficulties, contributes to better support for the young people. However, this was also important for practitioners to feel secure and supported:

'This is not always an easy job and staff need support too and that's where it's important to have strong communication and connections.' (CA 1)

A teacher made a similar comment:

'There's a physiotherapist, occupational therapist and speech therapist attached to my class and we have class team meetings and review meetings every couple of weeks... but even when we haven't set a meeting, there's always somebody to talk to and so you really feel supported... I couldn't do without that.' (Teacher 1)

Practitioners also raised the importance of good communication with parents:

'Regular contact with parents is really important for consistency... if you think about it, we don't see them for six weeks over the summer for instance and you need to be kept up to date.' (Teacher 2)

Regular contact between parents and practitioners was also a recurring theme in the consultations with parents. Mostly, parents felt that they needed to know how their child was and what they were doing at school, and many relied on the school to give them this information:

'Sometimes he's had a bad night and not slept and the school need to know that, and sometimes things happen at school that I need to know about… and so we need these daily updates that go backwards and forwards between us… but they are completely useful.' (Mel's mum)

Parents also mentioned the importance of communicating with other parents and cited other parents and parent groups as invaluable sources of support and information:

'When you take them to these different clubs you meet other parents and we're all sat around waiting and so you get chatting and it's great… you get to know about other stuff they could be doing, little knacks other parents have found to get to them to sleep like and you get to have a good old moan… it's therapy for me that is.' (Mary's mum)

'Getting to know other parents has been a god-send… you don't feel like you're the only one struggling.' (Kay's mum)

It appears that for parents and practitioners, good communication with each other is important both to provide better support for the young person, and also for themselves.

Ongoing training

Most practitioners spoke of the importance of regular and relevant training:

'We're always asking for more training… you have to because new ideas come along all the time.' (PT 1)

'The needs of the staff are recognised, that we need regular and relevant training… we go to conferences and know how important it is to keep up to date… you have to keep up with the training.' (OT 3)

Aside from practitioners' training relating to their particular disciplines, all practitioners are trained to use specialist equipment (e.g. hoists) and in basic medical awareness (e.g. first aid and epilepsy) and all practitioners, as well as parents, are trained to use the young person's method of communication.

Parents of young people at School 2 mentioned the training they had received in using their child's VOCA, and one parent from School 3 spoke of the invaluable autism training they had received:

'In the beginning, two amazing ladies from the NHS who were speech therapists offered this six week course to parents who had had a recent diagnosis… they explained everything so clearly and it changed my life.' (Finn's mum)

High staff ratio

Most practitioners mentioned that, particularly when working with young people with complex needs, it was necessary to have a high ratio of staff to young people, in order to involve them to the best of their ability:

'You have to have enough staff... you need someone and something to engage the child and on a one-to-one you see them flourish.' (Teacher 1)

'You've got your teacher and the class assistants like me and then the nurses and you need all of them all the time for toileting and feeding and that gives you the time to engage with them properly.' (CA 1)

'You need a high staff ratio so that you've got the flexibility to deal with a whole range of different abilities within the one class.' (Teacher 2)

A high ratio of staff is therefore important in allowing enough time and attention to be given to individual young people's needs.

Parents spoke more explicitly about needing time:

'You have to have the time to plan everything really carefully.' Kay's mum)

'It takes time to communicate with her and you have to give her time.' (Mary's mum)

'Sometimes I do things for her that I shouldn't, but I don't always have the time to let her do things for herself.' (Lily's mum)

This emphasises the point that involving disabled young people in decision making in a meaningful way, can be time-consuming.

Equipment

Another recurring theme among practitioners was the necessity of particular equipment. Among the most frequently mentioned was technology and materials:

'We work a lot on hand function and I've got a whole draw full of spoons of different shapes and sizes, I've also got a range of different toilet seats, all really necessary... they need access to technology and need iPads, they need their communication aids, and so on.' (OT 3)

'We're really lucky here, we're very fortunate with our resources... we've got a Magic Carpet which is amazing, we've got trampolines for Rebound Therapy, we've got the hydro pool, we've got technology... we go to exhibitions and the reps come in here and then we lobby Geraldine (Head teacher) to get what we need, we give her a wish-list every year... but you have to have the right equipment and the better the equipment, the better the therapy for the young person.' (PT 1)

A range of equipment not explicitly mentioned, such as wheelchairs, feeding apparatus and hoists, were also observed in use and were also entirely necessary for the comfort and well-being of the young people.

Finance

Most practitioners mentioned that the resources they need to help them better support the young people – ongoing training, high numbers of staff and a wide range of equipment - are all very expensive.

'Have you got any idea how much it costs just for PECS, how much the Tobii's cost, not to mention all the sensory equipment?' (Teacher 1)

Therefore, 'Money' was a frequent response from practitioners, when asked to sum up what is needed to involve young people more fully in making decisions.

Application of a diversity of tools and strategies

All practitioners spoke of the wide variety of tools and strategies that they employ with the young people, and that these are continually monitored and constantly updated:

'I have one child who's verbal and she can have worksheets in class, I've got two who are non-verbal, low cognitive age, they need sensory stuff so even if they don't understand they

have experienced… I use visuals, colour-coded sheets… a lot is trial and error and you keep trying different things to find what works.' (Teacher 1)

'We're always developing new resources, constantly updating symbols… you have to adapt to them, as they grow.' (SALT 2)

The diversity of tools and strategies used, reflects the diversity of abilities and disabilities across all the young people they support. This is perhaps why this theme was not raised by parents, as they typically are only supporting one child. However, the need to continually update strategies was raised by most parents and is an acknowledgement of the learning and developments the young people make, that change over time.

Young people's views

Due to the limitations of the various communication tools used in the consultations with the young people, together with the level of cognitive understanding of the young people taking part, the question, 'What helps you to make decisions?' was only asked to the young people at Schools 2 and 4 and to two of the young people at School 3. Most responded that they didn't know. However, one of the young people at School 2 responded, quite simply, 'Ask me!' and another two responded in a similar vein, adding, '…and listen.'

Approaches: what hinders youn

All parents and practitioners were asked to consider what prevents or hinders young people from having more involvement in making decisions. Many responses were given in terms of the negative of 'what helps': for example, practitioners mainly cited not enough staff or low staff ratios, and a lack of resources or lack of finance for the necessary resources; and parents mostly cited a lack of time as the main barrier. Not being given enough time to participate, was also the one response offered by two of the young people, with the remaining young people who were asked responding that they didn't know. Other responses included:

Cognitive ability

During consultations with parents and practitioners, it was apparent that they perceive the level of involvement of young people in decision making, as being dependent on the young person's level of ability:

'It's about getting it right for each one, supporting each one to the best of their ability… it's about offering reasonable choice, that's really important… some can more decisions than others.' (SALT 2)

'The only limiting factor is their cognitive ability… wherever possible you give them choice and if that's not possible then you give them involvement.' (Teacher 2)

'You can only involve him at his pace, it's baby steps, but we're getting there, bit by bit he is making more decisions for himself.' (Finn's mum)

It therefore appears that parents and practitioners feel that a young person's cognitive ability is the main limiting factor to their involvement in decision making.

Over-protection

Some parents acknowledged that their being over-protective narrowed the scope of their son's or daughter's decision making opportunities:

'I want her out and independent but I want to be in control of that, I want to make sure she's safe… I know it limits her but I can't help it.' (Lily's mum)

'I don't want her sitting in, but she can't go out and do things on her own even if she wants to.' (Mary's mum)

Parents generally acknowledged that they restricted the choices of their disabled son or daughter more than that of their siblings due to concerns over their safety.

Cultural lack of awareness

One parent and one practitioner cited the current attitudes and policies in Britain as directly limiting disabled young people's options. One parent was well-versed in European Law and culture and pointed out that, unlike other countries in Europe, **'Britain only deals with disability within certain environments and within particular hours' (Lily's mum)**, going on to say that, outside of these, being disabled is considered unacceptable and is not catered for. A general lack of awareness was also

cited by other parents and practitioners who told anecdotes concerning: the wider community making unfavourable assumptions about disabled young people; not knowing how to communicate with them and not giving them time to communicate.

Less frequently recurring themes

Two other barriers were identified by fewer than three practitioners and parents, but were deemed to be of great importance by those who raised them.

Young person's reticence

Two parents raised the issue that their daughters chose to opt out of making decisions:

'I'm trying to encourage her to make decisions but she doesn't always want to.' (Anne's mum)

'I'd like her to make more decisions but she's a bit nervous about it at the moment.' (Mary's mum)

Both of these parents spoke of their concern about this and about the need to increase confidence and reduce the disabled young person's sense of vulnerability.

Not providing their own signature

One parent and one practitioner were concerned about the inability of many disabled young people to sign their name, as this is a barrier to them taking control of their finances in the future:

'How many hours are put in to getting them to sign their own name? This will be really important for them in the future. For their own independence they really need to learn how to do this.' (Lily's mum)

'Learning to sign their own name will enable them to take control of their financial affairs in the future and this is fundamentally important.' (OT 3)

Both wanted schools to make the teaching of fine motor skills a priority for this reason.

Conclusion

This phase of the research aimed to identify tools, strategies and approaches that enable disabled young people to be more involved in making decisions that directly affect their lives. Beginning the research within schools enabled the systems and processes for participation and decision making already in place, to be documented.

As highlighted in the literature review, it became apparent that, given the right environment, disabled young people are able to make certain choices and decisions, depending on their level of cognitive ability. The approaches that help young people to make decisions, as identified in the previous section, appear to be interrelated and suggest a hierarchical relationship in which certain approaches can be seen as steps along a pathway leading to the creation of the 'right' environment. This section therefore sets out to describe the relationships that emerge when the approaches identified are considered together.

The first approach identified - the basic assumption that all young people, regardless of their disability, are both able to and have a right to communicate decisions - appears to be a prerequisite for their involvement in decision-making processes. It is this attitude that appears to motivate everything else. All practitioners, as well as parents, demonstrated a commitment to the child-focused approach that is necessary to achieve the right environment. Practitioners noted that the steps along the way to achieving this are collectively very expensive. It is also perhaps the 'can-do' (and 'should-do') attitude that underpins the provision of finance necessary to cover these considerable costs.

'Familiarity' appears to be enabled through having a 'high staff ratio', as a high ratio of staff allows individual practitioners the time needed to gain knowledge and understanding of the young people as individuals. Similarly, 'ongoing training' enables practitioners to develop their 'expertise'. This includes learning about new tools, technology and other useful equipment that can then be tailored to suit individual young people.

This expanding expertise, together with the increasing knowledge and understanding of individual young people gained through familiarity, needs to be shared through good communication networks. This includes communication: between practitioners; between parents; and between practitioners and parents. At least of equal importance, is that practitioners and parents keep up regular communication with the young people, involving them and listening to them.

Finally, this knowledge and expertise can be brought to bear, together with the necessary 'equipment', in the 'application of a diversity of tools and strategies' listed in the 'Tools' and 'Strategies' sections. The sharing of knowledge and expertise: allows for a more rounded understanding of the young person; encourages a reflexive approach that takes account of changes and developments in the young person; allows parents and practitioners to continually update the strategies they use with the young people; and enables a mix of experience and fresh ideas

to be implemented. A high staff ratio also provides practitioners with the time they need to prepare and adapt tools and equipment to their particular needs. Ongoing training also equips young people and parents, as well as practitioners, with the necessary skills to make use of the various tools.

However, barriers were also identified that may hinder disabled young people in making decisions. Parents acknowledged being over-protective of their disabled sons and daughters, and also reported some young people's reticence or nervousness about making decisions for themselves. Cultural attitudes and unsupportive systems and policies were also cited. It appears that there is a link between these themes: that parents are concerned about their child's ability to cope outside very particular, supported environments due to a general lack of awareness felt to exist within the wider community. Young people's reticence and nervousness may also be a reflection of this perceived vulnerability and may actually therefore be a lack of confidence, in their own abilities and in the abilities of the wider community to support them. This highlights the need, as reported in the literature review, for the long-term goal to be that of working towards building and extending a participative, inclusive and respectful culture more widely.

For the disabled young people, the goal remains one of greater involvement in decisions that affect them. The literature review highlighted the potential danger of taking this aim towards the goal of self-determination and autonomy, and of confusing greater

empowerment with self-sufficiency. Recognising that many of the young people taking part in this research will never be self-sufficient is important and the goals therefore need to focus on extending and expanding the horizons of these young people, enabling them to stretch themselves to their limit – whatever their limit happens to be.

Underpinning the responses from all participants, was a commitment to the belief that young people have opinions, have a right to an opinion, and that it is a universal child right for their opinions to be included in the process of making decisions that affect their lives - as outlined in the United Nations Convention on the rights of the Child (UNCRC: 1989). While this shifts the focus towards the importance of participation it is also important to recognise that, "the level of participation will vary depending on the objectives sought, the decision being made and the capability and choice of the children and young people" (VIPER 2013:10), as also evidenced in this report.

Where next?

During Phase 2 of the research, we will aim to work closely with three young people over a six month period, each in a different setting, using an action research approach to explore how they make everyday decisions and what works or is challenging for them. Initial discussions will allow the young people to define the area they would like to work in. The researcher will either observe current activities and decision-making, or assist the young person in a new area where they have been unable to make decisions before. This will allow for documentation of what is working well and what the challenges are. The action research phase will allow for learning in real time about the barriers to decision-making, and the spreading of good practice through the organisations involved and wider dissemination.

In March 2015, a final report will be written documenting the process of Phase 2, concluding with a description of those strategies, tools and approaches that have proven most effective. This, together with guidelines on implementation, will be disseminated to young people, parents and practitioners as widely as possible.

This document, along with the full Consultation Response Report and Literature Review as well as further information on the full action research project commissioned by the Scottish Government can be obtained by contacting Eric Mitchell, Policy Projects Manager, Capability Scotland. **Telephone**: 0131 347 1077 **Email:** eric.mitchell@capability-scotland.org.uk.

Alternative formats, including Easy Read, are available on request please contact our Advice Service. **Telephone**: 0131 313 5510. **Email:** advice@capability-scotland.org.uk

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