



The Communication Trust
Every child understood

Exploring the involvement of children and young people with speech, language and communication needs and their families in decision making - a research project

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Acknowledgements

We would like to thank all the children, young people and parents who gave their time to participate in this project and to share their experiences and ideas. We are also grateful to the schools and staff who supported the project and hosted the children's groups.

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Please note, the appendix to this report is available as a separate download

Executive summary

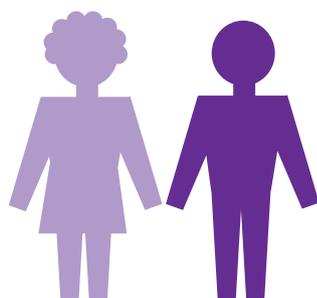
The Children and Families Act 2014¹ and the special educational needs and disability (SEND) 0-25 Code of Practice require that children and young people must be involved in “discussions and decisions about their individual support and local provision”². The Communication Trust has been commissioned by the Department for Education to provide evidence and guidance for the children’s workforce regarding the involvement of children and young people with speech, language and communication needs (SLCN). This report presents the findings of a research project to determine good practice from the perspective of children and young people with SLCN and their parents within the context of the reformed SEND system. For those people who have been actively involved with children and young people with SLCN, many of the recommendations will feel familiar. The majority confirm and reinforce principles of best practice for communication with these children and young people. However, the unique value of the recommendations is that they are based on the perspectives of the children and young people themselves. The report therefore adds important evidence to our understanding of how best to support and involve children and young people with SLCN in decision making.

The scope of the consultation

The project worked in small groups with 54 children between the ages of 7 and 16 years who had a range of SLCN. Children and young people were asked to talk about their experiences of starting school, learning in class, meetings, targets and people in school who are good at listening.

Telephone interviews were carried out with 16 parents; a further 100 parents from across England completed an on-line survey. These parents all had children who had a range of SLCN and were between the ages of 5 and 16 years of age. Parents were asked for their views on how their children had been involved in decisions about their individual support and their own experiences of being involved in decision making around their child’s needs and services they accessed.

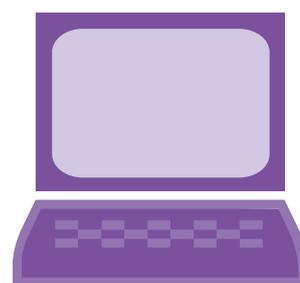
Once the research was completed, two sets of stakeholders were asked for their views on the findings. The stakeholders included practitioners and officers from health and education services and members of a school council in a secondary school for children who have Statements or Education Health & Care Plans.



54 CHILDREN BETWEEN THE AGES OF 7 AND 16 TOOK PART



16 PARENTS TOOK PART IN TELEPHONE INTERVIEWS



100 PARENTS COMPLETED AN ONLINE SURVEY

We identified events which seemed to have an element of choice or absence of choice.

Children and young people's perspectives

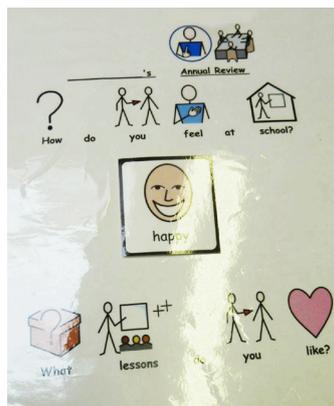
Asking children and young people with SLCN directly about their level of involvement in decision making can be challenging. They are not always aware of the possibilities for participation and can find it difficult to express their views. We therefore opted for a process which encouraged the children and young people to describe their experiences of school. Their discussions revealed some of the knowledge they have about their school, such as timetables and teacher's names; the school rules and reward systems seemed to be particularly important; children also knew about the school council and the meetings that happen between their parents and school. We identified events which seemed to have an element of choice or absence of choice. These involved both routine activities such as where they sit in class as well as the bigger decisions such as selecting subject options in secondary school. Children were generally positive about their school. They had their favourite subjects (and non-favourite subjects) and sometimes, teachers. They had a variety of strategies for getting help but this was not always a positive experience. Children and young people also talked about the kinds of classroom atmosphere that were helpful.

Parents' perspectives

Parents often described ongoing difficulties in establishing support that meets the complexity of their child's individual needs. Despite this, parents had many positive experiences of teachers and therapists who they perceive to be working hard to involve them as parents in the decision making process and to provide appropriate support. Whether or not these processes are experienced as positive seems to rest almost entirely on the nature of the communications between services and parents. Where schools and other services are actively seeking parents' views, inviting parents into schools, responding to parent concerns, taking forward parent suggestions and keeping parents informed, parents feel that they are suitably involved and happy about provision. Where parents feel there is little information, ideas are not followed through, or that they have to push to get a response from services, parents feel unhappy and concerned about the state of the provision.

Reflections on talking to children and young people with SLCN

The process of working with children in small groups highlighted some points of good practice that can be applied to future research with children with SLCN, to future consultations and to the process of involving children and young people and their parents in decision making. The actions we suggest can be regarded as good practice for any child or young person but they are particularly important for children and young people with SLCN because of their communication and/or processing difficulties.



The use of objects and supporting materials

Whilst pictures and symbols that represent the issues can support discussions, having access to the actual objects or paperwork that the children use can increase their contributions. It provides additional supporting context that helps them to remember the right words and remind them of the activity or event.

Talking about recent things

Where feedback is being sought, any exploration of a school system or process should take place as close as possible to the event, for example, if a school wished to explore children and young people's views about the annual review process, carrying this out as soon as possible after the event would be crucial.

Dynamic activities support engagement

It is helpful to include physical actions and dynamic activity that reflects the verbal activity, such as sorting cards for voting or indicating choices, choosing stickers to indicate preferences or moving levers or counters to show a score on a scale. This supports children's engagement with the involvement activity.

Advantages and disadvantages of having someone who knows the child and their context

Careful selection of the adult facilitator is needed to support effective involvement and participation; they need to know the child well enough to be able to act as a facilitator. However, if the activity is looking to gain feedback, this should preferably not be the person who delivers the service or activity that is being discussed. A commitment to the confidentiality of the child's responses is vital.

Small group versus individual

Within any consultation, it is necessary to create a relaxed conversation context. This is particularly important if the adult is unknown to the children and young people. Depending on the time available for the consultation, it may be possible to see children and young people on multiple occasions. In this case, it may be possible to establish an appropriate conversational context with individual children and young people. However, if a single consultation meeting is planned, then a small group may be more effective to reassure children and young people and to get conversations started. However, with children who have SLCN, group work can often be challenging in terms of taking turns and being able to contribute within a group setting. Some children may dominate or some may prefer to speak to the adult directly. It is therefore necessary to have additional adults available who can listen to children as individuals and support the dynamics of the group work to facilitate participation from all children and young people.

The language used

Checking children's understanding of words that are to be used in consultations will ensure that interpretations of their responses are more likely to be valid. Further research concerning children's interpretations of the vocabulary to be used in discussion of targets and outcomes would be helpful for future consultations.

The process of working with children in small groups highlighted some points of good practice that can be applied to future research with children with SLCN, to future consultations and to the process of involving children and young people and their parents in decision making.

Recommendations

Recommendations are organised using three themes from the children and young people's perspectives. These recommendations will be useful to all those working with children and young people with SLCN and their families and are transferable across different settings and contexts.

Knowledge of children and young people's role in decision making

1. There is a need for accessible, relevant and interactive information to support children's involvement in decisions. The materials need to convey information about the process of involvement, the possibility and expectation that children and young people have a part to play and clear information about how they can express their preferences and wishes.
2. There is an ongoing need to work collaboratively with parents and parent organisations to support parents' awareness and understanding of the reformed SEND system and its impact on practice.

Relevant decisions

3. It would be useful for schools and/or services to conduct an analysis of the decisions made within their context in order to map the range of pupils that have been actively involved in those decisions and to highlight if and where children and young people with SLCN are being left out or even excluded.
4. There is a need to identify the most appropriate level of involvement in decisions for any individual child or young person. This requires practitioners and parents to understand the different levels of involvement in decision making so that the most appropriate level can be selected, in association with the child or young person and with their parent.

Responsive to children and young people's preferences

5. Account should be taken of the child or young person's preference regarding their level of involvement.
6. Processes of involvement should involve action and physical movements to support their level of engagement with the process.
7. There is a need to make the short term steps (or targets) between a child's current achievement and their potential longer term outcomes more explicit so that everyone understands the purpose of a short term target, where it is leading and what future achievement will be.
8. Teachers and parents should work together with children and young people to identify manageable and timely processes to identify targets collaboratively.

Conclusion

This project has identified evidence of the involvement of children and young people with SLCN, and their parents in decision making within SEND frameworks and more broadly in school decisions. Children and young people with SLCN and their parents all indicated a desire to be involved in decision making. Children and young people in the stakeholder group expressed their views forcibly:

“the worst part is that they don’t tell us”

“I hate the fact that, that, some parents don’t respect your choices, and if you want to do it you should do it. But there are some cases where parents don’t respect it because they want you to be something else, and that’s what I hate about. That’s what I hate”

However, the level of involvement varied; some children and young people were put off by the talk-centred processes and some parents sometimes felt that they were ill-equipped to play a part in decision making. Practitioners have worked hard to listen to and include the voice of children, young people and their parents, but there is still much to be done. For the future, we need to identify the full range of decisions in our systems that could be opened to the involvement of children and young people and their parents.

The systems include classrooms, whole schools or settings and indeed whole services. We need to identify appropriate levels of involvement and provide information so that children, young people and their parents can take an informed part in the process. Finally, we need to initiate action oriented processes that reduce the emphasis on talk and promote the engagement of children and young people. These recommendations can be applied not only by schools and settings but can also provide a useful starting point for services who wish to improve the level of involvement of children and young people with SLCN in service development.

Background and purpose

The Communication Trust is a coalition of over 50 not-for-profit organisations. Working together they support everyone who works with children and young people in England to support their speech, language and communication. Their work focuses on supporting children and young people who struggle to communicate because they have speech, language and communication needs (SLCN) as well as supporting all children and young people to communicate to the best of their ability.

With funding from the Department for Education, The Trust has been commissioned to provide guidance for the workforce regarding the involvement of children and young people with SLCN in decisions that concern them. This is in response to the Children and Families Act 2014³ and the special educational needs and disability (SEND) 0-25 Code of Practice which requires that children and young people must be involved in “discussions and decisions about their individual support and local provision”⁴. Increasing participation and inclusion of children and young people is regarded as a key mechanism by which the quality of support can be improved. The Trust also wishes to provide evidence to the children’s workforce regarding the involvement of these children and young people. The purpose of the project was therefore to determine good practice from the perspective of children and young people with SLCN and parents both to provide additional evidence to those who work with children and young people with SLCN about their views and experiences of involvement and to ensure future guidance produced by The Trust would be informed by their views. This project provides an extension to the findings of the Better Communication Research Programme⁵.

The Trust identified the following questions of interest:

- a. What is best practice in involving children and young people with SLCN and their families in developing their individual support, particularly around setting outcomes?
- b. What is best practice in involving children and young people with SLCN and their families in developing services within the context of the SEND reforms?
- c. What is the experience of children and young people with SLCN and their families of the reformed SEND system to date, and what do they feel local agencies should be doing to ensure the best support?

| | |
|---|--|
| “Chocolate ... makes you hyper... makes you autism” (Kelly, 2005) | Adults are not always clear with the children about their difficulties; in that situation children draw their own conclusions. For this child, chocolate was discouraged because it was linked to hyperactivity which the child also linked to autism. |
| (McCormack et al, 2010) | Children do not always perceive themselves to have problems although they understand that their listeners are having trouble listening. |
| Merrick & Roulstone, 2011 | Children don’t talk about their speech and language problems – they’re more interested in other aspects of their lives |
| “It’s like they’re driving sports cars and I’m on a tricycle.” (Brinton et al, 2005) | This child with a language impairment describes his difficulties making friends and the gap between his social skills and those of his peers and of his negotiation of the American system |
| (Beresford et al, 2007) | Being able to communicate, being healthy and staying safe are perceived as fundamental to other outcomes |
| The Bercow Report | Talking is part of all important aspects of children’s lives – family, friendships, school, activities Children experience teasing, exclusion and lack of understanding of their condition |
| Roulstone et al, 2012 | Children valued support from teachers, friends and family; they enjoyed having fun; they wanted others to listen more, stop shouting and stop interrupting |

Table 1: A summary of research on the perspectives of children with SLCN

Involving children and young people in decisions

The recognition of a child’s right to be heard and have their views taken into account was recognised in the United Nations (UN) Convention on the Rights of the Child⁶, which came into effect in 1990. Prior to this, children were seen as unable to make decisions and the emphasis was on children’s vulnerability. However, there has been growing recognition of the balance between protecting children and young people and taking their views seriously⁷.

Most recently, the Children and Families Act 2014¹ has established new requirements for how local authorities in England work with children and young people with special educational needs and disabilities (SEND) and their families. This legislation means that when plans are made for supporting children with SEND, the child or young person and their family have a right to have their “views, wishes and feelings” taken into account. The importance of child, young person and family participation in these decisions is stressed and a duty has been placed on local authorities to provide information and support for children and their parents so that they can participate as fully as possible.

There are now some excellent reports of children’s participation in decision-making as well as guides for how practitioners and services can involve children and young people. In addition there is general agreement about what is needed for shared and informed decision-making:

- an expectation of being involved
- knowledge and understanding of the options available to us
- the ability to evaluate the options in terms of our own preferences and values

However, although previous reports have considered how best to involve children and young people with SEND, very few have focused specifically on children and young people with SLCN. There is now though a growing number of research projects which have explored the perspectives of children and young people with SLCN, an evidence base to which this research project contributes. Table 1 provides a taster of findings from such projects which provide us with insights into the experiences of children and young people with SLCN.

The overall approach

We used a ‘mixed method’ approach, with children’s groups, parent interviews and an on-line survey for parents. It can be challenging to explore children’s views, especially where children experience communication difficulties. For a variety of reasons, they may not be able to tell us about their opinions. So we used a story-telling structure with pictures and drawings to help the process. Our questions for the children focused on ‘what happens’. From their descriptions we can see what they know about the decisions that are made in school and we can learn something of how they feel about what happens.

In the next section, we provide a summary of how we went about consulting with the children, young people and their parents. More detail of the method is provided in the Appendix.

Who took part

The children and young people

We talked to children and young people in their schools from both mainstream and special schools and from different parts of the country. In Figure 1, the yellow stars show the locations of schools that we visited. These included:

- A primary school
- Two primary schools with language units attached
- A secondary school
- A secondary school with a language unit attached
- A special school (spanning primary-secondary)

Altogether, 54 children and young people took part, 40 boys and 14 girls aged from 7-16 years old. This balance between boys and girls is a consistent finding in research in that boys are 2-3 more times likely to be identified as having an SLCN⁸. Thirty four of the children and young people (63%) had education health and care plans or statements. Table 2 shows the numbers of children and young people from each school type. The children had a range of SLCN; however language impairment was the most commonly reported difficulty (17 children, 31%). Some children had other or additional SLCN. Thirteen of the children (24%) had mild to moderate learning difficulties. Nine of the children (17%) were reported to have autism spectrum disorders, a further seven (13%) were noted to have issues with social or pragmatic aspects of language, and six of the children (11%) had speech difficulties. Three children (6%) were diagnosed with cerebral palsy, two (4%) with Down syndrome and two (4%) with deafness.

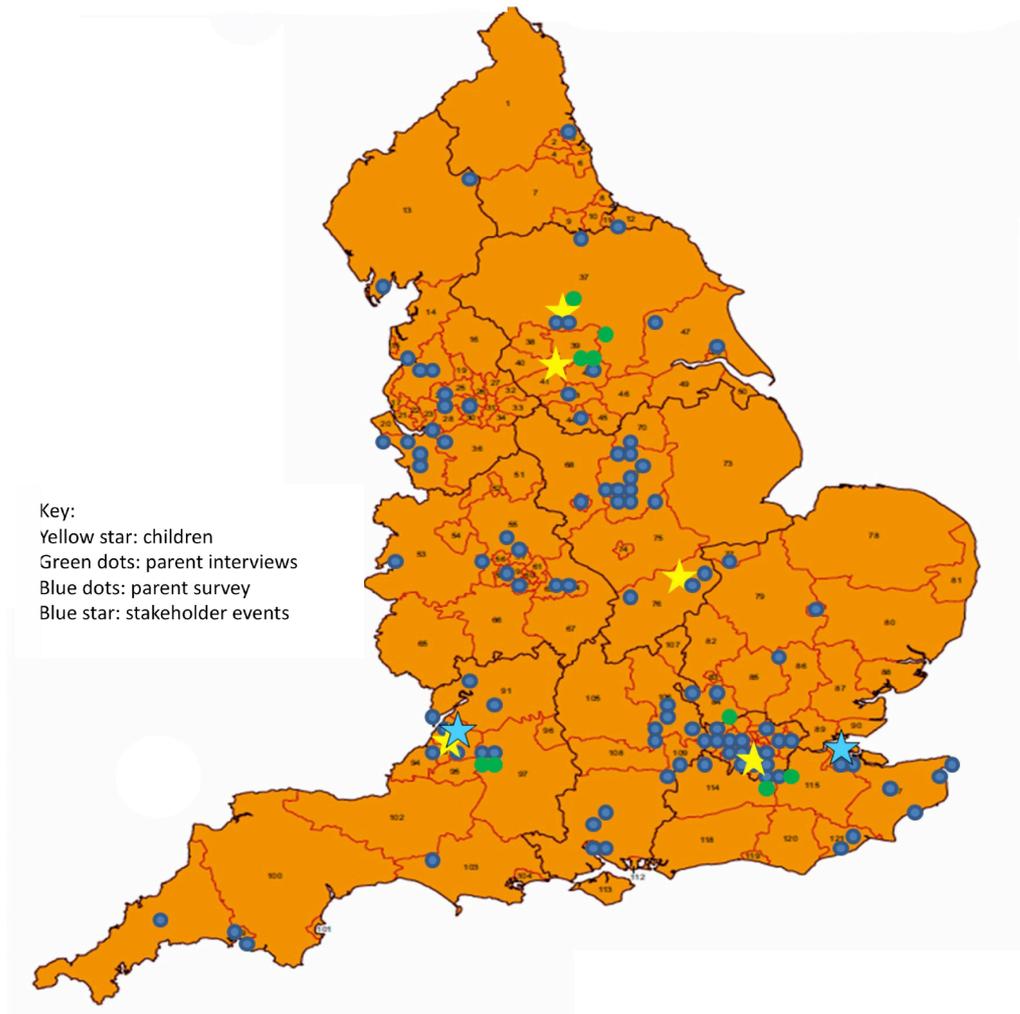


Figure 1: Who took part?

| School type | No. of participants | No. of groups |
|---|---------------------|---------------|
| Primary school | 12 | 4 |
| Primary school with language unit | 8 | 4 |
| Primary school with language unit (2) | 13 | 5 |
| A secondary school with language unit | 6 | 3 |
| A special school (spanning primary-secondary) | 13 | 4 |
| A secondary school | 2 | 1 |

Table 2: Number of children from each school type

| Parent | Parent responding | Child's age | Child's diagnosis |
|--------|-------------------|-------------|---|
| 1 | Mother | 9 | Specific language disorder, dyspraxia |
| 2 | Mother | 7 | Autistic (severe) |
| 3 | Mother | 14 | Cerebral palsy |
| 4 | Father | 14 | Down Syndrome |
| 5 | Mother | 11 | Autism |
| 6 | Mother | 7 | Autistic (pathological demand avoidance) |
| 7 | Mother | 12 | Epilepsy sclerosis, speech and language delay |
| 8 | Mother | 8 | Tourettes, global developmental delay |
| 9 | Father | 15 | Learning difficulties (result of brain damage as child) |
| 10 | Mother | 7 | Global developmental delay |
| 11 | Mother | 16 | Global developmental delay (learning difficulties) |
| 12 | Mother | 11 | Language delay |
| 13 | Mother | 14 | Autism spectrum disorder |
| 14 | Mother | 8 | Down Syndrome |
| 15 | Mother | 14 & 12 | Both children have global developmental delay |
| 16 | Mother | 8 | Emotional trauma |

Table 3: Age and diagnosis of child of parent interviewed

Parents

Telephone interviews were carried out with 16 parents; a further 100 parents from across England completed an on-line survey. The green dots on Figure 1 show the locations of parents who took part in the interviews; the blue dots show the locations of those responding to the on-line survey. Details of the children of the parents who took part in the telephone interviews can be seen in Table 3. The average age of the children of these parents was 11 years. Parents from across England (as identified by their postcodes) took part in the survey. Their children had a range of SLCN and were aged between 5 and 16 years of age with children from preschool, primary and secondary provision, mainstream and special provision; the majority of their children were boys (65%).

What we did

The children and young people's groups

Children were seen in small groups of up to four children organised by schools so that children knew each other and could work well together. The group sessions lasted about 45 minutes and were scheduled to fit into the regular school timetable. An arts-based approach was used to provide a context which supported conversation and the telling of small stories⁹. In particular we used a story format framed around children's school experience featuring six key topics:

- People in our story
- Starting school
- Learning in class
- Meetings
- Targets
- People in school who are good at listening

The six areas were designed to explore important information for the child, things that happen in school and to focus on aspects of school life where they may be involved in decision making about their individual support in particular. Children were presented with these six story parts, with accompanying drawings (Figure 2). This provided a structured and visual reference point which enabled them to see the progress of the session.

All sessions followed the same format, but were adapted to meet the needs of the different ages and abilities of the children. For example, with children with more severe learning and communication needs, questions were simplified, additional signing and symbols were used and activities were supported more frequently with objects and supporting materials. Resources from the school that were appropriate to the different key areas were available to prompt the children, for example target sheets, annual review forms and work books. Other resources provided by the research team included pictures of school topics



Figure 2: Story format

and activities; these were used to remind children of activities that they may have taken part in and to encourage them to reflect on these experiences.

Children and young people's groups analysis

The children's groups were analysed from video recordings using an adapted framework analysis¹⁰. This approach to qualitative analysis sets out categories which are then used to chart the data from each data collection process. Once all the data has been charted, further analysis identifies themes that cross categories.

Parent telephone interviews

The interviews lasted between 20 and 45 minutes. All interviews were digitally recorded. The questions focused on parents' experiences of the decision-making process regarding their child's individual needs; questions also explored any involvement parents had in more general service planning. There was a particular focus on things that have worked well and ideas for areas that could have worked better.

Parent telephone interview analysis

Researchers listened to the interviews to become familiar with the content. Ten interviews were transcribed in full. One of the researchers then identified key themes. Following this thematic analysis the remaining interviews were listened to again to confirm whether any other themes were present. This analysis was then independently verified by the researcher who conducted the interviews to ensure its validity.

Parent survey

Questions for the on-line survey were drafted in discussion with all members of the research team, focusing on similar topics to the parent interviews. The Bristol Speech and Language Therapy Research Unit (BSLTRU) Parent Panel reviewed the wording of the survey for clarity and suitability for a lay audience. The survey used a combination of multiple choice and free text questions to enable parents to record their views.

The findings

This section describes the findings from the three processes of data collection and analysis: the themes from the children and young people groups, the themes from the parent telephone interviews and the findings from the parent survey. The Communication Trust's priority was the voice and perspective of the children. Thus the findings from the children's groups are presented first and in presenting the findings from the parents' data we give priority to those data that highlight the children's perspective. Parents were also asked about their own experiences of decision making within the context of special educational needs and disability; these findings are also presented.

Children and young people's perspectives

The children and young people showed enjoyment of the groups and participated in the activities around the co-creation of a story about a new child starting school: they chose and described characters and then talked about aspects of school life that would be helpful for a new student to know about. They accompanied their talk with drawings about their school or making notes about the discussions.

The findings fall under three main headings:

- what children and young people know about their school
- times that children and young people are involved in decision making (or not)
- things that children and young people value (or not)

A description of each theme is given with examples from the conversations and illustrative quotes from the children. The codes in brackets indicate the code for the children and young people group. Initials are used rather than the children's names to ensure confidentiality.

What children and young people know about their school

Children were keen to show their knowledge about the school; this was seen in the discussions about what they might tell someone who was new to the school but also in the conversations about what happens in school.

General school knowledge

Children had a general knowledge of the school: they knew the names of key staff members but they did not necessarily distinguish all their roles, although the Head teacher and their Form Tutor (for the secondary children) were usually identified; they told us the names of classes and the names of topics being taught or subject lessons. Older children could give details of the school timetable and knew where to look for information about the timetable if they could not remember.

SC says *“at the beginning of the lesson ... they tell us like what we aim for and what our work is ... if we don't remember we use google classroom. They'll tell us what our objective is.”* (L3)

School rules and expected behaviours

Some information seems particularly important for the children and they prioritise it as information that a new child should be given. The school rules and expected behaviours featured strongly.

S says: *“no arguing and no shouting.”* (T2)

Another child says: *“not to shout out, not to make a big mess. You have to sit down and cross your legs.”* (C2)

Reward systems

Children also talked about reward systems that were in place in school, for example, getting free time once targets have been achieved (K1), getting stamps (K1) and 'golden time' on Fridays (T5), although not all the rewards were regarded positively by all the children.

C says: *“I don't like stamps.”* (L1)

The specific rewards systems that related to behaviour management were also mentioned such as the awarding of behaviour points. Children remembered occasions when classmates had been excluded (L3) or when the winner of the behaviour points was awarded a bar of chocolate (L1).



Figure 3: Drawings from some of the children and young people in the project

Child B says that he looks at his targets and he knows what they are, but was unable to remember at the time.

Targets

Children's targets were a key focus of the co-constructed story and we specifically asked children for information about their targets. Children varied in what they could remember and what knowledge they showed about their targets. The majority of children could either remember a target or tell us where they would look to remind themselves of their targets. Sometimes a prompt was needed; for example, if we gave children their workbook, they knew where to find their target. A few children indicated an understanding of the purpose of their target. Achievement of targets was frequently linked to short term reward systems.

Child P commented that his targets are in the classroom but he doesn't usually look at them. (T4)

Child B says that he looks at his targets and he knows what they are, but was unable to remember at the time. Later he writes "*manaching discracherns*" (managing distractions) as one of his targets. (T4)

C says: "*I have targets but I don't know what my targets are.*" (L3)

CA says that targets are "*always a rectangle*" and to "*use 'and' and 'but'*". He turns to the back page of his book indicating that he knows that his targets are usually written there. When asked what is there he says "*writing from our teachers.*" (E3)

S says: "*We need to know targets so we need to know to put more into our stories and writing and stuff.*" (E2)

Meetings

Finally, children told us about the various meetings that were held in school, including parents' evenings, improvement meetings and the school council. Some children attended these meetings; some knew about meetings that were held but did not attend; others showed less awareness. Annual reviews were not mentioned spontaneously by the children but some recognised the school paperwork that was associated with the review process.

D says "*no*", he does not go to any meetings but CA says "*sometimes we go to meetings.*" (E3)

E says that her parents are coming in soon for a meeting. (E4)

EW says that his mum goes to meetings but he doesn't. (T2)

L has been to school council meetings and was happy to go but could not report what had been discussed. (T2)

B went to school council meetings last year. He says "*you plan to make school a better place.*" (T4)

J and A say that they are not involved in school council and don't know what happens there. (T3)

C talked about a meeting that occurs for parents on Wednesdays when the teachers tell parents "*how much work we're doing, if there is anything you can improve on.*" (L3)

For all of these comments, it was not always clear how far the children are actively participating in decisions surrounding these events. However, information about aspects of the school system has clearly been communicated to the children in some way. The children are confident to describe to a stranger (or a new student) what is likely to happen in school.

Child A said “I wish to choose”

Times that children and young people are involved in decision making (or not)

As children talked about their different experiences of school, they mentioned a number of events or activities that involved some kind of decision. These involved both routine activities as well as the bigger decisions such as selecting subject options in secondary school. Following the focus of story-telling, children also told us about their level of involvement in target setting and about meetings. Researchers probed to explore if children were aware of potential choices or how far they felt they were involved in the decision making.

Daily routines

In the course of the conversations, children talked about the choices they had in their daily routines. For example, children said that their teacher told them where to sit but said that they could tell her if they were unhappy about it – “*if it was tricky*” (E1) suggesting that teachers attempted to accommodate children’s preferences when appropriate/possible. Children were able to choose activities for “golden time” – a free choice time, usually on a Friday afternoon and typically awarded to children who have completed their work. One young person commented that when they were younger they had a choice of books for study, but this choice disappears later as they “*have to do Shakespeare*” (L3). When talking about things they enjoyed in school, the subject of school trips was raised. Children indicated that they could choose whether or not they went on a trip but had no influence over the location. Child A said “*I wish to choose*” (T3), that is, he wished he could choose. When asked if they had any choices about what they were working on, children generally said “*no*” and one child added that “*she (the teacher) always tells us what to do*” (E2), although in L1, a secondary school, K said “*we decide*” what we work on, suggesting some joint decision making.

Target setting

Children’s perception about whether or not they had any influence over their targets was mixed. In E2 one child said “*we don’t choose it*” teacher “*makes a target for us*”. Other children indicated they can “*sometimes choose their targets*” (E1). Some groups reported that teachers do not talk to them about targets (E4); other children expressed uncertainty in whether or not teachers had talked to them about their targets: “*I’m not sure... probably.. probably*” (L3).

B was on school council last year *“you plan to like make the school a better place....well I didn’t say anything... but I liked it.”*

Meetings

Similarly, children’s views about their involvement in various meetings were mixed. In terms of parents’ evenings, many opted not to go. Some children did not like the idea of the teacher talking about them or felt nervous anticipation about what might be said. Other children saw the process as a more positive experience where parents would hear about their good work or for themselves to get positive feedback in front of parents.

“Parents evenings are a bit scary because you are not sure what the teachers are going to say to your parents.” (C1)

“I really hate it...I feel angry that they are going to talk about me, but happy because I don’t have to go.” (C2)

“I get to choose if I go to parents’ evenings.” (C4)

SC said: *“I felt a bit nervous at the start... because I was afraid what they were gonna say.”* (L3)

K anticipates a positive experience for her story character *“she’ll like them because... and she might get to hear what she’s done well.”* (T5)

Asked why he liked parents’ evening one child said: *“because the grown-ups get to see my work.”* (C3)

School councils were mentioned regularly, probably because at the time of the data collection, decisions were being made in most of the schools about which children would be on school council. Not only did children and young people show an awareness of the process of being elected onto the council, their comments showed understanding of its purpose, although not all children wanted to take part.

One child commented that school council was *“so we can get some more stuff for the school”* (K3); another child said that *“school council is boring”* (K4). Another child remarked that they did not want to be on school council because *“there would be lots of people talking at you, and staring at you while you were talking.”* (C1).

“It was like, everybody in my form was, when my teacher was asking ... who wanted to be on student council, um, there’s like, everyone was looking at me, saying so ... you gotta do it and then I decided, decided to do it.” (Children and young people stakeholder group)

J has been on school council and liked it for *“getting ideas about what could make the school better”*. He also reported council did not take forward his idea but seemed to accept that this was a reasonable outcome. (K4)

B was on school council last year *“you plan to like make the school a better place....well I didn’t say anything... but I liked it.”* (T4)

K said: *“it’s the best school”* and when asked why he said it because *“you have nice friends.”*

Valued (and non-valued) aspects of school life

Within the structure of ‘story’, researchers probed for aspects of school life that were positive or negative. So for example, if children were talking about learning in class, they were asked what helps them to learn in class, or what would their story characters like about being in class. Children were generally positive about their school. They had their favourite subjects (and non-favourite subjects) and sometimes, teachers. They had a variety of strategies for getting help but this was not always a positive experience. Children and young people also talked about the kinds of classroom atmosphere that were helpful.

Positive comments about school

The children used very positive language to talk about school and gave reasons for liking the school.

K said: *“it’s the best school”* and when asked why he said it because *“you have nice friends.”* (L1)

J said: it’s the *“best school ever”*, better than her last school as the teachers are *“more polite.”*(K4)

R said *“I like this school.”* (E2)

W said: *“The teacher makes us get smart so when I’m older I can get a job.”* (E1)

D said that getting the taxi is *“good.”* (E3)

H reported that this school is easier than the last and when asked why he said: *“I like playing with people.”* (T1)

P said that starting school was a *“bit fun”* and he has a fun teacher. (T4)

Favourite subjects

The children reported on their favourite subjects and activities. There was considerable individual preference within this although the emphasis was toward less academic subjects such as sports, art and drawing. Some children did report that they enjoyed maths, science and writing; golden time is mentioned a number of times and some children cite lunch and playing outside as their preferred activities.

When asked about what things they find hard or more difficult, many of the children reported that they did not find things particularly difficult, although maths and writing were the most commonly mentioned as being either difficult or not enjoyed. Children also used the word ‘boring’ about activities they did not enjoy.

L said that she finds homework hard and comments *“meetings, meetings!”* are boring because she has to *“sit and listen.”* (K1)

E said that there is *“nothing”* that she does not like *“except maths – its boring.”* (E4)

C and Sc agree that school used to be fun but things have changed now that they are in Year 10: C said: *“when I first started school it were fun but now I’m in Year 10 it’s a bit boring now”* and Sc said: *“it’s more harder because you get extra work.”* (L3)

A said that if there was one thing he could stop it would be *“people being noisy and stuff.”*

Getting help

When we asked children what they do if they get stuck or if they need help, they talked first and foremost about asking a teacher. However, having a number of strategies is clearly beneficial and the children are aware that their teachers are sometimes busy with other children.

One child reports that when you want help the teacher comes; the other child says they might already be helping someone else and *“your arms get really high and the best thing you can do is whisper to your partner and say can you help me”, “because the teacher is busy, she is busy helping people”* and the teacher has encouraged them to support each other – to *“try your best and help each other.”* (E1)

C said that sometimes he puts his hand up to ask for help and other times he gets on with his work and guesses. (L3)

One child said that his story character might find that *“it’s sometimes difficult [to get help] because he thinks he is going to get told off.”* (C2)

Classroom atmosphere

The children talked about the classroom atmosphere as sometimes being difficult.

A said that if there was one thing he could stop it would be *“people being noisy and stuff.”* (T3)

C said: *“it’s annoying when you’re trying to learn and they (naughty people) try and distract you.”*(L3)

E talks about people who bully *“makes me real mad.. it’s really horrible I don’t like it.”* (L2)

In conclusion, asking children and young people directly about their levels of involvement in decision-making is challenging. They are not always aware of what possibilities there are for participating in a decision making process or find it difficult to reflect upon a situation to work out what it is that they like or dislike about something. Because of these challenges we opted for a process which encouraged the children and young people to describe their experiences in school. The themes that emerged are ones that provide insights into the child’s perspective on decision-making. The knowledge that children and young people have about their school gives us an insight into which aspects of school life they understand and see as important; we have also identified events which seem to have elements of choice or absence of choice – which gives us clues as to how children and young people participate in those events. Finally, by identifying those aspects of school life that are valued (or not) by the children and young people, we can gain insights about how decisions that are made with and without children’s input might be received by them and how those decisions might impact on their lives.

Parent perspectives

The next section presents data from both the on-line survey and the interviews. We will focus first on the parents' views of how their children are being involved. We then consider parents' perspectives on their own involvement under the theme of 'informed, consulted or involved'. Parents' perspectives on the relevance of targets are then considered under the theme of 'target setting'. The last two themes focus on 'a new system' and the parents' 'story of diagnosis and difficulty accessing provision'. For each theme we present quantitative data from the on-line parent survey and then qualitative data from the telephone interviews and the free text responses to the survey. Understanding the perspectives of parents can help practitioners and service developers to refine their services although they can make challenging reading.

“Yes we talk about it all the time... we don't have discussions at school and leave her out... We don't keep her out of the loop, there's no point at the end of the day because it's about her”

Involving my child

The parent responses provide an insight into the enormous individual variation in terms of how parents feel about the way that their child is being involved. Some parents feel that it is going well; others feel that the process is currently unsuccessful and yet others feel that involvement of their child is inappropriate. These different responses seem to reflect different expectations and interpretations of what involvement of children means to parents.

In the on-line survey, parents were asked their opinion about if and how involved their children had been in the decision-making process and setting their own targets. About half of the parents who responded perceived that their child had not been involved in setting targets or decision making and more than two thirds of parents indicated that they were not pleased with the way that their child had been involved (Figure 4).

A small number of parents were aware that their child had been involved through decision-making activities and consultations in some way and were happy at how this was being done.

“I think she's been asked ... what she wants to get out of school.” (Parent 2)

“When they have the [meeting] that's every 3 months when he has his [meeting] he's asked what he would like to achieve out of school, what he likes about school, what he doesn't like about school, what he finds hard and what he finds easy. That's all discussed with (child).” (Parent 4)

“Yes we talk about it all the time with (young person) - we don't have discussions at school and leave her out. (Partner) and I discuss it after school or the teacher possibly the next morning,

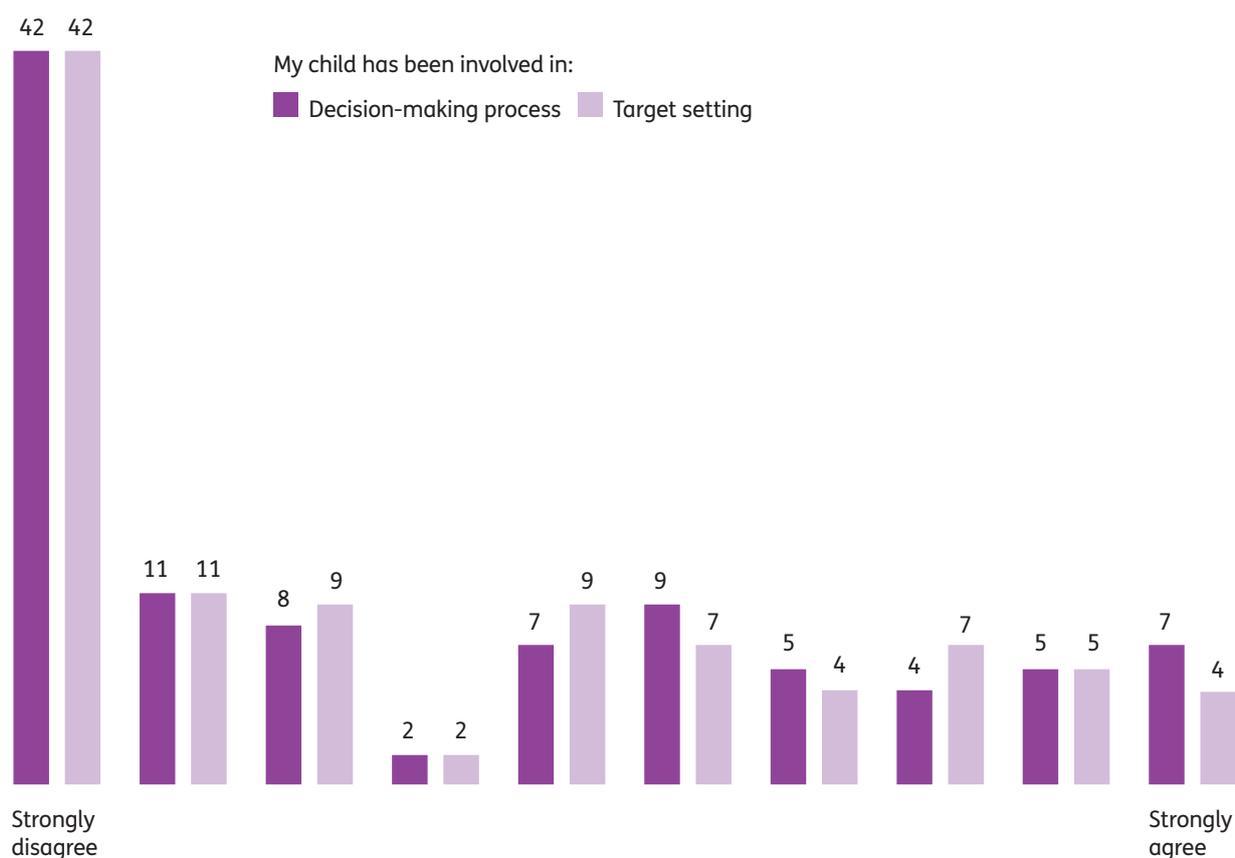


Figure 4: Parent perception of child's involvement

one of the 3 parties whether it's the teacher, myself or (partner), or all of us together we sit (young person) down. We don't keep her out of the loop, there's no point at the end of the day because it's about her." (Parent 6)

At parents evening child has to give positive and negative and then a way of parent/ teacher helping to reach target which makes the child in control and there's no right or wrong. (Survey)

Some parents commented on attempts to involve their child that they regarded as unsuccessful.

Evidence should be gathered in a more holistic way by encouraging discussion rather than simply questionnaires. Many of which he simply takes the adults lead in answering because he doesn't understand them. (Survey)

There has been a lot of 'observing' of my child and not a lot of actual involvement. (Survey)

"yes she comes into the meetings and like the other day she was getting really bored after a couple of minutes... they went through the questions they wanted to ask her first, and then she went back and they asked - well went through with me and then -she lost concentration after about a few minutes." (Parent 8)

One parent expressed concern that their child's responses are taken at face value without an understanding of the child's needs so the teachers were apparently following the child's wishes but not solving the issues about the child's difficulties in class.

"And I said well having a visual timetable would be good. But because they were giving him an 'individual' individual timetable (child) said he didn't want it because 'I don't want to be different from everybody else'. And it was like they took that as well (child) doesn't want that, but if he is disrupting a class by asking you all the time for help then it's

“Asking him for his opinions and acting on his suggestions. He is full of ideas and creativity and I’m afraid this hasn’t been noticed.”
(Survey)

not about what he wants – and actually a lot of the time he can’t communicate what’s wrong with him. He’s just frustrated and confused and especially - there’s actually probably nobody in the school he can actually... who he feels comfortable with... to say I have a problem with this.” (Parent 10)

In a number of instances, parents themselves considered that involvement in decision making would be challenging or even inappropriate for their child.

Due to her age it would be quite difficult to effectively involve her. (Survey)

My child has not been involved in the decision making process as she is unable to give her views. (Survey)

“I think it would be pretty pointless (consulting him) because he wouldn’t be able to grasp what they were saying.” (Parent 5)

“I can’t imagine that you’d involve any child up to age 11... your own child about decisions in their education. Whether they’ve got special needs or not.” (Parent 9)

Finally, some parents made suggestions for how the process could be improved.

The use of symbols to enable her to understand what is being asked. (Survey).

To attend meetings maybe at the end so as not all discussion is in front of her but she could bring examples of what’s being successful for her to share. (Survey)

Asking him for his opinions and acting on his suggestions. He is full of ideas and creativity and I’m afraid this hasn’t been noticed. (Survey)

At primary school when they did the annual review they presented her with choices so that she could be more involved in the review. This could be something that her current school could also do. (Survey)

Parents - informed, consulted or involved?

In the on-line survey, parents were asked if they had been involved in decisions about their child's targets and outcomes. Figure 4 shows how the parents were consulted. Those that indicated 'other' reported varied experiences, for example, "excellent communication with nursery", but also "SENCo decided outcomes, we had no say". Out of the 100 parents, 38 were happy with the level of involvement they had had in setting their child's targets and outcomes, a further 37 were happy but would have liked more involvement, and the other 25 were not happy with their level of involvement.

Similarly, in the interviews parents reported a range of experiences. One parent describes an example of a close working relationship with the school showing shared problem solving and

mutual support. Others talked about the ways that they could access staff to discuss concerns. The mutual use of a contact diary whereby both school and parents make a note of significant activities, achievements or difficulties was much appreciated by parents. This was seen as particularly important for parents whose children have SLCN and find it difficult to communicate what has been happening during the day and for those families where the child has transport to attend school and the informal contact at the start and end of the day between teacher and family is therefore not possible. Some parents feel that their concerns are taken seriously and acted upon. These two-way communications with school and the feeling that staff are open to suggestion seem to be linked to parent confidence about what is happening with their child and their satisfaction with the provision.

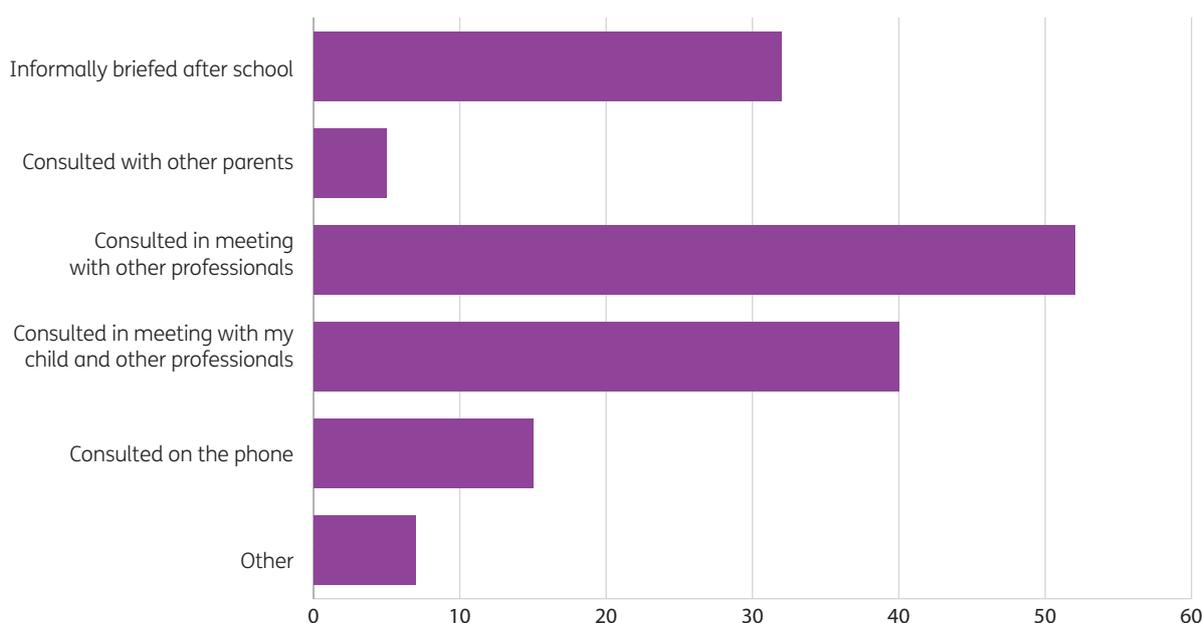


Figure 5: Ways that parents have been consulted

“...sometimes as a parent it’s out of your control you don’t know enough about disorder, you rely on the specialists.”

“school are very good actually we have lots of involvement ...we started meeting every umm, half every half term to have a meeting to discuss her umm, how that was going to be managed at school because her behaviour was very difficult and they were noticing that she was, the strategies that normally work with autistic children weren’t working with her because of xxx and so we worked very, we all worked very closely to come up with new ways of umm sort of teaching her at school and managing her behaviour and that was also and just to help with how we’re managing her at home as well.” (Parent 2)

“I’ve actually got a lady that I can ring anytime at all which is brilliant. Anywhere at all I can ring her on a daily basis, so yes it’s going ok at the moment. And they do inform me if he’s unsettled or if there are any worries, so I feel as if the communication with the school is very good. I think that’s why I feel quite happy.” (Parent 1)

“The communication’s fantastic you know we do a daily diary and school communicates through that and I’ll do my little bit in the morning, school do theirs in the night-time and any issues they will phone me up... and ... the yearly review went well, half a dozen of us sitting around the table discussing her needs.” (Parent 6)

Some parents reported that their child’s school informs them about targets and were confident that the school would alert them if there were any problems.

“they (virtual school consultant) flag up if (child) needs anything, they flag it up and they let me know. And they will say well we think the children need such and such, we’re going to put that in place.” (Parent 4)

Some, parents commented that they feel teachers and therapists are the experts and that they do not always feel able to make decisions that might make life tricky to manage their child in school. While some parents seem happy to leave decision making to schools, one parent was less happy about this situation and felt that a lack of information meant that she was not able to make informed decisions.

“I mean we’ve always done an annual review and I would say that is the only input that I’ve really had, unless I’ve been asked. I do feel that teachers as - long as things are going ok with (child) and we seem to think everything is going alright, I don’t like to interfere too much, because I feel that the teachers are the experts. I mean we did get asked did I want a say what they would they spend the money on, that he had at primary school and I said no because I felt they knew what they wanted to spend the money on and I wasn’t in a position to say.” (Parent 3)

“I wouldn’t say we’ve been involved but if I was to go in school and say actually I’d like to be... the issue is we don’t know the level of support he needs to make x, y, z progress, sometimes as a parent it’s out of your control you don’t know enough about disorder, you rely on the specialists.” (Parent 7)

“I know at the moment they are trying to get (child) to learn that there are two meanings to things. We have been involved in that they tell us what they are working on, rather than that we have a decision in it as we are not informed enough to be able to make that decision.”

(Parent 7)

Parents reported other involvement activities. For example, some parents had attended sessions at school to inform them about the new legislation or to tell them about different aspects of the curriculum. Some parents were part of parent support networks and had been invited to consultation meetings or were responsible for consulting on particular aspects of the changes such as personal budgets. Attendance at consultation meetings seemed to occur only if parents belonged to one of the voluntary sector parent organisations, but it was not clear if parent’s decisions to join a parent organisation happened before or after becoming involved with consultations within their child’s school.

Target setting

The interviews occurred early in the autumn term and for some parents whose children had just started a new school, this meant that they had not yet had discussions with the school about their child’s targets. However, even where children had been in a school for a number of years, parents were often quite vague about their child’s targets. They were quite apologetic about this and thought that they had probably had some communication from the school about the targets but could not always call this to mind. In one case, the interview seemed to prompt the parent to consider a follow-up conversation with the school. Some parents referred to paperwork from the child’s statement or an Education and Health Care Plan (EHCP) or from the last annual review which seemed to act as a reference point regarding targets.

“I can’t remember them specifically - a lot of the work that they’d be doing was getting her to actually participate in within the group because that was part of her difficulty.”

(Parent 2)

“Because at the end of the day (child) changes day to day. So it’s pretty much done weekly, plus there’s the general targets for her education that they work on, on a year they set the targets. But at the end of the day the weekly stuff, assessed pretty much every week and you can’t - for me you can’t ask for more than that.” (Parent 6)

Question: *“do you feel that they (targets) take account of broader, not just education aspects but things around socialisation..?”* Reply: *“I do yes, I have got a little list here I don’t know if this would be helpful. How to make friends, and how to negotiate conflict, to enable (child) to development his strategies to deal with his*

emotions, in particular anger, anxiety and frustration.” (Parent 1)

I can't remember any targets off the top of my head as I'm still waiting for my copy of the new EHC. (Survey)

“No I don't actually (remember his targets), that's awful. I just know that ... at the end of the year whenever they said - oh and he's met those targets and exceeded those targets and I thought well how have you set them, because he always seems to exceed them, so to me actually you probably haven't .. they don't seem to be set very well. They haven't had any involvement with me or discussions about what my hopes and aspirations are for him. That would be another helpful thing to understand how they do actually set the targets.” (Parent 9)

Where parents had some level of involvement in the target setting, they seemed to be happy that the targets were relevant and useful. However, others questioned how targets had been set, the relevance of the targets to the child's needs and in particular to the child's everyday functioning. Parents were concerned either that the child's targets were too easily achieved or unachievable or had not been updated.

“His targets are to sit in a group of at least 6 children and to widen his friendship, because he only has one friend. To widen his friendship and to take instructions from another child in the group.... the one for widening his circle of friendship circle, that was one that I asked to be put in.” (Parent 4)

All the targets on his current statement are irrelevant as they rely on the premise that my son will cooperate and engage, which he will not. (Survey)

They (targets) haven't changed since 2012. (Survey)

“I was getting a bit disappointed with the SALT [speech and language therapist] but they were sort of - you know ... she cannot distinguish between he and she, she says he for women and she for boys, she doesn't get it right. I just think it's one of the things she's never going to get. She can't do it and it's not a big issue for her. We correct her when she does it wrong. But the last lady I spoke to said she'd like to work on money and time and stuff that's going to be useful that she really struggles with so whilst she's still doing the SLT, she's going to be working on some lasting stuff - much better.” (Parent 8)

“The local authorities don’t have smooth processes in place yet and the experience is stressful. There doesn’t seem to be the right expertise either.”
(Survey)

The reformed SEND system

Parents were asked if they were aware of the changes to special educational needs provision. Nearly one quarter of the respondents (23%) reported not being aware, but this surprisingly high figure was not statistically related to whether or not the child had a SEN Statement, Learning Disability Assessment (LDA) or EHCP. The number of children with each type of provision is given in Table 4.

Parents who were aware of the changes (26%), thought that they would impact on their child. However when invited to comment on how they thought the changes would impact they tended to have a negative view:

Speech and Language was written out of the EHCP where it was previously in statement but no new assessment was done. (Survey)

It is giving my LA [local authority] further excuse to drag their heels and take even longer to meet his needs. (Survey)

The local authorities don’t have smooth processes in place yet and the experience is stressful. There doesn’t seem to be the right expertise either. (Survey)

It’s in the plan but not provided. (Survey)

The only positive statement about the EHCP was: he finally got the education he needs and deserves because I was able to understand and use the new legislation to get my LA to finally do something. (Survey)

For the parents responding in the telephone interviews, the majority had not noticed any real change associated with the new legislation. We asked parents if they felt that there was an increase in the involvement of their child or any changes that they had noticed. Parents who felt

| School type | No. of children |
|--|-----------------|
| Yes, they have a SEN statement | 33 |
| Yes, they have an LDA | 9 |
| Yes, they have an EHC plan | 10 |
| Yes, they have an EHC plan and previously had a SEN statement or LDA | 9 |
| No, they do not currently have an EHC, SEN statement or LDA | 42 |
| I do not know | 5 |

Key:

EHC = Education Health Care

LDA = Learning Difficulty Assessment

SEN = Special Education Needs

Table 4: Plans in place

that there had been recent positive changes either attributed these to individual practitioners or to schools rather than to the legislation. Parents commented that the schools were still in the early stages of sorting out their new processes.

“I would say it isn’t obvious to me that there really are any changes. I do know that it’s supposed to be that they are more involved. He does have a passport at his school but I’m putting that down to the school rather than the EHCP. I get the impression that any input that (child) had into that was what they would have done anyway. So I would say it doesn’t seem to be that different.” (Parent 3)

“I felt like we were guinea pigs. The SENCO at his primary school didn’t really know what was happening it was all a horrible panic this time last year.... So it was obviously new to her as well - I don’t know whether that’s accurate or not, but that was the impression she gave.”

So we had these meetings and all the stuff towards it, the form was more detailed than the annual reviews had been, but probably not as much work as getting the statement in the first place.” (Parent 3)

“But this year because it has been quite a noticeable difference I’m hoping there is going to be a lot more in his plan this year... he’s in year 5 now, and I didn’t even know he was academically behind until I spoke to her this week and that’s been 3 years he’s been in the junior school ... the 2 teachers that he had last year didn’t seem to - it seemed that everything I was asking for was extra work for them and they didn’t want to commit to it. And actually I think within the first meeting I had when I addressed some issues that I had to them and I said that I was looking into trying to get (child) statemented at the time, she told me that he’s far, far too bright to have a statement - He’ll never get it because he’s far too bright. So they don’t seem to have the knowledge and understanding of it to be honest... and it’s actually a brand new young really young teacher this year, and probably in 5 weeks I’ve had more communication with him than I did in the 2 years with the other teachers. So I’m hoping that this year it’s going to be a little bit more positive.” (Parent 10)

So, the views of the parents in this sample suggest varying levels of awareness of the reformed SEND system and its impact. Parents are experiencing the stresses of a system in change, reporting uncertainty both directly in terms of their own confidence in how things now work and also with regard to implementation of the new system in schools.

Story of diagnosis and difficulties accessing provision

Within the topic guide for the telephone interviews, there was no focus on the child’s previous history. However, it was not unusual for parents to talk in some detail about the route to diagnosis and provision. In many cases this was a story of struggle and of difficulty getting provision in place. In some cases these struggles had been over many years and were now resolving, but for others the difficulties were recent and ongoing. The stories told of the children’s own struggles, of ‘brilliant care’ and ‘amazing school’ support (Parent 6) and the anxiety of parents who feel they must push to resolve the questions of appropriate provision for their child.

“It’s quite a big process when you got a child with communication problems,... to be honest it’s difficult because unfortunately my son doesn’t actually have an actual diagnosis ... well he is behind at school but not enough for them to put an education care plan in place. So it’s just really, really difficult...he struggles to communicate with people, he cries a lot and actually he finds it difficult to find the words to tell people why he’s crying. So it is quite difficult and of course with having a child that just cries all the time, or maybe shows a bit of frustration, it’s difficult for the teachers to know how to handle him and so everything I’ve been doing, I’ve kind of really been pushing to be involved and make - it seems like in order to get any information at all I have to call a meeting, or complain about something.” (Parent 10)

“It’s quite a big process when you got a child with communication problems... it’s difficult for the teachers to know how to handle him and so everything I’ve been doing, I’ve kind of really been pushing to be involved...”

In conclusion, there are reported ongoing difficulties for parents who are seeking support that meets the complexity of their child’s individual needs. Despite this, parents spoke of many positive experiences of teachers and therapists who they perceive to be working hard to involve them as parents in the decision making process and to provide appropriate support. Whether or not these processes are experienced as positive seems to rest almost entirely on the nature of the communications between services and parents. Where school and other services are actively seeking parents’ views, inviting parents into schools, responding to parent concerns, taking forward parent suggestions and keeping parents informed, then parents feel that they are suitably involved and happy about provision. Where parents feel there is little information, ideas are not followed through, or that they have to push to get a response from services, parents feel unhappy and concerned about the quality of the provision.

Reflections on talking to children and young people with SLCN

Much has been written about how to support children's participation, some of it directed at children with SEND but relatively little specifically addressing issues of involving children who have SLCN. This consultation has focused entirely on children with SLCN. Children with a wide range of SLCN, associated with other developmental disorders (including learning disorders, motor disorders and autism spectrum disorders) and those whose difficulties are primarily with speech and language were included in the consultation process. The process has highlighted some points of good practice that can be applied to future research with children with SLCN, to future consultations and to the process of involving children and young people and their parents in decision making. The actions we suggest can be regarded as good practice for any child but they are particularly important for children and young people with SLCN because of their communication and/or processing difficulties.

Talking about recent things

The children and young people's groups were held in the first half of the autumn term, before half term. It is almost certainly this timing that led to so many children talking about the school council and not about annual reviews: most of the schools had recently been through the process of electing children to the school council; thus the role of the council had been discussed with the children and young people and they had been involved in deciding who should represent their class.

The timing of the parent interviews was also a factor in the discussion of targets in that some children had only recently started at a school and parents were therefore less familiar with the schools system and parents had not met their child's tutor.

Our ability to talk in detail about experiences is clearly linked to our memory of those experiences. For most people, the more recent those are, the easier that is, but for children and young people who have SLCN, this may be even more of a challenge as they may have difficulties with working memory.

Action: In terms of gaining feedback, any exploration of a school or service system process should take place as close as possible to the event or contact with the particular service in question. For example, if a school wished to explore the children and young people's views about the annual review process, carrying this out as soon as possible after the event would be crucial.

The use of objects and supporting materials

Even with recent events, children's ability to reflect on an event or activity in detail is supported by the use of objects or materials from the event or activity in question. Thus the level of detail in the data from the children and young people about annual reviews or target setting was increased in those contexts when we had access to, and could show the children, copies of annual review paperwork or the books in which teachers wrote the children's targets. During the discussion with the children and young people stakeholder group, some of the children and young people had remembered their targets and others had not. When they were asked where they might get information about their targets, they could not tell us where they would go. After the conversation, the accompanying teacher remarked that if we had been in the actual classroom instead of the meeting room, we might have got a different response, since the children's targets were all on display in their classroom walls.

Action: Whilst pictures and symbols that represent the issues can support discussions, having access to the actual objects or paperwork that the children use can increase children's contributions. It provides additional supporting context that helps them to remember the right words and remind them of the activity or event.

Dynamic activities support engagement

Children participated more actively in the conversations about their experiences if the conversation was situated within an activity. For example, the following activity was used with the school council stakeholder group: each member of the group indicated their level of involvement in particular decisions by voting with symbols. Each person had to choose one or more symbols that represented whether or not they had been informed, asked questions, made the decision on their own and so on. The activity became very noisy and busy as they moved their symbols around, picked them up, and reached to put them into the centre of the table. The activity allowed movement out of their seats, and there was a physical movement associated with their response. Whilst some pupils needed support to carry this out, the active process of choosing a symbol helped their level of engagement and stimulated conversation and discussion as well as providing a direct indicator of their response.

This need for dynamic action rather than merely a discussion was also noted in children and young people's comments on other activities. So for example, they commented that meetings were boring because everyone was just talking. One of the parents commented that her child lost concentration when asked a series of questions even though they had been prepared with the child in advance.

Action: It is helpful to include physical actions and dynamic activity that reflects the verbal activity, such as sorting cards for voting or indicating choices, choosing stickers to indicate preferences or moving levers or counters to show a score on a scale. This supports children's engagement with the involvement activity.

Advantages and disadvantages of having someone who knows the child/context

In terms of consulting children with SLCN about their views, there is a choice to be made about whether or not this should be carried out completely independently or with the presence of someone who is familiar with the child, their communication system and their context. The presence of an adult who is also present when the decision making takes place may support the child to communicate their views but it may also bias the child's responses. In this project, staff were present in the special school and at the stakeholder meeting; in the latter the member of staff was employed specifically to facilitate the school council and was therefore seen as different to the teaching staff by members of the council. In the special school there were a number of times that the presence of a staff member enabled children to be prompted and encouraged responses. There was also evidence however that some children tailored responses to please the staff member, for example looking at her while discussing something the staff member taught in school and hesitating to say their feelings about it.

Action: Careful selection of the adult facilitator is needed; they need to know the child well enough to be able to act as a facilitator, but preferably not the person who delivers the service or activity which is being discussed. For example, if the child's views of the classroom context are the subject of the consultation then it would be better to use someone who is not regularly in that particular classroom. A commitment to the confidentiality of the child's responses is vital.

Small group versus individual

Children and young people were seen in small groups, usually of two or three and a maximum of four with two researchers. The presence of a familiar child reassured other children and they were content to engage with the researchers and would often get into discussions between themselves so that the researchers did not always need to prompt them. However, sometimes the children followed the lead of one child and responded in the same fashion as the leader rather than making a different contribution.

Action: If children are to be seen over several sessions then it is feasible to see them individually since a relaxed relationship can be developed over a period. However, if a single consultation meeting is planned, then a small group may be needed to reassure the child, particularly at the beginning of the session. For children who have SLCN, group work is often challenging in terms of taking turns and being able to contribute within a group setting. Some children's contributions may dominate or they may wish only to speak to the adult. It is therefore necessary to have additional adults available who can support the group dynamic and listen to children as individuals if required.

The language used

Previous projects¹¹ have shown that discussion of what is 'easy' or 'difficult' is not always understood by children in the same way that the adults intend. For example, something that is 'easy' is sometimes dismissed as valueless; something that is difficult shows that you are clever and learning new lessons that are hard or difficult is part of growing up and to be expected rather than worthy of any particular comment. Whether lessons are perceived as difficult or hard or easy can be as much to do with how things are structured in class as to a child's confidence or persistence.

Action: Checking children's understanding of words that are to be used in consultations will ensure that interpretations of their responses are more likely to be valid. Further research concerning children's interpretations of the vocabulary to be used in discussion of targets and outcomes would be helpful for future consultations.

... the active process of choosing a symbol helped their level of engagement and stimulated conversation and discussion as well as providing a direct indicator of their response.

Recommendations

Before our final summary, it is important to draw attention to some caveats about the interpretation of the data. Firstly, the data is based on the perspectives of children and young people and of parents. They have told us about their experiences and we report them without prejudice. However, from the perspective of a practitioner, under pressure to deliver services in the face of new requirements and pressures on services, the findings may make challenging reading. Generally children and young people were enthusiastically positive about their school and many parents valued the support that particular schools or teachers had provided. A number of parents told us that they appreciated our efforts in gaining their views, but we must use their perspectives to improve services and make them more relevant and finely tuned for the individual children, young people and their families. The second caveat is that, although we have talked to more than 50 children and heard from over one hundred parents, this is still a small sample compared to the thousands of children and young people with SLCN in England. There were distinct and repeating patterns in the data, but we cannot guarantee that we have captured all the relevant views.

Recommendations are organised using three themes from the children and young people's perspectives: knowledge about their role in decision-making, the decisions which are relevant to children and young people and their preferences and interests which can shape the decisions that are made. These three themes are used as headings for a final discussion of the findings and presentation of recommendations for developments that could support the involvement of children and young people with SLCN in the decisions relating to SEND.

For those people who have been actively involved with children and young people with SLCN, many of the recommendations will feel familiar. The majority confirm and reinforce principles of best practice for communication with these children and young people. However, the unique value of the recommendations is that they are based on the perspectives of the children and young people themselves. The report therefore adds important evidence to our understanding of how best to support and involve children and young people with SLCN in decision making and these recommendations will be useful to all those working with children and young people with SLCN and their families and are transferable across different settings and contexts.

...the unique value of the recommendations is that they are based on the perspectives of the children and young people themselves.

Knowledge of children and young people's role in decision making

The need for accessible, relevant and interactive information for children

In order for children and young people to make a contribution to the decisions that concern them, whether at the level of individual support or at the level of service development, they need access to relevant information. The materials not only need to convey information about the process but also convey the possibility and expectation that children and young people have a part to play. They need to show that it is acceptable for children and young people to express their preference for different levels of involvement and set out what those different levels might be.

The materials should use accessible language and be delivered in a way that is appropriate to children and young people's level of understanding. To support their engagement with this material it should also be stimulating and fun. The children and young people in this project preferred active learning processes. Therefore interactive games, videos and role playing, art work, pop up books, stories and songs would be the kinds of materials that might appeal to children and young people with SLCN. These kinds of materials could be used as part of an induction process in which the children learn about how the school or service works, highlighting to them the possibility and expectation that they have a part to play in the process. They could also be used in preparation for a particular stage in the SEND process such as before an annual review. Materials which ensure that children and young people are familiar with the vocabulary needed for consultation and involvement processes might be particularly helpful.

The need to improve information for parents

The emphasis throughout this report is on how best to support the involvement of children and young people with SLCN. In order to achieve improvements for children and young people, it is vital that the process of communicating with parents is also considered. Parents welcomed opportunities to engage with the ongoing process of setting regular targets and supporting their children and young people on a daily basis. However, the time required to exchange information between school and home, from both teacher and parent perspectives, is challenging. This is picked up in the final recommendation below.

In addition, it is important to highlight parents' perspectives regarding awareness of changes to the SEND system. This research has highlighted that ongoing efforts are needed to provide relevant and timely information for parents about the reformed SEND system and the impact on their children. Collaboration with parents and parent organisations is vital to ensure that appropriate information is reaching parents and to further inform policy and practice in meeting the needs of children and young people with SLCN effectively.

Relevant decisions

The need to identify the range of decisions of relevance and interest for children and young people with SLCN

The recent legislation addresses involvement in decisions about a child's individual support and about service developments. However, in order to effectively involve children and young people in specific decisions, there has to be a culture of participation and an expectation that children and young people (and their parents) will be involved in a range of decisions. Many schools have already established school councils and other mechanisms to listen to children and young people's views and to capture the 'pupil voice'¹². Our data confirms the findings of other investigations¹³ that children and young people with SEND do not always get elected, or do not self-select, to be involved in these kinds of meetings and are thus less likely to engage with the whole process.

It would therefore be useful for schools and/or services to conduct a process analysis of the decisions made within that context in order to map the range of pupils that have been actively involved in those decisions and to highlight if and where children and young people with SLCN are being left out or even excluded. It is important to look beyond the SEND process to the wider school experience since we cannot expect children and young people with SLCN to engage with decisions about their own support when they are not otherwise involved in decision-making. A useful way to structure this mapping process whether at a school or whole service level, is to focus on the points of contact between a child, their family and the school or service.

The need to identify the most appropriate level of involvement in decisions

Data from this project suggests that the children and young people experienced five different levels of involvement in decision making (Figure 6) from no involvement and decisions being made without their knowledge or involvement through to making decisions or expressing a preference which is then taken forward or supported by the adult. These levels of involvement are similar to those described in other research^{14,15,16}, although they do not cover all possible scenarios. Being involved does not necessarily mean that the child makes the decision alone or even as a shared decision. It can mean being given access to information, having your values and preferences considered as part of the decision, being given a chance to ask questions and being informed about the outcomes of decisions.

Depending on a child's age and maturity², the nature of the decision being made and the child's own preferences, different levels of involvement may be appropriate. We would however in most instances hope to see the disappearance of the bottom two levels on the figure: making decisions without either a discussion with children or providing them with information.

Similarly, not all parents want to make all decisions alone or even to share in some decisions, but most wish to have some level of involvement; in particular, they would like to have their views listened to and respected and to be given information that allows them to participate in decisions in an informed way.

There is a need for practitioners and parents to understand these different levels of involvement in decision making so that the most appropriate level can be selected, in association with the child or young person and with their parent. Once the mapping analysis has been completed, then making the potential levels of involvement that might be appropriate to that decision explicit is necessary in order to muster the relevant resources to support the individual in being involved.



Figure 6: Levels of involvement experienced by children and young people with SLCN

Responsive to children and young people's preferences

The level of involvement is of course not just in the hands of the adults. The children and young people themselves also have preferences depending on the decision that is being made. For example, some of the children and young people loved to attend the parents' evenings and saw them as an opportunity to hear good news; others saw the process as excruciating and did not want to be part of it. Children, young people and parents will have different thresholds for participation in different activities and decisions. This will depend on personal preferences for children and young people and furthermore, for parents, other constraints such as the distance from school, working lives and other family needs are bound to impact on their levels of involvement.

Whilst we cannot assume that these differences are due to the ways that teachers conduct the sessions, we can increase the likelihood that children and young people will want to be involved in decision making by attuning the processes more closely to their interests and preferences. Following on from the mapping process described above, it is useful to discover from children and young people which decisions they perceived to be relevant to their interests. This is certainly a challenge for services, but highlights the need to check with children and young people and their parents regarding each activity and event and avoid assumptions.

Action and active processes

The process of involving children and young people with SLCN needs to take account of their preferences for activity rather than just talk. In this project, children and young people did get involved in meetings such as parents' evenings and schools councils. However, there was generally a dislike for those that consisted of a lot of talk. Given their SLCN, this is not surprising. Events that use talk as the main medium are likely to be challenging. Examples of more active engagement activities might include asking children and young people to take and present photos of their achievements, giving children and young people picture voting cards to indicate their preferences, having an art or photo competition when consulting about a new playground layout or encouraging children and young people to improvise a role play of a situation they would like to change. Such activities require thorough planning and take time. However, not only do they facilitate involvement of children and young people with SLCN they also support the development of their skills.

It is important to add finally, that we should not assume that we cannot use talk at all with children and young people with SLCN. However, instead of adults leading the talk, facilitating the children and young people to take a leading role is sometimes the preferred option. For children who have limited verbal communication or who are using alternative methods of communication, this is particularly important since they are often cast in passive roles within a communication situation.

Relevant and meaningful targets

In previous consultations with children and young people with SLCN¹⁷, the children and young people were rather vague about their targets and not particularly enthusiastic. It was clear from this project that much effort has been made to make children aware of their targets. However, the level of detail recall was widely variable; most could tell us at least one of their targets but found it difficult to expand on what they had to do to achieve it or the reason behind the target. Similarly with parents, although some knew their child's targets and felt that they were appropriate, others were apologetically vague or felt that targets lacked relevance to their child's longer term needs.

With the change in assessment processes used in schools, and the move away from the levels system in the National Curriculum, there will be an opportunity to rethink how targets are set. Two aspects are important: first, there is a need to make the short term steps (or targets) between a current achievement and more functional outcomes, such as independence, more explicit so that everyone understands the purpose of a short term target, where it is leading and what will be the future outcome. Using flow charts, pictures, diagrams will be important to help children visualise the link between their current targets and their own aspirations for the future.

Second, there is the challenge for parents and teachers in terms of the time necessary for involvement of children and young people and their parents. This is clearly a challenge that can't be underestimated but increasing the level of involvement is the way to increase ownership of the targets by the children and increase support from parents. This is not a problem to be solved by teachers alone. It can only be solved by teachers and parents working together with children and young people to find a way of communicating that is manageable, relevant and timely.

...there is a need to make the short term steps (or targets) between a current achievement and more functional outcomes... more explicit

Conclusion

This project has identified evidence of the involvement of children and young people with SLCN, and their parents in decision making within SEND frameworks and more broadly in school decisions. Children and young people with SLCN and their parents all indicated a desire to be involved in decision making. Children and young people in the stakeholder group expressed their views forcibly:

“the worst part is that they don’t tell us”

“I hate the fact that, that, some parents don’t respect your choices, and if you want to do it you should do it. But there are some cases where parents don’t respect it because they want you to be something else, and that’s what I hate about. That’s what I hate”

However, the level of involvement varied and some parents sometimes felt that they were ill-equipped to play a part in decision making; some children and young people were put off by the talk-centred processes. Practitioners have worked hard to listen to and include the voice of children, young people and their parents, but there is still much to be done. For the future, we need to identify the full range of decisions in our systems that could be opened to the involvement of children and young people and their parents. The systems include classrooms, whole schools or settings and indeed whole services.

We need to identify appropriate levels of involvement and provide information so that children, young people and their parents can take an informed part in the process. Finally we need to initiate action oriented processes that reduce the emphasis on talk and promote the engagement of children and young people. These recommendations can be applied not only by schools and settings, but can also provide a useful starting point for services who wish to improve the level of involvement of children and young people with SLCN in service development.

Useful resources available from The Communication Trust

Communicating the Code

This resource provides practical information and links to great resources to help all those involved with children and young people with SLCN fulfil their responsibilities effectively under the new 0-25 SEND Code of Practice. Communicating the Code is available here – www.thecommunicationtrust.org.uk/communicatingthecode

Involving children and young people with SLCN – A toolkit for education settings

This builds on the evidence presented in this research report and on *Communicating the Code* to provide information, guidance and practical support for staff working in education settings to help shape their approach to involving children and young people with speech, language and communication needs as part of everyday good practice. The toolkit launches in February 2016 and is available here – www.thecommunicationtrust.org.uk/involve

Support around involving children and young people with SLCN and their families in the reformed SEND system

These web-pages provide useful information from the Trust, our Consortium members and partners around the involvement of children and young people with SLCN in the reformed SEND system. They are available here – www.thecommunicationtrust.org.uk/sendreforms

The Consortium Catalogue

The Trust is a Consortium of over 50 not for profit organisations. This catalogue provides information on the products and services available from our Consortium Members for schools and those working with children and young people with SLCN including links to some activities, resources and training which will be useful in working to better involve children and young people with SLCN. The catalogue is available here – www.thecommunicationtrust.org.uk/consortiumcatalogue

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