Department
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The preferred outcomes of children with speech, language and communication needs and their parents

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ACKNOWLEDGEMENTS

EXECUTIVE SUMMARY

The Better Communication Research Programme (BCRP) was commissioned as part of the Better Communication Action Plan[1], the government's response to the Bercow review of services for children and young people with speech, language and communication needs[2]. This had recommended a programme of research 'to enhance the evidence base and inform delivery of better outcomes for children and young people' (p.50). This is one of 10 publications reporting the results from individual BCRP projects. These contribute to a series of four thematic reports and the main report on the BCRP overall in which we integrate findings and present implications for practice, research and policy from the BCRP as a whole (see Appendix 1 for full details[3]).

This report presents the findings of five projects that were part of the Better Communication Research Programme. The projects investigated the preferred outcomes valued by children and young people with speech, language and communication needs (SLCN), and their parents. The findings are considered in terms of the implications for practitioners, in both health and education, for research, and for policy development.

Key Findings

- Children valued their family and friends, their pets and the people who help them. They valued the fun they have with teachers and family. They were proud of their achievements and had individual aspirations for the future. They acknowledged areas of difficulty which included their own feelings and emotions. Rarely did they spontaneously raise the issue of their own speech, language and communication skills.

- Parents valued development in the communication skills of their children because this was seen as the development that was needed to facilitate their child's independence, acceptance and inclusion. In the same way, academic skills in literacy and numeracy were seen as necessary to a child's ability to be independent, particularly economically.

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[1] https://www.education.gov.uk/publications/eOrderingDownload/Better_Communication.pdf
[2] Bercow, J. (2008). *The Bercow Report: A review of services for children and young people (0-19) with speech, language and communication needs.* Nottingham: DCSF.
https://www.education.gov.uk/publications/eOrderingDownload/Bercow-Report.pdf
[3] Reports are accessible through the DfE's research site
http://www.education.gov.uk/researchandstatistics/research

- Parents would like to see an increase in knowledge about, and attitudes towards SLCN of those around them. This includes the general public, family and professionals they encountered.

- Children would like adults to listen more and not shout; they would like their peers not to tease them.

- A range of parent and self-report measures exist in the area of children's quality of life, although few have been used with children and young people with SLCN

Implications for practitioners.

Discussion of goals should take account of both parents' and children's perspectives and should make explicit links between immediate goals and the longer term outcomes of independence and inclusion

The knowledge, attitudes and inclusiveness of a child's environment and the child's emotional needs should also be considered when identifying goals.

Implications for research

Further research to improve the validity and usefulness of existing Quality of Life self- and parent-report measures and the feasibility of using them in everyday practice would be helpful in order to cover the range of outcomes that are valued by parents and by children and young people with SLCN.

Children's independence is a major concern to parents; furthermore parents appreciate the link between a child's communication skills and functional independence. Research to increase our understanding of how this plays out for children at different ages and with differing profiles of ability is needed.

Further research is needed to investigate the valued outcomes for younger children and those with milder SLCN and from families from a wide range of social and ethnic backgrounds.

Implications for policy

Commissioners of services should include self- and parent-report outcomes as measures of service effectiveness.

Measures which evaluate how well a child or young person is able to apply their academic skills in everyday life might be a useful addition to traditional academic outcomes for some children and young people.

1.   BACKGROUND

The Better Communication Research Programme (BCRP) was commissioned as part of the Better Communication Action Plan[4], the government's response to the Bercow review of services for children and young people with speech, language and communication needs[5]. This had recommended a programme of research 'to enhance the evidence base and inform delivery of better outcomes for children and young people' (p.50). This is one of 10 publications reporting the results from individual BCRP projects. These contribute to a series of four thematic reports and the main report on the BCRP overall in which we integrate findings and present implications for practice, research and policy from the BCRP as a whole (see Appendix 1 for full details[6]).

In order to ensure that these 'better outcomes' can be delivered, it is necessary to have a clear understanding and some consensus about what is meant by 'better outcomes'. The literature suggests that we cannot assume that there will be consensus between parents and children or between professionals and families about the needs of the children. A key component of the Better Communication Research Programme (BCRP) has therefore been a focus on the perspectives of parents and children, in particular a series of projects to explore their views about outcomes. This report presents the findings of five projects and examines the implications for practitioners for future research and for policy development.

1.1   Definition of 'outcomes'

Outcomes have been defined as the "observed or measured consequence of an action" (Fawcett, 2007); applied to education and to speech and language therapy intervention contexts, this is understood to be the result or consequence of education or of an intervention. We might be interested in outcomes at different levels, for example, the outcomes for an individual child, for a class or a school; for a speech and language therapy service or indeed for the population of a local authority (Hesketh &Sage, 1999) and these different purposes will determine the kind of outcome measure that is appropriate. Data from outcome measures can be used to provide information for managers for service or school

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[4] https://www.education.gov.uk/publications/eOrderingDownload/Better_Communication.pdf
[5] Bercow, J. (2008). *The Bercow Report: A review of services for children and young people (0-19) with speech, language and communication needs.* Nottingham: DCSF. https://www.education.gov.uk/publications/eOrderingDownload/Bercow-Report.pdf
[6] Reports are accessible through the DfE's research site http://www.education.gov.uk/researchandstatistics/research

planning purposes, to assist in decision making with respect to an individual child and it is unlikely that a single tool will meet the various purposes for which we need outcome information. The interventions that are provided for children with speech, language and communication needs are hugely diverse and they have varied effects. Frattali (1999) suggests that, if we are to capture these diverse effects, we will need a repertoire of tools.

1.2   The perspectives of children with SLCN and their parents

Evaluations of interventions for children with SLCN that are reported in the research literature use a range of assessment and outcome measures to examine the effects of interventions. However, typically, these focus on objective measurement of the child's speech, language and communication skills where the child's progress is being measured in terms of the changes in the underlying difficulties. Studies that use parent perceptions of a child's progress or the child's own perception of progress in speech and language are often viewed as less robust. This approach is more common in some types of speech, language and communication needs than others. For example parents of children who stammer undergoing the Lidcombe Programme are routinely asked to rate the severity of their child's stammer (Langevin, et al., 2010). In some studies, other related aspects of a child's performance are also measured, such as the child's attention, play or behaviour, but measurement of the broader aspects of a child's communicative functioning has been rare. Nonetheless, particularly within health contexts, services are increasingly seeking ways of using 'patient reported outcomes' to provide a measurement of the impact of an intervention (Hewlett et al., 2005)[7].

A number of frameworks exist that encourage a wider appreciation of outcomes. The World Health Organisation's classification of functioning[8] for example, reminds us that when considering a person's overall functioning, we should also be considering their levels of activity, participation and wellbeing as well as the underlying difficulties. This framework is increasingly being applied in the field of SLCN with consideration of how it could be interpreted for goal setting and evaluation of outcome (McLeod, & Bleile, 2004; Washington, (2007). The previous government's national policy framework, Every Child Matters set out five key outcomes, said to be those desired by parents and children: to be healthy, stay safe, to enjoy and achieve, to make a positive contribution and to achieve economic wellbeing.

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[7] http://phi.uhce.ox.ac.uk/home.php
[8] http://www.who.int/classifications/icf/en/

Investigations into the perspectives of children and their families are now beginning to appear in the literature (Palikara, Lindsay & Dockrell, 2008; Roulstone & McLeod, 2011) and a small number of these address the issue of quality of life for children with SLCN (Markham & Dean, 2006; Markham et al., 2009) and a consideration of their outcomes (Rabiee et al., 2005). For example, Beresford et al. (2007) report on work focusing more broadly on the perspectives of disabled children and their families regarding their desired outcomes from social care services. This research included a specific focus on children and young people with communication difficulties (Rabiee et al., 2005). They noted similarities in the outcomes identified by children with SLCN and those without, but also commented that what an outcome meant for a child with a disability was different to what it meant to a non-disabled child. In a subsequent analysis of their findings in the light of the Every Child Matters (ECM) outcomes, Sloper et al. (2009) concluded that for children with disabilities the ECM outcomes mostly represent higher level outcomes; for children with disabilities there were other fundamental outcomes which might (or might not) enable or lead to the emergence of the higher level outcomes. In particular they noted that 'communication' was an outcome omitted from the ECM framework but that was regarded by their participants as fundamental for all children. Research on outcomes for people with disabilities or with poor mental health has also pointed out that maintenance or the prevention of deterioration is also an important outcome (Sloper et al., 2009; Trauer, 2010).

Finally it is important to note that there are a considerable number of Quality of Life measures for children. Typically, these are not used in routine practice in the field of SLCN and are not common in research evaluations. We are not yet in the habit of routinely asking children and young people across the range of SLCN and across age ranges, or their parents, about outcomes – what they aspire to or what they believe has changed over time or as a result of an intervention. The Lamb Inquiry into special educational needs and parental confidence[9] commented:

> "What was apparent was that few of the parents the Inquiry met seemed to have been encouraged to have a discussion about the outcomes they expected, or aspired to, for their child or how best these outcomes might be achieved." (p.20).

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[9] Lamb, B. (2009). *The Lamb inquiry. Special educational needs and parental confidence.* Nottingham: Department for Children, Schools and Families.

1.3   Aims

The overall aim of the 'preferred outcomes' project was to explore the outcomes valued by children and young people with speech, language and communication difficulties and their families. We constructed a series of projects that would investigate the perspectives of children and their parents and examine the kinds of measures and frameworks that might be useful in guiding the measurement of parent- and child-reported outcomes.
The five projects were:

- Preferred outcomes: children and young people's perspectives
- Preferred outcomes: parents' perspectives
- A survey of parents' views on outcomes
- A systematic review of quality of life measures for children
- The development of a parent-reported survey on the behaviour and attitudes of others towards their child

This last project is reported only briefly in this document and is fully reported in the final thematic report on parents

For each project we present the specific aims for that project, what we did, who took part (where appropriate) and what we found. We discuss each project briefly and draw some specific conclusions from that project. Then at the end of the report, we discuss the overall findings and implications of the projects together.

1.4   Ethics Review

Projects two and three, including all supporting documentation including the letters of invitation, information sheets, consent and assent forms, were submitted for ethical review and were given approval by the then Faculty of Health and Social Care Ethics Committee at the University of the West of England, Bristol.

2.   PREFERRED OUTCOMES: CHILDREN AND YOUNG PEOPLE'S PERSPECTIVES

JANE COAD, HELEN HAMBLY AND SUE ROULSTONE

2.1   Aim

To explore children's views on outcomes that they valued.

2.2   What we did

Talking about outcomes

Talking about our hopes for the future is difficult for all of us; we often find it difficult to be specific about what we would like to achieve in our lives. For children, and particularly those with SLCN, this can be even more problematic. In order to do this, you need the language and cognitive skills to be able to conceptualise the future and formulate ideas in future terms. The result is that conversations about future outcomes can end up quite broad and non-specific. In order therefore to explore these ideas with children the primary focus was on the present – identifying the aspects of their current lives and experiences that they value or would like to see changed for the better. Our view is that if we understand those achievements and skills that a range of children and parents value in the present moment, one can extrapolate from this to consider them as indicators of what will be valued as outcomes for others.

Appreciative Inquiry (AI) was chosen as the most appropriate philosophy to underpin the investigation of children's views on outcomes. Fundamental to this approach is the desire to discover 'what works well' and 'why it works well (Cooperrider & Whitney, 1999). Appreciative Inquiry has been used effectively within a variety of complex, organisational structures including health and social care settings (Moore, Anderson, Carter & Coad, 2010).With its positive, constructive approach, it was felt to have a good fit with a project focusing on desired outcomes. From the starting point of 'what works well', we generated three key questions of relevance to the exploration of preferred outcomes we generated three research questions:
What is good? For example, what is good in your day to day life and in relation to your speech, language and communication?

What could be better? (Now) For example, what would you like to be better about you and in relation to your speech, language and communication?

What could be better? (Future) For example, what would you like your future to look like? What should the future be for services?

Arts-based participatory workshops:

The children and young people's strand of work included two phases. Phase 1 involved a series of participatory workshops across purposively sampled areas with groups of children and young people aged 8 to 16 years. Phase 2 included a one off focused workshop to explore initial findings further with children and young people within the same age range.

Phase 1 workshops:

Phase 1 workshops were held in mainstream and special schools in Bristol, Surrey (x3), Nottingham (x2) and Warwickshire. Children and young people with a wide range of speech, language and communication needs were invited to take part. They were targeted at two age ranges; 8 to 11 years and 12 to 16 years. Seven workshops were run, each over a 90 minutes time slot during the school day.

Each workshop began with a short period of time to settle the children and young people. This included checking informed assent/consent of all the children and that they understood the reasons behind the workshop. Following this, there were three key activities broadly linking to the three main questions:

Activity 1: What is good?

The children and young people were invited to draw a picture of their lives including family members, where they lived and any pets. They were then asked to tell the research team

what they really liked about themselves and their best achievements using specifically designed stickers and pre-prepared items. Older children were asked to write and draw about what happens on 'a good day', a 'bad day' and a 'perfect day'. Background information from the schools about the children acted as a platform for questions about speech, language and communication needs.

Activity 2: What could be better? (Now)

'Walls' and 'mountains' (specifically shaped paper) and specifically designed stickers were used to ask children and young people what they wanted to improve about themselves. A poster of a large ladder and/or a pipe cleaner was used to explore perceptions of how well children thought they were doing with their speech and language and school targets, with children using indicators on the pipe cleaners and ladders to show that they thought they were doing well (indicator at the top) or not so well (indicator further down).

Activity 3: What could be better? (Future)

The final activity focused on ideas for the future support of children and young people and

what their futures might look like if they could overcome the problem they had told us about. These ideas were written on cloud shapes, discussed with the team and then attached onto a washing line with pegs.

Phase 2 workshop:

Phase 2 included a one-off focused workshop to verify and explore early findings with eight children and young people aged from 8 to 15 years. Arts-based activities were developed by the authors around findings from phase 1 workshops.

Activity 1: Selecting statements important to individuals

This included sharing of key words and quotes that Phase 1 participants had told us about. The children and young people were each given a 'bag' and were presented gradually with a number of key words and very simple statements. They could choose or reject statements and if they chose a statement, it was collected in their personal bags.

Activity 2: Rating statements

Children and young people were invited to rate and mount the words from their bags on a

large pre-sprayed glue board. In this way the words moved from individual to collective messages under the main

15

themes. Some children and young people preferred to keep them in the bags but still rated them for us. Following a second active break we asked the children and young people in small groups to re-look at the words they had chosen which were now mounted on the boards or in some cases were still in bags. We used large archery boards to rate what was most important (the red centre) and least important (blue outer ring) of both the individually and collectively chosen words.

Data Analysis

The dataset consisted of children and young people's transcripts, drawings and arts based materials and field notes produced by the research team (HH, JC, SR). Data sets from Phase 1 were divided into age 8-11 years and age 12-16 years, whereas Phase 2 data set was examined collectively. Qualitative, thematic analysis was initially undertaken by HH and checked by JC and SR. Field notes were summarised and coded using tables in Microsoft Word. Codes and emerging themes were then checked against children's drawings and transcripts.

2.3   Who took part

Recruitment of Participants:

We sought a purposive sample of children age eight and above, from a wide geographical area, types of school context and with a range of SLCN. Participants were invited through the use of:
Direct contact with schools
Personal speech therapy networks
Charitable and voluntary sector organisations (including The Communication Trust, Afasic, ICAN)
It was decided that the children's workshops would be based in schools. This would allow the children to participate with other children in an environment with which they were familiar.

Phase I

We set up workshops based on inclusion of a mix of special and mainstream schools, of primary and secondary age children, and across a spread of locations in England. In total, we contacted eight schools. Seven workshops were subsequently conducted within five

schools. Table 2.1 shows the number of tracked contacts (i.e. those invited to take part) and the actual number of children who participated. The number of tracked contacts is likely to be an underestimation of the total number of people who received and considered the project information.

The school gave information about the children's identified speech, language and communication needs which were diverse, including mainly primary language impairment, Landau Kleffner Syndrome, Autism Spectrum Disorder, hearing difficulties and verbal dyspraxia. Three children relied mainly on sign language.

Table 2.1 Number of tracked contacts and participants in phase 1 workshops

Workshop	Invited (Tracked contacts)	Number of children aged 8-11 years	Number of children aged 12-16 years	Girls	Boys	Total number of children who participated
Bristol	8	6	0	3	3	6
Surrey	5	0	5	2	3	5
Surrey	5	0	4	0	4	4
Surrey	6	6	0	0	6	6
Warwickshire	7	0	4	1	3	4
Nottingham	7	6	0	3	3	6
Nottingham	6	0	6	2	4	6
Total	44	18	19	11	26	37

In Phase 1, we undertook seven workshops with a total of 37 participants taking part. Although families were approached from a wide range of diverse backgrounds and culture, children were mainly of White British background (32 White British, 1 Other White, I Chinese, 1 Indian, and 1 Bangladeshi).

Phase 2

Eight children and young people aged between 8-15 years participated in the phase 2 workshop. They were all from the Leeds area and had a range of speech, language and communication needs, many with more complex needs than those who participated in phase 1: three had Down's syndrome, three autism spectrum disorder (ASD), one with learning difficulties and hearing impairment and one with specific language impairment.

In general, the children and young people of all ages enjoyed Phase 2 and were able to engage with all the activities in the workshop, with the exception of one of the boys with ASD who may not have understood or completed the ranking activity as we had intended. Through conversation with him during the task the boy became animated about things that were important to him, such as cricket and ice cream.

2.4 What we found – phase 1

The findings are presented within three major themes: *What's good about me? What could be better?* and *Hopes for the future*. These themes reflect the three key questions that drove the study. The first major theme 'What's good about me?' has four subthemes: 'Who I am', 'the fun I have', 'the people around me' and 'my achievements' (see Figure 2.1). The second major theme 'What could be better?' has three subthemes: 'Other people', 'my abilities' and 'my feelings' (see Figure 2.2). Subthemes that were dominant in only one of the age groups have been colour-coded in the Figures: green subthemes represent those predominantly emerging from workshops with 8-11 yr olds and red subthemes represent those predominantly emerging from workshops with 12-16 yr olds. All other subthemes are blue and represent themes emerging from workshops of all ages. As the younger children found it difficult to talk about their future aspirations, the last theme 'hopes for the future' has been described broadly in two age categories with 12-16 yrs talking about individual career aspirations and 8-11 yr olds expressing their hopes for future support for children and young people like themselves.
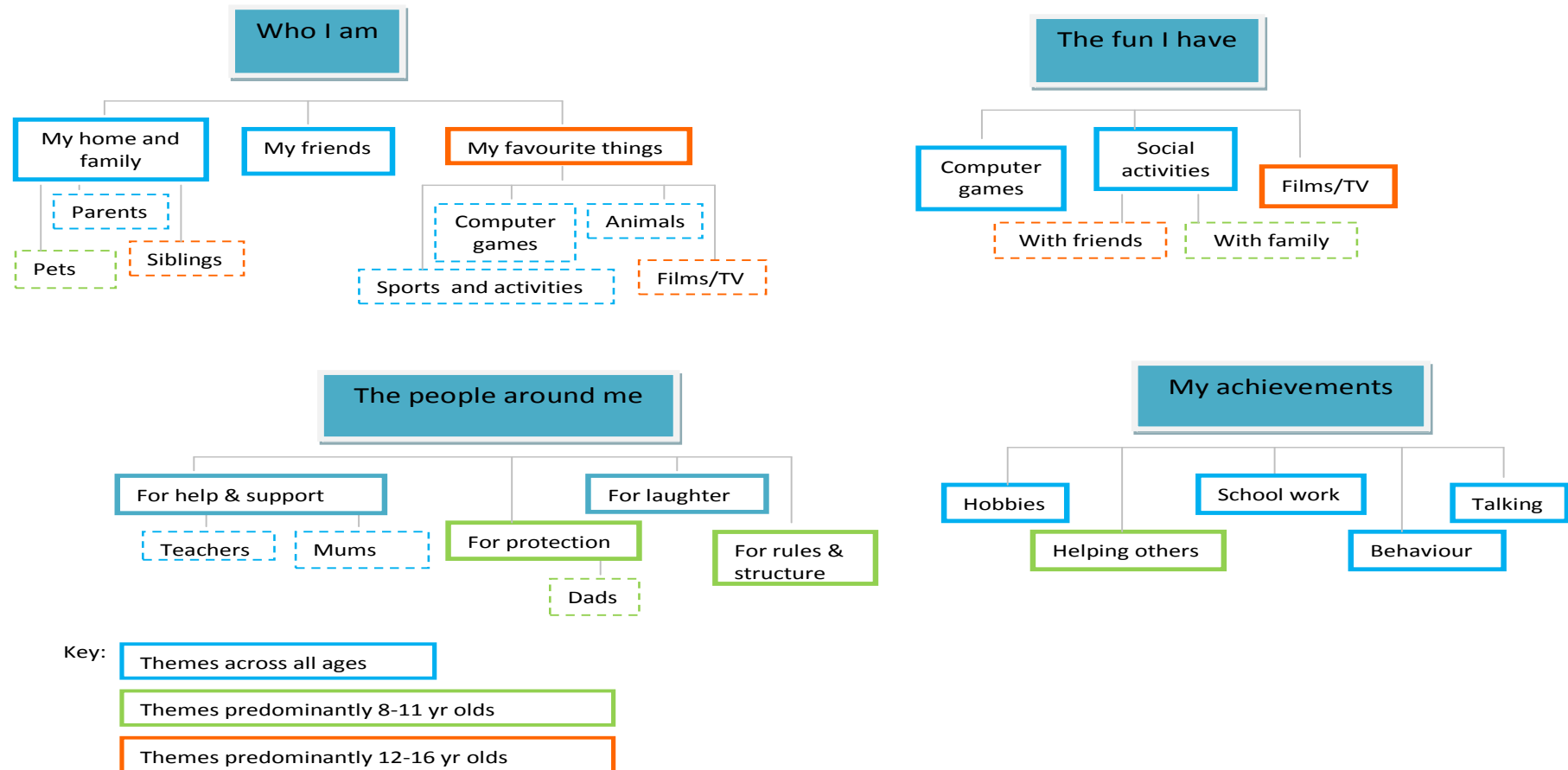
Figure 2.1 Overview of subthemes relating to 'What's good about me?'

Other people...

Helping

Listening

Understanding

Not shouting

Not teasing

Not interrupting

Not distracting

Not being annoying

My abilities

Talking and listening

Helping myself

Sports

Managing behaviour

Making friends

School work

Awareness of difficulties

My feelings

Anger

Sad

Boredom

Key:

Themes across all ages

Themes predominantly 8-11 yr olds

Themes predominantly 12-16 yr olds

Moderating factor

Figure 2.2 Overview of sub themes relating to 'What could be better?'

Findings by subtheme:

What's good about me?

Who I am

Collectively, the children and young people were happy to talk about themselves and their lives. Most described their home and families with pride. In addition to their parents and siblings, pets were often talked about with animation and affection and were seen as being part of the family unit, particularly by 8-11 year olds.

8-11 yr girl: 'I live in with my Mummy and Daddy and a sister called Cindy. And a hamster, a baby one.'

Older children and young people tended to describe themselves and what is important to them in terms of their favourite things, such as computer games, their hobbies, favourite footballers and different animals. They talked about their individual interests with enthusiasm.

> *12-16 yr girl: 'I have a brother and a cat and I go horse riding'.*
> *12-16 yr boy: 'I live on a farm. We go on walks. I like to help my dad on the farm'.*

Overwhelmingly, friends were important to the children and young people. Some younger children talked about their friends alongside their family, whilst others talked about some of the challenges they had with their friends and difficulties making friends.

> *8-11 yr girl: 'I have got a big group of friends – I have got about 6 best friends. I used to have one best friend but she went off with someone'*

> *8- 11 yr boy: 'Well I came to [this school to] make friends'*

The fun I have

One theme that became apparent through different workshop activities was the high importance children and young people gave to laughing and having fun. This was often related to having fun with friends, but also included laughing and joking with family members and teachers at school, going on school trips such as bowling, going on family holidays, watching television and movies, playing football and playing computer games. Spending time with friends was valued by the older children and young people particularly.

> *12- boy: (Writing about a good day) 'playing video games and playing football, on BMX wiv friends; taking the dog for a walk; stay up all night with friends'*

> *12-16 yr boy: 'We used to mess around in dormitory and whenever lady comes we hide in each others' beds instead of getting into trouble' [boys all laugh]*

The people around me

Children and young people recognized and valued the practical, supportive and social relationships they had with different people in their lives. Mums were talked about most frequently as a source of emotional support and someone who '*helped the most'*. Teachers and schools were also important to children and young people, although not all.

> *12-16 yr boy: (Why has this school helped you speak better?) 'I get a lot more help. I prefer them [teachers]. They are nice to me, joke with me.'*
>
> *8-11 yr boy: 'My teacher will help me... no, not my family. My friends help me.'*

For some, schools were the place around which the children and young people's day to day lives were based as a number of them were residential. The children and young people mentioned that both the physical environment and ethos of the school were important. Some had moved to their present school in order to be part of a community where they were not bullied and where their needs could be met**.**

> *8-11 yr boy: 'I couldn't speak at first and I didn't understand but people have helped me to speak.'*
>
> *8-11 yr girl: 'I went to this little group. I couldn't say little normal words like cat and stuff... it did help but it was like my Mum and Dad helped me a lot and then it came into my head.'*
>
> *8-11 yr boy: 'I don't have good days at school. A good day would be snow every day.'*

Some of the younger children talked about their Dads with pride. They talked about their Dads as a source of laughter and also talked about them as a source of support and protection.

> *8-11 yr boy: 'He's funny [Dad]. He does silly things to make me laugh.'*

In contrast the older children and young people talked more about their friends and siblings than their parents. At times some of the rules and structure set down by parents and adults

were met with feelings of embarrassment and frustration, perhaps as they wanted to be increasingly independent.

> *12-16 yr boy: 'family – they just embarrass you in front of your friends'.*
> *12-16 yr boy: 'I say 'there's nothing to do mum'. She says 'take the dog for a walk' every single time she says that. It's annoying. Dad takes [dog] in the morning and then I have to go again. It's annoying.'*

My achievements

Achievements were also really important to the children and young people interviewed of all ages. Younger children in particular were animated when talking about different things they were good at, such as helping at home or playing sports and computer games. Some children talked about the progress they had made with talking and associated behaviours, such as getting better at not interrupting others. Generally issues around their talking were only mentioned by children and young people when specifically prompted.

> *8-11 yr boy: 'I play darts. I'm good. I stand right back.'*
> *8-11yr girl: ' I'm good at looking after my sisters; I am kind.'*
> *8-11 yr boy: 'I'm happy at school. I'm just really proud. I'm proud of doing this (workshop).'*
> *12- 16 yr old girl: 'I'm good at reading'*
> *12- 16 yr old boy: I think I talk very nicely to all my friends and it's something I can't stop doing. I also feel strong about talking (written about 'how I feel about talking')*

What could be better?

Other people

Other people were referred to many times in the transcripts and could be both people close to them who should know about their needs, such as their parents and teachers, and also people who they did not know so well. Being understood and listened to by these *'other people'* was felt to be one of the biggest challenges that the participants, particularly older children and young people, faced in their day to day lives.

> *8-11 yr boy: People just listening to me would help*

Some children and young people indicated that misunderstandings were difficult as other people initially thought they understood but as conversations unfolded misunderstandings became apparent so affecting the dynamic nature of the conversation.

> *8-11yr girl: When I speak to my mum and Dad they interrupt me.*

Others spoke about how people had shouted thinking that this helped them to speak better or understand them (when usually they did) and several younger children talked about how others often interrupted them before they had finished speaking.

> *8-11yr girl: People say to me 'I can't hear you – I hate this. 'I don't understand you'; they shout at me questions but I can hear them but they shout. They shout at me. I want them to talk to me but they shout.*

Some children and young people recalled stories of being teased or bullied by their siblings or their friends, or other children at school. From the children and young people's perspective they had little control over other people's behaviour towards them, although in some instances of teasing they hit back. Older children and young people talked more about *other* children annoying them in different ways, some by distracting them from work or play they were concentrating on, others just irritating them through the way they behaved around them.

> *12-16yr boy: Some of my friends say shut up and stop talking … [How does it make you feel?] – A bit sad and a bit angry at the same time. It makes me want to hit them but they're my friends so I wouldn't want to do that.*

Although nearly all children and young people acknowledged and valued the help and support they received from their parents and teachers, they also talked about times when they would like *'more help'*. When probed further, many found it difficult to articulate what kind of help that they wished for. In some instances they felt misunderstood and not listened to, but children and young people appeared to be voicing an additional need for support which was difficult for them to put into words.

> *8-11 yr boy: 'Teachers don't do anything – they say 'oh dear'.'*

My abilities

Most of the children and young people talked about areas that they struggled with in school academically, socially and in games and sports. For some, these difficulties were mainly in the past in another school, whilst for the majority there were ongoing difficulties. Younger children tended to describe themselves as struggling with aspects of talking and communication, whereas many of the older children talked about struggling with different aspects of school work, such as specific school subjects, exams, learning and listening, reading and concentration, memory and organisation and making and keeping friends, rather than specific difficulties with their talking. Some of the older children and young people

talked about their targets focusing on aspects of self management of their 'behaviour', such as 'not getting cross' and 'keeping calm'. Being understood or getting muddled was another difficulty that some children and young people mentioned they struggled with. This could be compounded by difficulties in asking for help, which often depended on which lessons they were having or how confident they were.

> *8-11 yr girl: [I'm] 'going to make myself talk faster and higher'*
>
> *8-11 yr girl: [would like to get better at] 'making friends'*
>
> *8-11 yr girl: I don't know… sometimes I can't say what I want and sometimes I can.*
>
> *12-16 yr girl: [what would you like to be better at?] 'maths, exams'*
>
> *12-16 yr boy: [I'm not very good at] 'reading big words'*

There were mixed responses about sports. Some children and young people felt that they were good at sports and that this helped them feel accepted as part of the school or friendship group. Indeed, getting better at football was very important for many of the older boys and often mentioned first when probed about what they would like to improve. Other children and young people voiced some difficulties in sport. For these children and young people there was a real difference between school sports and sports that they could choose or sports they could do for fun.

Children and young people's awareness of their difficulties

Almost all of the 37 participants seemed aware of the help they were having for their speech, language and communication needs. However the extent of awareness of their difficulties varied across children.

> *8-11 yr girl: 'I had a speech therapist lady. I am seeing her today. Not too much seeing her. She just does stuff like reading and tests. Nothing is good about it.... dunno why I don't like it.'*

Some were aware that that their problems with speech and language were the reason they attended their special school or were receiving additional support at their mainstream school, but exhibited little awareness beyond this.

> *8-11 yr girl: B – I couldn't speak at first and I didn't understand but people have helped me to speak*

Other children and young people were able to talk about the specific things that they struggled with and how these impacted on their lives and their emotions. When we talked about targets with children and young people, some were familiar with their individual targets and whether they were achieving them, whereas others did not seem to know and many children appeared disinterested in talking about them.

> *HH's fieldnotes: 'He [8-11 yr boy] didn't know what his school targets were so we talked about his general targets and these were generally about helping in the forest and making tools.*

> *HH fieldnotes: [12-16 yr boy] thought he had come here [to workshop] for learning and for their [others] difficulties, but not for help with speech and language.'*

> *12-16 yr boy: [What are your targets?] 'remember people's names, remember teachers names, sit up straight, stop making silly noises'*

> *JC Fieldnotes: 'They all [12-16 yrs workshop] understood notion of targets and improving but did not really talk about them. Knew they had them'*

My feelings

The last subtheme 'my feelings' is closely linked with both the 'other people' and 'my abilities' subthemes as children and young people often talked about experiencing feelings of anger, frustration and sadness as a consequence of their perceptions of other people's behaviour towards them or their own (lack of) ability with different areas of talking, socialising and learning at school and at home. Within every workshop for 12-16 yr olds, feelings of frustration and anger were dominant.

> *12-16 yr boy: 'It frustrates me when I have a bad day when I don't get all my homework done, when I don't get time to do it.'*

The strength of emotion was particularly apparent within one group where the word frustration was scribbled out by one of the young people and replaced with ANGER in capital letters. Sadness was described in relation to perceptions of failure amongst younger children in particular

> *8-11 yr girl: [What makes you sad?] 'I'm always talking too much. I interrupt when the teachers are talking.'*

> *8-11yr boy: 'My speaking has not got better. I get cross with myself. Just myself... that I can't do it.'*

and also in relation to not being heard or understood or to being teased amongst children and young people of all ages.

> *8-11 yr girl: [When do you feel sad?] 'When people doesn't understand me'*

Boredom was talked about more frequently by the older children and young people and was often talked about in relation to lessons or other times at school and linked with feelings of frustration.

> *12-16yr boy: [when do you get angry?] 'When lessons are boring. Have to go out I get so mad'*

> *12-16yr girl: [when do you get angry?] 'When I have to go out for behaviour'*

Hopes for the future

Many of the children and young people found talking about their hopes for the future difficult, particularly younger children.   Some of the older young people talked more about their aspirations for the future, predominantly in terms of the jobs they would like to do when they are older. They had very individual aspirations such as to get better at the 'things' they were interested in or the 'things' that would help them get to where they want to. They included *joining a rugby team; being a footballer; doing well in maths and science; be a singer; working in a horse stables, being an architect; be a farmer; writing for a newspaper* or *being better on my BMX bike*. One young person said:

> *'To have great success at school and to get a good job by working hard. To be able to make the school a better place for the students and staff by talking to our school council'*

Two children under the age of 11 voiced concerns about moving on to secondary school,

> *8-11 yr boy: 'When I go to secondary school they are going to ask me more questions and don't like that'*

but in the main **younger children** talked more about their hopes for making things better for them and others with similar difficulties.

Helping special needs with more teachers. And a bigger school.

8-11 yr girl: 'everyone should be learning to sign' [another child interpreted this for us via sign]

8-11 yr boy: 'I think that their parents should encourage and read more often than twice a week.'

They frequently suggested improving the school facilities for children with speech, language

and communication needs both in mainstream and special schools. They felt that this would be facilitated with more teachers (able to help them) and bigger schools.

8-11 yr boy: 'To get more teachers so children could get more help'

2.5   What we found - phase 2

What's good? (Activities 1 & 2)

Several words and phrases were chosen and marked as very important by all or nearly all children and young people. These included, **'*my mum helps me the most*'** and **'*pets*'**. On choosing *'my mum helps me the most'* children talked about their mothers helping them in practical ways, such as making tea and with reading, and also being there for them in a supportive role. Although mums were commonly rated as most important in terms of the help they provide, children also talked about how other family members helped them, such as their dads and aunties, and several talked about helpful teachers at school. For some school was a happy place, whilst others found school difficult and preferred to stay at home. The theme of *'**fun and laughter**'* with friends was dominant among the boys, but not the girls who talked more about the help they received at home and at school. Only one of the girls talked about her friends and mentioned that some were not nice to her. The differences in girls and boys talk about friends and fun may reflect their separation into two groups and different conversations within these groups. For the boys, having fun with friends was talked about in terms of playing football and sports with friends, playing with friends at school and home and friends making them laugh. The importance of fun and laughter was not limited to

friends, but extended to teachers and family. For one boy it was very important for teachers to joke with him, more so than it was for teachers to be nice to him.   Each child had their own favourite sports or hobbies which they rated as very important, such as football, bowling and swimming, playing the clarinet and playing computer games.

What could be better? (Activities 1&2)

There were no words or statements about 'what could be better?' that all or most children chose and rated as very important, suggesting each child and young person had their own struggles and personal goals and aspirations. These included siblings being mean, other people not hearing or not understanding them and wanting to be a faster talker and good at listening. One boy attached more importance to wanting to speak faster and less importance to the support he was receiving at school, suggesting that these two statements were distinct in his view. Most children and young people selected statements about wanting to improve their talking, but only two rated this as very important to them. One girl told us, '*they say I have to talk more to them and quicker, but it's not that important to me'.*

Three of the girls said that they had friends but all claimed friends were not nice because they could not speak as fast as them. In terms of importance one said *'no … they are not nice so they are not important to me'.* For others this was not as important as some other things, such as other people listening and understanding them or dealing with a mean sister.

One aspect that emerged at Phase 1 was people shouting or saying they could not understand children. In exploring this at Phase 2 in terms of importance it scored as less important and was perceived with higher levels of acceptance. This was explained as *' they say this all the time so I am used to it but its not really that important cos I am used to it'.* The children and young people acknowledged that other people sometimes shouted or did not understand them, but they experience this as less problematic than some of the children and young people in the other workshops. These different experiences may in part reflect that the children and young people participating in the phase 2 workshop tended to have more complex needs than those in phase 1 workshops.

2.6   Discussion

Overall, the arts-based methods were very effective in eliciting the views of the children and young people in the workshops both at Phases 1 and 2. The children had a wide range of special needs and came from different backgrounds and home lives but the methods were

flexible enough to meet most needs. Children and young people spoke with one voice on several issues, such as valuing the help they receive from supportive individuals like their mums and teachers and the fun and laughter they have with friends, family and at school, but in general each child expressed their own individual struggles, achievements and aspirations.

There was a clear shift of emphasis on speech, language and communication needs with age. Many of the younger children and young people talked about their difficulties with different aspects of talking and speech, whereas many of the older children and young people did not feel they had difficulties with talking any longer. Some of these children and young people were still receiving support from speech and language therapists and had been described by their school as having difficulties with various aspects of receptive and expressive speech and language, but for them the challenges they faced were expressed in terms of behaviour, such as trying to keep calm or not make silly noises; struggling with specific aspects of school work, such as reading, writing, maths and exams; being organised and concentrating. It is possible that once a certain level of communication has been reached, particular speech, language and communication needs are less likely to be perceived as the central issue for the child. Other needs, such as literacy, behaviour, emotional, attention or memory difficulties are then perceived as more critical, either to the teachers who are managing them in school or to their parents or to the children and young people themselves[10].

Despite valuing the help and support they receive from key individuals in their lives, many children talked often about how other people could listen more and help more. Children and young people found it difficult to articulate exactly what they wanted in terms of help and being listened to, but it was clear that for some children and young people, the 'help' provided was not enough for them.

The emotional needs of many of the children and young people were striking. The actions of others interrupting, shouting and teasing appeared to lead to feelings of frustration and anger. This was especially notable in the older children and young people we interviewed. As they told us their stories their frustrations were clearly visible. Sadness was also apparent

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[10] See also Parents' Perspectives section of the BCRP Prospective Study: Dockrell, J., Ricketts, J., Palikara, O., Charman, T., & Lindsay, G. (2012). *Profiles of need and provision for children with language impairment and autism spectrum disorders in mainstream schools: A prospective study.* London: DfE.

in children and young people of all ages in relation to their struggles with various aspects of communication and making friends. Not all young people displayed feelings of anger and frustration. It is possible that some young people are more resilient than others (Nash, 2006), i.e. they have increased confidence and self-esteem, a belief in their own self-efficacy, are able to deal with change and have a repertoire of social problem-solving approaches, and are therefore better able to cope with their difficulties and the behaviour of others towards them. Nash (2006) has suggested ways in which children and young people's psychosocial wellbeing could be assessed and managed alongside their speech, language and communication needs through various intervention strategies. Some children and young people talked about strategies they used for managing their emotions, such as if they were feeling stressed they would count slowly in their head before acting out or they would squeeze a stress ball. However, whether such strategies were self-generated or suggested to them was not specifically followed up or probed upon during the workshops. How these children manage these emotions and are supported in this aspect of their experience is perhaps an area for future investigation.

Time for fun and laughter was very important for children and young people, not just in relation to socialising with friends, but was considered an important characteristic of a pupil-teacher relationship also. There was evidence of some great, jokey relationships between pupils and teachers at some of the schools we visited and these were highly valued by the children and young people at these schools. Given that friendships for some children and young people are difficult to maintain, relationships with teachers and other professionals may be an important additional influence in the emotional development of children and young people with speech, language and communication needs.

Children and young people found it difficult to talk about their future goals and aspirations. Older children talked about their longer term career aspirations and most children and young people were able to talk about what they would like to be better for themselves now, but in general, as we had anticipated, it was difficult to elicit children and young people's projections of themselves into the future. Consequently, it largely falls upon parents, professionals, researchers and policy makers to abstract children's and young people's perspectives on important outcomes longer term from children and young people's past and present experiences rather than from the children's own perceived goals and aspirations per se. We noted that very few children were interested in their school targets and some were not aware of them. Finding and improving ways to elicit children and young people's perspectives on their goals and engage them in goal setting may be an important area of further work.

2.7   Conclusions

Drawing upon the experiences of children and young people there are a number of different outcomes that may be important to children and young people with speech, language and communication needs. Each individual voiced different specific issues that they wished to change and improve in relation to their speech, language and communication, their behaviour and their abilities in school work, reading, writing, sports and making friends. In addition to these individual targets, several common themes emerged that are important for children and young people: (i) time for fun and laughter both in terms of social activities and in relationships with teachers and family, (ii) feeling supported and listened to (iii) dealing with emotions, particularly feelings of frustration, anger and sadness and (iii) improving other people's behaviour towards them in terms of listening more and interrupting less, teasing and shouting.

3.   PREFERRED OUTCOMES: PARENTS' PERSPECTIVES

ANNE AYRE AND SUE ROULSTONE

3.1   Aims

To explore parents' perspectives in order to discover what outcomes they perceive to be important for their children with speech, language and communication needs (SLCN).

3.2   What we did

Recruitment

Parents were recruited via a number of parent support agencies, chiefly through Afasic, the national organisation for children with SLCN and their families, but also through local Parent Partnership groups. Letters of invitation were sent out which invited parents to contact the research team. Although we had planned to recruit parents on a purposive basis, the eventual sample was opportunistic in that all parents who contacted the team and were able to attend the meeting, did so. Parents who indicated interest but were unable to attend were kept informed and involved in the subsequent survey (see next project). The aim was to hold groups in as wide a geographic area of England as possible. In the event, groups were held in Bristol, Cambridge, Huddersfield and Kidderminster with one follow-up group in Plymouth; family workshops were offered in Reading and Leeds but parents only came forward for the Leeds event.

Focus groups

Focus groups were chosen as the primary method of data collection since they provide the opportunity for people to provide a narrative of their own experience and also to discuss a range of views from perspectives as the group discussion progresses. The process was iterative in that findings from each focus group fed successively into the next. This enabled researchers to check out emergent themes and cross-check experiences, for example using reflective prompts such as "some parents have talked about change; is that something that is important to you and your child?"

Each focus group had two facilitators, one of whom led an activity whilst the other one made field notes. The sessions were all digitally recorded. The groups lasted for about two hours and were held at times suggested by the local recruiters. One was held in the evening and the other three during the morning. They were all held in comfortable surroundings and refreshments provided. One was held in a school where the group of parents usually met. Within each focus group, some parents already knew each other and other's were strangers, although from the locality.

For the initial activity each parent was invited to draw a timeline of their own child's achievements and then to share this with the group. Once parents had explained their timelines, the facilitators gained consensus from the group about key themes. Then facilitators probed within each theme to identify the detail of the small steps of progress that would be valued by the parents.

Thus the discussion focused on positive achievements of the children and these became the focus of discussions about valued outcomes. From experience with the Bercow Review consultations, the facilitators knew that the parents would wish to discuss their experience of service delivery, particularly where they perceived this as inconsistent and poor. These perspectives were acknowledged and then parents were encouraged to move onto discuss desired outcomes for their children.

Analysis

The digital recordings were transcribed by secretarial staff who are experienced in transcribing focus group data. The main thematic analysis was completed by one of the team (AA); the second member of the team (SR) independently read the transcripts and raised points for discussion and verification. These discussions led to minor reworkings of the themes. Quotations are referenced by a parent code, e.g. P10.

3.3   Who took part

As indicated above, four focus groups were held in Cambridge, Kidderminster, Huddersfield and Bristol, with 14 parents attending in total. A member of the research team also attended an Afasic parents day in Kidderminster at which 13 parents participated in a workshop activity based on similar questions to the focus groups, but using written responses. Two further events took place (a discussion group in Plymouth and a family workshop in Leeds) with a further 10 parents attending altogether.

Participating parents reported that their children had a range of SLCN, including children with speech sound disorders, specific language impairment, semantic-pragmatic disorder and autism. Their children attended mainstream schools, special schools and language resource bases and were aged between 4 and 18 years (mean age 12 years).

3.4 What we found

> *It's the first time I've ever been asked to write down what he's actually achieved, because every time you go anywhere they always want to know what problems you've got, what he can't do. They tell you what he can't do. You very rarely get the positives.* P10

Parents had experiences of services that they came ready to discuss and these perspectives were frequently part of the discussions although we have not prioritised these in the analysis. These could be more easily framed in terms of characteristics of the care pathway that parents would like to see implemented. However, parents were pleased to focus on the positive framing of 'outcomes' although this was clearly something of a novelty in terms of their typical experiences. Three key themes emerged, two of which related to outcomes that parents wanted for their child (social inclusion and independence) and one which related to the context in which the child and the family exists (other people's understanding of SLCN).

Underpinning theme and functional outcomes

When parents talked about outcomes they frequently linked success in communication to other life outcomes: success in developing communication skills, for parents, increases the likelihood of successful outcomes in a number of other aspects of the child's life.

> *I can't remember exactly how old he was when his speech improved so that he was able to be understood by non family members but that was a good point for him because it left him less frustrated. (P11)*

> *When he went for swimming lessons… to go in the cafe stand in the queue and ask for some sweets. So that's sort of a high point I remember. We had to rehearse mind before he went to the queue and there was a risk that he might have forgotten it while he was standing in the queue but he was able to get what he wanted (P14)*

he went in to buy his football magazine one week and I gave him a £10 note which was a bit foolish and he came back with the wrong change, I think they'd given him change for £5 and I said Child? that's not the right change'. Now he's very good at maths actually, it's one of his strong points and I think he knew but he didn't have the communication to be able to say (P14)

Functional outcomes

Two overarching themes emerged: to be included and to achieve independence; within these were a number of related subthemes. Figure 3.1 displays the two overarching themes with their related subthemes

Social inclusion – to be included

This was a broad interrelated theme which encompassed concepts of friendship, friends and peers. Parents worry about the ability of their children to develop friendships when they first go to school and are relieved when they do:

When he started at nursery school I was really pleased that he formed friendships because as a parent, that's one thing you really want your child to fit in socially. (P13)

However others relate less positive experiences:

Making friendships was very difficult for her. She didn't have friendships in the same way that other girls of her age did. (P3)

Later, and particularly in the secondary school environment parents become concerned about the increasing difficulty their children have in relation to belonging to and interacting with their wider peer group:

I wish that he could have a better quality kind of conversation interaction with his peers. That is pretty poor still for his age. Whilst there's a lot of speech, that masks it really. He can't just get in the middle of a conversation about whatever they're talking about, whatever their interest is, if it's not his, and I guess that would be the thing I'd really like to see. (P9)
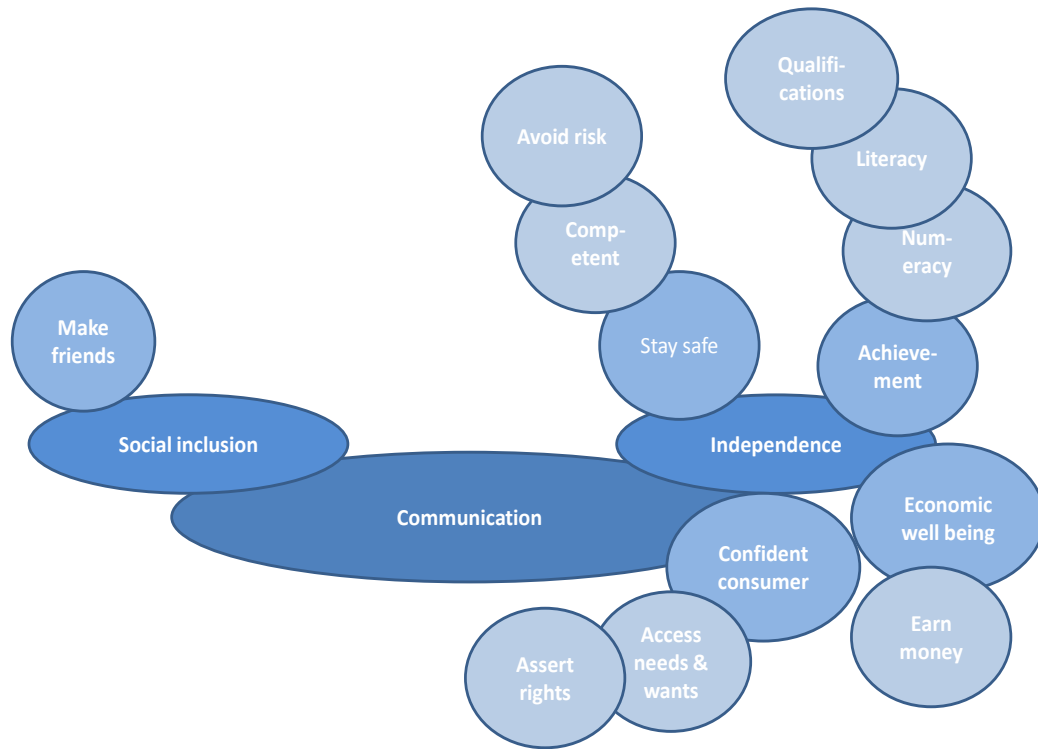
Figure 3.1 Outcome themes

Parents want their children to engage with their peers socially particularly outside the
structure of the family and the formal school day:

> *I've seen him getting off the bus when they've been to a match and I've gone
> to collect him. He's on his own and he just walks away and all the kids
> chatting and laughing and joking and it's the social side of things for me now.
> (P2)*

One parent expressed this as a wider tolerance of difference and suggested that it was more
than inclusion that she wanted for her child, it was 'acceptance'.

Achieve Independence

Achievement

Parents see academic achievement as important in so much as it enables independence. They are particularly concerned about the functional aspects of numeracy:

> *Time and money, you have to understand it. On a basic level you don't have to be some amazing mathematician but you need to understand the basics ...we all need to have acquired those basic skills, handling money and knowing what the time is and when we've got to be there*. (P1)

They are equally concerned about literacy and conscious of the benefit of developing skills beyond the simple decoding of text:

> *He now reads because he wants to read. He's discovered books that he likes and so it's gone from it being a chore and him not understanding the books, and word recognition but not understanding. That's something that will enhance his life isn't it as well? You know, so it's a life skill as well as a learning goal. (*P9)

Parents are also concerned about their children's ability to gain qualifications seeing this as a potential barrier to employment:

> *The biggest problem we've got (and I hope that you won't find it) is to be a fully qualified craftsman you've got to have an English GCSE. Now he's likely to get a Maths, but getting an English [GCSE], he hasn't a hope in hell. The battles we've had with Shakespeare are unimaginable. He spent ages doing The Tempest and I said to him "Do you know what a tempest is?" and he said "No". You think "Oh, why is he doing this?" You know that is going to be a hurdle for him and I'm hoping there's going to be a way round that, some sort of way round the fact he isn't ever going to get an English GCSE. Whether he can do it as a skills thing or some different... I don't know but it is an issue. (*P14)

Staying safe

Parents value the growing independence of their children. Some report being seen as overprotective by teachers:

> *When I'm at home I work to try to stop things happening. I have been told that I protect him too much so he can't find out his boundaries. (*P11)

However the children's actual levels of competence may be more apparent in the less structured and less predictable world out of school.

> *You like to keep them safe don't you? Don't like to think about the horrid things out there in the big wide world. (P12)*

Other parents report family and friends believing them to be taking risks as they allow their children more independence and talk about the challenge of *'letting go'* . Parents are concerned that these young people will always need an advocate:

> *As your children get older, there's a point where you think, well actually he may always need an advocate, because of the processing. If he's sitting in front of a consultant in the hospital and they're giving him lots of information or now he's older what if he gets arrested? (P14)*

Confident consumers

Parents value achievements such as independently buying sweets:

> *When he went to swimming lessons to go in the cafe and stand in the queue and ask for some sweets. So that's a sort of high point I remember. (P14)*

However relatively simple tasks such as buying a meal in McDonald's highlight difficulties which arise in everyday situations which can be unpredictable:

> *I didn't prepare him for that one and it just brings it all home again, that real lack of understanding of, because you prepare them for general things and it's almost learning lines isn't it rather than actually understanding what they're asking you. That will hopefully get easier as he gets older. (P1)*

Parents hope that these sorts of difficulties will lessen as they get older:

> *Well I'd like him to be able to take something back to a shop if he's not happy with it and be able to say why, I don't mean I want him to be aggressive, I just want him to have the confidence, because I think sometimes language impaired children are all right while things go as expected, but it's when something goes a bit pear shaped that he's not able to cope. (P14)*

Economic well-being

The final outcome, en route to achieving independence, that parents would like is readiness for employment:

> *Employability is the prime thing on your mind....because what can you do if you're not employable? (P13)*

Parents recognise their children may require additional support in post school education, vocational training and work experience so it is not surprising that they share concerns about their children's ability to cope in the adult world of work:

> *To be able to cope as an adult really and to be able to function as an adult ....I'm quite happy if he leaves school with no GCSEs and gets a job of cleaning, so long as it's something that he can sustain. (P11)*

They recognise that achieving appropriate and sustainable employment, which may be quite different from their expectations for their other children, underpins their hope for their child with SLCN to achieve economic independence and well-being:

> *The ability to earn some money so that she can have some independence would be what I would hope for. (P3)*

Others' understanding

This was a major theme for all parents and covered family members, education professionals and, potentially, work colleagues. Initially enabling family members, particularly parents, to understand these difficulties could be difficult:

> *Well it's tricky with parents isn't it …and that becomes a big issue. What you're doing is you're managing, you end up managing almost everybody and that becomes quite a big burden because you're excusing …and then sometimes you come to battle all their pre-conceptions about what is good parenting, what is a good child, and all that sort of stuff. You're constantly having to frame and re-frame, and adjust and re-adjust, and it's very difficult to do that with people who don't necessarily want to listen. (P8)*

Some parents have found it helpful if someone from the outside can provide other family members with an explanation:

> *They [SLT service] also do a day each year that's for grandparents and other members of the family. My parents have been to this and that's a brilliant thing to go and do and they just have this lovely innate understanding of all the difficulties. (P9)*

Whilst some parents found education professionals with knowledge and experience helpful others felt that this resulted in their child being seen as a type rather than an individual:

> *Although he's getting help now it's not the ideal help. He's managing to stay in school but that's .... I see [Child] as a square peg trying to be fitted into a round hole and I can't see any round holes where he should be and that's hard (P8)*

Parents are aware that their children will probably cope better in the primary school environment and that they will be more vulnerable in secondary school:

> *I wish social understanding would increase because in the forefront of my mind is high school at the moment. And I'm concerned how vulnerable that makes him because he can't read a situation, doesn't understand when someone's taking the Mickey or is being kind. (P9)*

Parental concerns do not stop once their child leaves school and enters the wider world of further study or employment:

> *But that's not to say he hasn't still got his difficulties, because they will never go because he can't process speech at the normal speed. So he can manage with reasonably slow chunked instructions, but now he's older people don't think to do that because it's sort of very hidden with [child]. You can't see that he's got a disability. So I think the problems may emerge as he moves on to college or further education or possibly into work, where they won't realise looking at him that's there's anything wrong with him. They might just think he's a bit dim. (P14)*

They are conscious that they cannot always be there as an advocate for their child:

> *You just want them to be happy really. [Child] is naturally bright in lots of ways I just want him to be happy to be honest and content. I want people to understand when he gets a job it's almost like you want to go in and tell them, but you can't do that. You can't go and say 'he's got this language impairment, can you just be bit more understanding because he's put on his own really. So*

that would be for me, that he would be happy and have people around him
that do understand a bit really. (P2)

3.5   Discussion

Although the numbers of parents attending the focus groups were quite small, their children attended a range of schools and were described as having a range of types of SLCN. Despite the relative heterogeneity of the sample, saturation of the major themes was achieved quite quickly. That is, after the first two focus groups, no major new themes emerged, only further exemplars of existing themes. However, the number of parents who had preschool children was small and it may be that such parents would generate different themes.

The underpinning relationship between communication and the other key themes emerged after the initial analysis. As communication was always coupled with mention of other outcomes, it was not immediately apparent as a theme in itself. However, a search for all those occurrences of words like communication, talking, understanding, showed that parents always talked about communication as the skill that would underpin their child's success in other life skills, and in particular to achieve independence and to be included and accepted. Skills such as literacy and numeracy were similarly linked to their functional usefulness as tools towards future life goals, particularly enabling children to achieve independence. This hierarchical nature of communication in relation to other skills shows similarities to the findings of Sloper et al. (2009). They identified the 'fundamental outcomes' physical and emotional well-being, being able to communicate and staying safe that needed to be achieved before other outcomes could whereas the higher order outcomes fell into the Every Child Matters categories of enjoying and achieving, making a positive contribution, and economic well-being.

Linked to the notion of independence and inclusion came a view of the world that these children and their families inhabit, in terms of the understanding of other people that they encounter. Parents talked about the knowledge and attitudes of professionals, the general public, family members, as well as the children's peers. They described situations which demonstrated a general lack of understanding of the problems experienced by children with speech, language and communication difficulties and they expressed concerns about the challenge this poses for them and their children, particularly in terms of the two key outcomes that they desire for their children: independence and social inclusion. Some parents acknowledged that their children are likely to need advocates throughout their lives.

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Interestingly, this mirrors a theme that emerged strongly from the children's workshops, in that the children also expressed a wish that others around them would change their behaviours towards them.

Over the year since these focus groups were held, the Communication Champion appointed by the government, Jean Gross, has led a national campaign to raise awareness of children's communication generally and in particular the needs of children with SLCN. In her final report[11], Gross describes a number of initiatives undertaken by speech and language therapy departments to provide information and training to a range of professionals who work with parents about the needs of children with SLCN. As yet there are no data to show whether parents and children have noticed a difference in the understanding of those around them, both in the general public and professionals, but such initiatives may well need continuous implementation over a number of years before they start to impact at a measurable level on the lives of children and their parents.

3.6   Conclusions

As parents reflected on their children's achievements their perception of the vital and underpinning role of communication in the achievement of independence and social inclusion became clear[12]. The nature of the particular steps being taken by their children at any particular point may be quite different. However, parents' views about their longer term aspirations for their children suggest that practitioners working with these children need to consider carefully how any short term targets position a child on the road to eventual independence and social inclusion. A consideration of how the child's environment and context will support that, though an understanding of the needs of those with SLCN may also need to be part of the ongoing planning for children.

In terms of being able to measure how effectively whole services, schools and particular interventions are delivering to these outcomes, measures will need to be identified that go beyond the measurement of the underlying difficulty to a consideration of how far the child's communication is facilitating functional goals.

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[11] Gross, J. (2012). *Two years on: Final report of the Communication Champion. Office of the Communication Champion.* London: The Communication Trust.

[12] See also Parents' Perspectives section in the BCRP prospective study. Dockrell, J., Ricketts, J., Palikara, O., Charman, T., & Lindsay, G. (2012). *Profiles of need and provision for children with language impairment and autism spectrum disorders in mainstream schools: A prospective study.* London: DfE.

4.   A SURVEY OF PARENTS' VIEWS ON OUTCOMES

HELEN HAMBLY, ANNE AYRE AND SUE ROULSTONE

4.1   Aim

Following the findings of the parent focus groups, it was felt that testing out those ideas in a wider sample would be useful in order to:

- investigate if parents valued any particular outcomes
- explore whether differences in parents' priorities was associated with differences in children's ages or the nature of the child's difficulties.
- explore the timescales that are used to frame outcome considerations

4.2   What we did

Findings from the parent focus groups informed the development of an online questionnaire. Links to the questionnaire were then distributed by national and local support groups and contacts in special schools via email; details of the survey were also posted on the Better Communication Research Programme website, with links from the websites of national and local parent groups and third sector organisations.

Parents were asked to indicate the age of their child and the nature of their child's speech, language and communication difficulties. They were then asked to rate, on a scale of 1 to 5, the importance of various outcomes that had been identified by parents in the focus groups. Parents were also asked about their children's next steps and the timescales they find useful for goal setting with their children.

Descriptive data are provided on the frequency of parents' priorities, the relative priority that they give to different areas of their children's lives. Differences between parents who had children with different difficulties were explored using inferential statistical methods. Text responses from parents about the next goals for their children were coded and/or summarised thematically.

4.3   Who took part

Ninety parents completed the survey. Respondents' children ranged between 4 months and 18;11 years, with a mean age of 10;4 years; 28% were girls and 72% were boys. Parents were asked to describe their child's difficulties by ticking one or more speech, language and communication needs (SLCN) categories. Most parents ticked more than one category of need with the most common SLCN being autism spectrum disorder (ASD, 57%), learning difficulties (44%) and expressive difficulties (40%). Frequencies of types of SLCN can be found in Table 4.1.

There were significant age differences in relation to two types of difficulty. Children with dyspraxia were older with a mean age of 156.3 months compared to children with other difficulties whose mean age was115.25 months ($p = .001$). Children with language delay were younger with a mean age of 95.8 months compared to the other children with a mean age of 137.9 months ($p = .001$). Parents' children were educated in a variety of ways with an even balance between those in mainstream and special schools (see Table 4.2).

Table 4.1 Frequencies of different types of SLCN[13]

Type of SLCN offered by parents	%
ASD	57
Learning difficulties	44
Expressive difficulties	40
Receptive difficulties	32
Dyspraxia	23
Specific language impairment	20
Speech sound disorder (SSD)	18
Hearing difficulties	8
Semantic impairment	6
Pragmatic impairment	6
Stammering	3

N = 90

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[13] All percentages are rounded to whole numbers

Table 4.2: Type of school attendance by parents' children

Type of school	%
Special Schools	35
Mainstream	34
ASD Resource base	10
Home Educated	10
Language Resource Base	6
Pre-school	6
Missing data	1

N = 90

4.4   What we found

Parents' priorities

Overall, parents most frequently rated independence, staying safe and improving communication as important or very important outcomes for their children. In contrast, only 34% of parents rated academic achievements as important or very important (see Figure 4.1). To explore importance ratings for children with different diagnoses, the 13 types of difficulty were kept as separate binary variables due to most children having more than one type of difficulty. ANOVAs were performed for each diagnostic category across all outcomes. Mean importance ratings in each diagnostic category were compared with mean ratings in all other categories.
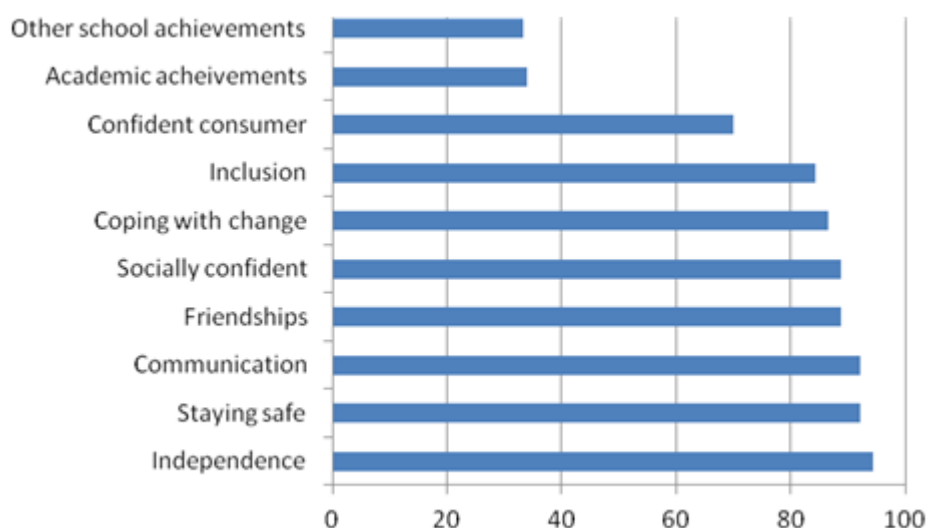
Figure 4.1: Percentage of parents rating as important or very important

Some differences were found between parents in their priorities for their child which were associated with their child's difficulties. For example **staying safe** was less important for parents of children with learning difficulties ($F(1,88) = 5.12$, $p = .026$) and language delay; improving **communication** was more important for parents of children with receptive difficulties ($F(1,88) = 6.92$, $p = .01$); being **socially confident** and making **friendships** was more important for parents of children with receptive difficulties ($F(1,88) = 4.24$, $p = .04$); **academic achievements** were less important for parents of children with learning difficulties ($F(1,88) = 7.56$, $p < .01$); c**oping with change** was more important for parents of children with ASD ($F(1,88) = 5.58$, $p = .02$ and less important for parents of children with speech sound disorders ($F1,88) = 4.94$, $p = .03$)**;** being a **confident consumer** was more important for parents of children with dyspraxia ($F(1,88) = 5.34$, $p = .02$) but less important for parents of children with learning difficulties ($F(1,86) = 7.70$, $p < .01$). There were no impairment specific differences in parents' importance ratings for **independence, inclusion** and **other school achievements.** There were no significant differences between parents in their priority ratings that were related to the age or gender of their child.

Parent's views on 'next steps' for their children

Parents were asked about the next three steps that they wished for their child to achieve. These were coded and counted. A quarter (24%) did not answer the question, but from the remaining respondents across all **'next steps',** the most frequent goals were related to *socialising with others*, mentioned by 38% of 90 parents; general *communication* of needs or thoughts (28%); specific *speech* related goals (27%) and *independenc*e (24%). Other

frequent goals included dealing with *emotions*, such as coping, self esteem and being happy (14%) and developing *confidence* in various areas, including speaking, socialising and life skills (12%). A number of other next steps were mentioned, such as transition from one school to another or from school to employment, getting help from speech and language therapists, achieving something that their child wished to achieve, being more aware of others needs and wants, understanding money and getting a boy or girl friend.

Most frequent **first steps** were specific improvements in *speech* (14%), *socialising with others* (9%), *communication* (9%) and *emotions* (7%). Parents of children with ASD were more likely to put a next step relating to socialising with others compared to those without ASD[14] ($p = .012$). Most frequent **second steps** were related to gaining *independence* in various daily activities or communication (14%), *socialising with others* (14%), *communication* (12%), and *speech* (9%). Again, parents of children with ASD were more likely to put next steps related to socialising with others ($p = .01$). Most frequent **third steps** were related to *socialising with others* (14%), *independence* (7%), *communication* (7%) and improving *confidence* (6%).

Timescales for targets

Relatively few parents responded to this item, with 33% offering no response at all,.8% said that they did not understand the question and a further 12% of parents gave other reasons for not answering the question, such as not believing specific time scales were appropriate for their child or that it depended on the goal or that they had not being consulted about goals for their child by their SLT or other professional so felt they were unable to comment.

The remainder of parents mentioned the following as useful **short term** time scales: 3 months (13%), 6 month (9%), 1 month (9%), 2 months (8%). Other suggestions included evaluating goals every week, 1 term, 2 terms, and 6 weeks. **Long term** time scales parents found useful were: 1 year (31%) and 2 years (3%). Other suggestions included 4 and 5 years and end of school. Timescales parents often used themselves were 1 year (10%), School year (10%), School terms (10%), half terms (3%), end of school/primary (3%), 6 month (3%) and 1 month (2%)

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[14] These analyses are by chi-square

4.5   Discussion

The number of parents who responded to this survey was rather small and consisted mostly of children with secondary SLCN, that is, the SLCN are associated with types of special educational need conditions such as autism or learning difficulties. Parents of only 3 children who stammered responded. Comparisons between parents with children who had different types of SLCN must therefore be treated with caution. Similarly, although the age range was wide, the numbers of children in the younger age range was limited, although the proportion of boys to girls was fairly typical of that reported elsewhere in the literature.

Nonetheless, the exploratory analyses did find differences between parents whose children had different types of SLCN, some of which one might predict from the types of difficulties reported for different diagnostic groups[15]. For example, parents of children with a diagnosis of ASD were more likely than any others to favour 'coping with change' as one of their priority outcomes. This is consistent with the pattern of impairment in children with ASD who show stereotypic behaviours and rigidity. However, it would be dangerous to assume that we can always predict parents' views of outcomes from the nature of their child's difficulties since the detail of the outcome desired at any particular point in a child's life may be very individualised and linked to their own particular context. It must be remembered that the outcome themes identified here are broad and encompass a range of detailed statements. The breadth of the outcomes is perhaps the reason that we found no differences for parents with children of different ages or gender.

These broad themes therefore appear to have some validity for the parents. New examples of outcomes were found in the text responses. However, they could be reasonably subsumed within the higher level categories. So for example, getting a boy friend might be a reasonable example of establishing friendships for a young person whereas with a younger child an equivalent might be to have one special friend. The outcome themes that have been identified within the focus groups and surveys might therefore act as a reasonable guide to those aspects of a child's progress that will be of concern to the family.

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[15] See also the Parents' perspectives section of the BCRP Prospective Study: Dockrell, J., Ricketts, J., Palikara, O., Charman, T., & Lindsay, G. (2012). *Profiles of need and provision for children with language impairment and autism spectrum disorders in mainstream schools: A prospective study.* London: DfE.

5. A SYSTEMATIC REVIEW OF QUALITY OF LIFE MEASURES FOR CHILDREN

HELEN HAMBLY AND SUE ROULSTONE

5.1 Aim

Having identified the outcome themes that parents and children valued, the aim was then to identify what self- or parent-report measures were already available that could be used as part of an evaluation process. Given that the emerging themes related to the independence and inclusion, we focused our search firstly on quality of life assessments, on measures that included aspects of independence and participation and on those measures which target children's functional communication skills. Specifically, we asked:

- What quality of life (QoL) measures exist for children and young people and specifically those with speech, language and communication needs (SLCN)?
- How far do existing measures address outcome themes that emerged from the discussions with children with SLCN and their parents?

5.2 What we did

A number of sources were searched to identify measurement tools that assessed concepts relating to quality of life, inclusion, participation and independence:

1. Medline, psychinfo, embase, cinahl, and Google Scholar
2. PROMS website: http://phi.uhce.ox.ac.uk/home.php

Previous systematic reviews of measures for children and adolescents on participation (Adolfsson, 2011), on health related QoL (Eiser, 2001; Solans et al., 2008) and on child report measures (Schmidt et al., 2002). Table 5.1 shows the search terms used.

Table 5.1 Search terms

Search terms				
Child$	Quality of life	Asess$	Language impairment$	Outcome$
Paed$	QoL	Measure$	Communication impairment$	Evaluat$
You$	Inclusion	Tool	Learning difficult$	ICF
Adolescen$	Independen$		Language disorder$	ECM
			Language delay$	
			Learning disorder	
			Speech$	

Abstracts were screened and articles discussing a potentially relevant measurement tool were retrieved. From these articles and through contact with authors and publishers, the measurement tools were assessed by HH. For each measure the following information was obtained: conceptual construct assessed, dimensions assessed, response format, respondent (i.e., parent or child report), age range, and the psychometric properties of the tools including reliability (internal consistency and test-retest reliability), validity and sensitivity to change. Figure 5.1 explains how these psychometric properties are assessed.

Internal consistency is assessed by calculating Cronbach's alpha to investigate whether a set of items measures a single, latent construct. George and Mallery (2003) suggest a Cronbach's alpha >.9 is excellent, >.8 is good, >.7 is acceptable, >.6 is poor, >.5 is unacceptable.

Test-retest reliability is usually assessed through calculating Intra-Class Correlations (ICCs) and investigates the stability of a measure over time. An ICC >.7 is considered acceptable.

Validity can be assessed in different ways, for example content and face validity might be explored through interviews with respondents or a panel of experts and construct or criterion validity might be examined through correlating scores with other measures that aim to assess the same underlying construct or through exploring theoretically predicted relationships with specific variables.

Sensitivity to change is another important psychometric property that refers to the ability of a measure to detect meaningful changes in the levels of a construct. This can only be explored when a measure has been used in a study where change is expected either due to intervention or over a period of time.

Figure 5.1 Assessing the psychometric properties of measures

In addition to reviewing the psychometric properties of measurement tools, each measure was analysed qualitatively, at the level of specific items, to investigate the extent to which there was overlap with outcome themes identified as important by parents and children.

5.3   What we found

Table 5.2 shows the names of all nineteen measures and the acronyms that are typically used for them and which are used in the rest of this text. For the rest of this chapter, references are provided only at the end of the report and in the detailed data tables in the Appendices.

Table 5.2 Acronyms of the measures identified in this review

Acronym	Measure
	Quality of life:
16D	16 Dimensions (Apajasalo et al. 1996)
17D	17 Dimensions (Apajasalo et al. 1996)
CHIP- AE	Child Health and Illness Profile- Adolescent Edition (Starfield et al. 1993; 1995)
CHIP-CE	Child Health and Illness Profile- Child Edition (Riley et al. 2004)
CHQ	Child Health Questionnaire (Landgraf et al. 1996; 1998)
COOP	Dartmouth Primary Care Co-operative Information Project (Wasson et al. 1994)
CQOL	Child Health Related Quality of Life (Graham et al. 1997)
ExQoL	Exeter Quality of Life Measure (Eiser et al. 2000)
GCQ	Generic Children's Quality of Life Measure (Collier et al. 2000)
ITQOL	Infant Toddler Quality of Life Questionnaire (Raat et al. 2007)
KIDSCREEN	KIDSCREEN Health Related Quality of Life Questionnaire for Children, Young People and their Parents (Ravens-Sieberer et al. 2007)
KINDL	Measuring quality of life in children – the KINDL project (Ravens-Sieberer & Bullinger 1998)
MSLSS	Mulitdimensional Student Life Satisfaction Scale (Heubner, 2008)
Ped SAL QOL	*Paediatric Speech and Language Quality of Life*
PedsQL	Pediatric Quality of Life Inventory (Varni et al. 2001)
QOLP-A	The Quality of Life Profile -Adolescent version (Raphael et al. 1996)
TACQOL	TNO-AZL Children Quality of Life; Verrips et al. 1999

TedQL	Quality of Life Measure for Children aged 3-8 years (Lawford et al. 2001)
VPIQL	Velopharyngeal Insufficiency Quality of Life (Barr et al. 2007)
YQOL	Youth Quality of Life Instrument (Patrick et al. 2000)
	Other outcome measures:
CAPE	Children's Assessment of Participation and Enjoyment (King et al. 2004;2006)
CASP	Child and Adolescent Scale of Participation (Bedell 2006, 2008, 2009)
FOCUS	Focus on the Outcomes of Communication Under Six (Thomas-Stonell et al. 2009)
-	Index for Inclusion (Booth and Ainscow, 2002)
PSPCSA	Pictorial Scale of Perceived Competence and Social Acceptance (Harter & Pike 1984)
SDQ	Strengths and Difficulties Questionnaire (Goodman 1997; 2001)
SEF-I	Social Emotional Functioning Interview (Howlin 2000)
SPPC	Self Perception Profile for Children (Harter 1985)
TOMs :COM	Therapy Outcome Measures : Client Outcome Measure (John 1998)
Vineland ABS	Vineland Adaptive Behavioural Scales (Sparrow et al. 1984)

Measures designed to assess generic quality of life (QoL)

Twenty two measures of generic QoL were identified, i.e. they had been designed for healthy, typically developing children and young people as well as children and young people with chronic illness or disability (See Table A.1 in the Appendix).

Target populations

Measures varied in terms of their target age and their focus. The majority of measures included self-report questionnaires and were designed for children and young people between the ages of 6 and 18 years, sometimes with different versions for different age groups (e.g. PedsQL, CHIP, 16/17D). Only one measure (TEDQL) has attempted to assess self-reported QoL in children under six years. TEDQL was designed to measure self-reported QoL for children aged 3-8 years. However, the authors found significant, large differences in parent and child reported scores (Lawford et al., 2001), and subsequently questioned whether young children are able to reflect and report on QoL in a meaningful

way. Two other measures (ITQOL and TAPQOL) assess QoL in infants and young children using parent report only.

Conceptual frameworks

QoL is a broad concept and consequently has been interpreted and measured in different ways. Several measures focused specifically on health related QoL and include a substantial number of items relating to physical health such as vision, hearing, breathing, physical pain, bladder problems and skin itchiness (e.g. CHIP, TACQOL, 16D, 17D, CHQ). Their content is more akin to measures of health status, such as SF-36 and the Warwick Child Health and Morbidity Profile and they have tended to be developed drawing upon health literature and clinical experts. In contrast, other measures have used exploratory work with children and young people to develop content. These latter measures tend to use more child-friendly language, attempt to measure QoL in a more general sense and include domains such as physical and emotional wellbeing, family and friendships, self-esteem and school (e.g. KIDSCREEN, KINDL, PedsQL, YQOL).

Two other measures (ExQoL and GCQ) have taken a different approach to the measurement of QoL by generating a discrepancy score between a child's ideal self and their perceived self. Whilst there is some evidence of validity for this method of assessing QoL (Collier et al., 2000; Eiser et al., 2000), Eiser et al., questioned whether discrepancy measures are able to adequately assess the multidimensional nature of QoL, given the specific content of each discrepancy item. The only other measure taking a different approach to the assessment of quality of life is the adolescent version of the Quality of Life Profile (Raphael et al. 1996) which assesses healthy adolescents' perceptions of their physical, psychological and spiritual 'being'; their physical, social and community 'belonging' and their practical, leisure and growth 'becoming' with success (Raphael et al., 1996).

Response formats

Measures vary widely in length, from the adolescent version of the CHIP with 108 items to a short version of KIDSCREEN or YQOL with 10 items. They also vary in terms of response format, although most involve responding on a Likert scale with questions, such as 'how often in the last 4 weeks have you had fun and laughed a lot'.   Length, language complexity, and response formats are an important consideration for children in general (Cremeens et al.,2007; Morris et al., 2009), and for children and young people with SLCN specifically (Dockrell & Lindsay 2011). We found that measures designed or adapted for use with

children with SLCN are either administrated with assistance via interview such as Ped SAL QoL, or they have simple response formats and include visual images or smiley faces, such as DISABKIDS for children with special education needs. However, of the generic QoL measures, only the TEDQL, ExQoL and GCQ are administered with adult assistance and/or involve visual images. Therefore, many of the generic measures require adapting for use with children and young people with SLCN and/or would need to be administered with assistance. With regard to phrasing of items, most measures include a mix of positive and negative items. However, the PedsQL is the only measure that includes exclusively negative items, such as 'I have trouble getting along with other kids', and as such has been identified as having the potential to undermine self-esteem (Morris et al., 2009).

Psychometric properties

Measures also vary in terms of their psychometric properties (see Appendix 1) and although nearly all report evidence for internal consistency and validity, only ten reported test-retest reliability, and four are reported to show adequate sensitivity to change (KIDSCREEN, KINDL, PedsQL, CHQ: Solana et al., 2008). Information on internal consistency and validity has been included in Appendix 1. Six measures demonstrated good or excellent internal reliability with an alpha>0.8 (CQOL, KIDSCREEN-10, KINDL, PedsQL, Quality of Life Profile-Adolescent version and the YQOL) and only two measures report acceptable test-retest reliability with an ICC>0.7 (MSLSS; YQOL). When taking into account evidence of validity in addition to reliability, five QoL measures hold up well all round and are in bold type in Table 3. (YQOL, PedsQL, MSLSS, Quality of Life Profile (adolescent version), KIDSCREEN).

Only a few of these generic measures of QoL have been used with children and young people with SLCN (Feeney et al., 2012). The PedsQL has been used to assess quality of life of preschoolers with a range of SLCN (Thomas-Stonell et al., 2010) and children and young people aged 5-17 years with velopharyngeal insufficiency (Barr et al., 2007). Both studies reported lower quality of life scores for children and young people with SLCN compared to typically developing, healthy peers. In addition, the psychosocial domain of the PedsQL was strongly correlated with communication ability. The TAPQoL has been used with parents of 3 year olds and discriminated between children with and without language problems in the communication and social functioning domains (van Agt et al., 2005). In contrast the 16D/17D measure did not discriminate between children and young people with SLI and their typically developing peers (Arkilla et al. 2009.; 2011) suggesting that this measure may

not be suitable for assessing quality of life in children and young people with SLCN. KIDSCREEN has been used within the BCRP Prospective study[16]

Measures designed to assess QoL of children and young people with SLCN

Two measures, the Ped SAL QoL (Markham, 2008) and the Velopharyngeal Insufficiency Quality of Life (VPIQL; Barr et al., 2007) have been specifically designed to assess the QoL of children and young people with SLCN. The VPIQL targets children and young people with velopharyngeal insufficiency[17], whereas the Ped SAL QoL is for children with a broad range of SLCN. The Ped SAL QoL was developed through exploratory group work with children and young people aged 6-18 year and has 37 items covering satisfaction, communication and feelings, independence and participation at school, support at school, and activities. Currently the response format is self-report and administered through a face to face interview. However, as yet the Ped SAL QoL has not been tested extensively. Some of the items are worded with double negatives and so may be difficult for children and young people with SLCN to interpret. However, the impact of this on the reliability of the measure may be negligible if an interviewer is present to check interpretation of items by respondents. Markham established that overall, the scale has a high internal consistency with a Cronbach's alpha score of .87 although two of the subscales had alpha's of <.7 (independence and participation at school); acceptable test-retest reliability was established; interobserver reliability was consistently below the .7 criterion level (Markham, 2008).

Another measure, DISABKIDS-SEN, is currently in development and is an adaptation of the KIDSCEREEN for use with children with special education needs (SEN). Once it has been published, it may also prove to be a useful tool to assess QoL of children and young people with SLCN[18].

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[16] Dockrell, J., Ricketts, J., Palikara, O., Charman, T., & Lindsay, G. (2012). *Profiles of need and provision for children with language impairment and autism spectrum disorders in mainstream schools: A prospective study.* London: DfE.

[17] Velopharyngeal insufficiency is when the soft palate at the back of the mouth does not close properly, particularly during speech, leading to a nasal tone to the voice.

[18] Further details about the development of DISABKIDS-SEN can be obtained from David Jodrell at The Social Research Unit, Dartington, Devon.

Measures assessing Independence, Inclusion, Participation and other outcomes identified as important by parents, children and young people

Ten measures (Appendix II) were identified as assessing one or more themes identified as important by parents, children and young people with SLCN, in addition to the QoL measures discussed in the previous section. A number of measures of independence and participation were identified within occupational therapy literature, such as the WeeFIM (Msall et al., 1994), but these have not been included as the content of these measures centres around functional independence and participation for children and young people with complex physical needs. Only measures that are considered appropriate for children with SLCN specifically have been included here.

Two measures of participation were identified (CASP: Bedell 2006; 2008; 2009; CAPE: King et al., 2004; 2007), both of which were designed for children with a range of complex disabilities. Of these, the CASP is shorter and has excellent internal consistency and test-retest reliability. However, it has not been tested with children and young people with SLCN specifically. The Index of Inclusion (Booth & Ainscow 2002) was also identified as potentially useful for a self-report of inclusion in school. It has not been designed as an outcome measure tool specifically. It is a collection of instruments and guidance materials for schools to promote inclusion. Within these materials are questionnaires for primary and secondary age school children to self-report on their perceptions of inclusion in school. As such, the materials have not been tested rigorously in terms of their psychometric properties, but they may prove useful assessment tools with further development.

Two measures of self-esteem (Self Perception Profile for Children: Harter, 1985; the Pictorial Scale of Perceived Competence and Social Acceptance: Harter & Pike 1984), the Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997; 2001) and the Friendships and Social relationships section of the Social-Emotional Functioning-Interview (SEF-I: Howlin, 2000; Durkin & Conti-Ramsden, 2007) were also identified during the literature search and are included within the table as examples of measures of self-esteem, self-confidence and social relationships that can be found in the psychology literature. These measures encompass some outcomes highlighted in workshops, such as social confidence, social acceptance and friendships. The SPPC and PSCSA all have some questions over their psychometric properties (see Appendix 2). There is continued debate as to whether self-esteem is a unidimensional, stable construct or whether it is multidimensional and unstable, varying with activities and situations (Vallerand et al., 1991; Marsh et al., 2006). The weight of evidence now indicates the benefits of distinguishing different self-concepts

(e.g. for academic attainment, social acceptance) i.e. a multidimensional rather than unidimensional approach (Marsh & Martin, 2011; Lindsay & Dockrell in press).

Two measures for children and young people with SLCN were identified that have been informed by the International Classification of Functioning for Disability and Health (ICF) domains of body functions, activities, participation, and personal factors. Firstly FOCUS (Thomas-Stonnell et al., 2010) was designed to measure change in communication skills of preschoolers and their impact on participation. This assessment of functional communication has only recently been developed and as such has not been tested widely, however, initial tests show excellent test-retest reliability and internal consistency. Secondly, TOMs (Enderby et al., 2006) assesses individuals of all ages in the dimensions of impairment, activity, participation and wellbeing. It has primarily been designed for use by therapists to make judgements about their clients, however, the COM, a self or parent report version of TOMs for clients, has been partially developed (John, 1998). Early piloting of COM showed poor test-retest reliability for the impairment dimension and moderate or good test-retest reliability for other dimensions. Half of respondents found some of the concepts within COM hard to respond to and there has been no subsequent development of COM as an outcome measure. However, it has been used as an informal tool for encouraging discussion between therapists and families.

The Vineland Adaptive Behavioural Scales (Sparrow et al., 1984) is another measure that has been used with children and young people with SLCN that assesses participation and independence to some extent within the domains of communication, daily living skills and socialization. It is a comprehensive survey instrument designed to assess personal and social sufficiency from 0 to 18 years using parent, therapist and/or teacher report. It has been standardized on a large sample in the USA and has excellent test-rest and internal reliability.
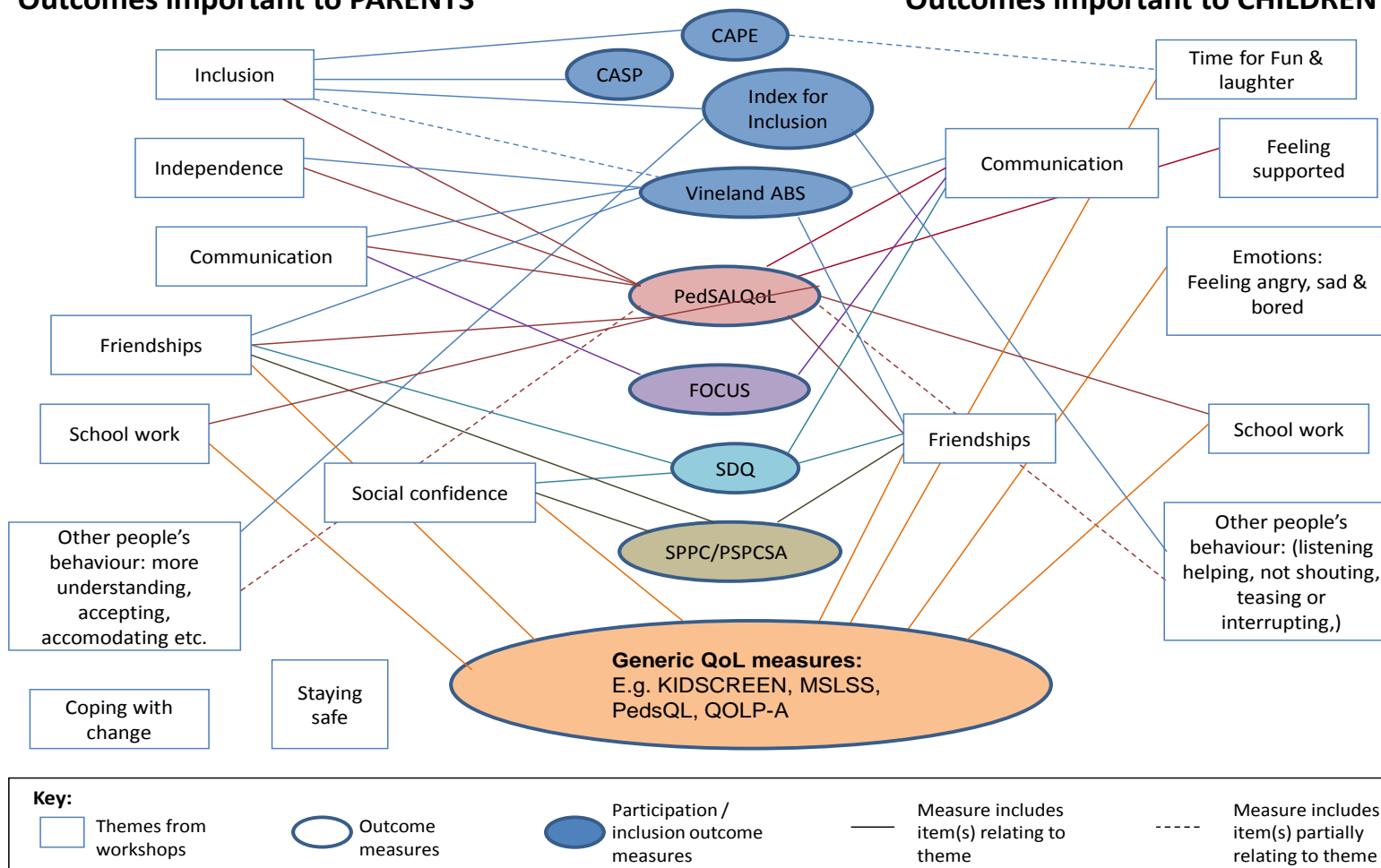
Figure 5.2 Measures available and how they link in to findings from workshops and focus groups

To what extent do measures assess outcomes valued by children, young people and parents?

The outcomes that children, young people and parents talked about in the focus groups and workshops are summarised in Figure 5.2 along with the various measures reviewed here. Most QoL measures assess children and young people's emotions, aspects of their friendships and teasing or bullying, some aspects school life and time for having fun. Some also include items on social confidence and acceptance by peers (e.g. TAPQL, KINDL, KIDSCREEN, PedsQL, CHIP, TACQoL, MSLSS) and some include items on the behaviour of others towards them (e.g. MSLSS and GCQ). Generic measures of QoL that most closely align with the values of children, young people and parents include the GCQ, KIDSCREEN, KINDL, MSLSS and PedsQL. However, they do not cover several themes that arose in exploratory work specific to children and young people with SLCN, including communication, inclusion, independence, staying safe, coping with change and a number of aspects of other people's behaviours towards them, such as listening, understanding, accepting and adapting, and not shouting.

The PED SAL QoL has most commonality with themes from our exploratory work, including covering aspects of inclusion, independence, friendships, emotions, feeling supported, school work, and others' understanding. There is considerable overlap between the content of the Ped SAL QoL and findings from the children's workshops within this study (see Figure 5.2), such as items on feeling angry and feeling sad, getting help at school and feeling supported and being understood by other people. This overlap in content not only validates findings from our workshops, but also provides some content validity for the Ped SAL QoL as a tool to assess QoL in this population. The only themes from workshops with children and young people that the Ped SAL QoL does not include items on are 'time for fun and laughter' and some aspects of 'other people's behaviour', such as others not listening and others shouting and interrupting. It also does not pick up on several themes mentioned by parents, including 'coping with change', 'staying safe', 'social confidence' and other people accepting and accommodating children and young people with SLCN. The underlying content of the Ped SAL QoL is very promising, but further development work is needed to increase its robustness as a measure (see above).

Communication was a theme that was raised by children, young people and parents frequently, not surprisingly as it was often (but not always) perceived as an underlying cause of other difficult experiences. The theme 'communication' refers to an array of speech, language and attention skills facilitating information and social exchanges in all aspects of

daily life. Speech and language therapists and researchers have a broad range of tools available to assess specific speech, language and memory skills. However, as noted in the introduction, those in general clinical and research use are carried out by the speech and language therapist or other professional; typically they do not include a self report or parent report element and generally focus on the child's difficulties rather than how that difficulty impacts upon the child's activity and participation. There are two exceptions: FOCUS measures functional communication in preschoolers, from speaking ability to confidence and independence communicating with others and the Vineland ABS provides an opportunity for parents to report on receptive, expressive and written communication skills, alongside other social behaviours and daily living skills. The COM version of TOMs also assess communication skills in the wider context of activity, participation and wellbeing via parent report, however it was found to have some problems with reliability and validity when trialled with adults with SLCN (John, 1998).

A recurrent theme for parents was their desire for meaningful inclusion for their children in school, with family and friends and within society more broadly. The Index of Inclusion includes an informal questionnaire designed to assess children and young people's perceptions of inclusion in school and seems highly relevant for children and young people with SLCN. Two other measures (CASP and CAPE) may be useful for assessing participation if they can be adapted for children and young people with SLCN. The CASP in particular measures inclusion in a broad sense, covering participation at home, at school and in the community. These measures of inclusion and participation are not currently designed to be used with children and young people with SLCN in formal assessment. However, with further development and testing, they may be useful in future.

5.4   Conclusions

In conclusion, QoL measures go some way to assessing outcomes that are valued by children, young people and parents, but some outcomes, such as independence, inclusion, staying safe and coping with change are not covered by these measures. There are some avenues for development of measures of participation and inclusion, but further work is needed to develop reliable and valid measures in these areas. Some work is currently being undertaken to develop a measure for assessing others' behaviour towards children and young people with SLCN as this was identified as an obvious gap, not only in terms of evaluating interventions, but also in terms of intervention targets. Another gap requiring further developmental work relates to assessing independence for children and young people with SLCN of different ages.

6. DISCUSSION

This report details the work carried out in four inter-related projects. These involved qualitative workshops with children and focus groups with parents, a survey of parents and a systematic review of measures that use parent- and child-report. Each project has been described and specific points of discussion raised for each one. Now, some final cross-cutting issues will be discussed.

It was a deliberate decision to collect data separately from the children and the parents and to keep the data separate for the analysis. It is often the case that parents' views are used as a proxy for those of their children (Morris et al.,) but we were keen to understand the views of both groups independently. Although there were points of overlap, the views of the parents and the children were distinct. The parents saw communication as a desired outcome that would underpin future outcomes of independence and inclusion for their children. The younger children talked about some specifics of their communication skills that they would like to improve, but on the whole, the children and young people did not mention their speech, language or communication unless specifically prompted. Like many other children, the children in these workshops talked about their aspirations for the future in quite broad terms; they were clearer about things that they valued in the present time and it is these views that give us clues about what might constitute relevant outcomes. They were aware of specific, individual aspects of their own abilities and emotions that they wanted to change or improve; having fun was also high on their agenda.

The finding that parents and children differed was not unexpected. Research into the quality of life of children with a whole range of disability suggests that parents and children are not always in agreement about how they rate the child's quality of life, with the parents of disabled children typically rating children as having a lower QoL than the children themselves (Jolovic et al., 2004). This is known as the 'disability paradox' (Morris et al., 2009) and is considered to be a reflection of the fact that the child has no experience of a life without disability and therefore sees their own life positively, whereas parents of disabled children see their child's life in contrast with that of non-disabled children. The children covered in this report do not necessarily have disabilities over and above their SLCN. However the developmental nature of their SLCN means that these difficulties have always been a part of the child's life and therefore a part of their everyday experience.

These separate views have implications for how we discuss goals with children and their parents. We cannot assume that they will all want the same thing. Furthermore, the views of the parents and children may also of course vary from the professional's view of what constitutes a legitimate goal. Although we did not investigate the views of professionals in this study, there are grounds to believe that professionals might prioritise different goals from those of parents and children. For example, Thomas-Stonell et al. (2009) asked parents and speech and language therapists about the changes they expected and observed in children receiving therapy. The parents talked more about the child's communication with peers and readiness for school than did the therapists. Parents also talked more about raising a child's confidence and lowering frustration than did therapists. This challenges us as professionals to think carefully about how we manage these discussions and negotiate goals that all can sign up to.

Despite their differences children and parents both raised issues about how other people behave towards them. Parents talked about the lack of understanding in the general population (families, friends and professionals that they encountered) of the needs of those with speech, language and communication difficulties. Children talked about people who shout over them or who bully or tease. As noted above, during the 2011 National Year of Communication, there were many initiatives across England to inform professionals and the general public about children with SLCN. At a public health level there is clearly an ongoing need for awareness raising. However, there is also a need to discuss this with individual children and their family to identify ways of managing the behaviour of other people to facilitate a more positive and supportive environment. This was the one area for which there were no measures available that could be used to evaluate a child's or parents' experience. The Better Communication Research Programme is therefore developing a questionnaire that might be used with parents to explore their views of the people around them and their child. The piloting of this tool is underway; its development and piloting will be included in the final thematic report on parents.

The systematic review identified plenty of QoL and other measures designed for parents and children to use as self-reports. Between them they covered many of the types of outcome identified by children and their parents although there were none that would cover all the aspects mentioned. However, typically, these children's QoL and similar measures are not used by practitioners in the evaluation of outcomes for children with SLCN, although this is beginning to change in the research field for example, including the prospective study that is

also part of the Better Communication Research Programme[19]. As Frattali (1999) noted, the diverse interventions that are on offer are likely to need multiple measures to tap the range of outcomes. The Better Communication Research Programme has identified over 150 different interventions in use in schools and clinics[20]. It is doubtful therefore that a single measure will be appropriate to evaluate the impact of all of them. Being clear about the purpose of the outcome measurement is therefore crucial to the choice of the most useful combination.

The majority of the measures identified were developed using existing quality of life conceptual frameworks and using experts to convert these into feasible and robust instruments for use by parents and children. Thomas-Stonell et al. (2009) argue that one of the first actions to take if you are designing an outcome measure is to identify the changes that are typically associated with the intervention for which you are designing an outcome measure. This is indeed important if an outcome measure is to be used for a particular intervention. However, it may be that the outcomes that children and parents really value are not those currently achieved by the interventions on offer. In order to stimulate the development of interventions that address the aspirations of the children and their parents, our starting point must be broader. Interestingly, the QoL measure that best covers the domains identified by parents and children in this project (Markham's PEDSAL QoL: Markham, 2008), started from a broad approach, using qualitative interviews and focus groups with children and parents (as well as speech and language therapists) to generate the items for the questionnaire.

The studies reported here have included responses from 127 parents and 45 children. These included parents and children from a range of backgrounds, some families from ethnic minority communities and some from areas of social deprivation; the children represented covered the whole age range and a wide range of SLCN. Saturation of the dominant themes was achieved in the data. Nonetheless, families from middle class white backgrounds with children who were aged 8 and over and who had secondary SLCN predominated. Within the parent survey data, there was some evidence of variation according to the SLCN of the child, for example, that parents whose children had ASD were more likely to value 'coping with change' as an outcome. It is therefore possible that families

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[19] Dockrell et al., (2012) ibid.
[20] Roulstone, S., Wren, Y., Bakopoulou, I., Goodlad, S., & Lindsay, G. (2012). *Exploring interventions for children and young people with speech, language and communication needs: A study of practice.* London: DfE.

with different ethnic or social background from the predominant respondents might suggest other areas of outcome or might place different priorities on some outcomes. For example, it may be that families whose children have milder SLCN or whose children are younger, might have higher aspirations for their children's academic achievements. There is also scope for further understanding how the families of younger children might interpret some of the themes, for example, what would be the particular communication related items within the theme of independence for a child approaching school age?

Recruitment of parents to studies can be challenging and attendance at focus groups, even where child care is offered, may not be the most useful way of achieving a wide range of participants. In this study we did attend one breakfast club for parents as a way of meeting with parents who were unlikely to attend a focus group. Approaches such as this, where the research is taken to contexts in which the parents already meet are likely to be necessary to widen the sampling process. Individual interviews may also be more suitable and this would be useful to discuss with parents prior to the establishment of a research project. In terms of the structure of the parent focus groups, the use of current and past achievements worked well as a basis for generating discussion about potential outcomes. Similarly, with the children, the use of the arts-based methods coupled with Appreciative Inquiry enabled the children to communicate what they value about their current lives.

These studies have therefore generated a useful framework of themes that can be used to inform discussions with parents and with children about future goals and in order to reflect on the outcomes achieved. Further study would be useful to identify whether or not these outcomes are valid for more particular groups such as families from diverse background and those with younger children or who have milder SLCN.

There is scope to use existing parent- and self-report measures within current practice and research. Measures are available which tap outcomes that parents and children value. These are not comprehensive in terms of their coverage of valued outcomes and only a small number have been tested with children with SLCN. Further development and use of existing measures would be helpful in order to test their usefulness with this population. Particular areas that are not well covered by existing measures include independence, particularly communication-related independence and the behaviours of others. Development of parent and self-report measures for these outcomes would be helpful. Such measures could then inform discussions with children and parents about interventions that are appropriate to achieve these outcomes and also to evaluate existing interventions in order to examine how far they address one of the key concerns of parents.

6.1 Implications for practitioners

The functionality of parents' preferred outcomes for their children was a strong message from the discussions. Parents want their children to develop meaningful communication that increases their ability to be accepted, included and independent. The children's message was different but not dissimilar in that they rarely focused specifically on their speech, language and communication but on other aspects of their abilities and aspirations. This poses challenges for the process of goal setting with parents and children in order that the different perspectives are taken account of and also an explicit link made between the next step and a future functional goal. The findings of these studies can be used as a framework for those discussions.

Three other areas emerged as strong contenders in terms of addressing the preferred outcomes of children and their families: a child's emotional needs, the attitudes and knowledge of those around the child and family and the inclusiveness of the child's school environment. Quite a number of the teenage children expressed feelings of anger and frustration with their own abilities. This might well be typical of all adolescents, but in view of the known risk of negative emotional outcomes for some children with SLCN (Conti-Ramsden & Botting, 2008), continued emphasis on social and emotional aspects of learning is important. Ayre and Roulstone (2009) noted that the SEAL[21] programme was well established in a number of secondary schools (Humphrey, Lendrum. & Wigelsworth, 2010)[22]. Findings from this study suggest that it might be useful to review the use of programmes such as SEAL with children and young people with SLCN.

The knowledge, attitudes and inclusiveness of a particular child's environment can be discussed within the context of goal setting. The Index for Inclusion might be a useful tool in this process: the self-report questionnaires can be used to help children and young people to rate the quality of inclusion within their school. Used with individual children and young people with SCLN, it could help to identify those practices within a particular school or classroom that might be targeted for improvement.

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[21] https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RB049
[22] https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR049.pdf

6.2   Implications for research

Research is needed to address the balance of the sample in these studies. Whilst the findings do illustrate common issues that are reflected elsewhere in the literature, further research is needed to investigate the outcomes valued by parents and children with SLCN from a wider social and ethnic range; the research should also focus on the valued outcomes regarding younger children and those with milder SLCN. There are a range of instruments that are designed to be used by parents and by children and young people to rate aspects of their quality of life. However, these are not widely used within the field of SLCN either by practitioners or by researchers; few of them have been tested or validated for children and young people with SLCN. Emerging instruments such as the PedSaQol are still under development. Further research to improve the validity and usefulness of these instruments and the feasibility of using them in everyday practice would be helpful in order to cover the range of outcomes that are valued by parents and by children and young people with SLCN. Morris et al. (2009) concluded that it would be feasible to collect child and parent reported outcome measures on a routine basis but noted a number of challenging considerations including a need for clarity over the purpose of the measurement, the age at which a child is competent to self-report independently or with support and when a condition-specific tool is appropriate as opposed to a generic tool. These are important questions to be addressed with respect to the use of these tools with children and young people with SLCN.

6.3   Implications for policy

Within a school context, the parents' and children's preference for functional outcomes over academic outcomes may be challenging. However this does not mean that the two are mutually exclusive. Indeed, parents emphasised the links between traditional academic skills such as literacy and numeracy and the use of these skills to support children's independent functioning. Changes that were made to the secondary curriculum[23] did emphasise the development of functional skills for life and work and the development of skills in the application of literacy and numeracy to problem solving. However effective communication skills are also required to enable children to apply their learning to their everyday lives. Understanding how this curriculum works for children with SLCN who struggle with the

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[23] The National Curriculum for England, key stages 3 and 4. QCA (2007)
http://curriculum.qcda.gov.uk/key-stages-3-and-4/index.aspx

speech, language and communication skills necessary to make these applications, would be helpful to ensure that these children can benefit from this change to the curriculum.

Those who are tasked with the commissioning of services for children and young people with SLCN will be keen to base their decisions on the proven outcomes of services. The addition of parent- and self-reported outcomes could add significantly to an understanding of the relevance and value of services to the parents and children and young people themselves. Selecting the appropriate outcome measures will be tricky since it is clear that no single measure can cover all the possible outcomes of the interventions that are currently delivered nor all the possible outcomes that parents and children and young people themselves value. Choosing one outcome measure as an overall indicator is not the way forward. Negotiation with stakeholders to ensure that the chosen measures reflect an appropriate range of valued outcomes would be preferred.

REFERENCES

Adolfsson, M., Malmqvist, J., Pless, M., & Granuld, M. (2011). Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disability & Rehabilitation, 33*(14), 1230-1244.

Apajasalo, M., Rautonen, J., Holmberg, C., Sinkkonen, J., Aalberg, V., Pihko, H., et al. (1996). Quality of life in pre-adolescence: A 17-dimensional health-related measure (17D). *Quality of Life Research, 5*(6), 532-538.

Apajasalo, M., Sintonen, H., Holmberg, C., Sinkkonen, J., Aalberg, V., Pihko, H., et al. (1996). Quality of life in early adolescence: A sixteen dimensional health-related measure (16D). *Quality of Life Research, 5*(2), 205-211.

Arkkila, E., Räsänen, P., Roine, R. P., Sintonen, H., Saar, V., & Vilkman, E. (2009). Health-related quality of life of adolescents with childhood diagnosis of specific language impairment. *International Journal of Pediatric Otorhinolaryngology, 73*, 1288 – 1296.

Arkkila, E., Räsänen, P., Roine, R. P., Sintonen, H., Saar, V., & Vilkman, E. (2011). Health-related quality of life of children with specific language impairment aged 8 – 11. *Folia Phoniatricaet Logopaedica, 63,* 27 – 35.

Ayre, A. & Roulstone, S. (2009). *Identifying the scope and format of resources to support the transition of pupils with speech, language and communication needs to secondary school.* London: The Communication Trust.

Barr, L., Thibeault, S. L., Muntz, H., & de Serres, L. (2007). Quality of life in children with velopharyngeal insufficiency. *Archives of Otolaryngology- Head and Neck Surgery, 133*(3), 224.

Bedell, G. (2006). Research update: The child and adolescent scale of participation. *Brain Inj Prof, 3*(4), 14.

Bedell, G. (2009). Further validation of the child and adolescent scale of participation (CASP). *Developmental Neurorehabilitation, 12*(5), 342-351.

Bedell, G., & Coster, W. (2008). Measuring participation of school-aged children with traumatic brain injuries: Considerations and approaches. *The Journal of Head Trauma Rehabilitation, 23*(4), 220.

Bercow, J. (2008). *A review of services for children and young people (0-19) with speech, language and communication needs.* Nottingham: DCSF.

Beresford, B., Rabiee, P. & Sloper, P. (2007). *Priorities and perceptions of children and young people and their parents regarding outcomes from support services.* DH 2147. York: Social Policy Research Unit, University of York.

Booth, T. & Ainscow, M. (2002). *Index for inclusion.* Centre for Studies on Inclusive Education. Accessed online 16/02/2012: http://www.csie.org.uk/publications/inclusion-index-explained.shtml

Collier, J., MacKinlay, D., & Phillips, D. (2000). Norm values for the generic children's quality of life measure (GCQ) from a large school-based sample. *Quality of Life Research,* 9(6), 617-623.

Conti-Ramsden, G. & Botting, N. (2008). Emotional health in adolescents with and without a history of specific language impairment. *Journal of Child Psychology and Psychiatry. 49(5)*, 516-525.

Cooperrider, D and Whitney, D. 1999. Collaborating for change. Berrett-Koehler. Communications, San Francisco Fawcett, A.J.L. (2007) *Principles of assessment and outcome measurement for occupational therapists and physiotherapists.* Chichester: John Wiley & Sons.

Cremeens, J., Eiser, C., & Blades, M. (2007). Brief report: Assessing the impact of rating scale type, types of items, and age on the measurement of school-age children's self-reported quality of life. *Journal of Pediatric Psychology, 32*(2), 132-138.

Dockrell, J.E. & Lindsay, G. (2011). Cognitive and linguistic factors. In S. Roulstone and S. McLoed (Eds), *Listening to children and young people with speech, language and communication needs.* Guildford: J&R Press.

Dockrell, J., Ricketts, J., Palikara, O., Charman, T., & Lindsay, G. (2012). *Profiles of need and provision for children with language impairment and autism spectrum disorders in mainstream schools: A prospective study.* London: DfE.

Durkin, K., & Conti-Ramsden, G. (2007). Language, social behavior, and the quality of friendships in adolescents with and without a history of specific language impairment. *Child Development, 78*(5), 1441-1457.

Eiser, C., & Morse, R. (2001). A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood, 84*(3), 205-211.

Eiser, C., Vance, Y. H., & Seamark, D. (2000). The development of a theoretically driven generic measure of quality of life for children aged 6-12 years: A preliminary report. *Child: Care, Health & Development, 26*(6), 445-456.

Enderby, P. M., John, A., & Petheram, B. (2006). *Therapy outcome measures for the rehabilitation professions: Speech and language therapy, physiotherapy, occupational therapy, rehabilitation nursing, hearing therapists.* Chichester: Wiley.

Fekkes, M., Theunissen, N., Brugman, E., Veen, S., Verrips, E., Koopman, H., et al. (2000). Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1–5-year-old children. *Quality of Life Research, 9*(8), 961-972.

Feeney, R., Desha, l., Ziviani, J., & Nicholson, J. (2012). Health-related quality-of-life of children with speech and language difficulties: A review of the literature. *International Journal of Speech-Language Pathology*, 14*(1),* 59–72.

Frattali, C.M. (1999). Measuring outcomes 'for the better'. *Advances in Speech-Language Pathology, 1(1)*, 47-49.

George, D., & Mallery, P. (2003). *SPSS for Windows step by step: A simple guide and reference. 11.0 update* (4th Ed.). Boston: Allyn & Bacon.

Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Journal of Child Psychology and Psychiatry, 38*(5), 581-586.

Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry, 40*(11), 1337-1345.

Graham, P., Stevenson, J., & Flynn, D. (1997). A new measure of health-related quality of life for children: Preliminary findings. *Psychology & Health, 12*(5), 655-665.

Gross, J. (2012). *Two years on: Final report of the Communication Champion. Office of the Communication Champion*. London: The Communication Trust.

Harter, S. (1985). *The self-perception profile for children.* Denver, CO: University of Denver.

Harter, S., & Pike, R. (1984). The pictorial scale of perceived competence and social acceptance for young children. *Child Development, 55 (6)*, 1969-1982.

Hesketh, A. & Sage, K. (1999). For better, for worse: outcome measurement in speech & language therapy. *Advances in Speech-Language Pathology, 1(1),* 37-45

Hewlett, S., Carr, M., Ryan, S., Kirwan, J.K., Richards, P., Carr, A. & Hughes, R. (2005). Outcomes generated by patients with rheumatoid arthritis: how important are they? *Musculoskeletal Care, 3*, 131-145.

Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—a follow-up comparison in early adult life. II: Social, behavioural, and psychiatric outcomes. *Journal of Child Psychology and Psychiatry, 41*(05), 561-578.

Huebner, E. S., Laughlin, J. E., Ash, C., & Gilman, R. (1998). Further validation of the multidimensional students' life satisfaction scale. *Journal of Psychoeducational Assessment, 16*(2), 118-134.

Humphrey, N., Lendrum, A. & Wigelsworth, M. (2010). *Social and emotional aspects of learning (SEAL) programme in secondary schools: national evaluation.   DfE Research Report RR049.*
https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR049.pdf

Jokovic, A., Locker, D & Guyatt, G. (2004). How well do parents know their children? Implications for proxy reporting of child health-related quality of life. *Quality of Life Research. 13(7)* 1297-1307.

John, A. (1998). Measuring client and carer perspectives. *International Journal of Language & Communication Disorders, 33*(S1), 132-137.

King, G. A. (2004). *CAPE/PAC manual: Children's assessment of participation and enjoyment & preferences for activities of children.* San Anotnio: PsychCorp.

King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al. (2007). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development, 33*(1), 28-39.

Lamb, B. (2009). *The Lamb inquiry. Special educational needs and parental confidence.* Nottingham: Department for Children, Schools and Families.

Landgraf, J. M., Abetz, L., & Ware, J. E. (1996). *Child health questionnaire (CHQ): A user's manual.* Boston, MA: The Health Institute, New England Medical Center.

Langevin, M., Packman, A., & Onslow, M. (2010). Parent perceptions of the impact of stuttering on their preschoolers and themselves. *Journal of Communication Disorders*, 43, 407-423.

Lawford, J., Volavka, N., & Eiser, C. (2001). A generic measure of quality of life for children aged 3-8 years: Results of two preliminary studies. *Pediatric Rehabilitation, 4*(4), 197-207.

Lindegaard, P. M., Bentzen, N., & Christiansen, T. (1999). Reliability of the COOP/WONCA charts: Test-retest completed by patients presenting psychosocial health problems to their general practitioner. *Scandinavian Journal of Primary Health Care, 17*(3), 145-148.

Lindsay, G. & Dockrell, J. E. (in press). Longitudinal patterns of behavioral, emotional and social difficulties and self-concept in adolescents with a history of specific language impairment. *Language, Speech, and Hearing Services in Schools.*

Markham, C. (2008). *The development and validation of a Quality of Life measure for children with speech, language and communication needs.* Unpublished PhD thesis. University of Portsmouth.

Markham, C. & Dean, T. (2006) Parents' and professionals' perceptions of Quality of Life in children with speech and language difficulty. *International Journal of Language and Communication Disorders. 41(2),* 189-212.

Markham, C., van Laar, D., Gibbard, D. & Dean, T. (2009). Children with speech, language and communication needs: their perceptions of their quality of life. *International Journal of Language and Communication* Disorders. 44(5), 748-68.

Marsh, H. W., Craven, R., & Martin, A. (2006). What is the nature of self-esteem? Unidimensional and multidimensional perspectives. In M. Kernis *(Ed), Self esteem Issues and Answers: A Sourcebook on Current Perspectives, pp.*, 17-25. London: Psychology Press.

McLeod, S., & Bleile, K. (2004). The ICF: A framework for setting goals for children with speech impairment. *Child Language Teaching and Therapy*, *20*, 199 – 219.

Moore, A.J., Anderson, C., Carter, B. & Coad, J. (2010). Appropriated landscapes: the intrusions of technology and equipment into the homes and lives of families with a child with complex needs. *Journal of Child Health Care,* 14, 1-3.

Morris, C., Gibbons, E., Fitzpatrick, R. 2009. *Child and Parent reported outcome measures: A scoping report focusing on feasibility for routine use in the NHS.* A report to the DoH. Patient Reported measurement Outcome Group. Accessed online at: http://phi.uhce.ox.ac.uk/

Msall, M. E., DiGaudio, K., Rogers, B. T., LaForest, S., Catanzaro, N. L., Campbell, J., et al. (1994). The functional independence measure for children (WeeFIM): Conceptual basis and pilot use in children with developmental disabilities. *Clinical Pediatrics, 33*(7), 421-430

Nash, P. (2006). Assessment and management of psychosocial aspects of reading and language impairments. *Dyslexia Speech and Language: A practitioner's Handbook. London*: Whurr, 278-302.

Palikara, O., Lindsay, G. & Dockrell, J. (2009). Voices of young people with a history of specific language impairment (SLI) in the first year of post-16 education. *International Journal Language and Communication Disorders. 44(1),* 56-78.

Patrick, D. L., Edwards, T. C., & Topolski, T. D. (2002). Adolescent quality of life, part II: Initial validation of a new instrument. *Journal of Adolescence, 25*(3), 287-300.

Rabiee, P., Sloper, P., Beresford, B. (2005). Doing research with children and young people who do not use speech for communication. *Children and Society*, *19*, 385-396.

Raat, H., Landgraf, J. M., Oostenbrink, R., Moll, H. A., & Essink-Bot, M. L. (2007). Reliability and validity of the infant and toddler quality of life questionnaire (ITQOL) in a general population and respiratory disease sample. *Quality of Life Research, 16*(3), 445-460.

Raphael, D., Rukholm, E., Brown, I., Hill-Bailey, P., & Donato, E. (1996). The quality of life profile--adolescent version: Background, description, and initial validation. *Journal of Adolescent Health, 19*(5), 366-375.

Ravens-Sieberer, U., Auquier, P., Erhart, M., Gosch, A., Rajmil, L., Bruil, J., et al. (2007). The KIDSCREEN-27 quality of life measure for children and adolescents: Psychometric results from a cross-cultural survey in 13 European countries. *Quality of Life Research, 16*(8), 1347-1356.

Ravens-Sieberer, U., Erhart, M., Rajmil, L., Herdman, M., Auquier, P., Bruil, J., et al. (2010). Reliability, construct and criterion validity of the KIDSCREEN-10 score: A short measure for children and adolescents' well-being and health-related quality of life. *Quality of Life Research, 19*(10), 1487-1500.

Ravens-Sieberer, U., & Bullinger, M. (1998). Assessing health-related quality of life in chronically ill children with the German KINDL: First psychometric and content analytical results. *Quality of Life Research, 7*(5), 399-407.

Riley, A. W., Chan, K. S., Prasad, S., & Poole, L. (2007). A global measure of child health-related quality of life: Reliability and validity of the child health and illness profile - child edition (CHIP-CE) global score. *Journal of Medical Economics, 10*(2), 91-106.

Roulstone, S., & McLeod, S. (Eds.). (2011). *Listening to children and young people with speech, language and communication needs.* London: J&R Press.

Roulstone, S., Wren, Y., Bakopoulou, I., Goodlad, S., & Lindsay, G. (2012). *Exploring interventions for children and young people with speech, language and communication needs: A study of practice.* London: DfE.

Schmidt, L., Garratt, A., Fitzpatrick, R. (2002). Child/parent-assessed population health outcome measures: a structured review. *Child: Care, Health and Development*, 28 (3): 227-237.

Simon, A. E., Chan, K. S., & Forrest, C. B. (2008). Assessment of children's health-related quality of life in the united states with a multidimensional index. *Pediatrics,* 121(1), e118-26.

Sloper, P., Beresford, B. & Rabiee, P. (2009). Every Child Matters outcomes: What do they mean for disabled children and young people? *Children and Society, 23*, 265-278.

Solans, M., Pane, S., Estrada, M. D., Serra-Sutton, V., Berra, S., Herdman, M., et al. (2008). Health-related quality of life measurement in children and adolescents: A systematic review of generic and disease-specific instruments. *Value in Health, 11(4),* 742-764.

Sparrow, S. S., Balla, D. A., Cicchetti, D. V., & Doll, E. A. (1984). *Vineland adaptive behavior scales: Interview edition, expanded form manual.* Pines, MN: American Guidance Service Circle.

Starfield, B., Bergner, M., Riley, A., Ensminger, M., Green, B., Ryan, S., et al. (1995). Child health and illness profile-adolescent edition (CHIP-AE). *Medical Care, 33(5),* 553-566.

Thomas-Stonell, N., Oddson, B., Robertson, B. & Rosenbaum, P. (2009). Predicted and observed outcomes in preschool children following speech and language treatment: Parents and clinician perspectives. *Journal of Communication Disorders*, *42,* 29-42.

Thomas-Stonell, N., Oddson, B., Robertson, B., & Rosenbaum, P. (2010). Development of the FOCUS (focus on the outcomes of communication under six), a communication outcome measure for preschool children. *Developmental Medicine & Child Neurology,* 52(1), 47-53.

Trauer, T (Ed) (2010). *Outcome measurement in mental health.* Cambridge: Cambridge University Press.

Vallerand, R. J., Pelletier, L. G., & Gagne, F. (1991). On the multidimensional versus unidimensional perspectives of self-esteem: A test using the group-comparison approach. *Social Behavior and Personality: An International Journal,* 19(2), 121-132.

van Agt, H. M. E., Essink-Bot, M. L., Van Der Stege, H. A., DeRidder-Sluiter, J. G., & De Koning, H. J. (2005). Quality of life of children with language delays. *Quality of Life Research*, *14,* 1345 – 1355.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL (TM) 4.0: Reliability and validity of the pediatric quality of life inventory (TM) version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39(8),* 800.

Verrips, E., Vogels, T. Koopman, H. M., Theunissen, N. C. M., Kampuis, R., Fekkes, M., et al. (1999). Measuring health-related quality of life in a child population. *The European Journal of Public Health, 9(3),* 188-193.

Vo, T. X. H., Guillemin, F., & Deschamps, J. P. (2005). Psychometric properties of the DUKE health profile-adolescent version (DHP-A): A generic instrument for adolescents. *Quality of Life Research, 14(10),* 2229-2234.

Washington, K.N. (2007).Using the ICF within speech-language pathology: Application to developmental language impairment. *Advances in Speech-Language Pathology*, *9(3)* 242-255.

Wasson, J. H., Kairys, S. W., Nelson, E. C., Kalishman, N., Baribeau, P., & Wasson, E. (1995). Adolescent health and social problems: A method for detection and early management. *Archives of Family Medicine, 4(1),* 51.

Waters E*,* Salmon L*,* Wake M*,* Hesketh K*,* Wright M*. (*2000*)* The Child Health Questionnaire in Australia: reliability, validity and population means*.* Australia & New Zealand *Journal of Public Health, 24:* 207–210.

APPENDIX 1 – BCRP REPORTS

All the BCRP reports are available from the BCRP page on the Department for Education's website: http://www.education.gov.uk/researchandstatistics/research and also from the BCRP page in the CEDAR, University of Warwick website: http://www.warwick.ac.uk/go/bettercommunication

Main report

1.   Lindsay, G., Dockrell, J., Law, J., & Roulstone, S. (2012). *Better communication research programme: Improving provision for children and young people with speech, language and communication needs.* London: DfE.

This report presents the main recommendations of the whole Better Communication Research Programme (BCRP). It draws on evidence provided in the thematic and technical reports. This report also considers the overall implications for policy, practice and research, and indeed seeks to bridge the gap between this substantial research programme and the policy and practice agenda.

Interim reports

2.   Lindsay, G., Dockrell, J.E., Law, J., Roulstone, S., & Vignoles, A. (2010) *Better communication research programme 1st interim report DfE-RR070. London: DfE.* (70pp). http://publications.education.gov.uk/eOrderingDownload/DFE-RR070.pdf

This report presents interim findings from the project that had been underway between January and July 2010; best evidence on interventions; the academic progress of pupils with SLCN; economic effectiveness; the initial phase of the prospective longitudinal study of children and young people with language impairment (LI) and autism spectrum disorder (ASD); and the preferred outcomes of children and young people with SLCN, and of their parents.

3.   Lindsay, G., Dockrell, J.E., Law, J., & Roulstone, S. (2011) *Better communication research programme 2nd interim report. DFE-RR 172*. London: DfE. (131pp). https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR172.pdf

This report presents interim findings of the project that had been underway between July 2010 – January 2011. Further work is reported from analyses of the national pupil data sets examining development and transitions of pupils with SLCN or ASD between categories of special educational needs, the prospective study, and parents' preferred outcomes (an online survey). In addition, interim reports from new projects include: the initial phase of development of a Communication Supporting Classrooms Tool; a survey of speech and language therapists' practice regarding interventions; a study of language and literacy attainment during the early years through Key Stage 2, examining whether teacher assessment provides a valid measure of children's current and future educational attainment (led by Margaret Snowling and Charles Hulme); two studies of the relationship between SLCN and behaviour, with Victoria Joffe and Gillian Baird respectively; cost effectiveness of interventions; and the setting up of a prospective cohort study of speech and language therapy services for young children who stammer.

Thematic reports

4.   Dockrell, J., Ricketts, J. & Lindsay, G. (2012). *Understanding speech, language and communication needs: Profiles of need and provision.* London: DfE.

This thematic report examines the nature of speech language and communication needs and the evidence from BCRP studies that have explained both the nature and needs encompassed by the category and the provision made to meet those needs. This report draws upon six projects (8, 9, 10, 11, 14 and 15).

5.   Law, J., Beecham, J. & Lindsay, G. (2012). *Effectiveness, costing and cost effectiveness of interventions for children and young people with speech, language and communication needs.* London: DfE.

This thematic report first considers the nature of evidence based practice in health and education before reviewing the evidence for the effectiveness of interventions for children and young people with SLCN. The report also considers cost effectiveness and how it might be measured before examining the evidence of the cost effectiveness of SLCN interventions. The report draws on projects, 8, 10, 11 and 12.

6.   Lindsay, G. & Dockrell, J. (2012). *The relationship between speech, language and communication needs (SLCN) and behavioural, emotional and social difficulties (BESD).* London: DfE.

This thematic report explores the relationship between SLCN and behavioural, emotional and social difficulties. . We argue that there are different patterns of relationship between SLCN and ASD, and different types of behavioural, emotional and social difficulties. The report draws on the 2nd interim report (report 3) and project reports 9, 11 and 15.

7.   Roulstone, S. & Lindsay, G. (2012). *The perspectives of children and young people who have speech, language and communication needs, and their parents.* London: DfE.

The BCRP ensured that the perspectives of parents and children were explored through a number of different projects. This project explores the evidence primarily from projects 9 and 12, drawing on evidence from a series of specific studies of parents' and children's perspectives and also those of the parents in our prospective study.

Technical reports

8.   Dockrell, J. E., Bakopoulou, I., Law, J., Spencer, S., & Lindsay, G. (2012). *Developing a communication supporting classroom observation tool.* London: DfE.

This study reports the development of an observational tool to support teachers, SENCOs, speech and language therapists and others to examine the degree to which classrooms support effective communication. The report comprises a review of the evidence base for developing effective communication and an account of the empirical study to develop and determine the technical qualities of the tool.

9.   Dockrell, J., Ricketts, J., Palikara, O., Charman, T., & Lindsay, G. (2012). *Profiles of need and provision for children with language impairment and autism spectrum disorders in mainstream schools: A prospective study.* London: DfE.

The prospective study was the most substantial project in the BCRP running throughout the whole period of the research. Focusing on children and young people initially 6-12 years old, we report on the nature of their abilities in language, literacy, behavioural, emotional and social development; the perspectives of the parents; the support provided as examined by classroom observations and specially created questionnaires completed by their teachers and SENCOs.

10.   Law, J., Lee, W., Roulstone, S., Wren, Y., Zeng, B., & Lindsay, G. (2012). *"What works": Interventions for children and young people with speech, language and communication needs.* London: DfE.

This report provides a review of 60 interventions for children and young people with SLCN, all evaluated against 10 criteria. The report will form the basis of a web-based resource to be developed by the Communication Trust for easy access by practitioners and parents.

11.   Meschi, E., Mickelwright, J., Vignoles, A., & Lindsay, G. (2012). *The transition between categories of special educational needs of pupils with speech, language and communication needs (SLCN) and autism spectrum disorder (ASD) as they progress through the education system.* London: DfE.

Analyses of the School Census and National Pupil Database are used to examine the transition made by pupils with SLCN or ASD over time and by age. We examine factors that are associated with transition between levels of special educational need (School Action, School Action Plus and Statement) and having no special educational need (non-SEN), including having English as an Additional Language and attainment. We also explore school characteristics associated with different transitions to other categories of SEN.

12.   Roulstone, S., Coad, J., Ayre, A., Hambley, H., & Lindsay, G. (2012). *The preferred outcomes of children with speech, language and communication needs and their parents.* London: DfE.

This report provides findings from four different studies addressing the perspectives of children and young people with SLCN, and those of their parents. Data are reported from arts-based participating workshops for children, focus groups and a survey for parents; and a systematic review of quality of life measures for children.

13.   Roulstone, S., Wren, Y., Bakopoulou, I., Goodlad, S., & Lindsay, G. (2012). *Exploring interventions for children and young people with speech, language and communication needs: A study of practice.* London: DfE.

As a complementary study to our analysis of the evidence for interventions, we also carried out an interview study of speech and language therapy managers and educational psychology service managers, on the basis of which we conducted a national survey of speech and language therapists to examine prevalence of use of the different approaches.

14.   Snowling, M. J., Hulme, C., Bailey, A. M., Stothard, S. E., & Lindsay (2011). *Better communication research project: Language and literacy attainment of pupils during early years and through KS2: Does teacher assessment at five provide a valid measure of children's current and future educational attainments? DFE-RR172a.* London: DfE. https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR172a.pdf

We report a study led by Margaret Snowling and Charles Hulme which explored whether teacher assessment and monitoring could be used to identify children with language difficulties in need of early interventions. This study was conducted to inform the Tickell Review of the Early Years Foundation Stage, in particular the proposals for a simplified framework and assessment process.

15.   Strand, S., & Lindsay, G. (2012). *Ethnic disproportionality in the identification of speech, language and communication needs (SLCN) and autism spectrum disorders (ASD).* London: DfE.

This report complements that of Meschi et al (number 11). Using School Census data from four years (2005, 2007, 2009 and 2011) the report examines the issue of ethnic disproportionality (i.e. over- and underrepresentation of pupils from different ethnic groups) with respect to SLCN and ASD.

16.   Roulstone, S., Hayhow, R., White, P. & Lindsay, G. (2012). *Prospective cohort study of speech and language therapy services for young children who stammer.*

This prospective cohort study follows children referred to speech and language therapy services because of stammering. The study tracks the children's process through the system and their outcomes.

17.   Meschi, E., Vignoles, A., & Lindsay, G. (2010). *An investigation of the attainment and achievement of speech, language and communication needs (SLCN).* http://www.warwick.ac.uk/go/bettercommunication

This technical report presents early analyses upon which the study reported in report number 11 is based.

Appendix 2: Child, adolescent and parent report measures of Quality of Life (QoL)

Measure (reference)	Country of origin	Target age	Respondent	No of items	Dimensions assessed	Reliability: Test-retest	Reliability: internal consistency	Validity
16D Apajasalo et al. 1996	Finland	12-15	Self	16	Vitality, vision, breathing, distress, hearing, sleeping, eating, discomfort and symptoms, speech, appearance , school and hobbies, mobility, friends, mental function, depression	Statistically significant increase in scores on retest. 91% of cases lying within two *SD* of the mean difference.	Not tested	HRQOL was able to differentiate different patient groups
17D Apajasalo et al. 1996	Finland	8-11	Self	17	Vitality, vision, breathing, distress, hearing, sleeping, eating, discomfort and symptoms, speech, appearance, school and hobbies, mobility, friends, anxiety depression, ability to concentrate, learning ability and memory	95% of cases lying within two *SD* of the mean difference.	Not tested	HRQOL was able to differentiate different patient groups

CHIP-AE (Child Health and Illness Profile-Adolescent Edition; Starfield et al. 1995)	USA	11-17	Self	183	Satisfaction (with self and health), Comfort (emotional and physical symptoms and limitations), Disorders, Resilience (positive activities that promote health), Risky behaviours (risky behaviours that influence future health) and Achievement (of social expectations at school/with peers)	ICC for subdomains ranged from 0.63-0.95, except for *home safety and health*(0.48)	>0.7 for all domains and sub domains except for *limitations of activity* (0.63 - 0.74); *academic performance* (0.53-0.67); and *home safety and health* (0.40-0.56).	Differentiated gender, age, SES and disorders as predicted. Also subscale of *emotional discomfort* correlated well with STAIT-C (0.67) and CDI (0.68) and subscale of *self esteem* correlated with CDI (-0.4)
CHIP-CE (Child Health and Illness Profile; Riley et al. 2007)	USA	6-11	Self /Parent	45/76	Satisfaction (with self and health), Comfort (emotional and physical symptoms and limitations), Resilience (positive activities that promote health), Risky behaviours (risky behaviours that influence future health) and Achievement (of social expectations at school/with peers)	ICC (intraclass correlation statistic) ranged from 0.35-0.76 and were less stable for younger children	0.7-0.82 for all domains except *risk avoidance* and *resilience* are <0.7 for 6-7 yr olds	Correlated with CHQ (r=0.53) and the 'Baltimore How I Feel' scale (r=0.63)

CHQ (Child Health Questionnaire; Landgraf et al. 1996; Walters et al., 2000)	USA	10-18/5-18	Self/Parent	87/98, 50,28	Physical functioning, bodily pain, role/social-physical, general health perception, role/social-emotional/behaviour, self-esteem, parental emotional impact, parental time impact, mental health	ICC in US sample: 0.49-0.78	UK sample: Subscales range from 0.61-0.94	8 of 9 subscales discriminated children with chronic illness. Subscale of *mental health* correlated with report of anxiety(r=0.35) and report of depression (r=0.31; Australian sample)
COOP (Dartmouth Primary Care Co-operative Information Project; Wasson et al. 1994; Lindegaard et al. 1999))	USA	12-21	Self	6	Physical, Emotional, School work, Social support, Family communication, health habits	kappa ranged from 0.57 to 0.84	0.60-0.94	High scores corresponded with number of problems detected
CQOL (Child Health Related Quality of Life; Graham et al. 1997)	UK	9-15	Self/Parent	15	Activities, Appearance, Communication, Continence, Depression, Discomfort, Eating, Family, Friends, Mobility, School, Sight, Self-care, Sleep, Worry	ICC for parent score ranged from 0.64 to 0.83 depending on type of disorder	Ranged from 0.81-0.87 for parents and children with different disorders	The parent score correlated with Global Adjustment Scale (r=0.64) and subscale scores varied between disorders intuitively.

Measure (reference)	Country of origin	Target age	Respondent	No of items	Dimensions assessed	Reliability: Test-retest	Reliability: internal consistency	Validity
DISABKIDS - SEN version (in development by Social Research Unit / Birmingham City Council)	UK	8-18	*Not yet published*	-	-	-	-	-
ExQoL (Exeter Quality of Life Measure; Eiser et al. 2000)	UK	6-12	Self (computer)	12	Discrepancy score between self and ideal self generated for each item. No specific domains.	Not tested	>0.64	Children with asthma had larger discrepancy scores than healthy children. QoL scores correlated with the Severity (r=0.48) and Distress (r=0.31) subscales of the CAQ
GCQ (Generic Children's Quality of Life Measure; Collier et al. 2000)	UK	6-14	Self	25	Discrepancy score between self and ideal self generated for each item. No specific domains.	Not tested	0.78	QoL scores correlated moderately with a general question on feeling happy with life (r=0.5)

ITQOL	Holland	0-5	Parent	103	Physical functioning, Growth and development, Bodily pain, Temperament and moods, General Behaviour, Getting along, General health perceptions, Parental impact emotional, Parental impact time, Family activities, Family cohesion, Change in health	4 of 12 subscales were adequate with ICC >0.70, 6 subscales ICC 0.5 > 0.7	Subscales ranged from 0.72-0.94	There were weak to moderate correlations (r=0.26 to r=0.63) between predefined corresponding ITQOL and TAPQOL subscale scores.
(Infant Toddler Quality of Life Questionnaire; Raat et al. 2007)								
KIDSCREEN (Ravens-Sieberer et al. 2007)	**International**	**8-18**	**Self/Parent**	**52/27/ 10**	**KIDSCREEN-52: Physical wellbeing, Psychological wellbeing, moods and emotion, self perception, autonomy, parent relation and home life, social support and peers, school environment, social acceptance, financial resources** **KIDSCREEN-27: Physical wellbeing, Psychological wellbeing, Autonomy and parents, Peers and social support, School environment.** **KIDSCREEN-10: One**	**Not tested**	**KIDSCREEN-52: 0.76-0.89** **KIDSCREEN-27: 0.79-0.84** **KIDSCREEN-10: 0.82**	**KIDSCREEN-52 subscales correlated moderately with corresponding KINDL subscales (r=0.52 - r=0.68)**

					HRQOL dimension			
KINDL (Ravens-Sieberer and Bullinger 1998; Bullinger et al. 2008) CATSCREEN is a computerised version of KINDL	Germany	8-16	Self/Parent	24	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, Every day functioning		8-16 yrs: 0.95 and subscales ranged from 0.74-0.90 11-17 yrs: 0.82	Ravens-Sieberer and Bullinger (1998): 60% of children judged the questions to be relevant. The KINDL total score correlated a little with the *General Health* score of SF-36 (r=0.36), and more so with the *Mental Health* (r=0.77) and *Vitality* (r=0.74) scores of SF-36. The KINDL (and SF-36 in this study) did not differ between healthy and ill children. Bullinger et al. (2008): Moderate correlations were found between KINDL-R subscales and KIDSCREEN subscales (see above). Children with chronic conditions had lower scores on each subscale compared to healthy peers.
MSLSS **(Mulitdimensional Student Life Satisfaction**	**USA**	**8-18**	**Self**	**40**	**Family, Friends, School, Living Environment, Self**	**Range from 0.7 to 0.9**	**Range from 0.7 to 0.9**	**A number of studies demonstrate validity for its use with different groups of children, including middle school children with emotional disorders.**

Scale; Heubner, 1998)								
Ped SAL QOL (Markham 2008)	UK	6-18	Self	37	Satisfaction, Communication and feelings, Independence and participation at school, Support at school, Activities	>0.7	0.87	Completed a range of tests to demonstrate validity including use with typically developing children which confirmed a distinct and consistent construct of condition specific QoL.
PedsQL (Pediatric Quality fo Life Inventory; Varni et al. 2001)	**USA**	**5-18 /2-18**	**Self / Parent**		**Physical, Emotional, Social, School Functioning,**	**Not tested**	**Range from 0.80 to 0.92**	**Differentiates between healthy children and children with a chronic condition. Correlations with morbidity indicators, such as care needed and days off school/work, were significant but weak (r=0.22 to r=0.38).**
The Quality of Life Profile -Adolescent version (Raphael et al. 1996)	**Canada**	**14-20**	**Self**	**54**	**Being (physical, psychological, spiritual), Belonging (physical, social, community), Becoming (practical, leisure, growth)**	**Not tested**	**0.80**	**Overall scores correlated moderately with measures of self-esteem (r=0.56), life satisfaction (r=0.51), social support (r=0.51) and life chances (r=0.45). Validated on healthy adolescents only.**
TACQOL (TNO-AZL	Holland	6-15	Self/Parent	56	Physical complaints, Motor functioning, Autonomous	Not tested	Ranged from 0.65 to 0.84	Children with chronic illness had lower scores than healthy children

Measure (reference)	Country of origin	Target age	Respondent	No of items	Dimensions assessed	Reliability: Test-retest	Reliability: internal consistency	Validity
Children Quality of Life; Verrips et al. 1999)					functioning, Cognitive functioning, Social functioning, Positive moods and negative moods			on all subscales apart from *Cognitive functioning*
TAPQoL (TNO-AZL Preschool Children Quality of Life; Fekkes et al. 2000)	Holland	1-5	Parent	43	Symptoms, Sleeping, Appetite, Motor functioning, Social functioning, Problem behaviour, Communication, Positive and negative emotional functioning	Not tested	Ranged from 0.43 to 0.88	Total scale scores correlated moderately with FS-II (R) scores for general population (r=0.54) and preterm infants (r=0.52). However, subscale scores correlated weakly, ranging from r=0.11 to r=0.40.
TedQL , (Lawford et al. 2001)	UK	3-8	Self	23	Total scale only but covers items on physical competence, peer acceptance, maternal acceptance, psychological functioning, cognitive functioning	Not tested	0.60	Total scale correlated weakly with child report of PedsQL (r=0.33), but did not correlate with parent report of PedsQL. Children tended to find the TedQL easier and more enjoyable than the PedsQL.
VPIQL (Velopharynge	USA	5-17	Self/Parent	43/48	Speech limitations, Swallowing problems, Situational difficulty,	Not tested	Not tested	Not explored explicitly although quality of life was lower for children with velopharyngeal

al Insufficiency Quality of Life; Barr et al. 2007)					Emotional impact, Perception by others, and activity limitations.			insufficiency compared to healthy children.
YQOL (Youth Quality of Life Instrument; Patrick et al. 2002)	**USA**	**11-18**	**Self**	**56/10**	**Sense of self, Social relationships, Culture and community, General quality of life**	**Total scale ICC=0.78; subscale ICCs range from 0.74-0.85**	**Total scale scores ranged from 0.94-0.96 for different populations; subscale scores ranged from 0.77 to 0.91**	**YQOL total score correlated well with the KINDL total score (r=0.73). YQOL scores were also lower for those who reported more symptoms of depression and ADHD.**

N.B. Measures in **bold** are those considered to have good psychometric properties.

Measures that are not currently in English are also not included, e.g. DUKE Health Profile-adolescent (Vo et al. 2005; French)

Measure (reference)	Country of origin	Target age	Respondent	No of items	Dimensions assessed	Reliability: Test-retest	Reliability: internal consistency	Validity
FOCUS (Focus on the Outcomes of Communicatio n Under Six; Thomas-Stonell et al. 20109)	Canada	0-5	Parent/ Clinician	50	Functional communication of preschool children with SLCN	ICC=0.95	Total scale: 0.96	Not tested/reported for final version. The development process was iterative and involved parent testing at each stage.
CAPE (Children's Assessment of Participation and Enjoyment; King et al. 2004;2007)	Canada	6-21	Self	55 (x5)	Assesses following domains of participation in 55 leisure activities: Diversity, Intensity, With whom, Where, and Enjoyment. Activities are formal and informal and cover: recreational, active-physical, social, skill-based, self-improvement. Does not assess participation in daily life activities or school	ICC=0.67 to 0.86 for intensity and diversity subscales ICC=0.12 to 0.73 for enjoyment sub scale	Ranged from 0.32 to 0.76 depending on activity type	Predicted correlations were small to moderate for the *Intensity* subscale (0.13 to 0.42) and small or non significant between the *Enjoyment* subscale and self perceived competence (r=0.14 to 0.25). Imms (2008) also questions the clinical interpretation of the 'Intensity' subscale.

					activities.			
CASP (Child and Adolescent Scale of Participation; Bedell 2006, 2008, 2009)	USA	3-21	Parent	20	Participation at home, Participation in school, Participation in the community and Home and community living activities	ICC=0.94	Total scale ranged from 0.96 - 0.98 across studies	CASP correlated with Paediatric Evaluation Disability Inventory subscales of mobility (r=0.51), social (r=0.65) and self care (r=0.72). Also children without disabilities had higher CASP scores than children with disabilities. The factor analysis demonstrated three factors rather than the five listed.
Index for Inclusion (Booth et al. 2002)	UK	5-18	Self/Parent	20/34/24	Assesses perceptions of inclusion in school and covers Cultures, Policies and Practices. The self-report questionnaire is part of a comprehensive set of tools that schools can use to promote inclusion	Not tested	Not tested	Not tested
PSPCSA (Pictorial Scale of Perceived Competence and Social	USA	4-7	Self	24	Cognitive competence, Physical competence Peer acceptance, Maternal acceptance,	Not tested	Total scale ranged from 0.59 to 0.78 across year groups. Subscales ranged from	No correlations were found between the cognitive competence subscale and a vocabulary test or teacher report of academic performance. However, the social competence subscale correlated with scores

							0.53 to 0.86 across studies and year groups	on the Loneliness and Social Dissatisfaction measure (r=0.47).
SDQ (Strengths and Difficulties Questionnaire; Goodman 1997; 2001)	UK	4-16	Self/Parent	25	Emotional symptoms, Conduct problems, Hyperactivity/inattention, Peer relationship problems, Prosocial behaviour	Only tested at 4-6 months, therefore difficult to interpret	Total scale: 0.80 Subscales range from 0.41 to 0.81	Factor analysis demonstrated validity for five dimensions. High SDQ scores were associated with increased risk for psychiatric disorders
Friendships & Social Relationships section of SEF-I (Social Emotional Functioning Interview; Howlin 2000; Durkin & Conti –Ramsden 2007)	UK	16+	Self/Parent	3	Friendships and Social Relationships	Not tested	Total scale: 0.89	Adolescents with language impairment showed poorer quality of friendships compared to typically developing adolescents (Durkin and Conti-Ramsden, 2007)

Measure (reference)	Country of origin	Target age	Respondent	No of items	Dimensions assessed	Reliability: Test-retest	Reliability: internal consistency	Validity
SPPC (Self Perception Profile for Children; Harter 1985)	USA	8-14	Self	36	Assess global self-worth in five domains: Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, Behavioral Conduct	Some evidence that scores are unstable over time (Shevlin et al. 2003).	Subscales range from 0.71 to 0.92 across studies	There is some evidence for validity with factor analysis demonstrating support for the domain structure (Granleese and Joseph 1993) and lower levels of self-esteem being found for victims of bullying (e.g. Boulton and Smith 1994). However, there is also evidence that the SPPC measures a single general construct of self worth, rather than five separate domains (Eiser et al. 1995; Shevlin et al. 2003).
TOMs: COM (Therapy Outcome Measures;: Client Outcome Measure; John 1998)	UK	0-18	Parent / Therapist	5	Impairment, Activity, Participation; Wellbeing; Carer wellbeing	r² for each dimension ranged from 0.19 to 0.83	Not reported	Face validity was explored with adults with SLCN: 50% were able to complete the questionnaire easily but 50% found some of the concepts hard; 95% felt it was useful
Vineland Adaptive	USA	0-18	Parent / Teacher/	297	Communication (receptive, expressive, written), Daily	ICC ranged from 0.95-	Subscales range from 0.83-	Comprehensive demonstrations of validity are provided by

| Behavioural Scales (Sparrow et al. 1984) | | | Therapist | | living skills (personal, domestic, community), Socialization (interpersonal relationships, play and leisure time, coping skills), Motor skills (gross and fine), Maladaptive behaviour | 0.99 | 0.94 | Sparrow et al. (1984). For example, factor analyses revealed that for 2-3 yr olds the *Daily Living Skills* and *Motor Skills* formed one factor and the *Written* subdomain was not significantly loading on the 'communication' factor at this age also. The total scale score correlated weakly to moderately with various intelligence scales. |

N.B The search aimed to identify measures of independence, inclusion and participation. Some measures of self-esteem were also identified and are included here as they are considered to address outcomes important to children, young people or parents; however, this is not an exhaustive list of measures of self-esteem as this term was not included within the search. For review of measures of self-esteem for young children see Davis-Kean and Sandler (2001); Butler et al. (2005).