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The perspectives of children and young people who have speech, language and communication needs, and their parents

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This research report was commissioned before the new UK Government took office on 11 May 2010. As a result the content may not reflect current Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DfE).

The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
Children’s perspectives: key issues	3
Parent perspectives: key Issues	4
Implications.....	4
1. INTRODUCTION.....	6
1.1 A word about SLCN	7
2. CHILDREN’S AND YOUNG PEOPLE’S PERSPECTIVES	9
2.1 Reduced quality of life	9
2.2 Room for improvement.....	11
2.3 Positive quality of life.....	11
2.4 Key issues.....	12
Social acceptance and emotional well-being	12
Target setting	14
3. PARENTS’ PERSPECTIVES.....	16
3.1 Identification of need	17
Age of identification.....	18
Early signs of concern.....	18
Needs in school.....	19
Diagnostic labels	20
3.2 Provision	21
3.3 Outcomes.....	24
3.4 Key Issues.....	27
Early identification	27
Satisfaction with provision.....	29
Pathways to independence and inclusion	31
4. CONCLUSIONS.....	32
Children’s perspectives: key issues	33
Parent perspectives: key Issues	33
Implications.....	34
REFERENCES	35
APPENDIX 1 – BCRP REPORTS.....	40

EXECUTIVE SUMMARY

The Better Communication Research Programme (BCRP) was commissioned as part of the Better Communication Action Plan¹, the government's response to the Bercow review of services for children and young people with speech, language and communication needs (SLCN). 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)². This is one of four thematic reports which synthesize the findings from the 10 technical reports that report the results from individual BCRP projects; there are also two interim reports and a report of the BCRP as a whole (see Appendix 1 for full details).

Any attempt to understand how best to configure services and to evaluate their impact must consider the perspectives of the people in receipt of those services, in this case, the children and young people with SLCN and their parents. These perspectives have been investigated within the BCRP by two key projects - the preferred outcomes study³ and the prospective study of children with language impairment (LI) and autism spectrum disorders (ASD)⁴.

This report presents first the children's perspectives; it covers their self-reported quality of life which suggests that children with speech, language and communication needs (SLCN) experience an impoverished quality of life compared to their peers. The report then focuses on aspects of their lives that children would like to improve and then finally focuses on the positive aspects of their lives that children reported. We identify two key issues for children with SLCN.

Children's perspectives: key issues

- Children's reports of their quality of life suggest that they are particularly vulnerable regarding social acceptance and emotional well-being.

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 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..

⁴ 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.

- Features of children's lives that cause enthusiasm and interest were not reflected in the school targets that they could remember.

The perspectives of parents are presented on the process of early identification, on the provision experienced by their child and their views on outcomes that they value.

Parent perspectives: key Issues

- Parents' reports of the process of identification showed variability in the age and process of early identification.
- Although many parents were satisfied with provision for their children, there were marked discrepancies: parents of children with ASD reported that their children received higher levels of provision and reported higher levels of satisfaction than parents of children with LI.
- Lack of clarity about the use of the term SLCN was also identified as an issue that may impact upon provision.
- There were a number of parents who were not aware of the level of provision that their child was receiving.
- Parents valued outcomes related to the increasing independence and inclusion of their children and recognised the vital role that communication skills play in the achievement of these skills. The challenge is to identify the pathway from the underpinning communication skill to the functional outcome and the evidence-based interventions that achieve them.

Implications

- Practitioners need to check and make themselves aware of the perspectives of children and young people, particularly in terms of their views on their own social acceptance and emotional well-being.
- Understanding the perspectives of children and young people is also fundamental to the process of developing relevant, meaningful, functional and motivational targets that are shared with and by the children and young people.
- Parents need easy access to information about developmental indicators of speech, language and communication development and the factors which practitioners recognise as cause for concern.

- Prospective research is needed to investigate the early concerns of parents to inform our understanding of the early developmental trajectories of children with SLCN.
- Parents need better ongoing information, not just at the time of assessment of special educational needs, about what is happening with their child, who is seeing the child, and when.
- Parents also need improved information about the evidence underpinning intervention decisions so that they can be real partners in planning discussions and can make evidence based choices.
- Services should systematically collect evidence of children's and young people's outcomes that can be shared with parents; importantly, the outcome data collected should reflect the concerns of parents.
- Research to investigate the effectiveness of interventions should include measures of outcomes relating to independence and inclusion.
- Since there will be differences of interpretation of the two higher level outcomes (independence and inclusion) for particular children and young people, an explicit discussion of the targeted outcomes for any intervention, whether in a practice or research context, should take place with children and young people and their parents.

1. INTRODUCTION

The Better Communication Research Programme (BCRP) was commissioned as part of the Better Communication Action Plan⁵, the government's response to the Bercow review of services for children and young people with speech, language and communication needs (SLCN). 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)⁶. This is one of four thematic reports which synthesize the findings from the 10 technical reports that report the results from individual BCRP projects; there are also two interim reports and a report of the BCRP as a whole (see Appendix 1 for full details).

The purpose of the BCRP was to examine the effectiveness and cost effectiveness of provision for children with SLCN and to identify good practice. Any attempt to understand how best to configure services and to evaluate their impact must consider the perspectives of the people in receipt of those services, in this case, the children and young people with SLCN and their parents. These perspectives have been present in BCRP in the form of projects and programmes of work, questions within projects, and through the advice received by the project team through its advisory board.

This report brings together the findings from two key projects within the BCRP that specifically set out to investigate the perspectives of parents and children - the preferred outcomes study⁷ and the prospective study of children with language impairment (LI) and autism spectrum disorders (ASD)⁸. These findings are discussed in the light of the broader literature and in the light of findings from other BCRP projects. Throughout the work carried out to complete this report, we have worked closely with Afasic⁹ to identify the key findings of particular relevance to parents, their children and young people with SLCN.

The 'preferred outcomes' study consisted of 5 linked projects starting with focus groups for parents and workshops for children to explore their views on outcomes that are valued for

⁵ https://www.education.gov.uk/publications/eOrderingDownload/Better_Communication.pdf

⁶ 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>

⁷ 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

⁸ 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.

⁹ Afasic is the national (UK) organisation for families of children and young people with speech, language and communication needs.

the children. This was followed by a survey of parents' views on the themes that had emerged from the qualitative work. We then carried out a systematic review of self- and parent-report tools to investigate whether or not the outcomes identified so far were represented in any existing instruments to measure children's quality of life. The findings of these four projects are described in detail in the 'preferred outcomes' report¹⁰. Finally we developed a short questionnaire for parents that focused on the attitudes and behaviour of other people towards their child. Some preliminary findings from this questionnaire, which was piloted with parents participating in the prospective study, are included in this report.

As part of the prospective study of children with language impairment (LI) and autism spectrum disorder (ASD)¹¹, parents of the participating children were interviewed using a semi-structured telephone interview to examine their understanding of the needs of their child and how those needs were being met in school. The children in this study completed a quality of life questionnaire.

All the projects completed as part of the Better Communication Research Project are listed in Appendix I. They are referred to as appropriate in the discussions and referenced accordingly.

This report addresses parents' and children's perspectives separately. We know from quality of life studies that, not only do parents and professionals differ in their views about a child's quality of life, so do parents and their children¹². It is therefore important to value the child's perspective in its own right. We start with the children's perspectives on their quality of life and features of their lives that they value or could be improved. The report then considers the parents' perspectives in terms of their perceptions of their children's needs, the interventions they receive and the outcomes that they value.

1.1 A word about SLCN

SLCN is the acronym for 'speech, language and communication needs'. This term was first coined by the Bercow report as a way of referring to *all* children with difficulties and needs in the area of speech language and communication. In that report it was used to include children with a range of medical diagnoses and special educational needs in recognition of

¹⁰ Roulstone, Coad, et al. (2012) *ibid*

¹¹ Dockrell, et al. (2012) *ibid*.

¹² 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.

the impact they have on a child's developing speech, language and communication. It can therefore be used with reference to children who have difficulties in the area of speech, language and communication in the absence or presence of other conditions. So in the way that the term is used in the Bercow report, SLCN can include children with learning difficulties, hearing impairment, ASD, physical difficulties, stammering, as well as specific speech sound and language impairments that exist in the absence of other developmental conditions. The acronym is now used extensively in the practice, policy and research literature in the UK although not in the rest of the world.

The term is also used in a more specific way by the Department for Education (DfE) for England to classify children's special educational needs – see the SEN Code of Practice¹³. In that particular context, SLCN refers to children whose primary *educational* need is in speech, language and or communication. This is the system used for the collection of national data through the School Census. The use of the SLCN category in this way does not differentiate between children with different types of speech, language and communication need (such as specific language impairment or stammering or speech sound disorder), the emphasis being on their related educational need. On the other hand, this use of SLCN *excludes* children whose *primary* special educational need falls within a different category, including hearing impairment and severe learning difficulties. Speech, language and communication needs are grouped with the separate category of ASD within a superordinate category of Communication and Interaction Needs. The different use of this term has been discussed on previous occasions¹⁴ and is picked up again in other BCRP themed reports¹⁵. In this report SLCN is used in the broader meaning as an overarching and inclusive category. References to other BCRP reports are given as footnotes.

¹³ DfES (2001). *Special educational needs: Code of practice*.

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DfES%200581%202001>

¹⁴ Lindsay, G., Desforges, M., Dockrell, J., Law, J., Peacey, N. & Beecham, J. (2008). *Effective and efficient use of resources in services for children and young people with speech, language and communication needs*. Department for Children, School and Families: Research Report DCSF-RW053 <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-RW053>

¹⁵ Dockrell, J., Ricketts, J. & Lindsay, G. (2012). *Understanding speech, language and communication needs: Profiles of need and provision*. London: DfE.

2. CHILDREN'S AND YOUNG PEOPLE'S PERSPECTIVES

In the past, it was assumed that children were unable to express their views or that somehow these were not legitimate. They were only children after all and unable to understand the adult world. If we wanted to find out about children's speech, language and communication, we observed them, tested them or asked their parents. This has changed over the last few decades and there is now an acceptance that the views of children and young people are important in their own right. Children's right to be heard in the decisions that affect them was enshrined in the United Nations Convention on the Rights of the Child in 1989 which gave children a right to freedom of expression (article 13) and a right to have their views heard in decisions that affect them (article 12)¹⁶. In the field of speech, language and communication needs (SLCN), research into children's perspectives is becoming more prevalent and there is an acceptance that children's views are taken into account¹⁷. Listening to the perspectives of children and young people can be a complex process since the very nature of their SLCN makes it more challenging for them to participate in such bodies as children's councils. Nonetheless, there are a range of resources now available to support this kind of engagement with children and young people¹⁸.

Children's perspectives were therefore considered to be important to this research programme as a matter of principle since the research was about them; it was felt that their voice should be used to ground some of the findings in the reality of what matters to the children and young people themselves. In particular, we wanted to gain an insight into their perceived quality of life as compared to their peers and to explore this in more detail in terms of the things they consider to be good in their lives and the things they wanted to improve.

2.1 Reduced quality of life

The children in the prospective study in Years 3, 5 and 7 completed the KIDSCREEN at the start of the study and again approximately 18 months later. KIDSCREEN is a self-report instrument for children and has ten subscales: physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, financial

¹⁶ UNICEF. (1989). *The United Nations convention on the rights of the child (UNCRC)*. <http://www.unicef.org/crc/>

¹⁷ Roulstone, S. & McLeod, S. (2011). *Listening to children and young people with speech, language and communication needs*. Guildford: J&R Press

¹⁸ For example: Kirby, P., Lanyon, C., Cronin, K. & Sinclair, R. (2003). *Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation. Handbook*. Nottingham: Department for Education and Skills and the National Children's Bureau. <https://www.education.gov.uk/publications//eOrderingDownload/DfES-0827-2003.pdf.pdf>

resources, social support and peers, school environment and finally, social acceptance. At the start of the study, the mean scores of children with ASD were significantly lower than the means of the normative sample on all subscales, showing that their perceptions of their own quality of life was below that experienced by the average child. In contrast, the children with LI were within the average range of the normative sample on most scores except for moods and emotion and for social acceptance/bullying where they did not differ significantly from the children who had ASD. These two domains receive the lowest ratings from all the children. At the follow-up assessment, both groups of children had improved scores on moods and emotions, self-perception and social acceptance subscales although the moods and emotion and social acceptance scales still received the lowest scores from the children.

So to summarise, according to their scores on this self-report instrument, children with LI experienced a reduced quality of life in terms of their moods and emotions and their social acceptance compared to their peers; children who had ASD experienced a reduced quality of life across all the dimensions.

Children who attended the 'preferred outcomes' workshops had a range of SLCN including those who needs were primarily and specifically speech, language and communication. In the workshops, the themes that emerged from the data have some resonance with domains in KIDSCREEN. They talked about their moods and feelings, about their parents and home life, about the people who support them and their friends, about the school environment and about social acceptance and bullying. The analysis completed as part of the systematic review of quality of life measures¹⁹ concluded that KIDSCREEN had a good fit with the themes emerging from the children's and parents' data, although there were gaps, 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.

Evaluating the quality of life of children with developmental conditions can be tricky since typically, they have no experience beyond their own lives and therefore potentially have no means of comparison with what life might be like without special educational needs or a disability. There is therefore the possibility that children rate themselves as having a higher quality of life than would adults around them who observe their interactions with the world. Nonetheless, the findings from the KIDSCREEN appear to be sensitive to the difficulties experienced by the children in the BCRP and to differences between children with different

¹⁹ Roulstone, Coad, et al. (2012) *ibid*.

types of SLCN. Furthermore, those domains of KIDSCREEN that were problematic for the children in the prospective study are similar to those identified as difficult by the children in the workshops. For example, children told stories of being teased or bullied by other children. They also talked about their feelings of frustration, anger and sadness. Sometimes this was in relation to others because of how people were behaving towards them but sometimes it was in relation to their own performance - “ *I get cross with myself. Just myself that I can't do it.*” Children in the workshops also talked about aspects of their school life which were a struggle for them. These included sports and social aspects as well as academic subjects and the process of learning such as memory, concentration and organisation.

2.2 Room for improvement

The data from the workshops also showed that there were aspects of the children's life that they wanted to improve. In particular, children hoped for changes in how other people interacted with them, for example, they wanted other people to listen to them, not to interrupt and to talk without shouting²⁰. This included family and friends as well as teachers. Aspects of their own abilities were also things that they wanted to improve, such as their talking, maths and reading. Some children could list their targets at school - “*remember people's names, remember teachers' names, sit up straight, stop making silly noises*” - but to a greater extent, were not particularly enthusiastic to talk about them. They raised these only when asked directly and there seemed to be a discrepancy between the areas in which children would like to see change and the targets that they could remember.

2.3 Positive quality of life

One should not assume from the preceding sections that these children were altogether unhappy. During the workshops, the children shared aspects of their life that they perceived to be good. The children talked positively about their families, their pets, their hobbies and their friends. Children indicated the high value they attach to having fun and talked about events and activities they enjoyed, and people who joke with them and make them laugh. They identified things that they were good at, such as playing darts, being kind, being good at reading and talking nicely. Finally they talked about the people around them who provide support; they named members of their family but also talked about their teachers, speech and language therapists (SLTs) and friends.

²⁰ This reference to shouting did not seem to be in terms of people telling children off, but in terms of people shouting in an attempt to communicate – as if people assume that saying something louder would help the child to understand.

2.4 Key issues

From the children's perspectives, two issues stand out as important: first, the children's perception of poor quality of life, in terms of their moods and emotions and social acceptance; and second the link between their current targets and what made them feel positive about life.

Social acceptance and emotional well-being

Within the BCRP projects, children and young people with a range of SLCN talked about being teased and bullied and excluded by their peers; they also talked about their own feelings of frustration and sadness. On the KIDSCREEN measure, the quality of life dimensions of social acceptance and moods and emotion showed poor levels for both LI and ASD children relative to the normative sample. They talked about the importance of their friends, being happy and having fun. These issues are clearly linked to some degree in that a child's emotional well-being can be affected by the presence of bullying and victimisation. Gini & Pozzoli²¹, in a meta-analysis across 11 studies, found that children who had been victimised were twice as likely to show problems such as headache, backache, abdominal pain, sleeping problems, poor appetite, and bed-wetting. Most of the studies included in this analysis were retrospective in design, but similar findings were also evident in a large prospective study of young people aged 13-14 years ($N = 2680$); this found that the incidence of self reported symptoms of anxiety and depression was significantly associated with reports of victimisation in the preceding year²². These two studies do not identify the particular risks for children with SLCN, and one cannot assume that the magnitude of risk will be the same; however, the studies do highlight the potential negative impact of victimisation on a child's emotional well-being.

All children will want to be free of bullying or social exclusion. The literature has mixed results about whether or not children with SLCN in particular are bullied. The samples and methods used vary, so it is not always possible to reconcile the differences; there is more consensus regarding perceptions of social acceptance and studies suggest elevated levels of social exclusion in children with SLCN.

²¹ Gini, G. & Pozzoli, T. (2009). Association between bullying and psychosomatic problems: a meta-analysis. *Pediatrics*, 123(3), 1059 -1065.

²² Bond, L., Carlin, J.B. Tomas, L., Rubin, K. & Patton, G. (2001). Does bullying cause emotional problems? A prospective study of young teenagers. *British Medical Journal*, 323, 480-484.

A recent systematic review of bullying²³ concluded that children with special educational needs and/or disabilities (SEND) are significantly more likely to be the subject of bullying or victimisation. They identified a number of factors that were related to bullying and victimisation including academic difficulties, low self esteem and anxiety, differences in physical attributes, shyness and submissiveness, uncooperative or aggressive behaviour, language and communication difficulties, inappropriate social behaviour and low social status. Sweeting and West²⁴, found that teasing and bullying were more commonly reported by children who were less physically attractive, overweight, had a disability such as a sight, hearing or speech problem, and performed poorly at school; they also reported that the associations were independent and therefore cumulative in their effects.

It is important to understand that these are associations and risk factors: they are not necessarily causative and do not mean that every child with SLCN will experience bullying. For example Lindsay et al.²⁵ found no statistically significant differences in the levels of physical or verbal bullying reported by children with specific speech and language difficulties and two comparison groups who were from the same school class – a group of typically developing children and a group with non-language based special educational needs. Children were aged 12 years and in Year 7 at school. Savage²⁶ reports a small scale study where 6 children in a language resource base (LRB) were compared to their 54 mainstream peers. As with Lindsay et al., not all the children with SLCN reported bullying, although it was a major concern for a proportion of the children.

Understanding the particular conditions that are associated with bullying and social exclusion is therefore important. Savage suggests that the inclusiveness of the educational placement might determine the level of bullying that occurs although it was not possible to test in his study. A recent study by Laws and Bates²⁷ supports this idea to some extent. This study shows a reduction in negative attributions to children with SLCN attending a LRB when the

²³ Byers, R., McLaughlin, C. & Peppin-Vaughan, R. (2012). The research perspective: vulnerability and prevalence. In C. McLaughlin, R. Byers, & C. Oliver, (Eds) *Perspectives on bullying and difference: supporting young people with special educational needs and/or disabilities in schools*. London: National Children's Bureau.

²⁴ Sweeting, H. & West, P. (2001). Being different: correlates of the experience of teasing and bullying at age 11. *Research Papers in Education*, 16(3), 225-246.

²⁵ Lindsay, G., Dockrell, J.E. & Mackie, C. (2007). Vulnerability to bullying in children with a history of specific speech and language difficulties. *European Journal of Special Needs Education*, 23(1), 1-16.

²⁶ Savage, R. (2005). Friendship and bullying patterns in children attending a language base in a mainstream school. *Educational Psychology in Practice: Theory, Research and Practice in Educational Psychology*, 21(1), 23-36.

²⁷ Laws, G. & Bates, G., (in press) peer acceptance of children with language and communication impairments in a mainstream primary school: associations with type of language difficulty, problem behaviours and a change in placement organisation. *Child Language Teaching and Therapy*.

school organisation changed to site the children within their relevant mainstream classes for most activities and withdraw for special support (as opposed to the previous arrangement in which children were placed in the LRB and then included in mainstream for particular activities). However, Knox and Conti-Ramsden²⁸ found no differences in the level of bullying between children with SLI who were attending a special school and those attending a mainstream school.

Over several years there has been an increasing emphasis in schools on children's personal and social well-being and on developing anti-bullying policies²⁹. These policies are designed, at a universal level, to be applicable to all children although they do draw attention to the possibility that children with special educational needs are particularly vulnerable. School improvement in the personal, social and emotional health of their pupils is captured in the 'Healthy Schools' status, whereby 'Healthy Schools' must demonstrate that children and young people, including those who are 'less vocal and visible', are given opportunities to air their views³⁰. Given the perspectives of the children with a range of SLCN in this study, schools should ensure that these conversations cover pupils with SLCN and the issues of social acceptance and emotional well-being.

Target setting

The Lamb Inquiry³¹ recommended that children's outcomes should be at the heart of the system of defining children's special educational needs. However, the setting of realistic, achievable and highly motivational targets that reflect children's views is challenging. Judging by their reactions, the targets mentioned by children in the workshops were perceived as boring if not irrelevant to their own aspirations and interests. Whilst they might be targets that are perceived by staff to be a necessary stage in the children's learning, there was no sense that these were shared goals or goals that the children had identified as meaningful. One recent approach to target setting with pupils with special educational needs

²⁸ Knox, E. & Conti-Ramsden, G. (2003). Bullying risks of 11 year-old children with specific language impairment (SLI): does school placement matter? *International Journal of Language and Communication Disorders*, 38(1), 1-12.

²⁹ NICE (2008). *Promoting children's social and emotional well-being in primary education*. NICE public health guidance 12. London: National Institute for Health and Clinical Excellence.

³⁰ Department of Health. (2005). *National healthy schools status: a guide for schools*. London: TSO http://www.uclan.ac.uk/schools/school_of_health/research_projects/hsu/files/national_healthy_schools_status_guide.pdf

³¹ Lamb, B. (2009) *The Lamb Inquiry. Special educational needs and parental confidence*. Nottingham: Department for Children, Schools and Families. <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-01143-2009>

and disabilities reports positive impact on the progress of pupils. 'Achievement for All'³² aims to support learners with SEND to fulfil their potential and as such emphasise appropriate goal setting. The approach used in the project involves listening to the views of pupils as part of the target setting process. The result is often innovative and unusual but breaks the mould of boring and unmotivating targets, for example, one school offered hairdressing lessons first thing in the morning to deal with late arrival for the school day. Another school used the 'circle of friends' process to support the reduction in social isolation that subsequently improved a boy's behaviour. Key to the approach is process of listening to the perspectives of the children and young people.

³² Humphrey, N. & Squires, G. (2011) *Achievement for all: National evaluation: Final Report*. DfE-RR123 <https://www.education.gov.uk/publications/RSG/AllRsgPublications/Page1/DFE-RR123>

3. PARENTS' PERSPECTIVES

Parental involvement in the decisions that affect their children is an accepted, indeed required process. In an education context, two different aspects of parental involvement are of importance³³: the first is where parents get involved in events in the life of their child's school such as helping out in the classroom and joining the parent teacher association; the second is where a parent supports their child at home with school related work, such as listening to them read, helping with homework and projects. This latter type of involvement has been found to be associated with educational benefits for the children³⁴.

In the context of interventions led by SLTs for children with SLCN, the role that parents can play has evolved over the years from an expert model with very limited involvement of parents to a more collaborative practice which engages the entire family³⁵. Watts Pappas et al.³⁴ point out that although historical models are now regarded as out-dated and not to be recommended, they are still evident in practice, not least in the research literature which evaluates the efficacy of interventions that are delivered by the SLT alone or with the 'parent-as-therapist aide'. Changes in practice have been stimulated by research into parents' opinions which has evidenced dissatisfaction where parents' opinions are not valued. Furthermore, the advent of outcomes based commissioning has brought an interest in the opinions of parents regarding the impact of interventions.

This section focuses on the two key projects within BCRP that investigate the perspectives of parents: one was a project to investigate parents' views regarding the outcomes that they value for their children; the second study was part of the prospective study of children with LI and ASD and used a telephone survey to investigate parents' understanding of the needs of the child and how they were being met in school.

³³ Department for Children, Schools and Families. (2008) *The impact of parental involvement on children's education*. Nottingham: DCSF
<https://www.education.gov.uk/publications/standard/Childrenandfamilies/Page9/DCSF-00924-2008>

³⁴ Harris, A. & Goodall, J. (2007) *Engaging parents in raising achievement: Do parents know they matter? DCSF Research report RW004*.
<https://www.education.gov.uk/publications/RSG/publicationDetail/Page1/DCSF-RW004#downloadableparts>

³⁵ Watts Pappas, N. & McLeod, S. (2009). *Working with families in speech-language pathology*. San Diego: Plural Publishing.

3.1 Identification of need

In the consultations that were held as part of the Bercow review³⁶, parents reported that the process of identification of their child's needs had been variable: in some cases it had progressed smoothly but in others parents felt that their concerns were not taken seriously. This had been a common theme emerging out of previous research where they report difficulty in persuading people to take their concerns seriously^{37,38,39}. Rannard et al⁴⁰ for example, found that an average of two years went by between parents noticing that something was wrong and getting any support, mostly because whoever they talked to about their concerns did not refer them on for assessment.

Despite parents' concerns about not being heard, there is consensus in the literature, in policy documents and in policy initiatives that early identification of children with SLCN is an imperative that should be embraced⁴¹.

In the prospective study⁴², the process of how a child's difficulties came to light varied in three ways: firstly in terms of who first noticed the problem, secondly at what age this occurred and thirdly in terms of what behaviours triggered the concern. In most cases, the child's parents had been the first to raise concerns. Health visitors, playgroup leaders and nursery staff accounted for a small percentage of those raising concerns in the younger age groups; other members of the family such as grandparents had also been the first to raise concerns in a small number of cases. This pattern is similar to that found by other studies⁴³. Only one parent reported that she had been told that their child was likely to grow out of their difficulties.

³⁶ 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>

³⁷ Glogowska, M. & Campbell, R. (2004). Parental views of surveillance for early speech and language difficulties. *Children and Society*, 18, 266-277.

³⁸ Lindsay, G. & Dockrell, J. (2004). Whose job is it?; parents' concerns about the needs of their children with language problems. *Journal of Special Education*, 37, 225-235.

³⁹ Rannard, A., Lyons, C. & Glenn, S. (2004). Children with specific language impairment: parental accounts of the early years. *Journal of Child Health Care*. 8(2), 165-176.

⁴⁰ Rannard et al, *ibid*.

⁴¹ Field, F. (2010). *The foundation years: preventing poor children becoming poor adults. The report of the independent review on poverty and life chances*. London: Cabinet Office
<http://webarchive.nationalarchives.gov.uk/20110120090128/http://povertyreview.independent.gov.uk/media/20254/poverty-report.pdf>

⁴² 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.

⁴³ Rannard et al, *ibid*.

Age of identification

In terms of the age at which the children were identified, concerns had been expressed before the age of 30 months in about half of the children (51%) and between 30 months and 5 years in approximately 34%, with about 15% of parents reporting this occurred 5 plus. In a study of children who attended a language unit, the parents of all 28 children had noticed problems before the age of 42 months⁴⁴. A study of referrals to a SLT service in the north of England showed that of all childhood referrals, 26% were referred to the service over the age of 5 years over a 15 month period: approximately 28% of children referred were under the age of 3 years and approximately 46% were referred between the ages of 3-5 years⁴⁵. Although it is difficult to equate the age at which parents noticed their child's problems in one study with the age of which referrals are made in a completely different study, there is the suggestion that the delay noted by Rannard et al is not unusual in that higher proportions of parents are noticing their child's difficulties under the age of three than are actually getting through to referral at this age.

Early signs of concern

In terms of the initial signs that parents in the prospective study reported, these differed between parents of children with language impairment (LI) and children with autism spectrum disorder (ASD). In the former, parents were more likely to refer to delays in the child's speech and language; although parents of children with ASD also referred to delays in learning to talk, they referred to a much wider range of behaviours that had caused concern including unhappy and clingy children, screaming and rocking, lack of eye contact and engagement with baby games. A number of parents from both groups also remarked that their child had been a placid or quiet baby. Some parents observed that their child was different (compared to siblings or other children); others, particularly parents of children with ASD, commented that they knew that something was wrong although they did not know what.

Once again, these findings are similar to Rannard et al⁴⁶ although in that case parents of those children with specific language impairment were also keen to emphasise the 'normal' cognitive ability of their children and the fact that the speech and language stood out as the problem rather than there being a more general developmental delay; the focus was particularly on the children's speech and intelligibility although parents did also mention the children's tantrums.

⁴⁴ Rannard et al, *ibid*.

⁴⁵ Broomfield, J. & Dodd, B. (2004). Children with speech and language disability: caseload characteristics. *International Journal of Language and Communication Disorders*. 39(3), 303-324.

⁴⁶ Rannard et al, *ibid*

Needs in school

Parents in the prospective study identified three areas of need in their children who were attending mainstream schools: speech and language difficulties, academic skills and social communication / behaviour. Parents of children from both LI and ASD groups mentioned difficulties in all three areas but, as with their initial concerns, the emphasis varied. So, as one might expect given the characteristics of the children, parents of children with LI were more likely to mention their difficulties with speech and language whereas parents of children who have ASD more commonly mentioned social communication difficulties. When talking about speech and language difficulties, parents mentioned pronunciation and intelligibility, use of sentences, the child's need for sign language.

In terms of academic skills, parents primarily talked about difficulties with aspects of literacy including reading, spelling, writing and 'putting things on paper'. However, some parents also mentioned other academic and learning skills such as maths, processing information, concentration and memory.

Finally parents mentioned children's difficulties with social communication and behaviour. These focused on problems with peers, understanding school rules, personal space. Only three parents mentioned conduct problems and these difficulties were linked to the child's frustration.

The aim must always be to identify a child's needs before they enter school. In so doing, there is a chance for early interventions to have an impact on the child's emerging speech and language before they have to deal with the social and academic demands on their emerging speech, language and communication skills. Also for those children who will need support in school, early identification enables this to be in place as the child enters school rather than waiting till they fail in school. However, for those children that do arrive at school with speech, language and communication difficulties, early years practitioners need a robust mechanism to identify those children. The BCRP study of language and literacy attainment⁴⁷ found that teachers' ratings of children's Communication, Language and Literacy on the Early Years Foundation Stage Profile (EYFSP) were able to predict later performance on reading, spelling, reading comprehension and arithmetic. Together with teacher rating of Phonics progress in Year 1, these ratings predicted almost 50% of the

⁴⁷ Snowling, M. J., Hulme, C., Bailey, A. M., Stothard, S. E., & Lindsay G. (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>

variability of children's later performance in Year 3, suggesting that teachers' early ratings on these aspects of the EYFSP can act as a useful indicator of which children may be at risk of later literacy problems. These data point to the importance of recognising the significance of poor performance on the communication, language and literacy aspects at the end of the EYFS for children's future literacy skills and as a mechanism for identifying children's SCLN.

The approach that is supported by research is the development of a *system of monitoring progress*, including response to the teaching and other interventions implemented. Evidence does not support a one-off screening as children's developmental trajectories vary. A well developed tool such as the revised Early Years Foundation Stage Profile examined in our study provides an important source of information from which teachers and others can build interventions. Children's responses to these should then be monitored and the information used to shape later support through a response to intervention model.

Diagnostic labels

Parents' use of diagnostic labels is of interest. When asked to describe their child's needs, some parents used terms such as Asperger's syndrome, ADHD or dyslexia; they referred to their child as 'dyslexic', 'slightly autistic or 'on the autistic spectrum'. No parents used a diagnostic label for speech and language difficulties, such as a specific language impairment or phonological disorder or speech sound disorder, although some parents referred to 'social communication difficulties'. Neither did parents spontaneously use the term speech, language and communication needs or SLCN, the term coined by the Bercow review.

In the interviews with practitioners⁴⁸, participants were asked what they understood by the label 'speech, language and communication needs (SLCN)'. In response, SLTs tended to list all the various diagnoses that would give rise to a range of speech, language and communication needs. For example, they would include stammering, ASD, learning difficulties, as well as specific language impairment and specific speech sound disorders. Thus SLTs appear to be using the broader and inclusive meaning of SLCN. Although education practitioners did not list diagnostic categories, they too were inclusive in their application of the term. For instance, one practitioner indicated that all children who had special educational needs were likely to have speech, language and communication needs. So in discussion, educational practitioners were also using SLCN in its broad and inclusive sense.

⁴⁸ 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.

3.2 Provision

Once identification and access have been achieved, children move into the phase associated with ‘getting on’⁴⁹ and making progress, with the expectation of benefits to both the child and parent⁵⁰. However the reality of this phase does not always match parent expectations⁵¹. At the point of identification, parents have often already begun to try and help their child⁵² and subsequently report dissatisfaction that intervention was ‘a waste of time’ because it has not provided new ideas or gone beyond what they have already tried at home⁵³.

For the families in the prospective study, support during the preschool years was variable with some children being seen two or three times, others receiving a six week block of intervention. This matches the findings of the SLT survey⁵⁴ which showed that although most commonly, SLTs were seeing children in the preschool years on a once a week basis over a period of six weeks, there was a range with some SLTs seeing children once a fortnight or once a month.

Generally parents in the prospective study were positive about the statutory assessment and statementing process and their level of involvement, about the progress their children had made and felt that the school was meeting their child’s needs. However in a number of ways, the experiences of parents of children with ASD was more positive than those whose children had LI: they felt more involved in the assessment and statementing process, more of them reported access to additional support and to SLT input. These differences were confirmed by data from special educational needs coordinators (SENCOs) who also indicated that children who have ASD were more likely to be receiving additional support than children with LI. Overall though, there was no difference between parents of children with ASD and with LI in their overall levels of satisfaction with the school, a similar finding to Parsons et al. (2009).

⁴⁹ Glogowska & Campbell (2004) *ibid*.

⁵⁰ Auert, H., Trembath, D., Arciuli, J. & Tomas, D. (2012). Parents’ expectations, awareness and experiences of accessing evidence-based speech-language pathology services for their children with autism. *International Journal of Speech-Language Pathology*, 14(2), 109-118.

⁵¹ Lyons et. al. (2010) *ibid*.

⁵² Marshall, J., Goldbart, J. & Phillips, J. (2007). Parents’; and speech and language therapists’ explanatory models of language development, language delay and intervention. *International Journal Language and Communication disorders*. 42(5), 533-555.

⁵³ Rannard et. al. (2010) *ibid*.

⁵⁴ Roulstone, Wren, et al. (2012) *ibid*.

Parents of children in mainstream schools with designated specialist resource were more positive than those in mainstream schools. Generally parents whose children were in mainstream settings were less aware of exactly what support was being provided than those in specialist resourced settings. Some parents of children who had recently made the transition to secondary school commented that their child was 'beginning to struggle' or that progress had stopped since moving to secondary. Overall, as one might expect, parent satisfaction with a school seemed to be linked to how well they perceived that the school met the child's needs, the children's progress and the child's general happiness and well-being.

For those parents who were more dissatisfied, comments were made about perceived shortages in resources or inappropriate staff training, the struggle to get decisions made and then implemented. Although many parents would have liked to see an increase in the support received, only a small number expressed concern that there was insufficient support. However, when asked about how well SEN services were tailored to their child's needs, nearly one third indicated that they didn't know or they didn't respond to this question. Knowledge about a child was seen to reside within a small number of staff (the head, the SENCO and the class teacher but not the rest of the staff).

Parents who were satisfied (overall about 80%) talked about good communication and having a sense of control. Some parents wanted more regular engagement with the school whereas others felt that their other commitments would have made more regular involvement difficult. Home-school books, which facilitate regular sharing of information about what is happening at school and at home were mentioned as a useful tool.

In response to parents' and children's concerns about the knowledge and attitudes of other people around the child (see 'outcomes' section below and preferred outcomes report), a parent-report questionnaire is currently being developed. This asks for parents' views on how other children behave towards their child, how teachers and teaching assistants behave towards their child, how teachers communicate with and support parents and about the general opportunities the child is given in school.

As indicated, more than two thirds of parents in the BCRP prospective study were satisfied with their involvement in decision making and about their involvement in the child's educational choices and progress; however, we do not have data on parents' actual levels of involvement in the education of their child or in current SLT interventions. We know from the

survey of SLT practice⁵⁵ that working with parents to deliver the intervention shows a gradually diminishing pattern as the child progresses through education. In the preschool years, over 60% of responding SLTs reported that their most typical pattern of intervention delivery was by working with parents. By secondary school this had reduced to less than 10% of SLTs who were working in this way. This probably reflects the general patterns of parental engagement in education as children progress through the system. However, parents in our studies have expressed concern about their child's progress as they enter secondary school and welcomed communications such as through home-school books. The extent of the tail-off in working with parents could therefore usefully be investigated, from both the child, and the parents' perspectives in terms of how best to maintain an effective partnership throughout a child's education.

The cost of involvement

One of the projects within the BCRP has focused on the costs and cost effectiveness of services for children with SLCN^{56,57}. There are a number of specific costing issues which are relevant to parents in their involvement in services for children with SLCN. Parents play a key role in supporting, and in some cases actually providing, the intervention that is offered. This balance changes somewhat as the child gets older and, as shown above, in many cases the focus of engagement shifts from the parent to the school. Nevertheless the supportive role remains key to the long term welfare of the child with SLCN as in all other areas and for some children. No one would assume that such support can reasonably be costed. It is what parents do. But the situation is rather different for the younger child where the specialist intervention – often provided by the speech and language therapist – depends not only on support but the active engagement of the parent. Parents are being explicitly trained to increase the relevant interactive behaviours which are then intended to improve the child's communication skills. Effectively the parent is becoming the therapist or at least is playing a key role in the therapy.

Whether this has an impact on the costs of the intervention depends upon how that intervention is costed. If we take a relatively narrow service perspective we include the cost

⁵⁵ Roulstone, Wren, et al. (2012) *ibid*.

⁵⁶ See Section 9 in 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>

⁵⁷ 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.

of health or educational services (personnel/material resources etc). If we take a broader societal perspective we should take into consideration the costs to parents in terms of transport to the clinic for example; or in terms of their time involved in the programme, both attending the clinic with their child but also the time taken carrying out the intervention in the home. This is not a trivial issue because it is likely to lead to consequences in terms of the choice of intervention. In our review of the cost effectiveness literature related to SLCN⁵⁸ we identified a relatively small number of cost effectiveness studies and, of the five, all involved young children and of these three included some costs for parents. Two actually costed parental time^{59,60}.

As these studies show, if parent-led SLCN interventions are to be evaluated but researchers do not include the cost of that parental input the overall cost of the programme is misrepresented. One might argue that it does not really matter if all parents respond the same providing the intervention as directed. However if there is differential responsiveness on the part of parents this might reasonably be expected to lead to a different response to the intervention – a fact that would be lost without the appropriate monitoring of parental time. So, for example, one might anticipate that an intervention that is both supported and carried out by highly motivated parents is likely to have a greater impact than one where the parents are disengaged. This might lead to a statistical difference in outcomes but, without knowledge about time and potentially costing of parental engagement, one might be forced to conclude that the first intervention worked because of the nature of the intervention rather than the commitment of the parent; and an intervention may appear unrealistically inexpensive if parental costs are not taken into consideration. This could have implications rolling out an intervention because one that worked in one context may well not work in another. A careful consideration of the costs of involvement for parents is therefore important.

3.3 Outcomes

Within the National Health Service in the UK, patients' experience of the quality and outcomes of care have become a major indicator of quality and will be incorporated in the

⁵⁸ Law, J, Zeng, B. Lindsay, G. & Beecham, J. (2011). The cost-effectiveness of interventions for children with Speech Language and Communication Needs (SLCN): A review using the Drummond and Jefferson (1996) "Referee's Checklist" *The International Journal of Language and Communication Disorders*. 47, 1, 1-10.

⁵⁹ Barnett, W. S., Escobar, C.M. & Ravsten, M. T. (1988). Parent and clinic early intervention for children with language handicaps: A cost-effectiveness analysis. *Journal of Early Intervention*, 12 (4), 290-298.

⁶⁰ Eiserman, W., McCoun, M., & Escobar, E. (1990). A cost-effectiveness analysis of two alternative program models for servicing speech disordered preschoolers, *Journal of Early Intervention*, 14 (4), 297-317.

indicators used to evaluate whether or not Health Commissioners are commissioning appropriate services for their local populations⁶¹. This shift in emphasis away from process measurement such as the number of children receiving a certain service, to a focus on outcome measurement, particularly 'patient-reported outcomes' is seen as the way to drive improvement in services and the development of services that are relevant to the needs and perspectives of those who use the services⁶². Measures that reflect the views of parents or children with SLCN are therefore an important tool in the improvement of services for these children.

Similarly within the education system, over recent years, there has been an emphasis on making outcomes the starting point for defining services. So for example, one of the conclusions of the Lamb Inquiry⁶³ was that there had been a lack of opportunity for parents to discuss their aspirations for their child and a general lack of confidence of parents in the special educational needs system. A key recommendation was that children's outcomes should be at the heart of the system.

Data for a consideration of outcomes come from the 'preferred outcomes' studies and from the telephone survey of the prospective study. The overarching view of preferred outcomes that emerged from the parent focus groups was the fundamental nature of communication as a skill underpinning other skills that lead to independence and inclusion. The theme of independence included sub-categories of achievement, staying safe, being confident consumers and economic well-being. The theme of social inclusion included concepts of friendships and peer relationships. A similar range of outcomes emerged from the telephone survey although the idea of hierarchy was not apparent in that study. This is probably related to the nature of the data, the telephone survey providing shorter responses whereas in the preferred outcomes study, the qualitative focus groups provided parents with an opportunity to explore the notion of outcomes in depth.

⁶¹ NHS Commissioning Board (2011). *Working together for a stronger NHS*. London: Prime Minister's Office.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_125848

⁶² 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*.
http://phi.uhce.ox.ac.uk/pdf/PROMs_WithChildren_Oxford_2009.pdf

⁶³ Lamb, B. (2009) op cit
<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-01143-2009>

From the telephone survey it appears that parents place more emphasis on academic outcomes. This may be related to differences in the sampling of parents. In the telephone survey, the children were all in mainstream schools (including schools with specialist resources) at the start of the study whereas the preferred outcomes study included parents with children in special schools as well as mainstream. Nonetheless, the parents in the preferred outcomes study did talk about academic outcomes particularly, literacy and numeracy. They also talked of the need for children to get qualifications. Parents in the preferred outcomes study usually made the link between these skills and life skills, for example with respect to maths one parent stated:

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.

Another similarity in the two sets of data is the evidence of different value placed on outcomes depending on the characteristics of the child. In the telephone survey, parents of children who have ASD talked more often about social outcomes than did parents of children with LI. In the preferred outcomes survey, there were differences between parents whose children had differing types of SLCN: for example, parents of children with receptive language impairments were more likely to value making friendships and being socially confident; academic achievements were less important for parents of children with learning difficulties; coping with change was an important outcome for parents of children who have ASD (see preferred outcomes report for further details on these differences).

Parents from the focus groups were not asked to discuss their views about access, current interventions or provision. However, when they discussed outcomes they valued, they talked about things that they would like to see change in terms of the understanding of other people around them and their child. In particular they focused on the knowledge and attitudes of family and professionals and the lay public. This angle did not emerge explicitly from the telephone survey. However, if one examines parents' areas of dissatisfaction in the telephone survey, aspects such as teacher knowledge and awareness do arise.

Another difference between the two data sets is that parents in the telephone survey mentioned their hopes for normality of their child. In the preferred outcomes data, normality was referred to in terms of a desire for their children to be engaged in 'normal' activities; for example one parent talked about their pleasure at hearing a child talking to friends through Facebook or hearing the "normal sort of teenage stuff coming from his room". Again the

differences here may be a function of sampling, with the telephone survey focusing on children in a mainstream context; or it may be related to the data gathering method of a semi-structured survey versus focus groups.

In the exploration of current practice, SLTs indicated the outcomes that they targeted with various interventions. The outcomes targeted were generally a reflection of the children's needs and difficulties; for example, intelligibility was an outcome that was particularly targeted for children aged between 4 and 7 years and for children with speech sound difficulties; social skills were targeted particularly with children with ASD. However, currently the research evaluating interventions for SLCN tends to use standardised assessments of the child's speech and language rather than more functional goals or quality of life measurements. The systematic review that was part of the preferred outcomes project did identify a number of parent- and self-report instruments that were relevant to the outcomes of interest to parents but they are not routinely used in research or in practice. Furthermore, the review identified a number of areas that were of concern to parents that were not covered by the existing measures. These included the ability to stay safe and to cope with change. Concepts which related communication to independence and inclusion were also missing. Finally, other people's attitudes and behaviours towards the children were not included in the existing measures.

3.4 Key Issues

Early identification

It is encouraging to note that only one parent's early concerns in the BCRP prospective study were dismissed. However, the process of identification was still variable and it is clear that not all the children had had their difficulties identified and had accessed some kind of intervention before they reached school entry age. So, the early identification of children with SLCN continues to challenge us. The key issue to be discussed here then is how to move this issue forward.

In recognition of the importance of early identification of children with SLCN, early years practitioners are now required to complete a progress check at the age of two years⁶⁴ or at a suitable time following the child's entry to the early years setting. The expectation is that this will be carried out in collaboration with the parent, taking account of their knowledge of the

⁶⁴ DfE, 2011 press release 6 July 2011
<http://www.education.gov.uk/childrenandyoungpeople/earlylearningandchildcare/a00191829/government-sets-out-reform-of-early-learning-and-childrens-centres>

child and using the 'Development Matters' support materials⁶⁵. These provide an outline of the stages of communication and language development (listening and attention, understanding and speaking) but do not function as checklists and do not provide criteria for the identification of children with SLCN. There is no prescribed format for this check or the report so there will be room for local practitioners to use a range of tools to support the process. Thus there is an ongoing difficulty of interpretation of the cut-off point at which concern should be raised, a referral to SLT be made and additional support be put in place.

The use of a single screening event is not supported by systematic reviews of the early screening process^{66,67}. The importance of listening to the concerns of parents about their children's speech and language development, in recognition of their expert knowledge of their child, has been stressed for a number of years (e.g. since Hall and Elliman⁶⁸) and comparisons of parent concerns with professional diagnoses and children's performance on standardised assessments show high correlations⁶⁹. However, the use of parent concern alone or indeed in combination with professional screening has so far proved insufficiently reliable as an indicator of need^{70,71}. The use of a more detailed parent- report instrument (the Children's Communication Checklist: CCC)⁷² produced a significantly better level of identification than language testing alone in the classification of children with and without language difficulties.

Thus, providing parents with more information about developmental indicators is likely to support their ability to evaluate the development of their own child. An additional possibility is to develop a parent report instrument that is based on more detailed descriptions of the concerns that parents prospectively identify as their children develop. The concerns voiced

⁶⁵ Early Education (2012). *Development matters in the early years foundation stage*. London: Early Education and the Department for Education. <http://www.ncma.org.uk/pdf/Development-Matters-in-the-Early-Years-Foundation-Stage.pdf>

⁶⁶ Law, J., Boyle, J., Harris, F., Harkness, A. & Nye, C. (1998). Screening for speech and language delay: a systematic review of the literature. *Health Technology Assessment*, 2 (9).

⁶⁷ Nelson, H.D., Nygren, P., Walker, M. & Panoscha, R. (2006). Screening for speech and language delay in preschool children; systematic evidence review for the US preventive services task force. *Pediatrics*, 117, 298-319.

⁶⁸ Hall, D. & Elliman, D. (1986). *Health for all children*. Cambs OUP.

⁶⁹ Roulstone, S., Loader, S., Northstone, K., & Beveridge, M. and the ALSPAC team, (2002), The speech and language of children aged 25 months: descriptive data from the Avon Longitudinal Study of Parents and Children. *Early Child Development and Care*, 172 (3), 259-268.

⁷⁰ Klee, T. (2007) Screening 3-year-olds for language delay using selected parent-report measures: the jury is still out. *Evidence-Based Communication Assessment and Intervention*, 1(2), 58-59.

⁷¹ Laing, G. J., Law, J., Levin, A., & Logan, S. (2002). Evaluation of a structured test and a parent led method for screening for speech and language problems: Prospective population based study. *British Medical Journal*, 325, 1152..

⁷² Bishop, D.V.M. & McDonald, D. (2009). Identifying language impairment in children: combining language test scores with parental report. *International Journal of Language and Communication Disorders*, 44(5), 600-615

by the parents in the prospective study did reflect the diagnostic category of their child: the parents with children with language impairment, spoke mostly about speech and language traits; parents of children who have ASD spoke more about social communication difficulties. However the questions to parents about their initial concerns required parents to reflect back several years to when their child was much younger. Their memory of what their child was like when they first became aware of a problem, might therefore be coloured by subsequent diagnoses and child performance. An alternative would be to gather data prospectively from parents when they first have concerns and to generate a detailed trajectory based on their observations as the child develops.

Satisfaction with provision.

The majority of parents in the BCRP studies expressed satisfaction with their levels of involvement in decision making and with the provision received by their child. However, there are important caveats to this. First, there was a striking difference between the parents of children with LI and those with ASD: the parents of children with ASD reported higher level of provision and higher levels of satisfaction than did parents of children with LI. These differences were confirmed by reports from SENCOs and by observations. Second, parents whose children were in mainstream with specialist provision were more satisfied than parents of children in mainstream. Finally, it is of particular concern that approximately 19% of parents were not aware of the additional support received by their child; approximately one third of parents responding to the pilot questionnaire did not know if they were satisfied with the level of provision from SLTs. Whilst saying that the majority of parents are satisfied this always means that the experiences of some parents are negative. These parents feel unsupported and dissatisfied with provision and feel that their child's needs are not understood. It is therefore important that, whilst we can celebrate the positives in how parents perceive the provision for their child, we should not ignore those for whom the system is clearly seen to be failing and is associated with marked unhappiness and distress.

Looking at the data from the prospective study, parents of children with language impairment could be forgiven for concluding that the best way to access services is to obtain a diagnosis of ASD. In another study of parents' perspectives⁷³ parents of children with autism did indeed believe that the chances of accessing services increased dramatically once they had obtained a diagnosis of autism. It is of concern that, despite the emphasis in the SEN Code of Practice on determining provision on the basis of children's special educational needs, it is the diagnostic label that is apparently related to the provision of support, not the particular

⁷³ Minnes, P. & Steiner, K. (2009). Parents' views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Child: Care Health and Development*, 35(2), 250-256.

needs of the child⁷⁴. The apparent lack of power of the label SLCN to generate resources in the same way as the label ASD will be of concern to parents whose children present primarily with speech, language and communication needs.

Findings from the BCRP have generated some potential indicators of the quality of schools in terms of children with SLCN. First, the BCRP has confirmed the particular vulnerability of children with SLCN for social acceptance and for their emotional well-being. So, parents of children with SLCN will be looking for schools that have a proven record with anti-bullying policies and programmes for supporting the emotional development of the children. They might also be looking for school staff that are prepared to listen to the views of the children and young people themselves. These attributes should all be present in schools that have 'Healthy School' status. This status suggests that the school has good universal provision for its pupils regarding their social and emotional well-being, that effective anti-bullying policies will be in place and that the school has effective mechanisms for listening to pupils who have special needs in the area of communication.

Second, parents are looking for outcomes that increase the independence and inclusion of their children. So they will be looking for schools that appreciate the functionality of skills, both academic and non-academic that are being acquired in school and that schools provide both parents and children with the opportunity to discuss their aspirations for their children and to be confident that children's own views will be taken into account. In this case parents might look for schools that have adopted the 'Achievement for All' programme. In these schools there should be a well structured format whereby parents can discuss their aspirations for their child, express concerns and agree targets. Parents who were satisfied with their child's provision talked about good communication practices between home and school such as the involvement in decision making and the use of a home-school book. Schools who are adopting the Achievement for All programme will be working towards effective communication practices with parents.

Third, the BCRP project 'Communication Supporting Classrooms'⁷⁵ has produced an evidence based checklist to support teachers and schools in the provision of quality first classrooms, to develop good practice at a universal level for supporting the communication

⁷⁴ 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.

⁷⁵ Dockrell, J. E., Bakopoulou, I., Law, J., Spencer, S., & Lindsay, G. (2012). *Developing a communication supporting classrooms observational tool*. London: DfE.

development of all children. Quality first teaching will not necessarily be enough to support all children with identified SLCN; for some children with greater difficulties, additional support that is targeted on specific needs will be required in order to support their continued progress and access to the curriculum. However, targeted or specific support is likely to be delivered to maximum effect in the context of and building upon universal good practice. Schools which show evidence that they regularly use the Communication Supporting Classrooms checklist to audit and improve classroom practices are therefore more likely to provide classrooms that are accessible for children with a range of SLCN.

Finally, the lack of awareness about provision that was expressed by some parents probably reflects poor communication between some schools and SLTs and the parents, signalling the need for better communication on an ongoing basis between school and parents and between SLTs and parents. Furthermore, it also indicates that better information is needed to facilitate parents' judgement about what type or level of provision is satisfactory. One resource developed within the BCRP can provide information for parents about some of the interventions available. The 'What Works'⁷⁶ report, soon to become an on-line resource hosted by the Communication Trust, takes the most commonly used interventions and evaluates what the research tells us about their effectiveness for which children. In the field of SLCN, the evidence underpinning interventions is still in the early stages so it is not yet possible to insist that any intervention used has to have strong levels of evidence. However, having information about what research has been carried out can support parents in having evidence informed discussions with practitioners.

Pathways to independence and inclusion

In their discussions of the outcomes they value for their children, parents have indicated that they value independence and inclusion for their children. These two outcomes represent overarching themes rather than concrete end states. So for example parents are looking for outcomes that contribute towards a child or young person's move towards increasing independence and reaching their own best possible outcome, rather than a single goal such as being able to live independently in their own home. For some parents, economic independence, within a job that they enjoy, living with their own spouse and children may be their eventual aspiration for their child. Others thought that their child may require some kind of support and advocacy throughout their lives. Whilst parents recognise and value academic success for their children they also have an holistic appreciation of the function of

⁷⁶ 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.

these skills in their children's longer term life course. In terms of inclusion, this included a range of ideas such as 'real' friendships, rather than those constructed by other adults, social acceptance and tolerance of their child's differences.

Given that parents value these outcomes for their child, they will be looking for interventions that target these outcomes. The particular interpretation of independence and inclusion will vary as a function of the individual child's needs and difficulties and also as a function of their age: 'independence' for a seven year old has different implications than for a young person of fifteen. This challenges us to identify the functional pathways, from the underpinning skills through to their enactment in context. So for example for a child of four who is about to enter school and who is unintelligible and using only two-three word utterances, what will the priority targets be to enable that child to function as independently as possible in school and to be included in the mainstream class with his or her peers. For children and young people with SLCN, their communication skills are a vital underpinning for steps towards independence and inclusion. The challenge will be to identify for each child the underpinning communication skills that are needed and the most appropriate evidence-based intervention programmes or strategies to achieve them. In order to develop the evidence-base around interventions, the collection of relevant data to evaluate progress towards these outcomes is required. Evidence from the BCRP study of current practice suggests that outcome data is collected by as few as one third of SLT services.

This suggests the need for a sea change in the approach of services: there is a need to systematically collect evidence of outcomes that can be shared with parents but, importantly, that the outcome data collected reflects the concerns of parents. Furthermore, there is little evidence that research into the effectiveness of interventions evaluates these outcomes. This is, therefore, another area for clarification, bringing agendas of both practice and research into line on this topic.

4. CONCLUSIONS

This report has drawn together findings from the Better Communication Research Programme related to the perspectives of children with SLCN and their parents. For children the focus was on their views of their quality of life and aspects of their lives that they would like to see improved. In particular we focus on children's social acceptance and emotional well-being and target setting. From the parents' perspective we focus on the process of

identification, satisfaction with provision and the pathways to outcomes of inclusion and independence.

The findings highlight a number of key issues for children and their parents. We report these and their implications below.

Children's perspectives: key issues

- Children's reports of their quality of life suggest that they are particularly vulnerable regarding social acceptance and emotional well-being.
- Features of children's lives that cause enthusiasm and interest were not reflected in the school targets that they could remember.

The perspectives of parents are presented on the process of early identification, on the provision experienced by their child and their views on outcomes that they value.

Parent perspectives: key Issues

- Parents' reports of the process of identification showed variability in the age and process of early identification.
- Although many parents were satisfied with provision for their children, there were marked discrepancies: parents of children with ASD reported that their children received higher levels of provision and reported higher levels of satisfaction than parents of children with LI.
- Lack of clarity about the use of the term SLCN was also identified as an issue that may impact upon provision.
- There were a number of parents who were not aware of the level of provision that their child was receiving.
- Parents valued outcomes related to the increasing independence and inclusion of their children and recognised the vital role that communication skills play in the achievement of these skills. The challenge is to identify the pathway from the underpinning communication skill to the functional outcome and the evidence-based interventions that achieve them.

Implications

- Practitioners need to check and make themselves aware of the perspectives of children and young people, particularly in terms of their views on their own social acceptance and emotional well-being.
- Understanding the perspectives of children and young people is also fundamental to the process of developing relevant, meaningful, functional and motivational targets that are shared with and by the children and young people.
- Parents need easy access to information about developmental indicators of speech, language and communication development and the factors which practitioners recognise as cause for concern.
- Prospective research is needed to investigate the early concerns of parents to inform our understanding of the early developmental trajectories of children with SLCN.
- Parents need better ongoing information, not just at the time of assessment of special educational needs, about what is happening with their child, who is seeing the child, and when.
- Parents also need improved information about the evidence underpinning intervention decisions so that they can be real partners in planning discussions and can make evidence based choices.
- Services should systematically collect evidence of children's and young people's outcomes that can be shared with parents; importantly, the outcome data collected should reflect the concerns of parents.
- Research to investigate the effectiveness of interventions should include measures of outcomes relating to independence and inclusion.
- Since there will be differences of interpretation of the two higher level outcomes (independence and inclusion) for particular children and young people, an explicit discussion of the targeted outcomes for any intervention, whether in a practice or research context, should take place with children and young people and their parents.

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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.

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