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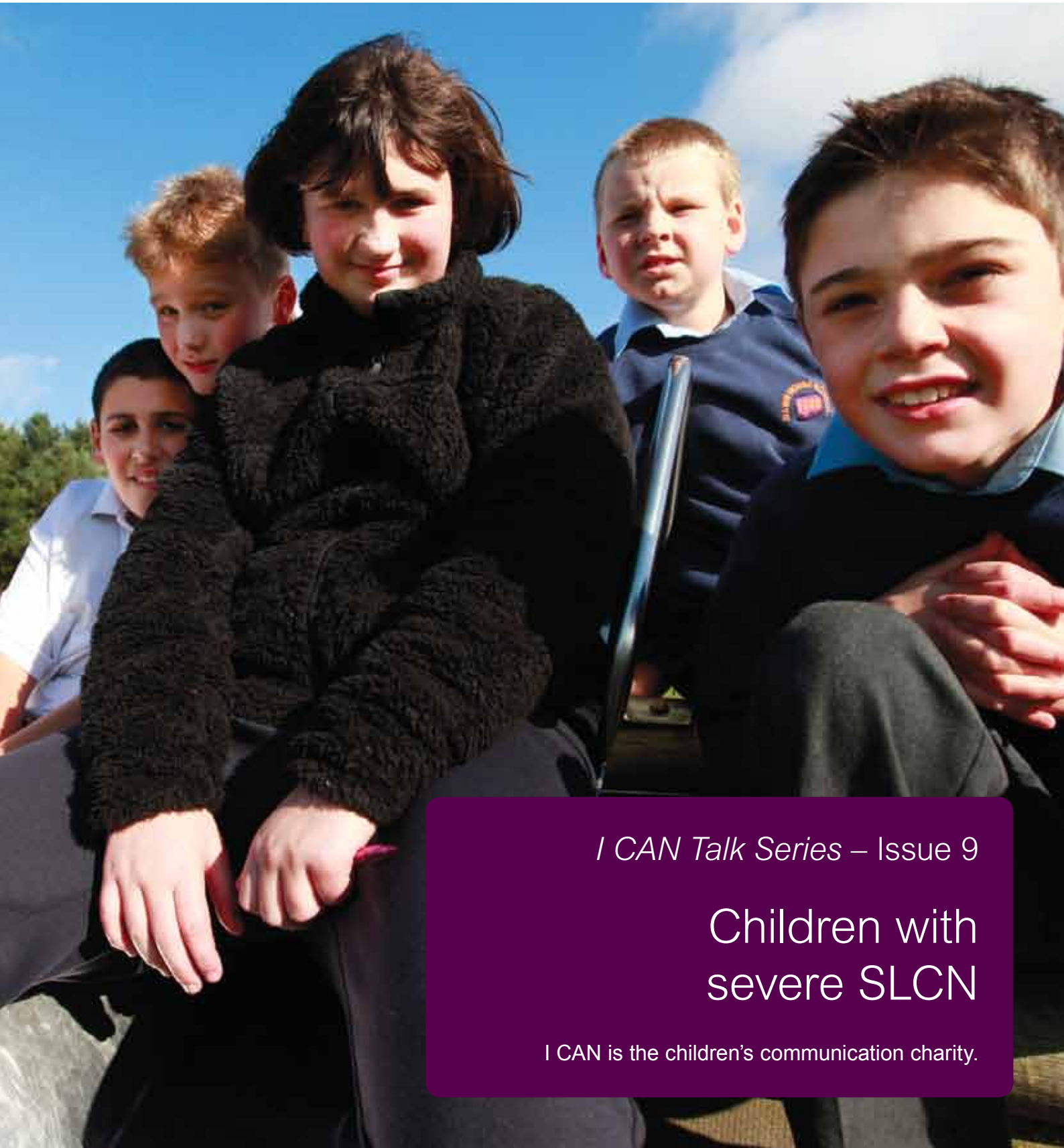

I CAN Talk Series – Issue 9

Children with severe SLCN

I CAN is the children's communication charity.

Children with severe SLCN

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Children with severe SLCN

Introduction

The Bercow Review[1] suggested that children with severe speech, language and communication needs (SLCN) are likely to represent less than 2% of the population "but are likely to have enduring difficulties". These children and young people may have very little spoken language, serious difficulties understanding language, or be completely unintelligible and be unable to indicate their basic needs, wants and desires when they begin school. They are likely to need long term intensive support and can therefore be seen as a 'low incidence/high needs' group.

This paper is about that 2%, who they are and how well their needs are being met.

1 *Lindsay. G., Desforges. M., Dockrell. J., Law. J., & Peacey. N, with Beecham. J., and Knap. M. Bercow Review: The effective and efficient use of resources in services for children and young people with Speech, Language and Communication Needs 008 http://www.dcsf.gov.uk/bercowreview/docs/7771-DCSF-BERCOW.PDF*

Children with severe SLCN

What communication difficulties do they have?

This group of children and young people often have a variety of medical and educational labels to describe their needs, making severe SLCN a pan disability issue. The **glossary** contains some of the many terms used by researchers, practitioners and families to describe children who have severe difficulty learning and using speech, language and communication.

Severe SLCN is a descriptive umbrella term where the child's primary needs may be described by another term or diagnosis. Children and young people with severe SLCN are a subset of children who have significant difficulties in one or more of the following areas:

- Problems with the muscles necessary for speech, or with motor co-ordination; for example, dyspraxia or dysarthria caused by Cerebral Palsy or in association with rare syndromes such as Angelman syndrome.[2]
- Severe social interaction difficulties, for example in Autism.
- Problems processing language; those with severe difficulty both understanding and using language e.g. due to Specific Language Impairment (SLI), Severe Learning Difficulty (SLD), Profound and Multiple Learning Difficulty (PMLD) or in association with syndromes such as Landau-Kleffner syndrome.[3]
- Children and young people with profound and severe hearing impairment.[4]

A National Framework for assessing children and young people's continuing care[5], which aims to identify health, social care and education needs, suggests the following as a description of a moderate to high level of communication need:

- Even with frequent or significant support from carers and professionals the child or young person is rarely able to communicate basic needs, requirements or ideas, even with familiar people.
- Communication about basic needs is difficult to understand or interpret even when prompted by those who know the child or young person's needs well.
- Support is always required to facilitate communication e.g. use of choice boards, signing, or communication aids.

OR

- The child or young person demonstrates severe frustration around their communication, for example causing challenging behaviour or withdrawal.

Another way of characterising their strengths and needs is provided by The World Health Organisation's International Classification of Functioning Disability and Health.[6] It aims to provide a view of disability from a biological, individual and social perspective.

2 *Baird, G. Assessment and investigation of children with developmental language disorder. In C, Frazier., Norbury, J.B., Tomblin, and D.E.V.M. Bishop. (eds) Understanding Developmental Language Disorders – From Theory to Practice Psychology Press*

3 *ibid*

4 *Wake, M., Poulakis, Z., Hughes. E., Carey-Sargeant, C. and Rickards, F. (2005) Hearing impairment: A population study of age at diagnosis, severity and language outcomes at 7-8 years. Archives of Disease in Childhood 90 238-244*

5 *Partnerships for Children, Families and Maternity (2008) A National Framework for Assessing Children's Continuing Care*

6 *The ICF (International Classification of Functioning, Disability and Health) (World Health Organisation) www.who.int/classification/icf*

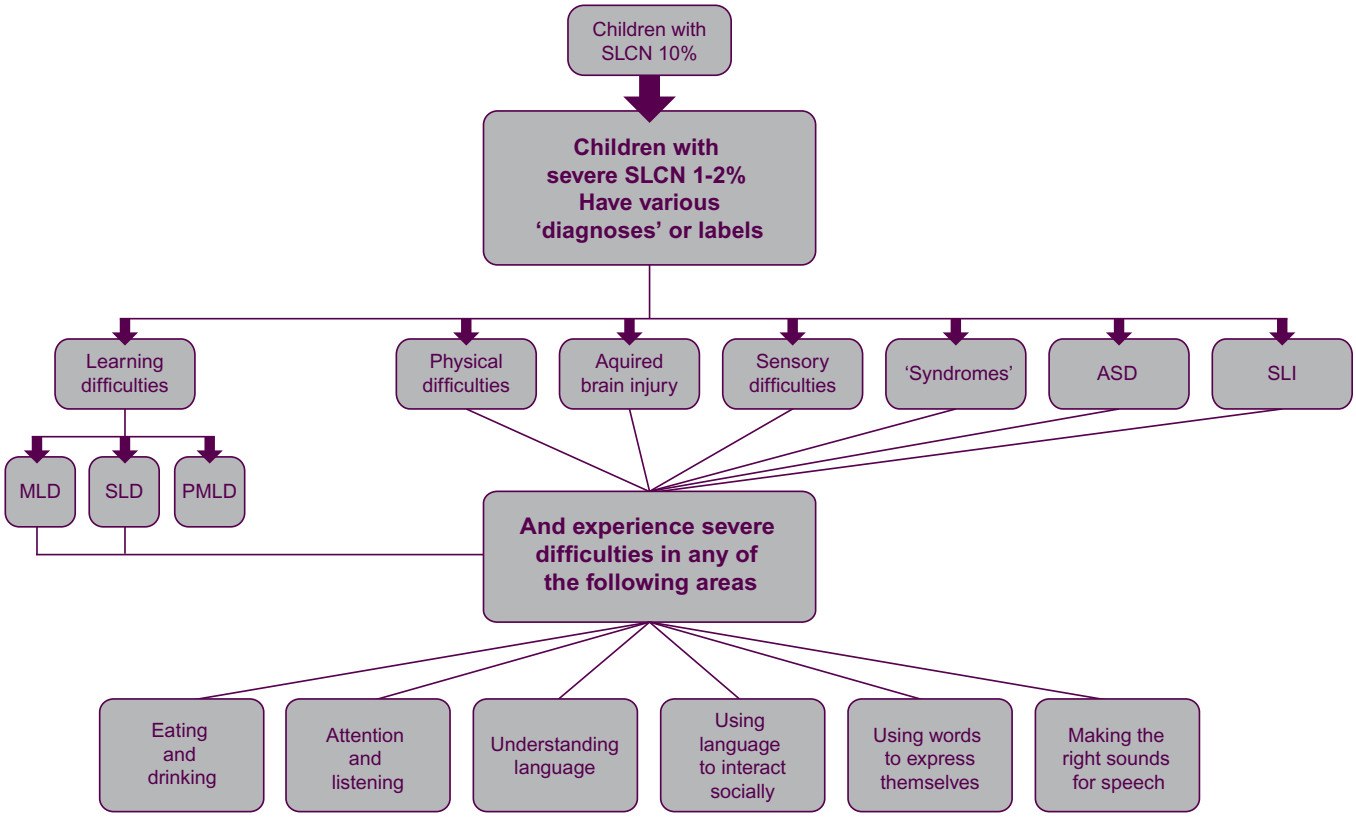
In this framework, *disability* includes:

- **Impairments** – e.g. a difficulty with interpreting speech sounds, which can lead to...
- **Activity** Limitations – e.g. problems understanding what others say, which can result in...
- **Participation** Restrictions – e.g. hampering social interaction or limiting their access to lessons.

Children with severe SLCN are likely to face significant activity limitations and participation restrictions.[7] Formal assessment may help identify these children by comparing them to others, their language skills are often in the lowest 1-2% of the population.

As the diagram shows, knowing the diagnosis or special educational needs (SEN) category which might be applied to a child or young person with severe SLCN does not necessarily help to understand their individual strengths and needs in relation to communication.

Children with severe SLCN: Neither diagnosis nor SEN category predicts type of SLCN



7 *McLeod, S., Threats, T.T. (2008) The ICF-CY and children with communication disabilities. International Journal of Speech-Language Pathology; 10(1-2): 92-109*

Children with severe SLCN

What communication difficulties do they have?

Two children with severe SLCN

Case Study: Sarah

Sarah is 8 years old. She has Worster Drought Syndrome which makes her speech unintelligible and she uses few words. She also has severe difficulties understanding what people say. She spent the first three years of her school life with additional support in a mainstream school, but struggled to cope as even the language of a simplified curriculum became too complex for her to understand. She was isolated and relied on adult support. During Year 3 she began attending a specialist school for pupils with severe speech, language and communication needs. Here she worked with a range of professionals (teachers, speech and language therapists, occupational therapists and care staff) who have specific skills in communicating and helping children develop their own communication skills. She has benefited from a range of specialist interventions including consistent use of a signing system[8], cued articulation[9] and finger spelling[10], colour coding of language[11] to support literacy work (where parts of speech are underlined in particular colours to help children recognise, understand and use them) and a multisensory approach to learning vocabulary. She has also developed her social skills through the support of a structured approach to social communication. Sarah is now a full participant in all lessons at the special school, understanding what's happening and offering her ideas without prompts from an adult.

Case Study: Luke

Luke is 10 years old and has severe difficulty understanding language and using language to express himself, he has a diagnosis of dyspraxia (see glossary). When he started in a special school for pupils for severe speech, language and communication needs at age 6, his speech was difficult to understand and he was extremely frustrated by his inability to communicate. This led to some problem behaviour. His attention and listening skills were very poor and he had severe difficulties finding the right words to express himself. His difficulties with recognising and using sequences affected his ability to read and write and his ability to express his ideas coherently. Specialist support to develop his sequencing skills using visual frameworks and Paget Gorman Signed Speech[12] have helped with both literacy and spoken language. He was helped greatly by being given time to formulate responses and by being given strategies to help him find the words he needed. Luke is now a sociable boy who is able to cope with all class based tasks in the special school and has a huge interest and enthusiasm for learning.

Further case studies are available on the ACE centre website.[13]

So with the right support and continuing support, children with severe SLCN can make progress.

8 *Paget Gorman Signed Speech*

9 *Passy, J., Armstrong, S. (1993) Cued Articulation STASS Publications*

10 *http://www.rnid.org.uk/information_resources/communicating_better/fingerspelling/fingerspelling_tool/#here*

11 *Bryan, A. (1997) Colourful Semantics. In S, Chait., J, Law., & J, Marshall. (Eds) Language disorders in children and adults: Psycholinguistic approaches to therapy. London Whurr*

12 *Paget Gorman Signed Speech*

13 *http://www.ace-centre.org.uk/index.cfm?pageid=F4AB7797-3048-7290-FEC1ACB8D19A1885*

Who are the children and young people with severe SLCN?

Children and young people with severe SLCN are not often seen as a distinct group because their needs are very different, although they all have serious difficulties with communication. Nonetheless there is some information available on which children might be considered to have severe SLCN.

- Children and young people with **Specific Language Impairment** (SLI) have language skills which are less well developed than their other skills. Children and young people with SLI have a difficulty with learning language which can last through childhood[14] and for some, a lifetime.[15] Approximately 7% of children have this kind of difficulty when starting school, where learning language is the main or primary need and where there is no known cause.[16] A small proportion of these children will have severe SLCN. Their communication needs are often missed as their other skills are better developed.
- 1.5 million people in the UK have a **learning disability** – around 3% of the population.[17] The majority of children with learning difficulties have additional SLCN.[18,19] However severe SLCN is more likely in those with severe learning disabilities, approximately 80% of those with severe learning difficulty (SLD) do not acquire effective speech[20], so they would be considered to have severe SLCN.
- It is estimated that 0.1% of the population have **Autism** and 0.6% have Autistic Spectrum Disorders (ASD).[21] Although others found that Autism and ASD together affected 1% of the population.[22] It is more likely that children with Autism would be considered as having severe SLCN.
- Currently about 0.2% of children are affected by **Cerebral Palsy**, up to 80% of children with Cerebral Palsy have some impairment of speech[23] although a minority will have severe SLCN.
- Approximately 3,000 children each year (in the UK) acquire a significant SLCN due to **brain injury**[24] and some of these cases will be severe in nature.
- 840 babies are born each year in the UK with significant **deafness** and about half of these are severely deaf.[25] Some children with hearing impairment have significant difficulty acquiring verbal language similar to that experienced by children with SLI.[26]
- There are many rare 'syndromes' which can be associated with severe SLCN for example Velo-Cardio-Facial syndrome.[27] The prevalence of Velo-Cardio-Facial syndrome in the United States is approximately 0.5%.[28]

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14 Law, J., Boyle, J., Harris, F., Harkness ,A. and Nye, C. (2000) *Prevalence and Natural History of Primary Speech and Language Delay: findings from a systematic review of the literature* IJLCD Vol 35 no.2

15 Clegg, J., Hollis, C., Mawhood, L. and Rutter, M. (2005) *Developmental language disorders – a follow-up in later, adult life. Cognitive, language and psychosocial outcomes* Journal of Child Psychology and Psychiatry 46 2 128-149

16 Tomblin, J.B. et al (1997) *Prevalence of Specific Language Impairment in Kindergarten Children* Journal of Speech, Language and Hearing Research 40 in Lindsay, G. and Dockrell, J. with Mackie, C. and Letchford, B. (2002) *Educational Provision for Children with Specific Speech and Language Difficulties in England and Wales* CEDAR

17 mencap http://www.mencap.org.uk/

18 Dorothy Angus (Head of supporting and Safeguarding Children Division at the Department of Education) RCSLT Conference 2008

19 Foundation for People with Learning Disabilities, 2000

20 RCSLT (2006) *Evidence for the Treasury: The benefits of early speech and language therapy intervention with disabled children.*

21 Newschaffer, C.J., Croen, L.A., Daniels, J. et al. (2007). *The epidemiology of Autism spectrum disorders* Annu Rev Public Health 28: 235–58. doi:10.1146/annurev.publhealth.28.021406.144007. PMID 17367287.

22 Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., Charman, T. (2006) *Prevalence of disorders of the Autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*. Lancet. 15;368(9531):210-5

23 Odding, E., Roebroeck, M.E., Stam, H.J. (2006) *The epidemiology of Cerebral Palsy: incidence, impairments and risk factors* Disability & Rehabilitation 28; 28(4): 183-91

24 *Communicating Quality 3 RCSLT's guidance on best practice in service organisation and provision* (2006) The Royal College of Speech and Language Therapists

25 RNID http://www.rnid.org.uk/information_resources/aboutdeafness/statistics/statistics.htm#baby

26 Mason, K., Rowley, K., Marshall, C.R., Atkinson, J.R., Herman, R., Woll, B. & Morgan, G. (in press). *Identifying SLI in Deaf children acquiring British Sign Language: Implications for theory and practice* British Journal of Developmental Psychology, 28, 33-49.

27 Goorhuis-Brouwer, S.M., Dikkers, F.G., Robinson, P.H., Kerstjens-Frederikse, W.S. (2003) *Specific language impairment in children with velocardiofacial syndrome: four case studies* Cleft Palate-Craniofacial Journal; 40(2): 190-5

28 Shprintzen, R.J. *Velo-cardio-facial syndrome: 30 Years of study.* Dev Disabil Res Rev. 2008;14(1):3-10

Children with severe SLCN

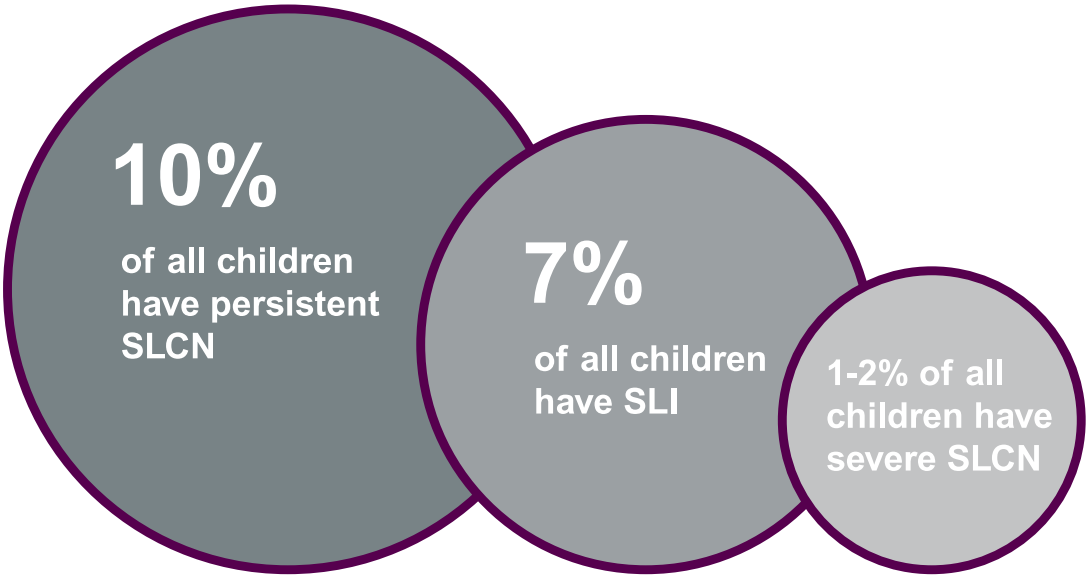
Who are the children and young people with severe SLCN?

Swallowing problems are very common in children with learning disabilities[29] and in children with Cerebral Palsy[30] and are likely to affect those with severe SLCN.

Clearly estimating the number of children with severe SLCN is complex. Some[31] conclude that nearer to 1% of the population have severe communication difficulties. It may also be that the number of children with severe SLCN is on the increase; with improvements in neonatal care, more children with complex disabilities and those born early are surviving.[32] This seems to be the case for those with Cerebral Palsy[33] and PMLD.[34]

Recognising children with severe SLCN as group with some communication needs in common, whatever their diagnosis or special educational need category, is important in identifying their need for services.

Approximately 240,000 children have severe SLCN in the UK



29 NPSA, 2004 www.npsa.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=7033

30 Reilly, S., Morgan, A. (2008) Dysphagia is prevalent in children with severe Cerebral Palsy Developmental Medicine & Child Neurology, 50(8),. 567

31 Enderby., P. and Pickstone, C. (2005) How many people have communication disorders and why does it matter? Advances in Speech-Language Pathology 7 (1): 8-13.

32 Epicure study 2005 http://www.epicure.ac.uk/about-us

Defining and describing severe SLCN

Terminology

A recurring issue in addressing SLCN is that they are described both from a *medical* perspective in terms of diagnoses and from an *educational* perspective, where there are categories of special educational needs. Both sorts of terminology will be used here where it is helpful, but in practice different professions may not be familiar with, or use each others' terminology. There can also be confusion because the term SLCN has a specific meaning as a special educational need (SEN) category for those who have primary needs in this area. It is also used as an umbrella term to describe all children with any kind of Speech, Language and Communication Needs. These issues can affect both the way individuals' needs are identified and how they are identified on the school special needs census. In this paper (as in the Bercow Review), the term SLCN is used to refer to **all children who have any kind of Speech, Language or Communication Need**. It is ironic that these sorts of communication issues can impact on our understanding of children with SLCN.

Primary or secondary?

Practitioners are often asked to decide whether a child's SLCN is primary or secondary in order to allocate services, even when they have severe and complex needs. However this can be difficult to establish. Firstly, it is often difficult to decide what is a child's most significant need. Secondly, within the special educational needs system, there are differences between Local Authorities, and between schools, in the use of primary categories of need.[35] This affects the number of children placed in the SLCN category. Some say that SLD and Profound and Multiple Learning Difficulty (PMLD) should be used as primary categories. Although most children in these categories will have SLCN, it is not often considered their primary need. Others say that some pupils with SLD and PMLD could be categorised as having SLCN as their primary need, depending on the degree of need in SLCN. Recent research has found that the situation is even more complex. Lindsay et al[36] for The Bercow Review reported that:

- There are differences between Local Authorities in the way ASD is categorised, as a subset of SLCN, or as a separate category.
- Some thought categorising pupils as having behavioural, emotional and social difficulties (BESD) or SLCN was difficult, and the primary need may change over time depending on the environment and type of support offered.
- Several SEN managers expressed reservations about the reliability and validity of the way SEN were categorised by schools, with factors such as availability of Speech and Language Therapists and Educational Psychologists affecting the category under which schools sought funding or alternative placement for pupils with SEN.

In practice, a number of problems arise out of how the terms 'primary' and 'secondary' needs are used. As a result, there is a danger that children with severe SLCN may not get access to services to help them develop their communication skills.

33 *Vincer, M.J., Allen, A.C., Joseph, K.S., Stinson, D.A., Scott, H., Wood, E. (2006) Increasing prevalence of Cerebral Palsy among very preterm infants: a population-based study Pediatrics, 118(6): 1621-6*

34 *Sheffield Care Trust (2006) – summary of findings from Adult Learning Disability Day Services PMLD sub group and additional Case Register information*

Children with severe SLCN

Defining and describing severe SLCN

Co-occurrence

Another reason why trying to define a primary need is problematic is that many developmental disorders occur together[37] and this seems to be more likely as the severity of these difficulties increase.[38] Children who have SLCN often have other difficulties, in particular developmental co-ordination disorder[39], especially when their speech is affected.[40] It is therefore very difficult to tell which difficulty is primary and which is secondary when children have complex needs.[41] It seems to be the nature of SLCN that the set of difficulties is different for each child and that its nature changes over time. The same is likely to be true of severe SLCN.

There also seem to be unclear boundaries between SLCN and ASD, and as a child's pattern of difficulties changes over time, sometimes it is less clear which is the appropriate diagnosis.[42,43] Associations within families between Autism and specific language impairment have also been found.[44] The diagnosis of ASD is more likely in children who have already been identified as having SLI[45] and the language difficulties they experience are similar to those experienced by children with SLI.[46]

Given these difficulties defining and describing severe SLCN, it seems more appropriate to characterise the various strengths and needs of someone with severe SLCN (perhaps using a framework like the ICF[47] as described on page 4), as a first step towards meeting these needs. For those whose needs are severe, a detailed analysis is imperative.

The relevance of general intelligence

The interplay between language and learning ability is complex. For example one study found that children with Cerebral Palsy (CP) and learning difficulties were also more likely to have language impairments.[48] However, children with Down's syndrome often have SLCN similar to that of children with specific language impairment, although they also have other learning difficulties.[49] The outcomes for children with poor language skills, even if their non-verbal ability is only moderately limited, are similar[50] and tend not to be positive.[51]

The key question is whether the ability to learn affects progress in intervention. This argument

37 Richardson, A.J., Ross, M.A. (2000) Fatty acid metabolism in neurodevelopmental disorder: A new perspective on associations between attention-deficit/hyperactivity disorder, dyslexia, dyspraxia and the autistic spectrum Prostaglandins Leukotrienes & Essential Fatty Acids. 63(1-2)(pp 1-9),

38 Kaplan, B., Crawford, S., Cantell, M., Kooistra, L. and Dewey, D. 2006 Comorbidity, co-occurrence, continuum: what's in a name? Child Care Health Dev. Nov ;32 (6):723-31

39 Webster, R., Erdos, C., Evans, K., Majnemer, A., Kehayia, E., Thordardottir, E. et al (2006) The clinical spectrum of developmental language impairment in school-aged children: Language Cognitive and motor findings Pediatrics 118 E1541-E1549

40 Visscher, C., Houwen, S.J.A., Scherder, E.J.A., Moolenaar, B. and Hartman, E, 2007 Motor Profile of Children With Developmental Speech and Language Disorders Pediatrics 120 1, 158-163

41 Florian, L., Rouse, M., Black-Hawkins, K., & Jull, S. (2004) What Can National Data Sets Tell Us about Inclusion and Pupil Achievement? British Journal of Special Education, 31, 3 p115-121

42 Michelotti, D.J., Baird, G. (2002) Follow-up of children with language delay and features of Autism from preschool years to middle childhood Developmental Medicine & Child Neurology;. 44 12 812-819,

43 Bishop, D.V.M., Norbury, C.F. (2002) Exploring the borderlands of autistic disorder and specific language impairment: a study using standardised diagnostic instruments 43 7 p917-929,

44 Tomblin, J.B., Hafeman, L.L., O'Brien, M. (2003) Autism and Autism risk in siblings of children with specific language impairment International Journal of Language & Communication Disorders; 38(3): 235-50

45 Conti-Ramsden, G., Simkin, Z., and Botting, N. (2006) The prevalence of autistic spectrum disorders in adolescents with a history of specific language impairment (SLI) Journal of Child Psychology and Psychiatry 47 621-628

46 Tager-Flushberg, H. (2006) Defining language phenotypes in Autism. Clinical neuroscience Research 6 (3-4) 219-224

47 http://www3.who.int/icf/icftemplate.cfm?myurl=introduction.html%20 &mytitle=introduction

48 Pirila, S., van der Meere, J., Pentikainen, T., Pirjo Ruusu-Niemi, P., Korpela, R., Kilpinen, J. and Nieminen, P. (2007) Language and motor speech skills in children with Cerebral Palsy Journal of Communication Disorders 40, 2, 116-128

49 Laws, G. and Bishop, D.V.M. (2004) Verbal deficits in Down's syndrome and specific language impairment: A comparison International Journal of Language and Communication Disorders 39 4 423-451

50 Tomblin, J.B. (2008) validating diagnostic standards for specific language impairment using adolescent outcomes. In C Frazier Norbury, JB Tomblin, and DEVM Bishop (eds) Understanding Developmental Language Disorders – From Theory to Practice Pyschology Press

51 Law, J., Rush, R., Parsons, S. & Schoon, I. (forthcoming) Modelling Developmental Language Difficulties from School Entry into Adulthood: Literacy, mental health and employment outcomes. Journal of Speech, Language and Hearing Research

about 'potential' is often used in the allocation of speech and language therapy services or for entry into special units for children with SLI. In one study of children with Autism, those with higher initial cognitive levels and fewer social interaction difficulties, made the most progress in developing their language skills in response to intervention.[52] However, non-verbal IQ does not necessarily help predict who will benefit from language intervention.[53] Also outcomes for children with SLI, ASD and pragmatic language impairment suggest that these are related disorders, where individuals experiencing them have varying problems with language structure, language use and narrowed interests.[54] This highlights the need for individual assessments of skills and areas of need.

It seems that, except where learning difficulties are severe, the nature of the speech, language and communication needs affect outcomes more than general learning ability. Some researchers would suggest that all children with SLCN should receive services to help develop their language skills, regardless of any additional moderate learning difficulties[55] because progress is similar in both groups.[56]

So the evidence suggests that it might be more appropriate to make decisions about allocation and type of intervention based on the nature of the SLCN, how it impacts on functioning and the young person's response to intervention, rather than the child's non-verbal IQ.

52 *Ben-Itzchak, E., Zachor, D.A. (2007) The effects of intellectual functioning and Autism severity on outcome of early behavioral intervention for children with Autism Research in Developmental Disabilities, 28, 3, 287-303*

53 *Fey, M.E., Long, S.H. & Cleave, P. (1994). Reconsideration of IQ criteria in the definition of specific language impairment. In Watkins, R. V., & Rice, M. Eds. Specific language impairments in children. vol. 4 (pp.161–178). Baltimore, MD: Brookes*

54 *Whitehouse, A.J.O., Watt, H.J., Line, E.A., Bishop, D.V.M. (2009) Adult psychosocial outcomes of children with specific language impairment, pragmatic language impairment and Autism International Journal of Language & Communication Disorders, 44, 511 – 528*

55 *Rice, M.L., Tomblin, J.B., Hoffman, L., Richman, W.A. and Marquis, J. (2004) Grammatical Tense Deficits in Children With SLI and Nonspecific Language Impairment: Relationships With Nonverbal IQ Over Time Journal of Speech, Language, and Hearing Research Vol. 47 816–834*

56 *Fey, M.E., Long, S.H., & Cleave, P. (1994). Reconsideration of IQ criteria in the definition of specific language impairment. In Watkins, R. V., & Rice, M. Eds. Specific language impairments in children. vol. 4 (pp.161–178). Baltimore, MD: Brookes.*

Children with severe SLCN

What are the consequences of severe SLCN?

Most of what we know about outcomes for children with SLCN comes from longitudinal studies of children with SLI, whose outcomes are very variable although there is a strong association with literacy difficulties in adolescence.[57] However, Tomblin's[58] longitudinal study also included children who had language and other moderate learning difficulties. As adolescents, both groups had similarly poor academic, social and behavioural outcomes. Another longitudinal study followed individuals with specific language impairment, or language impairment with additional learning difficulties. It showed that they were all at risk of problems with literacy, mental health and employment as adults.[59] While we don't know to what extent these studies included children with severe SLCN, it is unlikely that their outcomes would be more positive. Children who have hearing impairment are likely to have SLCN, linked to the degree of hearing impairment.[60] A follow-up study from a school for children with severe SLCN suggests that their communication difficulties tended to persist into adulthood, although this was related to the amount and type of support they received.[61]

Social isolation

A survey by Contact a Family found that over 70% of the 615 families who took part said that: "understanding and acceptance of disability from their community or society is poor or unsatisfactory".[62] It is likely that some of these families had children with severe SLCN. Sometimes the ability of a child with severe SLCN to participate in decision making can be severely restricted, leading to potential ethical dilemmas.[63] It may be difficult to know how much they can understand and therefore whether they can give informed consent, even if communication can be achieved. Communication difficulties are frequently given as the reason why disabled children are not consulted.[64] Young people themselves want to be seen as individuals first and disabled second,[65] but in some cases the views of children with communication difficulties are ignored.[66]

Pressures on families

There is evidence to suggest that supporting children who have learning difficulties (some of whom will have severe SLCN) has a major social and psychological impact on families.[67] It also leads to economic disadvantage for some families, especially in the current economic climate.[68]

57 Conti-Ramsden, G. *Heterogeneity of specific language impairment in adolescent outcomes.* In C, Frazier Norbury., J.B. Tomblin., and D.V.M. Bishop. (eds) *Understanding Developmental Language Disorders – From Theory to Practice* Pyschology Press

58 Tomblin, B. *Validating diagnostic standards for specific language impairment using adolescent outcomes* In C ,Frazier Norbury., J.B. Tomblin., and D.V.M. Bishop. (eds) *Understanding Developmental Language Disorders – From Theory to Practise* Pyschology Press

59 Law, J., Rush, R., Schoon, I., Parsons, S. (2009) *Modeling Developmental Language Difficulties from School Entry into Adulthood: Literacy, Mental Health, and Employment Outcomes* Journal of Speech, Language, and Hearing Research, v52 n6 p1401-1416

60 Delage, H., Tuller, L. 2007 *Language Development and Mild-to-Moderate Hearing Loss: Does Language Normalize with Age?* Journal of Speech, Language, and Hearing Research, 50 5 1300-1313

61 Ansorge, L. (2009) *Life Outcomes in adults with childhood histories of severe and complex communication difficulties who attended a special residential school: A summary of a PhD project* (unpublished)

62 *What makes my family stronger* A report into what makes families with disabled children stronger – socially, emotionally and practically http://www.cafamily.org.uk/pdfs/wmmfs.pdf

63 Brady Wagner, L.C. (2003) *Clinical ethics in the context of language and cognitive impairment: rights and protections* Seminars in Speech and Language, 24/4(275-84)

64 Dickens, M. *Listening to young disabled children* National Children's Bureau

65 Watson, N., Shakespeare, T., Cunningham-Burley, S. and Barnes, C. (2000) *Life as a Disabled Child: a qualitative study of young people's experiences and perspectives.* Edinburgh: Department of Nursing Studies, University of Edinburgh.

66 Ward, L. (1997) *Seen and Heard: Involving disabled children and young people in research and development projects.* Joseph Rowntree Foundation

67 Emerson, E. (2003) *Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties* Journal of Intellectual Disability Research 47 4-5, 385 – 399

68 http://www.carersuk.org/Newsandcampaigns/Research/CarersInCrisis

Access to learning/literacy difficulties

We know that children with SLCN tend to have low educational attainment[69] and that those with SLI are at a greater risk of literacy difficulties.[70] One study matched young people using Bliss Symbolics[71] with peers of a similar intellectual level and the results showed that those using symbols had lower levels of literacy.[72] So as children with severe SLCN often have to use slower or less efficient means of communication, they are likely to face considerable barriers to learning.

Behavioural issues

Many children who have difficulty with communication subsequently develop a variety of behaviour problems.[73] It also seems to be the case that children with more severe language impairments tend to have more behaviour problems[74] and are at greater risk of psychiatric difficulties in adolescence.[75] This link is emphasised by approaches such as functional communication training[76] which successfully replaces problem behaviours with communicative alternatives. Pupils with special educational needs (especially BESD) are nine times more likely to be excluded from school than other pupils.[77,78] Young people themselves say that not being understood and misunderstanding others can lead to a loss of self-control.[79]

Positive outcomes

We know that early identification of SLCN and intervention can have positive effects[80] and as the case studies show, children with severe SLCN can make good progress, given appropriate specialist support. There are also young people with significant hearing loss who are able to develop good spoken language skills following cochlear implants.[81] In addition to this, some children with severe language delays and autistic features do go on to develop their language skills, although autistic features remain.[82]

Severe SLCN can result in serious long term consequences but with the right specialist support for children, outcomes can be more positive.

69 *Lindsay, G., Desforges, M., Dockrell, J., Law, J. & Peacey, N. with Beecham, J. and Knap, M. Bercow Review: The effective and efficient use of resources in services for CYP with SLCD – 2008 http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RW053.pdf*

70 *Conti-Ramsden, G. Heterogeny of specific language impairment in adolescent outcomes In C. Frazier Norbury., J.B. Tomblin., and D.E.V.M. Bishop. (eds) Understanding Developmental Language Disorders – From Theory to Practice (2008) Pyschology Press*

71 *http://www.blissymbolics.org/bliss.shtml*

72 *Sandberg, A.D., Hjelmquist, E. (1996) A comparative, descriptive study of reading and writing skills among non-speaking children: a preliminary study International Journal of Language & Communication Disorders, 31, 3 289 – 308*

73 *Carson, D.K., Klee, T., Lee, S., Williams, K.C. & Perry, C.K. (1998) Children's language proficiency at ages 2 and 3 as predictors of behavior problems, social and cognitive development at age 3. J. Children's Communication Development 19 2 21-30*

74 *McCabe, Paul C. (2005) Social and Behavioral Correlates of Preschoolers with Specific Language Impairment Psychology in the Schools, 42/4 373-387*

75 *Snowling, M.J., Bishop, D.V.M., Stothard, S.E., Chipchase, B., Kaplan, C. (2006) Psychosocial outcomes at 15 years of children with a preschool history of speech-language impairment Journal of Child Psychology and Psychiatry, 47/8 759-765*

76 *Durand, V.M., Merges, E. (2001) Functional Communication Training A Contemporary Behavior Analytic Intervention for Problem Behaviours Focus on Autism and Other Developmental Disabilities, 16, 2, 110-119*

77 *TreeHouse, (2009) Disobedience or Disability? The exclusion of children with Autism from education*

78 *Department for Children, Schools and Families (2008) National Statistics SFR 14/2008 Permanent and Fixed Period Exclusions from Schools and Exclusion Appeals in England, 2006/2007 http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000793/SFR14_2008.pdf*

79 *2008 Secretary of State Report on progress towards disability equality across the children's and education sector /2008SecretaryofStateReport_a.pdf*

80 *DCSF (2008) The Bercow report: A Review of services for children and young people (0-19) with Speech, Language and Communication Needs*

81 *Stacey, P.C., Fortnum, H.M., Barton, G.R., Summerfield, A.Q. (2006) Hearing-impaired children in the United Kingdom, I: auditory performance, communication skills, educational achievements, quality of life, and cochlear implantation. Ear & Hearing 27(2): 161-86*

82 *Michelotti, J., Baird, G. (2002) Follow-up of children with language delay and features of Autism from preschool years to middle childhood Developmental Medicine & Child Neurology; 44 12 812-819*

Children with severe SLCN

What services do children with severe SLCN need and how effective are they?

The Bercow Review (as set into context by Gascoigne[83]) identified a group of young people who would need specialist support for developing their speech, language and communication. It is likely that this would include those with severe SLCN. This support should include:

- Specialist support for parents.
- Joined up multidisciplinary support.
- Access to a range of settings and schools where appropriate support and learning opportunities are provided.
- Settings and schools which have appropriate levels of skills and environmental modifications to support children with severe SLCN.
- Access to specialist interventions under the guidance of a speech and language therapist.

It is difficult to evaluate the effectiveness of interventions for children with severe SLCN because they are a group of very complex children and young people. It is also difficult to determine the precise aim of any intervention, how to evaluate it[84] and indeed what a good outcome is for a child with severe SLCN. Therefore there is very little research and many of the studies available are based on very small samples of young people, so it is often difficult to know whether the results apply to others.

A recent survey of parent's views on services for disabled children (perhaps the first of its kind), rated them as 59/100[85], this is seen as a baseline to progress from. Reviews of the literature suggest that: "healthcare, education, criminal justice, financial and social services" are failing to meet the specific needs of people with Communication Support Needs (CSN)[86] (SLCN as described in Scotland). The Bercow Review[87] found that parents of children with SLCN often felt that information and advice was difficult to find, that children's needs were not always identified early, and accessing services, particularly Speech and Language Therapy, all too often involves a "fight" because they are a scarce resource. There was no specific provision recommended for children and young people with severe and complex SLCN in the *Better Communication Action Plan*.

Specialist support for parents and families

We don't know a great deal about what the families of children with severe SLCN need, although much of what is known about families of children with special needs is likely to apply to them. In a survey by Contact a Family[88] over 60% of the 615 families who took part said they did not feel listened to by professionals. Apart from the importance of listening to parents as experts on their children, empowering and collaborating with families can have positive outcomes for children.[89,90] Family centred services (for Cerebral Palsy) seem to be beneficial for the psychological well being of children and families and satisfaction with services; there is less evidence for other outcomes.[91] Good information is very important to families.[92] Family stress can be increased when their expectations are not

83 Gascoigne, M. (2009) *Supporting children with Speech, Language and Communication Needs: Implementing Bercow* Afasic news, Winter

84 Granlund, M., & Olsson, C. (1999). *Efficacy of communication intervention for presymbolic communicators.* Augmentative and Alternative Communication, 15, 25-37.

85 *Survey of parents' experiences of services provided to disabled children (BMRB)* http://www.dcsf.gov.uk/rsgateway/DB/STR/d000846/index.shtml

86 Law, J., van der Gaag, A., Hardcastle, B., Beck, J., MacGregor, A,. Plunkett, C. (2007) *Communication Support Needs a review of the literature* Scottish Executive Social Research

87 *Bercow Review of Services for Children and Young people (0-19) with Speech, Language and Communication Needs Interim report* http://www.mkparents.org/gDocs/08.03.20%20-%20DCSF%20Interim%20Executive%20report%20on%20Services%20for%20CYP%20with%20SALCN.pdf

88 *What makes my family stronger A report into what makes families with disabled children stronger – socially, emotionally and practically* http://www.cafamily.org.uk/pdfs/wmmfs.pdf

89 Desjardin, J.L. (2006) *Family Empowerment: Supporting Language Development in Young Children Who Are Deaf or Hard of Hearing* Volta Review;. 106 3, 275-298

90 Shields, J. (2001) *The NAS EarlyBird programme: partnerships with parents in early intervention.* Autism, 5 (1), 49-56

91 King,S., Teplicky, R., King, G., Rosenbaum, P. (2004) *Family-centered service for children with Cerebral Palsy and their families: a review of the literature.* Seminars in Pediatric Neurology 1(1): 78-86

92 http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/practitionersfamilies/familyviews/familyviews/

met. This is also the case where the child has communication difficulties, or where relationships with professionals are not good.[93] There are also benefits to be gained for families from support groups[94] specialising in SEN and SLCN. Families who contributed to the Bercow Review[95] of services for children with SLCN also wanted continuity of specialist support, especially when their children had complex needs.

Joined up multidisciplinary support

Multiagency working is very important for children with severe SLCN; families who contributed to the Bercow Review[96] often saw themselves as: "The unwitting victims of an incomprehensible relationship between health and education providers", especially when this led to delays or denials of the services their children need. The Bercow Review states that: "No single agency can deliver any one of the five Every Child Matters outcomes for children and young people by working in isolation.[97] This is particularly the case for children with severe SLCN, for example, a speech and language therapist and an occupational therapist may need to work closely together[98], especially when a child has eating and drinking difficulties.[99] Multidisciplinary teams can be very effective, costing no more than other models of service delivery, but increasing the participation of those they work for.[100] Where such teams involve parents in the design of services for children with complex needs, this can result in better services.[101]

In practice, achieving this collaboration can be difficult. Both special schools[102] and mainstream schools[103] often feel they don't get enough outside support; they would especially value more speech and language therapy. Collaboration is often easier to achieve in small multidisciplinary settings as in the case studies on page six, and it is a feature of outstanding special schools.[104] However there is evidence that in some multidisciplinary teams headed by medical consultants, therapists may be reluctant to contribute their views and that this might lead to a culture of conformity.[105] Effective inter-professional teams do not use jargon, continually share information and use a collaborative approach.[106] Developing such an effective team can strengthen the communication environment.[107]

93 Zaidman-Zait, A., Most, T. 2005 *Cochlear Implants in Children with Hearing Loss: Maternal Expectations and Impact on the Family.* Volta Review; 105 2, p129-150

94 Evans, A. (2003) *Empowering Families, Supporting Students Educational Leadership;* 61 I 2, 35-37,

95 *Bercow Review of Services for Children and Young people (0-19) with Speech, Language and Communication Needs Interim report* http://www.mkparents.org/gDocs/08.03.20%20-%20DCSF%20Interim%20Executive%20report%20on%20Services%20for%20CYP%20with%20SALCN.pdf

96 Lindsay, G., Desforges, M., Dockrell, J., Law, J., & Peacey, N. with Beecham, J. and Knap., M. *Bercow Review: The effective and efficient use of resources in services for CYP with SLCD– 2008* http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RW053.pdf

97 ibid

98 Francis, H. and Lloyd, J. (2008) *About a boy* Speech and Language Therapy in Practice Autumn 08

99 Logemann, J.A. 1994. *Multidisciplinary management of dysphagia.* Acta Oto-Rhinio-Laryngologica Belgica 48 (2): 235-38.

100 Bent, N., Tennant, A., Swift, T. et al. (2002) *Team approach versus ad hoc services for young people with physical disabilities: a retrospective cohort study.* The Lancet 360: 1280–6.

101 DH (2009) *Transforming Community Services & World Class Commissioning Resource Pack for Commissioners of Community Services.* p.60

102 Male, D.B. and Rayner, M.R. (2007) *Who goes to SLD schools? Aspects of policy and provision for pupils with profound and multiple learning difficulties who attend special schools in England* Support for Learning;. 22 3 145-152

103 *Bercow Review of Services for Children and Young people (0-19) with Speech, Language and Communication Needs Interim report* http://www.mkparents.org/gDocs/08.03.20%20-%20DCSF%20Interim%20Executive%20report%20on%20Services%20for%20CYP%20with%20SALCN.pdf

104 *Twelve outstanding special schools – Excelling through inclusion* (2009)http://www.dcsf.gov.uk/pns/DisplayPN.cgi?pn_id=2009_0170

105 Atwel, A., Calwell, K. *Do all health and social care professionals interact equally: a study of interactions in multidisciplinary teams in the United Kingdom 2005,* Scandinavian Journal of Caring Sciences; 19, 3, 268-273,

106 Sheehan, D., Robertson, L., Ormond, T. (2007) *Comparison of language used and patterns of communication in interprofessional and multidisciplinary teams* Journal of Interprofessional Care; 21 1, 17-30,

107 Dobson, S., Dodsworth, S., Miller, M. (2000) *Problem solving in small multidisciplinary teams: a means of improving the quality of the communication environment for people with profound learning disability* British Journal of Learning Disabilities; 28 1, 25-30

Children with severe SLCN

What services do children with severe SLCN need and how effective are they?

Appropriate support and learning opportunities

Where should children with severe SLCN learn?

In England, there is a statutory requirement for all schools to provide effective learning opportunities for all pupils[108] and children with special educational needs have a right to be within mainstream classrooms, accessing an appropriate curriculum.[109] Inclusion in mainstream school is also central to educational policy in Scotland[110], Northern Ireland[111] and Wales.[112] Many children with SEN make good academic and social progress in mainstream schools.[113] However; definitions of good progress for SEN learners are not yet robust, guidance about this has only recently been published.[114] There is some evidence that students with PMLD can be involved in more communicative interactions in mainstream rather than special educational classes.[115] In addition to this, at least one study has also found that children with disabilities were happier when interacting with typically developing children.[116] However a recent review of the literature found that there is little evidence overall for the positive effects of including children with SEN in mainstream schools.[117] Key factors for good progress for children with SEN in mainstream schools seem to be: "the involvement of a specialist teacher; good assessment; work tailored to challenge pupils sufficiently; and commitment from school leaders to ensure good progress for all pupils".[118]

Although it may be positive academically for children both with and without SEN to be in mainstream settings, it does seem to be the case that children with SEN have a less favourable social position than those without SEN in these settings.[119] Inclusion in mainstream school is not always what parents want either[120] and in Northern Ireland this is seen as a reason not to include a child in mainstream.[121] Children and young people themselves can be critical of both mainstream and special provision; more consultation with the children themselves may develop a more nuanced approach to inclusion.[122] Interestingly, one study on inclusion for children with ASD suggested that considering possible alternatives to mainstream schools increased the chances of successful integration.[123] It is also important to note here that many excluded children have SLCN[124] and this may be an indication that their special educational needs have not been recognised or met within a mainstream setting. We do not know whether this applies to children with severe SLCN.

Children with severe SLCN often need lots of specialist input to provide an effective learning environment, what is not clear is the extent to which this can best be provided – in specialist

108 QCA (2000) *'General statement for inclusion' in Curriculum 2000.* London: QCA.

109 SENDA (2001) Special Educational Needs and Disability Act 2001, HMSO

110 Curriculum for Excellence / Scottish Executive Education Department – Edinburgh: Scottish Executive Education Department (SEED), 2004

111 http://www.nicurriculum.org.uk/inclusion_and_SEN/SEN/pmld.asp

112 Inclusion and Pupil Support – Section 1 – Inclusive Education; Summary of guidance for schools; Annex 1.i: Checklist for LEAs; Annex 1.ii: Checklist for schools; Annex 1. iii: SEN and Disability Act 2001

113 Nind, M., Wearmouth, J., Collins, J., Hall, K., Rix, J., Sheehy, K. (2004) *A systematic review of pedagogical approaches that can effectively include children with special educational needs in mainstream classrooms with a particular focus on peer group interactive approaches. In: Research Evidence in Education Library.* London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.

114 http://nationalstrategies.standards.dcsf.gov.uk/node/190123

115 Foreman, P., Arthur-Kelly, M., Pascoe, S., & Smyth King, B. (2004). *Evaluating the educational experiences of students with profound and multiple disabilities in inclusive and segregated classroom settings: An Australian perspective.* Research and Practice for Persons with Severe Disabilities, 29(3), 183-193.

116 Logan, K.R., Jacobs, H.A., Gast, D.L., Murray, A.S., Daino, K., & Skala, C. (1998). *The impact of typical peers on the perceived happiness of students with profound multiple disabilities.* Journal of The Association for Persons with Severe Handicaps, 23(4), 309-318.

117 Lindsay, G. (2007) *Educational psychology and the effectiveness of inclusive education/mainstreaming* British Journal of Educational Psychology 77, 1–24

118 Ofsted 2006 *Inclusion: does it matter where pupils are taught? Provision and outcomes in different settings for pupils with learning difficulties and disabilities* HMI 2535

119 Ruijs, N.M., Peetsma, T.T.D. (2009) *Effects of Inclusion on Students with and without Special Educational Needs Reviewed* Educational Research Review, 4, 2, 67-79

120 Porfeli, E.J., Algozzine,B., Nutting, B., Queen, J.A. (2006) *Predictors of Parents' Inclusion Decisions* Journal of School Public Relations 27,. 1, 6-26,

121 Statutory Instrument 2005 No. 1117 (N.I. 6) *The Special Educational Needs and Disability (Northern Ireland) Order 2005* http://www.opsi.gov.uk/si/si2005/20051117.htm#3

122 Davis, J.M. & Watson, N. (2001) *Where Are the Children's Experiences? Analysing Social and Cultural Exclusion in 'Special' and 'Mainstream' Schools* Disability & Society, 16, 5, 671–687

123 Waddington, E .M., Reed, P. (2006) *Parents' and Local Education Authority Officers' Perceptions of the Factors Affecting the Success of Inclusion of Pupils with Autistic Spectrum Disorders* International Journal of Special Education 21, 3. 151-164

124 Ripley, K., Yuill, N. (2005) *Patterns of language impairment and behaviour in boys excluded from school* British Journal of Educational Psychology 75(1):37-50

or mainstream schools. The data on SEN in England[125] shows that children and young people with all sorts of SEN are educated in both mainstream and special schools, however this data doesn't allow for an analysis of how this relates to severe SLCN. It may be that relatively high functioning children benefit more from integrated settings, whereas those with more significant difficulties benefit more from specialist provision.[126] There is some evidence for positive outcomes for children and young people with SLI, who had attended a residential special school for children with SLI.[127] The degree of participation of children in mainstream schools seems to increase when they have relatively minor physical impairments and few communication or learning difficulties.[128] Many children with SLCN are educated in mainstream schools, but those with expressive language problems may be more likely to attend special schools for children with SLI or language units/resources, at least until they are eleven.[129] Nearly half of those who applied for a communication aid from the Communication Aid Project were at special schools and most had statements of SEN.[130]

I CAN undertook a project (funded through the Department of Children, Schools and Families' Children and Young People's Fund 2008-2009), whereby speech and language therapists and specialist teachers from a school for children with severe SLCN worked with staff in mainstream schools to support children with severe SLCN through consultation, staff training and individual contact with pupils. The outcomes were:

- Children achieved their individual speech, language and communication targets; became more confident and engaged in school; presented fewer behavioural challenges and appreciated the support they received.
- Parents were confident about the support their children had; they thought it appropriate that their children were supported in school and valued the training provided to school staff; they had concerns for their children in the future and wanted more help to enable them to better support their children.
- Mainstream school staff increased their understanding of Speech, Language and Communication Needs and developed more appropriate communication supportive environments and teaching strategies, benefiting all children, as well as appropriate support for individual children. They also became more aware of their own needs for continuing professional development in this area.

125 *Special Educational Needs in England, January 2009* DCSF Statistical first release SFR 14/2009

126 Mills, P.E., Cole, K.N., Jenkins, J.R. & Dale, P.S. (1998). *Effects of differing levels of inclusion on preschoolers with disabilities.* Exceptional Children, 65, 79-90

127 Carroll, C. and Dockrell, J. (2010) *Leaving Special School: Post-16 outcomes for young adults with Specific Language Impairment* European Journal of Special Needs Education

128 Schenker, R., Coster, W.J., Parush, S. (2005) *Neuroimpairments, activity performance, and participation in children with Cerebral Palsy mainstreamed in elementary schools* Developmental Medicine & Child Neurology,. 47/12(808-814)

129 Dockrell, J.E. and Lindsay, G. *Inclusion versus specialist provision for children with developmental language disorders* In C Frazier Norbury, JB Tomblin, and DVM Bishop (eds) *Understanding Developmental Language Disorders – From Theory to Practice* (2008) Pyschology Press

130 Wright,J., Clarke, M., Donlan, C., Lister, C., Newton, C., Cherguit, J., Newton, E. and Weatherly, H. (2004) *Evaluation of communication aid project Research report 580* Dfeshttp://www.dcsf.gov.uk/research/data/uploadfiles/RR580.pdf

Children with severe SLCN

What services do children with severe SLCN need and how effective are they?

A communication friendly environment

It is important to consider the child's communication strengths and needs in various contexts; similarly intervention is likely to be more effective in real and functional situations. A language focussed curriculum with targeted activities can benefit a wide range of children[131] in the early years. However, as there is little research to guide this work, it is important to have rigorous outcome measures for any kind of language intervention.[132]

It is possible to include children with SEN in mainstream classes, but in order to do this teachers benefit from being part of a 'pedagogic community'[133] where they can share ideas of how children learn best. As regards children with severe SLCN, an expert on SLCN should be included in this information sharing.[134] There are also resources to guide inclusion: 'Including Me'[135] is a guide for schools to help include children with significant additional needs. Communication passports for those with SLCN contain information which can help others understand the young person and therefore have more successful interactions.[136] This sort of information can also be held in computer based personal profiles.[137] There is also guidance on developing communication friendly spaces.[138] The Speech, Language and Communication Framework (SLCF)[139] helps staff identify their own competencies around speech, language and communication.

Special teaching approaches

Special schools are being asked to educate an increasing number of children with diverse and complex needs, which is a challenge both in terms of staffing and offering a broad and balanced curriculum.[140] There is a similar challenge for mainstream teachers in including those with SEN. It can be argued[141] that how children are taught is more important than the setting itself. There is guidance for teachers working with students with learning difficulties, which includes some information on SLCN.[142,143] However, children with severe SLCN are likely to need more than modifications to the curriculum and its delivery; they may need specialist approaches and significant differentiation.

Some specialist approaches for specific groups of children with severe SLCN have been shown to be effective, e.g. TEACCH for those with ASD.[144] Another is Intensive Interaction which involves quality one-to-one time between a teacher/support worker and the young person.[145,146] Information and Communication Technologies

131 Rice, M.L. and Hadley, P.A. (1995). Language outcomes of the language focused curriculum. In M. L. Rice and K. A. Wilcox (Eds.), Building a language-focused curriculum for the preschool classroom: A foundation for lifelong communication (pp. 155-169). Baltimore, MD: Brookes Publishing Co.

132 Lindsay, G., Dockrell, J.E. (2008) Language intervention in the school years: a systemic approach Revista de Logopedia, Foniatría y Audiología. 28,. 4, 207-217

133 Sheehy, K., Rix, J., Collins, J., Hall, K., Nind, M., Wearmouth, J. (2009) A systematic review of whole class, subject-based pedagogies with reported outcomes for the academic and social inclusion of pupils with special educational needs University of London. Institute of Education. Social Science Research Unit. Evidence for Policy and Practice Information and Co-ordinating Centre

134 Gascoigne, M. (2009) Supporting children with Speech, Language and Communication Needs: Implementing Bercow Afasic news, Winter

135 Carlin J Including Me: Managing complex health needs in schools and early years settings NCB http://w ww.ncb.org.uk/dotpdf/open_access_2/including_me.pdf

136 http://www.communicationpassports.org.uk/Home/

137 from mencap bercow submission www.acting-up.org.uk

138 http://archive.basic-skills.co.uk/sharingpractice/detail.php?SharingPracticeID=1424955579

139 www.communicationhelppoint.org.uk.

140 Male, D.B. and Rayner, M.R. (2007) Who goes to SLD schools? Aspects of policy and provision for pupils with profound and multiple learning difficulties who attend special schools in England Support for Learning 22 3 145-152

141 Dockrell, J.E. and Lindsay, G. Inclusion versus specialist provision for children with developmental language disorders In C Frazier Norbury, JB Tomblin, and DVM Bishop (eds) Understanding Developmental Language Disorders – From Theory to Practice (2008) Pyschology Press

142 QCA (2001a) Planning, teaching and assessing the curriculum for pupils with learning difficulties [range of documents relating to different curriculum subjects] QCA (2001b) Planning, teaching and assessing the curriculum for pupils with learning difficulties: Developing skills

143 Achievement for all working with children with special educational needs in mainstream schools and colleges Association of Teachers and Lecturers http://www.atl.org.uk/Images/Achievement%20for%20all.pdf

144 Panerai, S., Ferrante, L. and Zingale, M. (2002) Benefits of the treatment and education of autistic and communication handicapped children (TEACCH) programme as compared with a non-specific approach. Journal of Intellectual Disability Research 46 (4), 318-327.

145 www.intensiveinteraction.co.uk

146 Caldwell, P. (2006) Speaking the other's language: imitation as a gateway to relationship Infant and Child Development; 15 Issue: 3 275-282,

(ICT) can benefit students with PMLD, but there may be practical difficulties in implementing them.[147] Visual approaches to supplement spoken language can also be valuable.[148] For example, Talking Mats, which uses small groups of symbols.[149] There is mixed evidence for multisensory environments, (where young people are given the opportunity to control various sensory stimuli) as some show that they are no more stimulating than other interactions[150], whilst others show benefits.[151] The Picture Exchange Communication System (PECS) (which uses symbols in an interactive context) has been shown to have modest effects on increasing the initiation of interactions and symbol use in children with Autism, although these effects did not persist once the intervention stopped.[152]

Therefore children with severe SLCN not only require specialist teaching approaches, but these need to be ongoing and responsive to the changing needs of children.

Alternative communication systems/Special equipment

Some children with severe SLCN need additional tools to help them understand language and to communicate. This can include signing, pictorial systems and highly technical devices. These extra supports are known as Augmentative and Alternative Communication (AAC). Even for those who have no comprehension of language, pictures and pictograms can be useful communicative tools.[153] Some children and young people need special equipment to provide them with a 'voice', which can then help them access more social opportunities and increase their independence and self esteem.[154] Highly technical devices such as voice output communication aids and even 'low tech' aids such as the Picture Exchange Communication System can be expensive, and finding the appropriate expert advice to help with their selection and use can also be problematic.[155] However, they make a significant difference to a child's quality of life.

"Without my communication aid I can't say what is in my heart and in my head."[156]

Providing very specialist AAC services for a relatively small number of children has proved problematic, and services have often been: "fragmented and inconsistent across geographical areas".[157] As part of the Better Communication

147 Ware, J and Thorpe, P. (2007) Assessing and teaching children at the early stages of development. Combining psychology and ICT: an evaluation of a short inservice course for teachers of pupils with PMLD Support for Learning 22 3, 131-136

148 McConnell, S. (2002) Interventions to facilitate social interaction for young children with Autism: review of available research and recommendations for educational intervention and future research Journal of Autism and Developmental Disorders 32 (5), 351-372.

149 Murphy, M. and Cameron, L. (2008) The effectiveness of Talking Mats® with people with intellectual disability British Journal of Learning Disabilities;. 36 4 p232-241

150 Vlaskamp, C., de Geeter, K.I., Huijsmans, L.M., Smit, I.H. (2003) Passive Activities: the Effectiveness of Multisensory Environments on the Level of Activity of Individuals with Profound Multiple Disabilities. Journal of Applied Research in Intellectual Disabilities, 16(2), 135-143.

151 Lindsay, W.R., Pitcaithly, D., Geelen, N., Buntin, L,. Broxholme, S., Ashby, M.(1997) A comparison of the effects of four therapy procedures on concentration and responsiveness in people with profound learning disabilities Journal of Intellectual Disability Research 41 3 201-207,

152 Howlin, P., Gordon, R.K., Pasco, G., Wade, A. and Charman, T. (2009) The effectiveness of Picture Exchange Communication System (PECS) training for teachers of children with Autism: a pragmatic, group randomised controlled trial Research in Autism Spectrum Disorders 3, 1, 98-112

153 Tetzchner, S., Ovreeide, K., Jorgensen, K., Ormhaug, B., Oxholm, B., Warme, R. (2004) Acquisition of graphic communication by a young girl without comprehension of spoken language Disability and Rehabilitation 26/21-22

154 Sloper, P., Rabiee, P. and Beresford, B. (2007) Outcomes for Disabled Children, Research Works, 2007–02, Social Policy Research Unit, University of York York

155 Newton, C., Wright, J.A., Clarke, M., Donlan, C., Lister, C., Cherguit, J. (2006) Supporting children with communication aids in transition: the perspective of children and adults involved with the Communication Aids Project (CAP) Support for Learning 21 3, 141-148

156 Communication Aids Survey respondent, 2007

157 Bush, M., Abigail, A. and Scott, R. 2008 No Voice, No Choice: Professional experiences of the provision and support of Alternative and Augmentative Communication (AAC) Full report Scope

Children with severe SLCN

What services do children with severe SLCN need and how effective are they?

Action Plan[158] is producing a review on the Communication Champion effectiveness of AAC provision in local areas. The Scottish Government has accepted recommendations from the Scottish Government's Short Life Working Group on AAC. However, the schedule of implementation of recommendations remains to be confirmed.

Support with transitions, between schools and into adulthood

Support for children with severe SLCN might be difficult to access as they get older and move towards adult services[159], this is certainly the case for other children and young people with SLCN.[160] In addition to this, pupils with behaviour problems, SLD, ASD and PMLD – all groups of young people who may also have severe SLCN – have been found to have more difficult transitions than other SEN groups.[161,162] Disabled young people's ambitions for the future are the same as their peers, until they reach adulthood.[163] Often their aspirations for the future are thwarted because the support they need is no longer available[164] or difficult to find. Unsurprisingly, there is evidence for the benefits of early and careful transition planning for children with complex health needs.[165] Guidance on transition planning is available[166] which includes reference to communication needs. Ideally a transition plan should be developed by the young person with the support of a multidisciplinary team. In order to help children with transitions to adult life in England, The National Transition Support Team has been set up.[167]

Settings and schools with a skilled workforce

Following on from the Bercow Review, the Better Communication Action Plan[168] states, "All professionals working with children should support the development of all children's speech, language and communication skills". [169] There is online training available,[170] however there are additional challenges when working with children with severe SLCN. Nonetheless, everyone who works with a child with severe SLCN, or who regularly comes into contact with them, including health professionals,[171] should have the skills to understand and use the child's preferred means of communication.[172] Similarly everyone needs to know about how to help a child use augmentative and alternative communication (AAC) if appropriate and also how to encourage natural interaction and communication[173] even if a child is non-verbal.[174] Language development is likely to be enhanced through developing the interaction styles of the adults[175], and this can be successfully

158 *Better Communication An action plan to improve services for children and young people with Speech, Language and Communication Needs http://www.dcsf.gov.uk/slcnaction/downloads/Better_Communication_Final.pdf*

159 *http://www.ace-centre.org.uk/index.cfm?pageid=27B06FF3-3048-7290-FE6766A6FFF93C96*

160 *Ayre, A. & Roulstone, S. (2009) Transition to secondary school: supporting pupils with Speech, Language and Communication Needs Report to The Communication Trust*

161 *Polat, F., Kalambouka, A., Boyle, W. and Nelson, N. (2001) Post-16 transitions of pupils with special educational needs DfES research report 315*

162 *http://www.Autism.org.uk/content/1/c6/01/97/89/NAS0171_APPGA_book_A4_24pp_Web2.pdf*

163 *Burchardt, T. (2005) The education and employment of disabled young people: Frustrated ambition. York: Joseph Rowntree Foundation, Policy Press.*

164 *Ko, B. and McEnery, G. (2004) The needs of physically disabled young people during transition to adult services. Child: Care, Health and Development 30(4): 317–23.*

165 *Association for Children's Palliative Care (2007) The Transition Care Pathway: a framework for the development of integrated multi-agency care pathways for young people with life threatening and life-limiting conditions. Bristol: ACT.*

166 *Transition: moving on well A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (2008) DH Partnerships for Children, Families and Maternity/ CNO Directorate http://www.bacdis.org.uk/publications/transition_moving-on-well.pdf*

167 *http://www.transitionsupportprogramme.org.uk/*

168 *Department for Children, Schools and Families (2008b) Better Communication: An Action Plan to Improve Services for Children and Young People with Speech, Language and Communication Needs. www.dcsf.gov.uk/slcnaction*

169 *Fraser, H. (1998) Early Intervention: key issues from research. Edinburgh: The Scottish Office Education and Industry Department*

170 *The Inclusion Development Programme http://nationalstrategies.standards.dcsf.gov.uk/node/165381*

171 *Aiming high for disabled children: delivering improved health services http://www.nhsconfed.org/Publications/Documents/aiming_high_sep09.pdf*

172 *Sloper, P., Rabiee, P. and Beresford, B. (2007) Outcomes for Disabled Children, Research Works, 2007–02, Social Policy Research Unit, University of York York*

173 *Pennington, L., McConachie, H. (2001) Predicting patterns of interaction between children with Cerebral Palsy and their mothers Developmental Medicine and Child Neurology 43 2 83-9*

174 *Mitchell, W., Franklin, A., Greco, V., Bell, M. (2009) Working with children with learning disabilities and/or who communicate non-verbally: Research experiences and their implications for social work education, increased participation and social inclusion Social Work Education, 28(3), 309-324*

175 *Pennington L.; McConachie H (1999) Mother-child interaction revisited: communication with non-speaking physically disabled children International Journal of Language & Communication Disorders, Volume 34, Number 4, 1*

achieved using video techniques.[176]

Teaching assistants can play a key role in the inclusion of children with severe or profound learning difficulties[177] but crucially they need to be well trained in order to do this.[178] However, the role of teaching assistants is not always well supported and sometimes the time they spend with pupils with special needs means less time is available from qualified teachers.[179] A recent survey of special schools concluded that there was not enough specialist training available for teachers.[180] Currently some communication training is available, but it is not resourced or prioritised to be as effective as it might be[181] and does not always include those who spend the most time with children.[182] Nonetheless, support for mainstream schools is available from specialist schools for SLCN in some areas and is a feature of outstanding special schools.[183]

Speech and language therapy

Speech and language therapy is valued by parents and they see the difference it makes to their children.[184] However, the effectiveness of different speech and language therapy approaches for severe SLCN is under researched and there is little evidence about what works best. For other groups of children with SLCN there does seem to be a dosage effect, in that intensive work has been shown to be effective[185] while short interventions are less effective.[186] This may be particularly relevant to those with severe SLCN; pre-school children with SLI made significant improvements when they had direct intensive group speech and language therapy as opposed to those who had a less intensive consultative intervention.[187] This research also highlights the value of early intervention. It also seems to be the case that progress does not continue after intensive speech and language therapy stops.[188]

Although there is evidence for the effectiveness of speech and language therapy in helping children develop their expressive language, there is less for effective interventions for those with problems understanding language.[189] For children with severe and persisting language impairment (some of whom might be considered to have severe SLCN), a model of speech and language therapists (SLTs) working through school staff has been shown to be less effective than when specific targeted interventions, directed by an SLT, take place.[190] There is also a lack of good intervention studies to guide support for childhood

176 Anderson, C. (2006). *Early communication strategies: using video analysis to support teachers working with preverbal pupils.* British Journal of Special Education, 33(3), 114-120.

177 Lacey, P. (2001) *The Role of Learning Support Assistants in the Inclusive Learning of Pupils with Severe and Profound Learning Difficulties.* Educational Review; 53 2, 157-167

178 Blatchford, P., Bassett, P., Brown, P., Martin, C., Russell, A. and Webster R. (2009) *Deployment and impact of support staff project* Institute of Education, University of London

179 ibid

180 Male, D.B. and Rayner, M.R. (2007) *Who goes to SLD schools? Aspects of policy and provision for pupils with profound and multiple learning difficulties who attend special schools in England* Support for Learning; 22 3 145-152

181 Health professional, PMLD Network questionnaire 2006

182 Aird, R. 2000 *The case for specialist training for learning support assistants employed in schools for children with severe, profound and multiple learning* Support for Learning, 15(3), 106-110

183 Twelve outstanding special schools – Excelling through inclusion (2009)http://www.dcsf.gov.uk/pns/DisplayPN.cgi?pn_id=2009_0170

184 *Bercow Review of Services for Children and Young people (0-19) with Speech, Language and Communication Needs Interim report* http://www.mkparents.org/gDocs/08.03.20%20-%20DCSF%20Interim%20Executive%20report%20on%20Services%20for%20CYP%20with%20SALCN.pdf

185 Adams, C. (2007) *The effects of speech and language therapy intervention on children with pragmatic language impairments in mainstream school* British Journal of Special Education 34 Issue: 4 226-233

186 Law, J. (2000) *Treating children with speech and language impairments: Six hours of therapy is not enough,* BMJ4; 321(7266): 908–909.

187 Gallagher, A.L. and Chiat, S. (2009) *Evaluations of speech and language therapy interventions for pre-school children with specific language impairment: a comparison of outcomes following specialist intensive, nursery-based and no intervention.* International Journal of Language and Communication Disorders 44 5 616-638

188 Boyle, J.M., McCartney, E., O'Hare, and Forbes, J. (2009) *Direct versus indirect and individual versus group modes of language therapy for children with primary language impairment: principal outcomes from a randomised controlled trial and economic evaluation* International Journal of Language and Communication Disorders 44 6 826-846

189 Law, J., Garrett, Z., Nye, C. *Speech and language therapy interventions for children with primary speech and language delay or disorder* Cochrane Database of Systematic Reviews 2003, Issue 3. Art. No.: CD004110. DOI: 10.1002/14651858.CD004110

190 McCartney, E., Ellis, S. and Boyle, J. (2009) *The mainstream primary classroom as a language-learning environment for children with severe and persistent language impairment – implications of recent language intervention research* Journal of Research in Special Educational Needs 9 2 80 -90

apraxia of speech.[191] However there is emerging evidence for successful intervention for children with dysarthria[192] and Cerebral Palsy[193] although more research is necessary to strengthen the evidence base for this.[194]

What do children and young people with severe SLCN want?

It is important to include children and young people in decisions about support services because this can extend our understanding of their difficulties[195]; it helps to develop more appropriate services and reflects good practice.[196] However, this does require a flexible use of approaches to enable them to express their views[197], especially when children and young people have severe SLCN. In a recent survey[198] only half of schools that took part involved children with little or no speech in decisions about their education. A recent review of adolescents who had attended language units[199] found that the young people had a mostly positive view of their experiences. Although it is unclear how many of them had severe SLCN, many continued to need support in adolescence with their language difficulties, confidence and self-esteem.

191 *Morgan, A.T., Vogel, A.P. Intervention for childhood apraxia of speech Cochrane Database of Systematic Reviews 2008, Issue 3. Art. No.CD006278. DOI: 10.1002/14651858.CD006278.pub2*

192 *Pennington, L., Smallman, C., Farrier, F. 2006 Intensive dysarthria therapy for older children with Cerebral Palsy: findings from six cases. Child Language Teaching and Therapy 22, 3, p. 255-273,*

193 *Pennington, L., Goldbart, J., Marshall, J. (2005) Direct speech and language therapy for children with Cerebral Palsy: Findings from a systematic review. Social Policy and Practice Developmental Medicine and Child Neurology, .47, .1 57-63.*

194 *Pennington, L., Goldbart, J., Marshall, J. Speech and language therapy to improve the communication skills of children with Cerebral Palsy. Cochrane Database of Systematic Reviews 2003, Issue 3. Art. No.: CD003466. DOI: 10.1002/14651858. CD003466.pub2*

195 *Porter, J., Harry, H., Georgeson, J., Hacker, J., Gallop, V., Feiler, A., Tarleton, B. and Watson, D. (2008) Disability Data Collection for Children's Services Research Report No DCSF-RR062*

196 *National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs (Standard 8): marker of good practice 6*

197 *Lewis, A., Robertson, C. and Parsons, S. (2005). Experiences of Disabled Students and their Families. Phase 1. Research report to Disability Rights Commission, Birmingham: University of Birmingham, School of Education. http://83.137.212.42/sitearchive/DRC/library/research/education/experiences_of_disabled.html*

198 *Watson, D., Tarleton, B., Feiler, A. PARTICIPATION IN EDUCATION (PIE) 1 Full report on the findings from research on the involvement of children with little or no verbal communication NHS Evidence – Patient and Public Involvement Specialist Collection – Publisher: Norah Fry Research Centre*

199 *Simkin, Z. and Conti-ramsden, G. (2009) 'I went to a language unit' Adolescents' views on specialist educational provision and their language difficulties Child Language Teaching and Therapy 25 1 103-122*

Conclusion

Disabled children and their parents would argue that alongside physical and emotional well being and personal safety, **communication should be considered as a fundamental desired outcome**.[200] Children with severe SLCN are a 'low incidence/high needs' group and the following issues are key to them fulfilling their potential:

- **Children with severe SLCN need to be recognised as a group so their needs can be met.** This group may include children with SLI, PMLD or profound deafness. There is also an urgent need for more research into effective interventions for young people with severe SLCN.
- **Their functional communication needs should be considered and met regardless of diagnosis.**
  In order to support their communication development, we need to characterise their various strengths and needs rather than attempt to identify a primary need.

  Notwithstanding other diagnoses or needs, the child's SLCN should be fully assessed and addressed.

  It is probably more appropriate to make decisions about intervention based on the nature of the SLCN, and the young person's response to intervention rather than their non-verbal ability.
- **There is a need for training and support for those who work with children with severe SLCN**, as well as a continued need to work towards equity of access to services and support. The development of best practice guidelines would support this.

Best practice guidelines for children with severe SLCN.

These could be developed along the lines of 'In it together', a best practice guide to commissioning care and education for children with complex needs.[201]

The discussion and analysis in this paper would support the inclusion of the following points:

- Information and support should be easily accessible to families at every stage of their child's development.
- Children and their families should be involved in informed decision making about the services they require and the development of services to meet their needs.
- Access to specialist multidisciplinary services for initial assessment planning and ongoing support, especially through transitions. This could include access to staff from specialist provision, perhaps in an advisory role, even if the child attends a mainstream school.
- Wherever the child or young person goes to school they should have access to communication supportive environments including skilled adults, specialist approaches and equipment, where necessary.
- At a strategic level, The Better Communication Action Plan[202] aims to help commissioners plan specialist services, based on local needs and evidence of what works. This should clearly and specifically involve those with severe SLCN. Effective regional and national commissioning arrangements should be put in place for children with severe SLCN as they are a low incidence/high needs group.

200 *Sloper, P., Rabiee, P. and Beresford, B. (2007) Outcomes for Disabled Children, Research Works, 2007–02, Social Policy Research Unit, University of York York*

201 *In it together: achieving quality outcomes for young people with complex needs. Best practice examples of partnership working between local authority commissioners and providers of care and education services for children with complex and challenging needs. http://www.lga.gov.uk/lga/aio/4070185*

202 *Department for Children, Schools and Families (2008b) Better Communication: An Action Plan to Improve Services for Children and Young People with Speech, Language and Communication Needs. www.dcsf.gov.uk/slcnaction*

Children with severe SLCN

Glossary

AAC Augmentative and Alternative communication.

Angelman syndrome symptoms of Angelman syndrome include developmental delay, lack of speech, seizures, and walking and balance difficulties.

Apraxia is used to describe complete loss of the ability to coordinate and perform certain purposeful movements and gestures in the absence of motor or sensory impairments. It is sometimes used interchangeably with dyspraxia.

Autistic Spectrum Disorders (Also known as Autistic Spectrum Condition) these are lifelong difficulties which affect the way a person communicates and relates to others. The problems a person with ASD faces affect social interaction and communication and thinking might be rigid, behaviour repetitive and there is often a narrowing of interests. The spectrum includes people with the diagnosis of Autism and Asperger syndrome. People with Asperger syndrome generally have fewer problems with communication than those with Autism.

BESD Behavioural emotional and social difficulties.

Bliss Symbolics is a symbolic, graphical language that is currently composed of over 3,000 symbols.

CP Cerebral Palsy. This term covers a number of neurological disorders that permanently affect movement or co-ordination. Most children who have this are born with it although it may not be detected at birth.

CSN Communication Support Needs.

Cued articulation is a set of hand cues used to teach the individual sounds in words.

Developmental language disorder describes children who fail to acquire their native language at the typical rate, for no obvious reason. Used in C Frazier Norbury, JB Tomblin, and DEVM Bishop (eds) Understanding Developmental Language Disorders.

Dysarthria occurs when there is a weakness or lack of co-ordination of the speech muscles which can make speech slow, slurred, imprecise and therefore difficult to understand. There might also be difficulties with breathing for speaking, voice quality and nasality.

Dyspraxia is a difficulty with planning a sequence of coordinated movements which can affect speech. This is also known as Developmental Verbal Dyspraxia. There might be difficulties with making speech sounds and sequencing sounds and words appropriately.

Language disorder describes when the child's language achievement results in an unacceptable risk of undesirable outcomes. (Bruce Tomblin)

Landau-Kleffner syndrome is very rare, children who experience it lose their language skills and may also have seizures.

PMLD Profound and Multiple Learning Difficulties

SEN Special Educational Needs

SLD Severe Learning Difficulty

SLI Specific Language Impairment describes when the language impairment is disproportionate to other areas of development including non-verbal ability, although these children often have associated difficulties with motor skills, cognition and attention.[203]

SSLD Specific Speech and Language Difficulties a primary language problem unattributed to moderate learning difficulties, severe or profound hearing loss or lack of linguistic opportunity.[204]

SLCN Speech, Language and Communication Needs.

Worster Drought is a type of Cerebral Palsy where the main difficulties occur in the mouth, tongue and swallowing muscles.

203 *Hill, E.L. 2001 Non specific nature of specific language impairment; A review of the literature with regard to concomitant motor impairments. International Journal of Language and Communication Disorders 36 149-171*

204 *Dockrell, J. E. & Lindsay, G. (2008) 'Inclusion versus specialist provision: Ideology versus evidence based practice for children with language and communication difficulties' In Eds C. Norbury, B. Tomblin & D.V.M. Bishop., Understanding Developmental Language Disorders. Psychology Press.*

Children with severe SLCN

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I CAN Talk is a series of reports exploring contemporary issues in children's speech, language and communication. *I CAN Talk* reports review current research and literature and offer practical evidence based solutions to inform debate on speech and language and to support practitioners, parents and policy makers.

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