SCOTTISH EXECUTIVE

Communication Support Needs: a Review of the Literature

Social Justice

social research

COMMUNICATION SUPPORT NEEDS
A REVIEW OF THE LITERATURE

Professor James Law
Centre for Integrated Healthcare Research, Queen Margaret University, Edinburgh

Dr Anna van der Gaag
Honorary Research Fellow, Section of Psychological Medicine,
University of Glasgow

Professor Bill Hardcastle
Speech and Hearing Sciences, Queen Margaret University, Edinburgh

Dr Janet Beck
Speech and Hearing Sciences, Queen Margaret University, Edinburgh

Andrew MacGregor
Scottish Centre for Social Research, Edinburgh

Charlene Plunkett
Centre for Integrated Healthcare Research, Queen Margaret University, Edinburgh

Scottish Executive Social Research

2007

Further copies of this report are available priced £5.00. Cheques should be made payable to Blackwell's Bookshop and addressed to:

Blackwell's Bookshop
53 South Bridge
Edinburgh
EH1 1YS

Telephone orders and enquiries
0131 622 8283 or
0131 622 8258

Fax orders
0131 557 8149

Email orders
business.edinburgh@blackwell.co.uk

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ACKNOWLEDGEMENTS

We would like to express our thanks to members of the team from the Social Justice (Equalities) Research team and the Equality Unit in the Scottish Executive

- Dharshi Santhakumaran
- Graeme Bryce
- Catherine Bissett
- Leyla Charlaff

We would like to thank members of our reference group

Including the Communication Impairment Action Group (CIAG)

- Mary Turnbull
- Kim Hartley
- Christine Malcolm
- Nancy Little
- Anne Edmonstone

And finally we would like to thank those who contributed to the discussion by reading versions of the document at different stages in the process

- Dr Stuart Aitken, Principal Officer (Research and Practice) with Sense Scotland and Senior Research Fellow with the CALL Centre, University of Edinburgh.
- Professor Susan Balandin, NHMRC Senior Research Fellow, Director of Disability Initiative, Faculty of Health Sciences, University of Sydney.
- Sally Millar, Senior Research Fellow/Joint Coordinator, CALL Centre, University of Edinburgh
- Dr Susie Parr, Freelance Communication Consultant

EXECUTIVE SUMMARY

BACKGROUND

Communication allows us to express ourselves and to have our needs met, it affects the way in which we form our relationships, negotiate the classroom, get through interviews, hold down a job and interact with our families. Although most of us may experience slight difficulties with aspects of our communication when we are nervous or when we forget things, the fact is that we tend to take communication for granted and pay it relatively little attention. It is just something that we do like walking or eating.

However, there is a sizeable group of people, both children and adults, who experience difficulties expressing themselves and understanding others, such that it affects everyday functioning. These people are variously described according to the perceived cause of their impairment, for example from stroke or learning disability, or in terms of the specific nature of the difficulty that they experience, such as expressive language disorder or stammer. What they all have in common is some level of communication support need (CSN). This review addresses the needs of this broad group of people and their ability to access a range of services.

It is difficult to be precise about the number of people falling within this group but, taking together referral data to speech and language therapists and the more conservative prevalence estimates, we would anticipate that there would be between 1 and 2 % of the population at any one time with such severe communication support needs that they need specific assistance in order to have their needs met. There is a much larger group, perhaps up to 20% of the population, who may experience some difficulties with communication at some point in their lives relative to the population as a whole. Although these figures are drawn from a number of sources and refer to a number of different countries it is reasonable to assume that they will be true for Scotland as they are for other countries.

One of the key features of this group is that, unlike those with more visible disabilities, their difficulties are less apparent and less easily recognised by the public. It is often difficult for the general public and service providers, when interacting with people with CSN, to appreciate the nature of their experiences, and this can lead to false assumptions about the person's disposition, intelligence and mental health. Associated with this is the inherent difficulty that many people with CSN have experienced lobbying for their needs within the political system. All too often they have to rely on the intermediary role of those in the voluntary sector and others who speak on their behalf.

THE REVIEW

Recent policy within Scotland has focused on a commitment towards a more comprehensive provision of services that meets the needs of individuals with communication support needs. This provision should be informed by robust research that links the needs and experiences of this group with policies underpinning service delivery. It was felt by the Scottish Executive that policy with regard to CSN at the time that the present project was commissioned lacked coherence. Therefore a literature review of communication support needs across all public sector services was commissioned by the Scottish Executive in 2006. This review explores how people with CSN engage with services. The review is set within the context of the Education (Additional Support for Learning) (Scotland) Act (2004) and the Adults with Incapacity (Scotland) Act (2000) in Scotland. The Education (Additional Support for

Learning) (Scotland) Act (2004) requires that extra provision should be put in place for children and young people who have additional support needs because of a variety of reasons such as bullying or behavioural problems, in order for them to fully benefit from the education system. Under this Act education authorities are responsible for identifying and meeting the needs of these children and young people. Other agencies such as health and social work will assist the local education authority in providing coordinated support plans to overcome their barriers to learning and accessing services. Coordinated support plans are long term strategies involving various agencies to ensure that the child or young person achieves their learning objectives and enables them to move smoothly through transitions periods such as leaving school. This legislation has specific implications for children with communication support needs and their management within the classroom. The Adults with Incapacity (Scotland) Act (2000) allows other people to make decisions regarding the finances and property of adults who have poor mental health or communication skills when these adversely affect their decision making skills. Under the act, all decisions made on behalf of the adult with impaired capacity must benefit the adult by taking on board the adult's wishes and desires or those of their primary care giver or nearest relative. Any decisions made should promote the use of existing skills or growth of new skills without imposing too many boundaries on the individual's freedom. Again at the root of this legislation is the need for the individual to communicate their intention and those with communication support needs are, by definition, likely to experience particular difficulties in this area.

The aims of the review are:

- ☐ to identify literature which illuminates the experiences of people with communication support needs,
- ☐ to identify the barriers that people with communication support needs experience in society and ways in which it is possible to overcome these barriers
- ☐ to identify gaps in the available literature
- ☐ to make specific recommendations for a programme of research addressing issues arising out of the literature.

The review is based on a systematic review of the literature carried out using electronic data bases, a search of relevant websites and information provided by people working with people with communication support needs (practitioners, academics and members of the voluntary sector). The resulting documents come from a wide variety of sources.

FINDINGS

The findings from the review are organised into a number of areas reflecting the experiences of people with CSN. Those with a reasonable level of information include health and social care, education, employment, and criminal justice. Those with less, but nonetheless relevant, information include housing, travel and self expression and leisure.

There is evidence that healthcare, education, criminal justice, financial and social services are failing to meet the specific needs of people with CSN. People with CSN are likely to be disadvantaged on a number of fronts. By comparison with the general population they are more likely:

- ☐ to be unemployed or employed at an inappropriately low level
- ☐ to experience negative social interactions/communication within education, health care, criminal justice system, etc.

- to be misjudged in terms of cognitive and educational level
- to be victims of crime
- to be convicted of crime
- to have difficulty accessing information required in order to utilise services
- to live in socially deprived areas.

The specialised terminology and forms of language associated with health, criminal justice, financial services, etc. may be especially problematic for people with CSN. Particular difficulties are associated with transitions within and between services, where individuals with CSN face increased communication demands with unfamiliar people.

Awareness and understanding of CSN is limited amongst both professionals and the general public. There is a need for more training and education aimed at increasing awareness and understanding of CSN, promoting good practice in facilitating effective communication and challenging negative stereotypes and attitudes. A number of initiatives have shown positive results in improving the ability of people with CSN to access and benefit from services, but these tend to be localised geographically and linked to small parts of a single service.

Specific problems experienced by people with CSN and some solutions to these problems in the areas covered by the review as follows:

Health and social care

Problems identified

- Healthcare services are still failing to meet the needs of individuals with CSN.
- In spite of initiatives to improve the communication skills of healthcare staff, their knowledge and understanding of CSN may be limited; e.g, communication difficulty may be misinterpreted as a sign of limited intellectual function.
- Poor communication between healthcare staff and people with CSN may compromise accurate diagnosis and effective treatment. The specific vocabulary required to describe and understand symptoms and illness may be unavailable to people with CSN.
- There is an over-dependence on carers to report symptoms and perceptions of individuals with CSN.

Potential for improvement

- All staff working in healthcare would benefit from communication training which fosters awareness and understanding of the needs of CSN individuals.
- Simple changes to the physical environment may improve communication between people with CSN and their healthcare staff.
- All healthcare contexts (i.e. hospitals, residential, home settings etc) and all aspects of service delivery (including written correspondence and instructions) could be improved by being considered in relation to CSN.
- A few initiatives are already under way that are focussing on developing the knowledge and skills of service providers. Some have very specific service users in mind (eg. the SENSE toolkit) whereas others are working towards opening up communication access to services for people with a variety of communication issues (eg. The Communication Access Toolkit).

Education

Problems identified

- Many children with CSN are subject to bullying. Adults report negative interactions with school peers and teaching staff which impact on their adult lives.
- Children who rely on AAC technology (artificial speech aids) often have negative attitudes towards this mode of communication. Their difficulties increase in secondary school and beyond, due to multiple teaching and communication styles.
- Although access to further education for people with CSN has improved, some barriers still remain and transitions to higher education are difficult.

Potential for improvement

- Full integration within the education system requires measures to promote awareness and understanding of CSN amongst staff, peers and the public.
- Managing the needs of children and their families can be improved though collaborative goal setting between professionals from different disciplines.
- Children should be included in decision making about their CSN; e.g, children using AAC may choose to adopt more accepted means of communication technology eg. text messages or email.
- All relevant staff should be familiarised with the child's communication needs and style of communication in order to adapt accordingly.
- AAC users need ongoing support as they move through the education system.

Employment

Problems identified

- Although employers may report positive attitudes towards employing people with CSN, these people are still more likely to be unemployed or employed at levels below their education status, and may be at a disadvantage for promotion opportunities.
- Even supportive employers may lack understanding of CSN and make only limited adjustments, leading to a gradual withdrawal of people with CSN from the workforce.
- Common employment barriers for people with CSN are noise, tasks requiring speed, speaking to groups of people, attitudes of others and their knowledge about communication difficulties.
- Employment experiences of families and carers of people with CSN may also be affected, e.g. parents of children with CSN may have difficulty in finding suitable childcare.

Potential for improvement

- The mechanisms and policies which are already in place to help people with physical disabilities get into the workplace could be extended to address the specific needs of people with CSN.
- The use of "social networks" may be useful in helping some groups of people with CSN into employment.
- Many of the barriers mentioned above can be removed through the use of relatively straightforward low cost adaptations.

Criminal Justice

Problems identified

- A high proportion of individuals in young offenders institutions have communication difficulties.
- Individuals with disabilities are more likely to be victims of crime.
- The court tradition of oral argument automatically places individuals with CSN at a disadvantage.
- The formality and complexity of language used in interview and court contexts may place excessive demands on people with CSN. As a result, they may be unable to provide necessary information and/or be misrepresented as uncooperative.

Potential for improvement

- Individuals with CSN can provide reliable testimonies if suitable adaptations can be made. Professionals need specialised training in recognising and meeting the needs of people with CSN in order to communicate appropriately and to avoid underestimating or overestimating their capabilities.
- Some people with CSN may benefit from the 'Appropriate Adult Scheme', where a professional such as a speech and language therapist facilitates communication at each stage of the legal process.
- Preliminary reports indicate potential benefits of speech and language therapy provision for young offenders.

GAPS IN THE LITERATURE

There are a number of prominent gaps in the literature. Discussion with the project reference group identified a number of key areas where literature is limited.

- Public awareness and understanding of communication disability and public attitudes towards people with communication support needs;
- The costs of communication support needs to the individual and to society as a whole;
- The relative value of an enhanced "communication accessible" model of service delivery across sectors;
- Specific gaps in the evidence base related to aspects of service delivery include:
    - Children and young people's experience of CSN within the educational context;
    - Transition periods and attitudes of criminal justice professionals;
    - Attitudes of criminal justice professionals;
    - Housing (problems identified include limited choice, lack of privacy, abuse and exploitation, increased probability of social deprivation);
    - Travel (problems identified include difficulty accessing and understanding information, negative attitudes, anxiety associated with crowding);
    - Leisure (problems identified include that the communication demands of some leisure activities inhibit involvement by people with CSN, limited availability of appropriate group activities);
    - Financial services (problems identified include communication demands associated with complex documentation when accessing services/benefits, staff may lack appropriate training).

CONCLUSION AND RECOMMENDATIONS FOR FURTHER RESEARCH

Communication support needs must be seen within the broader disability rights framework. Under the Disability Discrimination Act (1995) all service providers have a duty to provide a "reasonable adjustment" to enable a disabled person to access their services. This refers not only to making changes to the physical environment (producing ramps etc.) but also to adapting the ways that services are delivered. The latter has a direct consequence for people with CSN who, as the literature indicates, experience considerable difficulties in accessing the services that they need.

We conclude that there are three lines of enquiry or "research strands" which have the potential to make a substantive contribution to the field and fill gaps in the overall knowledge base associated with CSN. In each case it is proposed that a group of people with communication support needs be instrumental in setting up and monitoring the project.

Study 1. Expectations and improvements for service users with Communication Support needs

The literature, by its nature, reports specific aspects of the experiences of subgroups of people with CSN, for example the health needs of people with aphasia following stroke. It is proposed that a study be set up to obtain a comprehensive picture of experiences of the full range of services of the full range of people with CSN. In order to map different levels of need across groups it is proposed that such a study should make use of a single scale of "need" which would help provide a snapshot of current need in Scotland. The aim of such a study would be to go beyond the identification of barriers towards establishing key directions for policy makers and other agencies in making living with a communication support need easier. Such a project might also have an economic dimension, capturing the financial impact of their difficulties on people with CSN and on society as a whole. Such a study would be likely to make use of questionnaire and qualitative interview data.

Study 2. Public attitudes to and understanding of people with Communication Support Needs

The literature clearly indicates that there are concerns regarding public knowledge about, and attitudes towards, people with CSN. It is proposed that a study be set up to obtain a comprehensive picture of public experience of and attitudes towards people with CSN across Scotland and address issues of ignorance and prejudice associated with CSN. Such a study would be designed in two elements. In the first part a national representative survey would be taken of the public experiences of CSN in their own lives and in the public domain. This would include an element designed to establish what could be done to meet the needs of people with CSN. The aim of this study would be to address some of the prejudice and lack of awareness surrounding CSN, which were identified as significant barriers in this review.

Study 3. Developing and evaluating a communication friendly environment across local services

Much is already known about what is required of services in improving the opportunities for people with CSN, and a number of training packages aimed at promoting communication access are already available. It is proposed that these be developed for the full range of people with CSN and introduced and evaluated in a coherent fashion across the full range of services in the public and private sectors within a given geographical area. This would include publicity, training and the availability of support workers related to specific aspects of services for example employment and criminal justice. The results of such an evaluation would be reported in terms of uptake and performance amongst the professional groups concerned and in terms of improvements to the experience of people with CSN. Such a project would require the “buy in” of a forward looking local authority which wanted to act as a beacon for social inclusion and which is already well integrated with local health, education and social services. Such an evaluation would be likely to adopt a mixed methodology, making use of survey and quantitative audit data coupled with nested interview and diary studies.

CHAPTER ONE: INTRODUCTION

Background

1.1. Communication allows us to express ourselves and to have our needs met, it affects the way in which we form our relationships, negotiate the classroom, get through interviews, hold down a job and interact with our families. Although most of us may experience slight difficulties with aspects of our communication when we are nervous or when we forget things, generally we tend to take communication for granted and pay it relatively little attention. It is just something that we do like walking or eating.

1.2. However, there is a sizeable group of people, both children and adults, who experience difficulties expressing themselves and having their needs met. These people are variously described according to the perceived cause of their problem, for example from stroke or learning disability, or in terms of the specific nature of the difficulty that they experience such as expressive language disorder or stammer. What they all have in common is some level of communication support need (CSN).

1.3. Recent policy has focused on a commitment towards a more comprehensive provision of services that meets the needs of individuals with CSN. This should be informed by robust research that links the needs and experiences of this group with policies underpinning service delivery. This review will explore how people with CSN engage with services. The review will highlight barriers to effective service delivery, provide examples of good practice, indicate gaps in the literature and make recommendations for subsequent phases of research.

1.5. Disability has been traditionally explained by what has become known as the "medical model" of disability. This model tends to locate a problem within the individual and suggests that given a particular regime, the problem can be "cured", and that there is a normal state of "health" which can be achieved. This is associated with terms such as disease, disorder and impairment, which emphasise the pathological nature of the problem. This in time results in individuals being seen in terms of diagnostic categories and a focus on specific difficulties (Smart and Smart 2006). This approach has been criticised as failing "to value people and to celebrate difference" (Jordan and Bryan 2001). An alternative to the medical model is the "social model" of disability. The social model of disability describes disability as arising from barriers within society not the individual (Finkelstein 1980). This model focuses on societal barriers and what can be done to remove those barriers, rather than on the nature of specific impairments. Therefore the focus for change is societal and environmental rather than individual, and environments must be adapted to accommodate differences and be inclusive of all members of the community. This review draws heavily on the social model of disability, considering the experiences and barriers common to people with a wide range of communication support needs. "Needs" in this context refers to both the needs of the individual and to what society needs to do in order to improve the individual's access to all aspects of society.

Aims and Objectives

1.6. The aim of this review is to review the existing literature on the experiences and needs of people with communication support needs (CSN) in order to help define and assess the scale and range of needs. It is anticipated that the review will inform further phases of a programme of research designed to address the concerns of people with communication supports needs.

1.7. The key objectives of the study are to:

1. Define 'communication support needs' for the purposes of this review;
2. Scope out the range of barriers to communication experienced by the heterogeneous groups who have CSN;
3. Explore the heterogeneous nature of the various groups and draw out the commonalities, differences and complexity of needs according to emerging principles (for example, depth of needs and multiplicity of needs);
4. Analyse how barriers to communication impact across all areas of the lives of those who have CSN;
5. Analyse how having CSN affects people's experience of service provision (including their use or non-use of services);
6. Analyse the available literature relating to the extent to which service providers understand and are able to address the specific requirements of people with CSN;
7. Identify where there are gaps in the literature;
8. Make recommendations for subsequent stages of the research on, for example the range of participants to include in the research, research topics that should be addressed.

The review does not focus on speaking English as a second language, or adult literacy and numeracy issues.

Research Methods

Reference group

1.8. As part of the project a reference group was set up. This comprised practitioners, academics and members of voluntary sector organisations working with people with CSN. This group met on two occasions, discussed the direction of the review and made recommendations related to specific literature which was relevant for the review.

The process of the review

1.9. The review was based on what is known as a systematic review of the literature. Systematic reviews are commonly used in the fields of health and education to provide a summary of all the relevant literature in a given area for the purposes of informing policy or practice. Such reviews start with the development of a search strategy to identify relevant published literature. This search strategy is then applied to a range of predetermined electronic or on-line databases. The studies identified are then sorted for relevance and summarised in a consistent fashion. The present review was supplemented by an examination of policy documents and documents related to practice regarding communication support needs and a review of the "grey literature" that is unpublished literature derived from practitioners and researchers in the field

1.10. Such reviews are intended to be replicable in that another party could follow the same procedure and reach the same conclusions. Furthermore they are updated to reflect the developing evidence base in a given subject area. The extent to which a systematic review is feasible is partially dependent on the specificity of the topic concerned. The more clearly defined the category under review the easier it is to carry out such a review. A wide range of terminology is used in the area covered by the present review, and the term 'communication support needs' is relatively new, and this made aspects of the searching process problematic and increased the reliance on alternative sources of information. The systematic review element was therefore only the starting point of the present review.

Search strategy

1.11. The full search strategies are provided in Appendix 2.

1.12. A combination of thesaurus terms and free text terms were entered into several online bibliographic databases. Initial searching identified 908 publications that could be of potential relevance to the research question (see Appendix 3 for a breakdown of the results of the search strategy).

1.13. In addition to this the reference group were asked to provide unpublished/grey literature or literature that would not be identified in the online databases but was available in the public domain.

1.14. The results of the systematic searching were entered into Reference Manager software. The titles and abstracts of studies identified from systematic searching of the online databases were screened against the selection criteria (see below). The full reports of the titles and abstracts that met the criteria at the first stage of screening were then obtained for further screening. Material obtained from the reference group was also screened against the selection criteria.

Inclusion and exclusion criteria

1.15. Like the search strategy, the inclusion criteria for the study were kept broad. Priority was given to studies that provide data on methods used to support communication. Studies that focus on individual therapeutic interventions which do not specifically address the issue of the restriction of activity or participation in society have not been included. The selection criteria for included studies are provided in Appendix 4.

1.16. Studies were included if they fell into one of the following categories:

1. Types of communication support needs (CSN)
2. What are the impacts of CSN on the individuals concerned and more broadly on society
3. What has been done to address CSN:
    - At a societal level in terms of the knowledge, attitudes skills and practices of services providers both in the public and private sectors

- For individuals with CSN and the role that they can play

1.17. It was not the intention of this review to address the issue of communication support needs related to speaking English as a second language. These have been addressed recently within the Scottish context (Perez, Wilson, King et al. 2006). However, the distinction is not always very clear in some areas. For example, the Perez at al. report clearly seeks to address a broader group of people who fall within the remit of the Translating, Interpreting and Communication Support (TICS) services including people with hearing and/or visual impairment. Similarly, in a recent consultation entitled "Strategy for Scotland's Languages: Draft Version for Consultation" (Scottish Executive 2007) includes, within it, a statement "It is important that communication strategies are developed for people with communication support needs" (SE 2007 p.15).

Quality judgements

1.18. It is characteristic of the systematic review process to impose quality judgements on the papers which meet the inclusion criteria. Such criteria commonly include blind assessment or quality of randomisation. The nature of the greater part of the studies identified in the present search precludes such a stringent criteria. In the main they reflect the experiences of individuals with communication support needs and do not include experimental manipulation of any sort. It is much more difficult to make clear judgements as to the quality of this range of papers and for this reason we have not sought to make such judgements.

1.19. The majority of studies included in the review came from the literature identified by the reference group. Most of this literature was not written in a manner similar to published articles in peer-reviewed journals and therefore could not easily be submitted to the data extraction processes that traditionally feature in conventional approaches to systematic reviewing.

Structure of Report

1.20. This chapter has looked at the methodology of the search strategy and the sources of grey literature. Chapter 2 goes on to address the issue of who can be described as having communication support needs. Chapter 3 provides an overview of the findings. The remaining chapters look at the more detailed findings across a series of contexts. These contexts are as follows:

- Health and Social Care
- Education
- Employment
- Criminal justice
- Housing
- Experiences of other services, including housing and financial services

1.21. In each case the findings are discussed in terms of the **barriers** to inclusion experienced in the specific area and in terms of effective strategies to reduce the impact of these barriers. These personal experiences are seen in terms of their impact on the person with the disability, their family and immediate social circle. They are also seen in terms of the **attitudes** of those in the wider society. One area which is of particular concern to people with communication support needs, as it is to many people with disabilities, is their experience of **transitions,** both across the age span, and between and within services. Each section includes information on the evidence for potential improvements in each of the areas covered. Finally, a summary of the main findings is included at the end of each chapter.

CHAPTER TWO: WHO HAS COMMUNICATION SUPPORT NEEDS?

Terminology

2.1. The review concentrates on the experiences of individuals with *communication support needs*. The term is used to encompass the experience of a wide range of communication difficulties associated with a number of different disabilities. Although the term "communication support needs" started to come into use in the 1990s and we begin to see definitions emerging at the start of the new millennium (Millar 2001), different combinations of these words have been in use for some time.

2.2. The term owes its origins in the 1973 Rehabilitation Act in the US and the series of highly influential subsequent publications, including the UN Convention on Human Rights which followed. It is important that CSN is one aspect of this broader movement which emphasises the rights of the individual and prefaces the move from doing "to" to doing "with" the person with the disability or condition. CSN, as a relatively new term, has not yet entered the disability vocabulary but the fact that self-realization is so intimately connected to the individual's communication skills means that it is, in effect, at the heart of what is understood by disability rights.

Definitions

2.3. People with communication support needs have difficulties associated with one or more aspects of communication. *Communication* refers to all aspects of interpersonal communication. This includes verbal understanding, expressive language, speech and the capacity to understand someone's intended meaning rather than the words themselves. It also refers to literacy and other means by which individuals interact with one another. More specifically for the purposes of this review, it refers to the way in which individuals function in the public domain and interact with people that are in a position to affect their everyday lives. The key feature of communication is that it is both the medium and the message. It is important in its own right, in that an individual needs to be able to understand what others say and express themselves in order to function socially, and for the implications it has for all aspects of our lives, including accessing services, employment, education etc. *Support* refers to the activities put in place to support such individuals, whether at the request of the individuals themselves or at the recommendation of others, for example a doctor, a therapist or a social worker. It can refer to specific interventions designed to facilitate new communication techniques but, again, for the purposes of this study, it refers to the use of adaptations that individuals and organisations can make to facilitate the effective involvement of individuals with difficulties in understanding and making themselves understood. Support also refers to the assistance that is available from others in the individual's environment, whether family member, professional or volunteer. *Needs* occur when an individual or group perceive themselves or are perceived to have difficulties associated with their communication which inhibits their involvement in society. As Aitken and Millar have observed, **the term communication support needs has the benefit of emphasising the needs arising out of the difficulty rather than the difficulty itself** (Aitken and Millar 2002). It places the onus on others to find ways to communicate with, listen to and find out the preferences of the individual. Finally, it emphasises the fact that there may be more differences within any group of people with disability ie. at the level of the individual, than between diagnostic group. Thus it emphasises person-centred rather than generic models of care.

2.4. This approach to disability is encapsulated in the Disability Discrimination Act (1995) in the UK. This concept of discrimination applies to all service providers if they make it “impossible or unreasonably difficult” for a disabled person to access their services. Along with physical access the Act specifically refers to “access to and use of means of communication” and “access to and use of information services”. This legislation has far reaching implications for service providers with respect to communication support needs. For example, in a recent publication from the Disability Rights Commission on improving health service for disabled people, it states explicitly that “[I]t is the legal responsibility of the health services to provide and pay for communication support and to provide information in alternative formats for those service users who need it” (DRC 2006a, p.3).

2.5. Key to the concept of need is how the level of need should be described. Work by Thomson, Stewart and Ward (1996) at the University of Edinburgh has helped to differentiate levels of need. An indicative table representing this multidimensional approach to level of needs with regard to children who use augmentative and alternative means of communication is provided in Appendix 1. Although no such table has been generated for communication support needs as a group there is every reason to suppose that this system could be adapted to meet a wide range of different groups. Needs are appraised across six strands:

1. The physical environment or context within which the individual can function optimally
2. The mode of service delivery and adaptations required
3. The level of support required by the individual to enable her/him to engage optimally with the curriculum or other activities
4. Access to specialised resources, facilities or technologies required by the individual
5. Access to specialised agent(s) required to support the individual
6. Access to the most specialised resources

2.6. These needs can be very specific, for example isolated problems in speech production, or they can be pervasive, for example in the case of people with learning disability who have difficulties understanding what is said to them, formulating what they are trying to say and in using speech effectively. In practice, difficulties commonly co-occur and it is necessary to take into consideration this range when approaching the needs of a given individual. They can also be very severe, as in a person who has severe learning disability or a pronounced expressive difficulty following stroke and can therefore produce little more than single words, or they can be relatively mild, so that it would only be possible to identify the difficulty with specific reference to the individual’s relatives and friends. Similarly, it may only be possible to identify a need in the context of the life course, as lower levels of communication skills are the norm in young children. So a problem may emerge relative to other children only when the child goes to primary school, or later to secondary school.

2.7. These needs can be difficult to characterise because of a number of factors:

- There is a tension between dealing with all communication support needs at the level of the individual and improving the way that society can interact effectively with these groups
- Needs change across the lifespan
- Needs can be affected by context (communication demands of school, home or work setting, use of the telephone, ambient noise etc.)

2.8. Some communication support needs may be easier to recognise than others and this may lead to more appropriate responses by the public. For example, CSNs that are related to problems in speech (e.g. stammering) are more apparent to the public than CSN associated with difficulties in understanding language comprehension. In general, there is an identifiable gap in popular perceptions of people with communication support needs. This relates to the identification of the nature of the difficulties, the best ways to respond to those difficulties and to the ways that the communication difficulties interact with other disabilities.

2.9. Having established the significance of the social model of disability as a framework for understanding communication support needs it is important to illustrate the range of people who may be classified as falling within this group. In the main those involved have difficulties which are associated with recognised physical, sensory, cognitive or medical conditions resulting in communication impairments. Table 2.1 provides a list of specific disabilities which may have associated communication support needs. In some cases the disabilities are specific to communication. In other cases communication is an associated manifestation of the disability. This group could also include people with communication difficulties associated with schizophrenia, depression and other mental health problems. Key to this discussion is the fact that the communication impairment associated with a specific condition does not determine the nature or the extent of the communication support need.

Table 2.1 The range of specific groups of people with disabilities which may have Communication Support Needs

Aphasia following a stroke	Hearing impairment
Autistic spectrum disorder	Huntingdon's chorea
Asperger's syndrome and other disorders of social communication	Learning disability
Alzheimer's disease	Laryngectomy
Cerebral palsy	Motor Neurone Disease
Cleft lip and palate	Multiple sclerosis
Deafness	Muscular dystrophy
Developmental language delays and disorder	Neurological disease
Dyslexia	Specific language impairment
Dementia	Stammering
Friedreich's ataxia	Visual impairment
Head injury	Voice disorders

For many groups communication support needs are present throughout the lives of the individuals concerned but the nature of those needs change across time. Likewise, early experiences associated with an individual's condition and the possible stigma associated with it can have a cumulative effect on the individual concerned. For others, communication needs emerge with the onset of illness. There are also those who adjust to their communication difficulties and would not consider that they had any additional needs. It is recognised that there are both common and separate factors affecting the experiences of the groups concerned.

How many people have Communication Support Needs?

2.10. It would be helpful to identify both the number of individuals likely to have communication support needs and the extent of anticipated need in terms of severity of the communication difficulty experienced. Commonly this would be ascertained by testing the performance on communication measures of the individual, on the understanding that this provides an objective measure of need. The terms commonly used to describe the numbers concerned are incidence and prevalence. Incidence means the number of new cases in the population, prevalence is the total number of cases. It is important to recognise that this approach is essentially medical in origin and reflects an assumption about the ability to define a "case". In attempting to ascertain the number of people with CSN it is important to recognise that such an approach provides a measure of performance but not necessarily of need.

2.11. There are four reasons why it may be difficult to obtain a definitive picture of the number of people with CSN at this stage:

1. While data are available for the prevalence of communication need in some of the individual groups identified above, there is no recognised definition of CSN which has been developed sufficiently well to be used at a population level.
2. As the term "communication support need" suggests, the definition is, to a considerable extent, socially rather than objectively determined. That is, the extent to which something is a need is partially determined by the individual's recognition that they have such a need and this is partially a function of the extent to which their community responds to that need. Thus two people with comparable levels of speech and language difficulties following a road traffic accident might have similar, objectively determined, impairments in terms of their performance on language tests, but have very different communication support needs. In one example, they may have a positive family environment and an employer prepared to adjust the nature of the job that they used to do to meet their needs. In another, where the person lives alone or without family support the trauma associated with the accident may set off a chain of events that make it much more difficult for the individual to adjust in a positive manner. If this is accompanied by an inflexible employer who makes the person redundant, it may result in a far higher level of communication support need.
3. The pattern of difficulties experienced can change across time as the need increases or decreases. For example, the needs of someone with speech and language difficulties following stroke who experiences a second stroke, with a resulting increase in their dependency and communication need, can be contrasted with a child with an identified delay in language development whose difficulty may recede with time, the group commonly called "late bloomers" (Rescorla and Roberts 2002). A comparable pattern is identifiable in stammering where the number is higher in the early years. The reverse pattern is identifiable in hearing loss which increases with age (see Figure 2.1 below). There may also be new technologies coming onto the market which influence the extent to which an individual is likely to have communication support needs. For example, people who use augmentative and

alternative communication (AAC) devices will require support at different times to learn new systems as their needs change and technology advances. Similarly, it is likely that the relatively widespread introduction of the cochlear implant may reduce the number of people with hearing loss who are excluded from mainstream society. Similarly, while the introduction of improved neonatal care increases the chances of survival for individuals, these groups often have a high level of subsequent need of which their communication support needs are only a part.

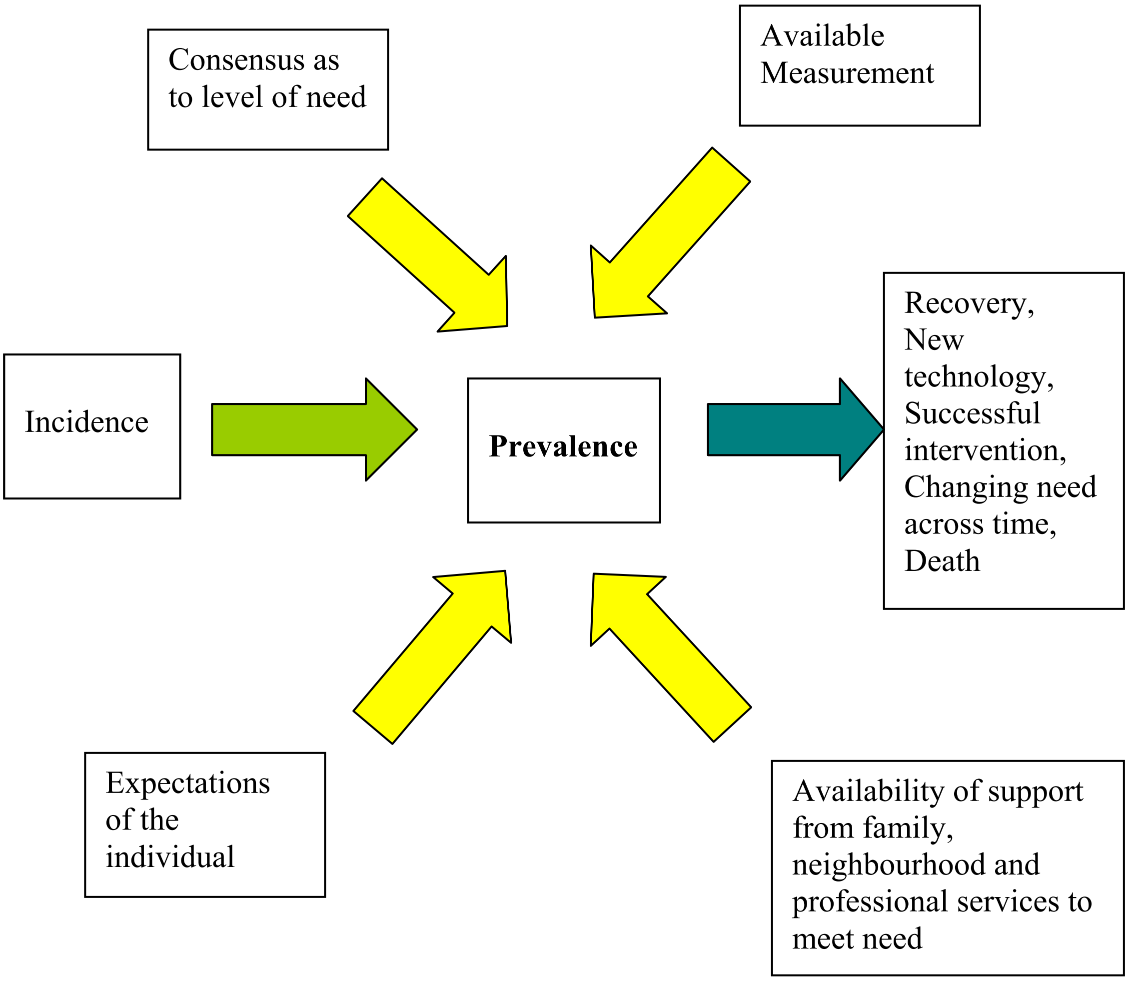
4. Finally, any estimate of CSN is related to the existing services and whether they seek to identify the group concerned. Services develop to meet the identified needs of specific groups of patients. The two are symbiotically linked. If there are no services, the groups concerned will not manifest at all. One obvious example here would be children with persistent developmental language difficulties. Historically, services were developed around a principal of relatively early identification and treatment. Recent longitudinal data have shown that, for many, these difficulties continue through primary, in to secondary school and beyond. Services have yet to catch up with this and the identification of prevalence has lagged still further behind. Thus, while there is extensive provision for such children in primary school, this virtually disappears in secondary school and there are no services at all for such children when they become young adults. Not surprisingly, therefore, while we can estimate a prevalence figure in primary school (Tomblin et al 1997), no such figures exist for secondary school children or for adults with developmental language difficulties.

2.12. Despite these difficulties, there have been attempts to summarise the prevalence literature across the field, most notably in Enderby and Daves (1989) and a recent edition of *Advances in Speech Language Pathology* (Ferguson 2005). In this last volume, for example, Enderby and Pickstone (2005) summarise data on the incidence and prevalence of acquired communication and swallowing disorders from a number of different sources. Summing their figures for prevalence indicates a figure of 1193 per 100,000 or 1.2% but this figure does not include people with either general or specific developmental difficulties (see Table 2.2 below). Nor does it include people with communication support needs associated with deafness or visual impairment. In short, the literature in this area leaves a good deal to be desired and any estimates of the population are likely to be a function of what the individual perceives to be a difficulty and whether someone can do something about it. The interaction between prevalence and factors influencing its calculation are represented graphically in Figure 2.1.

Table 2.2 International figures on people with acquired communication difficulties in adulthood (from Enderby and Pickstone 2005)

	Incidence per 100,000	**Prevalence per 100,000**	**Number of speech or swallowing problems**
Stroke	220	500	66 with communication disorder 120 dysphagia
Parkinson Disease	20	160	69 dysarthria 30 dysphagia
Multiple Sclerosis	3.0	144	76 communication disorder 10 dysphagia
Dysphonia	28	28	28
Motor Neurone Disease	4	7	6
Myasthenia Gravis	3	30	10
Head injury	Severe 10-15 Moderate 15-20 Mild 250	228 longstanding problems	160
Brain tumour	20	-	7
Encephalitis	7	-	5
Tourette Syndrome	0.5	40	20
Progressive supranuclear palsy	-	6	6
Muscular dystrophy	-	50	20
Guillian-Barre syndrome	2.5	-	2.0

Figure 2.1 Factors impacting on the number of people with Communication Support Needs



2.13. Taking these provisos into consideration, Table 2.3 overleaf provides estimates of the numbers of those likely to experience communication support needs. Although there are some precise figures from specific studies, these estimates fluctuate, largely because the definitions and cut-offs change. All figures follow the pattern of reporting prevalence in terms of number of individuals per 100,000. Where populations are known to change across the lifespan, estimates of overall prevalence are taken from published sources and are not calculated separately.

Table 2.3 International prevalence estimates for people with communication support needs

	Number per 100,000	**Source**
General Learning difficulty (severe)	600	Foundation for People with Learning Disabilities, 2004.
Specific speech and language difficulties	7800	Tomblin et al.1997
People with Alternative and augmentative communication needs	1200	Light et al. 2003
Autism	600	Charman 2004
Hearing impairment/deafness	8600	National Center for Health Statistics 1994
Acquired neurological difficulties	1193	Enderby et al.2005
Stammering	720	Craig et al. 2002.
TOTAL	20713	

2.14. These categories are intended to emphasise specific groups with recognisable communication disabilities. They draw no explicit distinction between communication disabilities and communication support needs. Although they are intended to be different from one another there is a possibility that some of these groups overlap to some extent. Moderate learning disabilities or specific learning disabilities other than those specifically related to speech and language development are not included because it would not generally be true that all such children have communication needs. The figures do not take into consideration communication support needs that change across the lifespan or the impact of environmental modifications which might affect the definition of that need. Furthermore, these figures do not indicate the proportion of people in the groups who would define themselves as having communication support needs.

2.15. It is important to note that the figures above do not directly compare with many others. For example, Enderby and Philip concluded that 1% of the population, or 1000 in 100,000, have severe communication difficulties. This is comparable to the 1.8% from the Australian household survey (Harasty and McCooey 1994). The most recent study to specifically collect data on the full range of people with communication disability, rather than adding up reports related to a wide range of groups such as that above, is from Victoria, Australia (Perry, Reilly, Cotton et al. 2004). They identified people with complex communication disabilities and paid particular attention to the level of communication disability within other disabilities. The total number reported was 1 in 500, or 200 in our notional population of 100,000, but did not include people with dementia. These data are included to highlight the role of definitions in the process of reporting prevalence. Complex communication needs were described in the Victoria study as follows:

"*People who have complex communication needs are unable to communicate effectively using speech alone. They and their communication partners may benefit from using alternative and augmentation (AAC) methods, either temporarily or permanently. Hearing limitation is not the primary cause of complex communication need.*" (Perry et al. 2004 p. 261)

2.16. A survey of the needs of adults with "speech disabilities" in Newcastle (UK) was carried out by the Joint Advisory Group (sensory and physical disability) and Disability North. Using a "household survey" method this study identified 0.4 % or 400 in 100,000 (Knight, Sked and Garrill 2003). The definition of speech disabilities is not specified, but it is clear that they are only dealing with the most pronounced cases and the authors indicate that they feel this figure is an under estimate.

2.17. Another route into the data is to look at the referral to speech and language therapy services. By definition people referred through this route will tend to be those with the most pronounced problems. They will also be those who are able to access services because of availability of appropriate referring agents and existing speech and language therapy staff. Consequently this approach to the data is also likely to represent a considerable under estimate of the number of cases in the population. The most recent figures available for Scotland indicate that in 2005 the total number of individuals on speech and language therapy caseloads was 46,833, which represents a figure of one case in every 110 people in Scotland or slightly under 1% of the population (Information Services Division 2006).

2.18. Much depends on whether one takes a more stringent (conservative) or a more inclusive (liberal) approach to the identification of need. In recent years the term "low incidence disability" has come into circulation, particularly with regard to children at least. As the name suggests this tends to refer to only the most serious cases. In the U.S. the Individuals with Disabilities Education Improvement Act (IDEA) of 2004 defines low incidence disabilities as "a visual or hearing impairment, or simultaneous visual and hearing impairments; a significant cognitive impairment; or any impairment for which a small number of personnel with highly specialized skills and knowledge are needed in order for children with that impairment to receive early intervention services or a free appropriate public education" (United States Congress 2004 1462 § 662(c)(3)). Of course many of these children will have communication support needs by virtue of their other disabilities. In some cases, the use of the term low incidence disabilities specifically refers to children with communication support needs as a distinct group (Scottish Executive 1999). In others, they are not covered directly but the communication needs of all children with disabilities and social and emotional needs are recognised (DFES 2006). The use of the term low incidence conditions suggests that only people with the most serious impairments are being considered and that this group as a whole is likely to have the highest level of need. While it is likely that the level at which incidence is set is probably inversely related to the level of individual need. A more liberal approach to need results in the inclusion of a much higher number of people but for many their needs are like to be much less pronounced.

2.19. In summary, if you ask people to indicate whether they have a problem that would merit identification as a communication support need the figure tends to be in the region of 1000 in a 100,000 or 1%. If you examine populations using explicit criteria such as those often identified by practitioners the figure tends to be much higher. It is reasonable to assume that this partly reflects the variation in perception of what is a need that requires support of one sort or another. The public tend to identify only the most severe cases, whereas practitioners take a broader view because they believe there are more people whose situation might be improved by additional support. **Given the range of the data we would take the position that it is reasonable to assume that a conservative estimate of the number of people with marked communication needs such that they would find it difficult to communicate their needs effectively without help would be in the region of 1-2% of the population**.

CHAPTER THREE: OVERARCHING ISSUES

3.1. Communication support needs is a relatively new term which is intended to act as an overarching expression for all the different communication disabilities listed. Attempts to unify these different disabilities at all are relatively new. The first attempt that we could identify in the UK was the report for the Communication Forum in England entitled *Living with Communication Impairment* (Parr, Byng, Woolf et al. 1997). Drawing on the experiences of people with dyslexia, aphasia, autism, head injury, learning disability and laryngectomy the authors describe the consequences of communication impairment and conclude that:

> "*While some people became overcome by such barriers, others indicate issues which need to be tackled and how this could be done. They feel that the emphasis should shift from fixing the impairment to removing the barriers in society through education, information, awareness raising, legislation and applying the principles of equal opportunities and human rights to the issue of communication impairment.*"
> (Parr, Byng, Woolf et al. 1997 p.3)

3.2. A recent initiative in Scotland has proposed the conceptualisation of people with communication support needs as a single group. In *The Case for Action: A Strategy for People with Communication Impairment* Turnbull and colleagues have highlighted the disadvantages of separating out the needs of the different groups that come under the umbrella of communication support needs and attempts to characterise the impact of communication impairment (Turnbull, Macintosh, Edmonstone et al. 2004). They ask readers to imagine living for a day as a person with a communication support need:

> - Unable to fully understand what is being said to you
> - Unable to understand the "funny side" when everyone else laughs
> - Wondering as you speak how or indeed if the words are going to come out to express your thoughts
> - Unable to make sense of written words
> - Wondering if the next person you try to speak to will wait and listen, or turn away or even accuse you of being drunk.
>
> Turnbull, Macintosh, Edmonstone et al. 2004 p.5.

3.3. The concept of an inclusive communication strategy as a way of providing for these needs has started to be rolled out in some areas in Scotland (eg. the Lothian Inclusive Communication Strategy 2006) but such strategies tend to be local or relate to specific services and are by no means generally applied.

3.4. The sense that there are moves in the direction of combining the needs of people with CSN is reflected in a recent paper produced for The King's Fund in England as part of The Communication Access Toolkit project (Parr et al 2006, forthcoming) has attempted to develop this further by looking in more detail at the provision for the needs of the following groups with communication disabilities:

- People with learning disabilities
- People with dementia
- People with mental health issues
- Older people
- People who use technologies and devices in communication
- Deaf people and those with hearing impairment
- People with aphasia

3.5. The review looked at different initiatives around **access** for people with communication difficulties rather than support needs.

Given the disparate nature of access initiatives for people with different communication impairments, this study imposed a coherent conceptual framework, and considered each initiative along the following parameters:

1. Model of disability
2. The relationship between the person with communication disability and the service provider
3. Access to different services
4. Levels of access
5. Focus of efforts to enhance access
6. Relevance to other groups and to the wider community

The conclusion drawn from this review was that many initiatives work along similar or related lines, and that people with different communication impairments would broadly benefit from the same attempt to lessen or remove disabling barriers, although obviously specific skills and techniques for supporting interaction might vary from impairment to impairment. However, the links between the issues faced by people with different impairments have not often been made explicit within the literature.

3.6. The survey of the needs of adults with “speech disabilities” in Newcastle (UK) carried out by the Joint Advisory Group (sensory and physical disability) and Disability North (Knight, Sked and Garrill 2003) has highlighted the level of public ignorance about this group, an ignorance that runs across society from the health and social service sector through to the retail and utilities sectors.

3.7. In the main the focus of this review is the experience of individuals with communication support needs, the barriers that they face and the mechanisms which facilitate their access to services. But another dimension which is important is the economic implications of communication support needs. It has been argued that the nature of employment has changed considerably over the last century, with white collar jobs replacing blue collar jobs in western economies (Ruben 2000). This has considerable implications for the person with communication support needs. One of the features of the increasing proportion of white collar jobs is the rise in the demand for adequate communication skills. Indeed it is not uncommon for business leaders to complain about the poor levels of communication and literacy skills in those leaving schools. The argument is used to imply that the school system is failing children but, of course, this shortfall may well also be a function of the increasing expectations of the workforce. Economic analysis is not a feature of this review but it is important to draw attention to a recent review from the children's charity ICAN entitled the Cost to the Nation of Children's Poor Communication (Hartshorne 2006). In it, the case is made for the significance of communication as a matter of social policy. This is a significant issue because the rationale for action on communication support needs must rest on both humanitarian and economic issues.

3.8. Finally, it is important to recognise that there are many documents related to disability of one sort or another which have a direct bearing on the needs of people with communication support needs, but which do not explicitly refer to them. For example, the Disability Rights Commission regularly produces documents which are highly relevant. The DRC published their guidance on web access for people with disabilities in 2004 (DRC 2004). No mention is made of communication support needs specifically, but every aspect of the document is relevant. Similarly, three relatively recent reports on the state of health and disability in Scotland and in England (Scottish Council Foundation 2005, *Disability in Scotland 2005-2020: A state of the nation report;* Scottish Executive (2004) *Social Focus on Disability; Disability Rights Commission (2006 a and b) Parts 1 and 2 Equal treatment: Closing the gap)* scarcely mention people with communication support needs at all.

CHAPTER FOUR: HEALTH AND SOCIAL CARE

Background

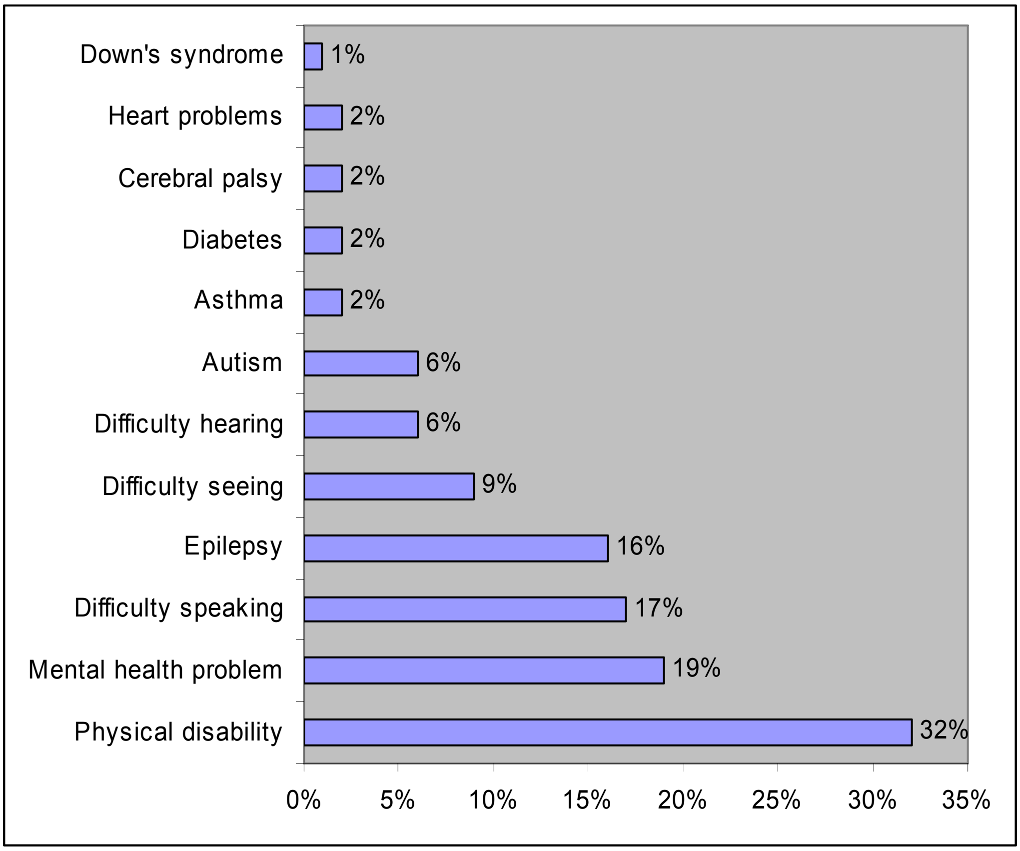
4.1. Many people with communication support needs are first identified by the health services, whether this is young children with slow development seeing their health visitor, or the people with aphasia who are admitted to hospital having had a stroke. In many cases, people may actually be ill and continue to need active medical involvement, although this is not necessarily the case. The effect is that historically the field of communication disabilities has been intricately linked with a range of health disciplines. This primacy effect has coloured the way that many people are perceived by the system. This is exacerbated somewhat by the fact that speech and language therapists, the group of professionals to whom people with communication support needs are most commonly referred, are employed in the health system. There has been a shift in this emphasis in recent years, driven by the move towards a more social model of disability, but this pattern is very apparent for many groups.

Barriers

4.2. People with communication disabilities often report that they find it particularly difficult getting their needs met in primary care (Law, Bunning, Byng et al. 2005, Murphy 2006). In part this is a function of the training of the medical staff involved which, in the main, excludes any emphasis on these individuals. However, it is also true that, whereas in secondary or tertiary care the diagnosis has already been made and the medical procedures are more likely to have a momentum of their own, in primary care the role of the patient in negotiating their needs with the primary care team is paramount. This is part of a broader agenda related to the quality of communication between doctors and their patients (Charles, Gafni, and Whelan 2000). Problems with doctor-patient communication experienced by the general public can be magnified for patients with communication impairments. For example, poor communication skills make it difficult to take patients' histories, can lead to poor compliance with management plans, consultation time constraints and difficulties with examinations and problem determination (Lennox, Diggens and Ugoni 1997). A recent focus group study looking at GPs' knowledge about communication disability and the use of appropriate strategies to manage consultations with people with communication disability identified that they were frustrated in not being understood and in not understanding their patients, but there was a lack of awareness of the reasons behind the difficulties (Murphy 2006). GPs relied heavily on carers to convey messages. People with communication disabilities identified a range of difficulties in having their needs met in primary care, both in terms of the manner of the interaction and in the transfer of messages about specific procedures or medication. It was found that "[w]here patients find GP consultations stressful or unsatisfactory they lower their expectations, attend less and feel generally disaffected. This results in ineffective healthcare" (p.9 Murphy 2006).

4.3. The largest single study of the views of people with learning disability included 2893 people across all ages (Emerson, Malam, Davies et al. 2005). The use of health services in this group is high. 61% said that they had an illness or disability that they had had for a long time, twice as many as would say this in the population as a whole (see Figure 4.1). But this may go beyond a matter of co-morbidity. Mencap's *Treat Me Right* report highlighted the health inequalities of people with learning disabilities and attributed some of these inequalities to issues related to communication (Mencap 2004).

Figure 4.1 Percentage of people with learning disabilities who have specific long standing illness or disabilities (taken from Emerson, Mallam, Davies et al. 2005)



4.4. The number of people with identified difficulty speaking is not as high as might be expected given the developmental level of many of the respondents, but this is probably because "speaking" tends to be quite specific and does not refer to broader language difficulties. The majority of people were registered with their GP and three quarters had seen their GP in the past year. Half said that they would choose to go to their GP for help. The study did not ask how easy respondents found it to access health services but it is noteworthy that no more than a quarter of women had ever had a cervical smear or had breast screening. This suggests that this population may not be making very effective use of GP services. Other findings show that individuals with learning disability make the same amount of GP visits as the general population but are less likely to receive health checks. For example the Emerson et al. study's findings are supported by another study, which found that only 19% of women with learning disabilities had received cervical smear tests compared to 77% of women in the general population (Disability Rights Commission 2005).

4.5. One of the problems is that understanding of communication support needs is generally fairly rudimentary and rests largely on the experience of the practitioner concerned rather than their training. This means that training input tends to be somewhat ad hoc, based on the approach of local speech and language therapists or the development of specific guidelines such as the *Primary health care workers project* related to stammering (Christie, (unpublished).

4.6. Although primary care is an obvious focus because this is where most people with chronic conditions are managed, the need for effective communication is just as important in the secondary and tertiary health sectors. *We're still waiting: deaf people's experiences of the struggle to improve their health and well being* is a publication from the Scottish Human Services Trust (Henderson and Weston 2004) which, as the title implies, highlights the shortcomings of the health system in addressing the needs of a particular group of people with communication support needs. The experiences of members of the deaf community were used to highlight the sort of problems that can arise if health staff are not aware of the communication needs of the patient. Similarly, people with learning disabilities have been reported to experience considerable difficulty in general hospital settings. On the one hand this can be attributed to the fact that they have a higher level of medical need than the population as a whole, for example associated with increased rates of gastro-intestinal and respiratory disease. On the other hand they experience difficulties in communicating their needs and in understanding their illness and treatment and there has also been a tendency for "diagnostic overshadowing" whereby the individual's behaviour, often associated with the stress of the intervention, is attributed to the learning disability rather than being separately treatable (Brown and Macarthur 2006). The example below describes a situation where a patient with CSN was inappropriately labelled due to the staff's inability to communicate with them in a manner that was suited to their CSN:

> "*She was only in hospital for 3 or 4 days when she got labelled as having dementia because they could not communicate with her. I had visited her up to that time and was able to have good conversation with her (although she was frail and profoundly deaf). But the staff just didn't seem to understand at all how to communicate with her (ie. much more slowly, clearly and using eye contact) so her death certificate marked her as having dementia. Her husband was just distraught and I was furiously angry.*"
>
> Henderson and Weston (2004) p.6

4.7. Many individuals with CSN may have to rely on the use of Alternative and Augmentative Communication (AAC) systems. AAC refers to any form of communication used in addition to or instead of speech (i.e. when speech is not functional as the primary mode of communication). AAC systems are specific to the individual and these can vary from pictorial symbols to computer based messages with text processing and synthetic voice output (Augmentative Communication in Practice 1998). For individuals who use AAC to communicate, the limitations of the technology itself can be a barrier to obtaining adequate healthcare. For example AAC systems may not contain the relevant vocabulary to discuss intimate aspects of healthcare such as making reference to body parts or voicing concern over sexual health (Lever 2003).

4.8. Individuals with CSN may engage with health and social care services, not just to meet their own needs, but also in the capacity of a parent. A review of the issues in supporting parents with learning disabilities revealed that all of the 13 parents on the advisory group, with the exception of one couple, had had their children taken into care at some point as a result of inadequate support (Tarleton, Ward and Howarth 2006).

Attitudes

4.9. The shift in emphasis towards quality of life as a potential outcome for health services necessarily raises the question of how best to elicit those attitudes in the populations concerned, especially in those who have poor functional communication. There has been a tendency to assume that it is possible to rely on carers to indicate how the person feels about a given issue. The study of quality of life measures in relation to children with communication support needs is currently in its infancy (Markham and Dean 2006). It has been much more comprehensively developed in relation to adults and particularly with aphasia following a stroke (Hilari et al 2003). Indeed the question has now been raised about the comparability of the judgements about quality of life from the perspective of patient and carer (Cruice, Worrall, Hickson et al. 2005). This study compared the response to quality of life measures between patients with aphasia and their family members and friends, finding that the latter tend to have much lower ratings of global health and physical quality of life, although they were comparable for feelings, daily activities and well-being.

4.10. The attitudes of health practitioners are key to the judgements that they make. If they interpret a set of signs in a given way it is likely to lead to certain conclusions. For this reason the ability of the practitioners to judge the severity of communication impairment is important. A recent study has suggested that doctors tend to assume that acquired dysarthric speech reflects poorer overall intellectual abilities of the individual (Fox and Pring 2005).

4.11. Parents with learning disabilities reported the attitudes of others as major barriers to accessing adequate parenting support (Tarleton et al. 2006). Professionals supporting this group report that these negative attitudes are particularly true of staff with no specialist experience with adults with learning disabilities. This is illustrated in the following statement:

> "*There is, in general, a negative attitude from many professionals involved with these parents. That having a learning disability prevents them from being 'good enough' parents. That the parents will not be able to learn to parent more effectively, or that it will take more time and children cannot wait. Also that giving families additional support will be prohibitively expensive.*"
>
> (Tarleton, Ward & Howarth 2006 p23)

Parents commented that they felt staff in support services were constantly waiting for them to make a mistake. Often parents felt that they were expected to meet unrealistic standards of parenting that parents without disabilities would not be expected to meet. Furthermore, inconsistency in staffing meant that they constantly had to adapt to varied and sometimes conflicting ideals of what makes a 'good parent'. For example one mother received both praise and criticism from professionals for leaving her child with a grandparent one day a week to go to college.

Transitions

4.12. There is sometimes a tendency to see communication disabilities as being stable and long-term. It is expected that individuals with communication support needs will need long term support. The reality is rather different, with people feeling better able to cope at some stages and perhaps needing more support at difficult times such as when they leave hospital. There are many groups who experience changes in their pattern of difficulties, ie. they get better or worse. For example, people who stammer commonly report "relapses", when they return to earlier behaviours and lose the ability to control their stammer (Crichton-Smith 2002). Studies of people with aphasia, a communication impairment that commonly occurs following stroke, suggest that different pressures and obstacles arise as the person moves through different life phases and life events (Parr, Byng and Gilpin 1997). For example, helping children with their homework, advising a young person, supporting a sick family member, moving house and dealing with illness or bereavement can all put particular pressures on communication skills. As life events unfold, people may need to enlist the help of different public services. In other words, communication impairment is not just a 'one-off' static condition but is continually exposed to changing circumstances.

Potential improvements

4.13. Primary care has been identified as an area where people with disability have particular difficulties (Macdonald and Ritchie 2005). They identified a series of factors which help promote good practice:

- Effective partnership working
- Consultation with disabled people
- Awareness of the needs of disabled people
- Effective use of resources
- Flexibility
- Support for staff
- A learning culture including evaluation and feedback.

4.14. Two key changes have been taking place in recent years which have a bearing on the provision of services for people with CSN within the health system in the UK. Firstly, concerns about the communication skills of doctors have been highlighted in recent documents related to medical training and practice (Scottish Executive 2003b). In the main these are generic guidelines and communication skills training exercises which teach a very basic level of communication skills to help the patient feel more positive about their experience of visiting their doctor and ultimately to reduce litigation. This has the potential to make a considerable improvement to the experience of the majority of individuals. However, it does not generally include training about effective interaction with patients with communication support needs. Secondly, the expectations about the provision for people with disabilities has increased considerably. Although the disability legislation such as the Disability Discrimination Act (1995) now requires employers and service providers to pay attention to the needs of people with disabilities, the emphasis remains firmly with their physical needs (Disability Rights Commission 2004, 2005). However, there have been recent signs that communication access needs are being taken into consideration, at least as far as access to health services is concerned (DRC 2006). It is obvious that this focus is necessary if basic modifications to service delivery and the development of public spaces is to become the norm, but it is not in itself sufficient to meet the needs of a great many service users. One way to address this is to include specific competencies within the jobs of those working in health and social care. There is evidence that such frameworks have been developed for example by the Scottish Qualifications Authority but it unclear how this translates into outcomes as far as the service user is concerned.

4.15. The area which has probably had most attention is services to people with learning disability. The health needs for this group have been extensively documented in Scotland (NHS Health Scotland 2004) and the recently published best practice statement is a good example of the range of modifications that need to be made by healthcare providers. These include a number which relate primarily to communication inclusion (NHS QIS 2006). For example there are appendices with an extensive range of tips for effective spoken and written communication in the health setting. Clearly these sort of recommendations have the potential to be invaluable across all aspects of the public and private sector and can be generalised to a wide range of groups of people with communication support needs.

4.16. One of the primary needs is simple and efficient methods to improve communication between people with communication disabilities and their doctors. There are various methods of doing this which are readily available and have a developing evidence base (Law et al. 2005, Murphy 2006). But this is more than a matter of a specific procedure. For example there is a real need for people with communication disabilities, their families and their carers to be better informed about what to expect within a hospital setting. Materials such as Stroke Talk, a communication toolkit, have been developed specifically for people with aphasia, in order to address this issue in an accessible format. This resource is used by patients and hospital staff to discuss and understand stoke and stroke care through the use of simple language, keywords and illustrations provided in the toolkit (Cottrell and Davies 2006). As consultations with service users have demonstrated there is a wide range of improvements to services, for example concerning involvement with families, the development of accessible and appropriate information and the appropriate involvement of people with communication support needs, which will need to be made before the needs of individuals are likely to be met. A number of such consultations have recently taken place in Scotland with specific reference to people with aphasia following a stroke (Dare Foundation 2005, Wood 2006, NHS Forth Valley 2007 and Law, Pringle, Irving, et al. (forthcoming)). While needs are now relatively well recognised it is by no means clear whether all the recommendations made have been implemented.

4.17. This has been taken one step further in the "Better Health through Better Communication" project (Hartley 2003). This was designed to improve access to primary health care services for a range of different groups of people with communication difficulties. It included development of an array of materials to modify the environment of the primary care practitioner's premises. Similarly, good practice guidelines for working with people with CSN have been produced for support workers and personal assistants (Scope 2002). The charity SENSE have published a toolkit for working for older people who have hearing and visual impairment, which provides a list of guidelines for promoting communication access over a variety of communicative media such as one to one interaction, communicating over the telephone, by text phone or in written correspondence (Sense 2006).

4.18. One of the key issues is the level of training received by those likely to be working with groups of people with CSN in health and social care settings. One such programme, called the Communication Access Toolkit has been developed for providers of health, social care, voluntary and private services. (Parr, Pound and Hewitt 2006). Developed by Connect (a voluntary sector organisation based in London) with and by people with aphasia, the Communication Access Toolkit is a training programme and resource that enables service providers to make their service accessible to people with a range of communication disabilities. The training is structured into eight modules that build up a set of core concepts and strategies that service providers can use to make their services communicatively accessible. Part of the programme involves enabling service providers to understand and identify the barriers faced by people with communication disabilities when using services. This is done through thinking about stories, drawn from the experiences of people with aphasia, that depict different types of obstacles as they are played out in different service settings. Six different scenarios are used: visiting a GP, admission to a hospital ward, an outpatient appointment, routines in a residential care setting, taking part in a volunteer led support group and having a service provider make a home visit. Service providers then develop practical skills and techniques to make their service accessible, by attending to and adapting their service interactions, documents and environments.

4.19. Healthcare professionals should also receive training in involving patients with CSN in the decision making process as a means of removing barriers to healthcare service. For example a study for improving communication access in healthcare decisions for people with aphasia trained professionals by providing those involved with the knowledge and skills of supporting communication access. The study successfully increased team members' knowledge and skills in communication access, their understanding of access and inclusion for aphasia. There was also a shift in attitude from placing the responsibility for communication access upon the individual to a shared responsibility by all parties (Simmons-Mackie, Kagan, Christie et al. 2007).

HEALTH AND SOCIAL CARE - KEY POINTS

Problems identified

- Healthcare services are still failing to meet the needs of individuals with CSN.
- In spite of initiatives to improve the communication skills of healthcare staff, their knowledge and understanding of CSN may be limited; e.g, communication difficulty may be misinterpreted as a sign of poor cognitive function.
- Poor communication between healthcare staff and people with CSN may compromise accurate diagnosis and effective treatment. The specific vocabulary required to describe and understand symptoms and illness may be unavailable to people with CSN.
- There is an over-dependence on carers to report the symptoms and feelings of individuals with CSN.

Potential for improvement

- All staff working in healthcare would benefit from communication training which fosters awareness and understanding of the needs of CSN individuals.
- Simple changes to the physical environment may improve communication between people with CSN and their doctors.
- All healthcare contexts (i.e. hospitals, residential, home settings etc) and all aspects of service delivery (including written correspondence and instructions) could be improved by being considered in relation to CSN.
- A few initiatives are already under way that are focussing on developing the knowledge and skills of service providers. Some have very specific service users in mind (eg the Sense toolkit) whereas others are working towards opening up communication access to services for people with a variety of communication issues (eg The Communication Access Toolkit).

CHAPTER FIVE: EDUCATION

Background

5.1. Education has a key role to play in our understanding of the needs of people with communication support needs. Children's first experience of society often comes through school and those with communication support needs may have distinct experiences of the school system which are outlined in greater detail below. However, education does not exclusively relate to school. Individuals with learning and other disabilities continue to have a wide range of opportunities in the further and higher education sectors.

5.2. Within the statutory education system it is now broadly accepted that children with special educational needs are, in the main, best provided for in mainstream schools within their community. UNESCO's 1994 Salamanca Statement triggered a major revision of the way in which services are offered to children with special educational needs leading to a series of policy initiatives across the UK (DFES 2004) of which the most recent in Scotland has been The Education (Additional Support for Learning) (Scotland) Act (2004). The Act aims to ensure that all children and young people are provided with the necessary support to help them work towards their fullest potential, and that, where possible, they should be included in their local school. It is now understood that the system needs to address the individual child's needs in a flexible manner so that schools are able to respond to those needs appropriately at different points in the child's educational career. The Education (ASL) Act also promotes a more integrated model of service delivery built around the child's needs and collaborative working among all those supporting children and young people and their families. Nonetheless, concerns have been raised about the "presumption of mainstreaming" for all children, especially those with autism and emotional and behavioural difficulties (Pirrie, Head and Brna 2005).

5.3. One of the key components of an adequate support system is integrated policy to identify and manage the needs of all children (DFES 2003; Scottish Executive 2005). This is particularly relevant where different public agencies are involved – eg. education, health and social services. Allied health professionals, such as speech and language therapists and occupational therapists, feed into this process of support for individual children with additional learning support needs. Although, historically, such professional groups, with their close association with the health system, have tended to work with children outside the context of the school environment i.e. within clinics or hospitals, this has been changing both within the NHS (Scottish Executive 2002) and in terms of the interaction between other agencies. Indeed it is now common practice for speech and language therapists, and perhaps to a lesser extent occupational therapists, to offer the greater part of their services within the school, their practice embedded within the curriculum. There remain groups of children with complex health needs who require focused attention from an individual therapist but it is now assumed that, even for these children, best practice requires services to be delivered within the classroom (Carlin 2005) and the playground (Wooley, Armitage, Bishop et al. 2005). Inevitably such changes offer challenges to those concerned and this has led to the pressure to develop models of best practice that can be adopted for use within the educational context.

5.4. An area that has attracted considerable interest in recent years, especially for the professions covered by this review, is that of children's mental health. There is considerable pressure to integrate health, social care and educational systems delivering services to children experiencing difficulties in relation to their mental health (PHIS 2003). While many activities are designed to be community based public health interventions involving nursery and teaching staff and more generic practitioners, occupational therapists and speech and language therapists are commonly involved in providing specialised services for the more severe complex or persistent mental health problems where assessment and treatment are the core function (Scottish Executive 2005). It is now also recognised that many of the children referred to specialist services such as Speech and Language Therapy are at risk of mental health problems.

5.5. Good models of practice are underpinned by systematic review and clinical guidelines (RCSLT 2005; RCSLT 2006). There is now a range of such published guidelines, but these are usually derived from the literature and are thus sensitive to the nature of that literature. For example, gaps in the literature and low quality of available evidence will limit the strength of any recommendations and models of good practice that emerge from the existing evidence base. There are many gaps in the evidence base and as a result services commonly develop their own, more informal, guidelines reflecting custom and practice. A number of such guidelines related to the ASL legislation are available within the geographical area covered by the present project (Scottish Executive 2005; Midlothian Council 2004; City of Edinburgh Council 2004). There is also an increasing emphasis on the role that parents can play in the process of identifying and contributing to the support of children with additional support needs (Enquire 2005). Key variables in such guidelines include the range of children covered by a given service, the severity of the difficulties experienced by those needing intervention, the intensity and duration of the support provided, and the extent to which face to face contact is provided by the specific professional concerned or a non specialist professional, such as a teacher or an untrained assistant whether provided within the health system (ie. a speech and language therapy assistant) or within the education system (a teaching assistant). It is also important to recognise that good practice results from a combination of teacher and therapist input, parental involvement and an integrated management system designed to support practitioners (Law, Lindsay, Peacey et al. 2000).

5.6. There are a number of variables beyond current educational policy that affect the model of service delivery employed. Of these, one of the most persistent is the supply of therapy staff. While this is not necessarily true of the local context, it is often difficult to recruit and retain therapy staff and this can reduce the scope of service delivery, for example restricting coverage and having a negative effect on waiting lists within the service (Scottish Executive 2003a). This, in turn, can affect the skill mix of the service providers with pressure for less qualified but more readily available staff to fill gaps in services. One solution to the problem of availability of staff is to plan services that include specialists overseeing a larger group of relatively untrained practitioners, whether speech and language therapy assistants, occupational therapy technicians, or the teaching assistants found in most schools. While appealing both as a practical solution to the availability of therapists and in terms of the coverage needed to provide support to children within their local school the implementation of a "consultative model" is not always straight-forward (Law, Lindsay, Peacey et al. 2002). For example, there is concern that services that are addressed indirectly may lack the specificity focus and intensity of services provided by specialists.

5.7. Clearly different children have different needs and the system needs to be sufficiently responsive to this varying demand. It has been suggested that it may be useful to conceive of a number of different levels of need (Gascoigne 2006). The first of these might be termed *the population level* where provision is characterised as modifying curriculum delivery to improve the learning of all children. In this example good practice reflects what best meets the needs of children with additional support needs, but rather than working with the individual child, the decision is made to extend that practice out to all children. Examples here might be adapting strategies used with children with developmental co-ordination disorders or specific language impairment to help the organisational and listening skills of all children. The second level is aimed at *targeting vulnerable children* and is characterised by the use of specific intervention packages targeting the needs of individuals or groups of children with specific difficulties. This level would typically be carried out by learning support staff under the guidance of the therapist. The third level is aimed at *providing specialised services* to children with the most serious learning needs. At this level the child's needs are sufficiently complex to warrant individual attention from the therapist. There are various different versions of this model but the principle of a differentiated level of input relative to need is clearly a central tenet of the provision for children who have additional support needs. Although this approach was developed for England the same has been developed for Scotland at both a national (For Scotland's Children 2001) and local level (Mitchell, Smith and Stevens 2005).

Barriers

Statutory education

5.8. As indicated above, for many children with communication difficulties their first experience of services is through their health service, but with the increasing accessibility of nursery places for all and the extension of education services into nurseries it is commonly education services which have the central role in interacting with parents and children. A snapshot of the experiences of parents going through the process of having their child identified as being in need of support services was taken by the children's charity AFASIC (1993). As the name of this report, *Alone and Anxious*, suggests, for most parents their interaction with services, whether within the education or the health system, was considered to be negative. Although such tensions remain, the ground has shifted somewhat since then. Services in nursery and primary school have developed to a considerable extent and there is an increased awareness of the needs of children with developmental speech and language difficulties. There is also an acute awareness that there is very little provision to support transition across primary and secondary school and into employment, and there is almost no support for children when they are in mainstream secondary school. The barriers to effective provision in this area have been well described (Law, Lindsay Peacey et al. 2000) but tend to focus on problems at a system level such as the co-location of practitioners or the co-terminosity of authorities. There is relatively little in the literature about the attitudes of young people with CSN themselves to their difficulties, although there are clear moves to increase participation of children and young people in the educational process (AFASIC 2002).

5.9. Although there is a great deal of literature about the tested performance of children in schools there is less information about the experience of school as far as children with CSN are concerned. One way of assessing this is to look at the way that children are treated in class, and specifically the extent to which they are bullied. The largest UK study of language impaired children examined the risk of bullying in this population and identified a three fold risk in language impaired children relative to children with normally developing language skills (Knox and Conti-Ramsden 2003). The rate for the latter group was 12% and for children with difficulties 36%.

This type of experience has often been reported in the deaf community where individuals have found it very difficult to integrate into mainstream schooling. The following is taken from a study of social alienation in the deaf community with a deaf adult looking back at his experience of education in a mainstream school:

> "*I did not know how to hang around with the hearing people. They constantly made fun of me, they tried many times to put up a fight with me. Several times I was involved in a …street fight. I really don't have much of a bitter (feeling) at it all now at what happened in the past. You know I just feel sorry for them, because they did not understand me as I didn't understand them…So I think that had a lot to do with what's happening to me as a person I am now…I've become shy. I learned to be shy as I was growing up. I learned to be quiet. Most of my friends today are complaining that I keep it to myself too much...many times I (would) like to talk out interpersonal relations, insights. Many times I can't. I don't trust them. I don't know, that's the way I am. I don't get close enough to anyone who is willing to listen or share with me.*"
>
> Foster 1989 p.232.

5.10. One of the groups of children readily recognisable with CSN, are those who use alternative and augmentative communication systems (AAC). Alternative and augmentative communication systems pose some very real challenges for the school system (Kent-Walsh and Light 2003, Hunt-Berg 2005). Not only do the children have major needs as far as communication is concerned but the equipment itself poses challenges, for example in distinguishing between the cost of the equipment and the "real cost" of installing and maintaining it, and ensuring that those around the child are able to use it (Parette and Marr 1997). The role of the family and their attitudes to the equipment and the services concerned are key to successful uptake in school (Parette, Brotherson and Blake-Huer 2000) and for use in leisure (Dattilo, Light, Peter et al. 1995). There are also likely to be culturally specific approaches to the introduction and use of such equipment (Parette, Blake-Huer and Brotherson 2001, Parette and Blake-Huer 2002). Parents views as to who is most and least helpful in meeting the needs of their children can make instructive reading. A survey of stressors and supports to families of children who use AAC found that mothers relied on their parents as a source of support within the family in meeting their child's needs. Fathers, on the other hand, relied on their spouses and their spouses' parents as sources of support. Professionals need to be aware of the family systems when advising parents of appropriate use of AAC technology and available support services. As parents rely on the wider family as a means of support then professionals may include extended family members in educating families on the implementation of AAC (Jones, Angelo and Kokoska 1998).

5.11. Adults who stammer also report experiences of being teased by peers, feeling alienated by teaching staff who lacked an understanding of their difficulties, and consequently being prevented from participating in extra-curricular events such as school plays. These early negative experiences led them to avoid stressful situations such as reading aloud or speaking in public (Hayhow, Cray and Enderby, 2002).

Higher and further education

5.12. Historically, little provision was made for people with disabilities going to further or higher education. This changed in Scotland with the Further and Higher Education (Scotland) Act 2005. The authors of this piece of legislation used the term "support needs" to refer to "support for the purposes of overcoming a difficulty of learning or a difficulty in participating in learning." Although this covers the full range of disabilities it is clear from the examples given in the consultation into the development of a needs led model of funding in this sector arising out of the legislation that young people with communication support needs come within its remit Scottish Funding Council (2006). Indeed one could argue that people with CSN are in many ways a focus of this legislation because the nature of the core business in the further and higher education sectors is completely dependent upon communication.

5.13. Yet it is clear from a recent report on the views of young people with disabilities on the accessibility of Further Education that there is still along way to go (Millar and Aitken 2005). A series of reasons were cited for not accessing or having difficulties accessing existing options:

- There is a severe lack of information, transparency and awareness of FE options, a particular obstacle faced by people who have severe difficulties accessing information
- Many college placements appear to be provision rather than needs led
- Those who provide services may find it difficult to communicate with and support the communication needs of students with specialised systems of communication
- There be no local additional specialist support for students with highly specialised additional needs
- Major funding problems arise for non-specialist areas particularly transport, escorts and helps for personal care
- Where services are identified and costs are involved there are often lengthy negotiations before agreements to fund are obtained. This results in delays in gaining access to both the college placement and to support services needed to access a given course

5.14 By contrast, people who stammer appear to experience fewer problems in further education, although concern was expressed that people with stammers do not pursue further education because of their earlier negative experiences of education (Klein and Hood 2004).

5.15 There is relatively little literature associated with the higher education sector. For some people with more severe CSN there may be funding available for assistants and other help in further education, a facility which is not generally available in higher education (Knight, Sked and Garrill 2003 p.18).The experiences of a visually impaired student training to become an occupational therapist suggested that attitudes remained a barrier even at this level, and within a professional group well versed in the expectations associated with disability (Sivanesan 2003).

Attitudes

5.16. In a relatively recent study of the impact of cochlear implantation, 181 school-aged deaf children were asked to report on their psycho-social adjustment, and their parents were asked to comment on how their children were managing in school. The children generally perceived themselves to be well adjusted in most aspects of daily life. Parents too were positive. Interestingly, parents' perception of their children's progress was significantly related to the child's speech and language development (Nicholas and Geers 2003). Parents' attitudes and expectations have also been seen as critical to the update of computer assisted devices for children with cerebral palsy.

5.17. Inclusion of children in school depends, at least in part, on the acceptance of peers. A child's experience is likely to be far more positive if their peers want to play with them. This is particularly true for people with communication disabilities, and within this group those who use alternative and augmentative communication (AAC). Although there are a variety of ways of improving this (Beck, Thompson, Clay et al. 2001, Beck and Fritz-Verticchio 2003, Beck, Bock, Thompson et al. 2006), one of the main obstacles is probably that the children themselves commonly perceive AAC to be "uncool and boring" (Clarke, McConachie, Price et al. 2001). Indeed it could be argued that this very response is a classic example of the expectations of those in the child's immediate environment disabling the child.

Transitions

5.18. Transitions can be problematic for all children, but have the potential to be even more so for children with additional support needs, especially when they leave school. Guidance is now available to help young people manage this in Scotland. This became available when the new Additional Support for Learning legislation came into force on 14th November 2005 (Contact a Family 2005).

5.19. The transition from primary school to secondary school can present a new set of challenges to adolescents who rely on AAC technology. Secondary school staff may have limited experience of non-speaking children. Furthermore, the structure of secondary education can put excessive demands on pupils with specific speech and language disorders. For example subjects are taught in separate classes by different teachers, who may have varied levels of experience of this group of children, thus different communication styles are likely to have a differential impact on the communication needs of the children concerned (AAC 2000).

5.20. When young people leave the education system there are not always provisions in place to aid them with any ongoing problems they may have with their AAC device. For example if their equipment breaks or they require new updated technology – where do they turn for assistance? There may be organisations that provide assistance and support to this group after leaving school, however these services as yet may not be standard issue throughout the country (Larcher, 1995).

5.21. Transitions within education can be changing from primary to secondary, moving to a school in a different area or leaving school. In order to manage these transitions effectively the Additional Support for Learning (Scotland) Act recommends that local education authorities begin planning for these changes with other authorities such as health and social work at least 12 months in advance. Necessary information should be passed on to other schools and agencies at least 6 months before the transition occurs. For young children entering pre-school provisions planning should commence 6 months before the transition and the relevant information should be provided at least 3 months before the child starts. In the case of school leavers planning should begin at least 12 months before. Information should be passed on to the relevant agencies, such as the careers services of further education institutions, no later than 6 months before the young person leaves school (Contact A Family 2006).

Potential improvements

5.22. One of the key barriers to overcome in the education sector is that between the different professionals concerned. If these individuals are working to different goals it is probably unlikely that the child and family will have an altogether positive experience of the education system. Much has been written about this and the considerable implications for those delivering services as well as those training the practitioners concerned (Wright and Kersner 1998). Although this is true for all children with additional support needs, in schools it may be that children with CSN are especially vulnerable to misunderstanding because of the different professional backgrounds of the professional groups concerned. For example, there are clear differences in the way that speech and language therapists and teachers are trained to conceptualise disability.

5.23. A highly differentiated set of recommendations have been made as to how to include children in the decision making about their needs in school, for example in terms of eliciting the views of the young person, and conducting meetings to discuss the child's needs (AFASIC 2002). These have much in common with the inclusion of children with a wide range of different needs. The nature of the communication difficulty experienced by the child means that there are likely to be specific issues for this group, but the principle of participation is now well established.

5.24. There has been an increasing emphasis on consulting children directly about their needs within the system and this process has been extended to people with learning difficulties, and by extension communication support needs (Lewis 2004, Lewis and Porter 2004). But there is relatively little literature on how this is done with children who find oral and written communication difficult.

5.25. One area which is starting to become potentially very promising is encouraging children to use new technologies to support their learning. By this we mean going beyond the idea that a relatively small group of children need access to alternative and augmentative communication towards a position where a much wider range of children use texting and e-mail as a way of communicating their needs and supporting their school work. This type of activity remains in its infancy at present and has to ensure that it can deal with the potential resistance from adults who might see this mode of communication as degraded (Plester and Wood 2006, Conti-Ramsden (forthcoming)). Apart from the obvious appeal of the technology, this approach may be able to enhance the children's ability in retaining instruction for assignment and develop their interactive skills.

5.26. Including people with communication and other disabilities into further education has become a focus of considerable interest in recent years. For example it has been shown that careful management of people in further education using AAC has considerable potential (Foley and Staples 2003).

5.27. The attitudes of the public as a whole are a key dimension of any policy of inclusion. Currently there is very little evidence available about attitudes to CSN, partly because the term is relatively new. An interesting recent development has shown that there may be a case for encouraging people to volunteer to work with children with disabilities (Fichten, Schipper and Cutler 2005). In this study adult volunteers working with children with physical disabilities and hearing impairment were assessed before and after starting to work as volunteers on scales of social distance and stereotyping. Not only does this appear to increase their understanding of the needs of the children concerned, but it also appears to have a beneficial effect on individuals' attitudes towards adults with disabilities.

EDUCATION - KEY POINTS

Problems identified

- Many children with CSN are subject to bullying. Adults report negative interactions with school peers and teaching staff which impact on their adult lives.
- Children who rely on AAC technology (artificial speech aids) often have negative attitudes towards this mode of communication. Their difficulties increase in secondary school and beyond, due to multiple teaching and communication styles.
- Although access to further education by people with CSN has improved, some barriers still remain and transitions to higher education are difficult.

Potential for improvement

- Full integration within the education system requires measures to promote awareness and understanding of CSN amongst staff, peers and the public.
- Managing the needs of children and their families can be improved through collaborative goal setting between professionals from different disciplines.
- Children should be included in decision making about their CSN; e.g, children using AAC may choose to adopt more accepted means of communication technology eg. text messages or email.
- All relevant staff should be familiarised with the child's communication needs and style of communication in order to adapt accordingly.
- AAC users need ongoing support as they move through the education system.

CHAPTER SIX: EMPLOYMENT AND FINANCIAL SERVICES

Background

6.1. The employment of people with disabilities has been on the agenda for many years and has been the subject of a wide range of legislation. It has long been recognised that the attitudes of employers are a key issue (Whigham and Mattson 1969). In many ways the issues are more straightforward when the nature of the disability is explicit. For example it may be easier to put facilities in place to improve the employment opportunities for those with a visual impairment than it is to provide for the needs for less apparent communication support needs.

6.2. While many individuals with CSN will seek and find employment there will also be numbers within this group likely to rely on financial assistance during periods of unemployment. Therefore this chapter will also consider people with CSN's access to and experience of financial services.

Barriers

6.3. Broad workforce issues are relevant to the discussion. Major unemployment such as that experienced in the UK in the 1980s is likely to have a differentially negative effect on the employment prospects of someone with CSN. But with increased employment greater opportunities arise as long as they are in the right sector and do not place too much pressure on the communication skills of the individual concerned.

6.4. It is common for people with CSN to experience difficulties finding work. For some this may be partly a function of their confidence in interview situations or in expressing themselves on paper during the application process (Klein and Hood 2004). They may be particularly poorly suited to the type of "communication" focussed job which has come to play such a large part of the employment opportunities currently available.

6.5. While this is true for all people with communication disabilities irrespective of whether they are going back into the labour market or renegotiating their terms of employment following, for example, a stroke, it is particularly sensitive for young people entering the labour market for the first time. When they have little to offer in terms of experience their communication skills and confidence are likely to make the most difference to whether or not they obtain work. This has proved to be a major problem for young people with developmental language difficulties as they leave school (Stone 1992) and the same is true of a wide range of other groups of young people entering the increasingly "communication focussed" labour force.

6.6. It has been suggested that about half of the disabled population are unemployed (Riddell and Banks 2001). Although it is not quite clear how the population with CSN overlaps with this group it is likely that most people with learning disabilities would be seen as having communication support needs of one sort or another. There is a major concern about the growing number of people claiming incapacity benefits against a background of increasing employment opportunities in the population as a whole. This appears to be particularly true in Scotland (Riddell, Banks and Tinklin 2005). This is probably off-set by an increasing number of people with learning disability entering the workforce. This clearly has all sorts of positive benefits in terms of increasing independence and contributing to the economy, but it can lead to its own complications as far as the individuals are concerned as they have to learn to negotiate all the other aspects of public life that accompany employment. For example, getting to and from work can be problematic for individuals with autism. Those individuals may experience anxiety in every day situations such as queuing at the bus stop, negotiating routine mechanisms such as getting on and off the bus and coping with delays (Broach 2003). For people with more marked needs the experience of going into work may be rather better than it is for those with less identifiable difficulties. For example, from interviews about employment with a group of people using alternative and augmentative forms of communication the majority of respondents reported satisfaction with their job duties, immediate supervisors co-workers and current salaries. The real problem for this group was the sizeable proportion who were dissatisfied with their opportunities for progressing (Light, Stoltz and McHaughton 1996).

6.7. The largest single review of services for people with learning disabilities, carried out by Emerson et al. (2003/04) interviewed 2898 people with learning disabilities about a range of experiences and access to services. A quarter of the interviews were carried out solely with the individual with learning disability, the rest were accompanied by a support person. The youngest person they interviewed was 16, the oldest 91, and half the people were under 30 years. Only 17% of people with learning disabilities who were of working age had a paid job. The figure for the population as a whole is 67% of men and 53% of women. Two thirds of the people with learning disabilities who were unemployed said that they would like a job. It would be reasonable to assume that the majority of those interviewed had some sort of communication support need, although this issue is not addressed directly. All the interview materials were modified to increase their communication accessibility. Almost all employed respondents (92%) said that they liked their jobs but 13% of them said that they had been bullied at work. Those most likely to get a paid job were those who:

- Had lower support needs
- Did not have a long standing illness or disability
- Were male
- Lived with fewer people
- Saw friends who had learning disabilities less often
- Were white
- Lived in an area with higher employment
- Had good general health
- Saw friends who did not have learning disabilities more often

6.8. People with a stammer have commonly reported negative experiences in the workplace. A review of the experiences of this group has highlighted these issues (Crichton-Smith 2002).With specific reference to employment they report that confrontation in the workplace was often viewed as a necessary, if daunting and unrewarding, exercise and commonly leads the individual with a stammer to try to avoid social situations, as described below:

"*There are things I would avoid doing…there were other things which I would take on against my better judgement and make a mess of. It was a very fraught time really*

"In public I avoid where I can, I get my daughter to do it for me."

Crichton-Smith p.346

6.9. Career planning that promotes career awareness in advance of school leaving may be a key ingredient here, and it has been suggested that aspects of employment can be particularly problematic for people with visual impairment (Salomon and Paige 1984). It is intended that career planning will improve the career decision-making process for this group and equip the individual with employable skills that make employment more accessible for this CSN group. Common barriers include attitudes of employers, transportation, reading print, obtaining adaptive equipment and accommodations, limited job opportunities associated with visual impairment, personal fears and uncertainties and recognizing faces (Crudden and McBroom (1999).

6.10. Perhaps not surprisingly the level of impairment experienced by an individual, whether it is the severity of the speech or language difficulty or the level of visual acuity, affects their level of employment. One feature which has started to emerge from the literature on visual impairment is the concept of under-employment, that is the likelihood that they will be employed at a level below their education and skills. In a recent study from New Zealand under-employment was reported to be of the order of 37% (La Grow 2004). Interestingly in this study it was suggested that the severity of the disability did not affect whether an individual was underemployed or not. Women and those with lower initial levels of education tended to have higher rates of underemployment.

6.11. Once in work it does not necessarily become easier. For example, people who are deaf are sometimes considered to be passive and withdrawn in the workplace but this may be largely a function of the environment and its communication accessibility, as described below:

"Before I worked for the Deaf organisation, I used to work with the hearing. I would get on with my job although there was a communication barrier. Since I have worked for the deaf organisation, it has really opened my eyes. All the information is available, and accessible. It was a great culture shock for me. Now if I have to go back to work with hearing – no thank you. I would rather be unemployed."

Kyle, Reilly, Allsop et al. 2005 p36

6.12. It is clear that employment represents a significant challenge for individuals with CSN. Klein and Hood, for example, report that nearly three quarters of a group of 232 people who stammer believed that stammering affected their chances of being employed in the first place and considered that their stammer would affect their chances of promotion (Klein and Hood 2004). Of particular concern is the relationship with people in senior positions at work rather than colleagues (Anderson 2005).

6.13. Stroke can also have dramatic effects on the employability of the individual. Many who experience stroke are beyond employment age but there is a substantial group of people who have strokes at a relatively young age for whom this issue is central. One of the few studies to directly address the needs of this group is Banks and Pearson’s 2002 study of fifty people who had strokes between 18 and 49 years (Banks and Pearson 2002). One third who had been employed prior to their stroke returned to work. Their experience suggested that employers tended to be supportive initially but there was little understanding of the type of difficulties that people with stroke were likely to experience (tiredness, problems with concentration and memory) and as a result they were often reluctant to make the necessary adjustments to the work environment. The result, then, is a transition back into the workplace for a substantial proportion but a gradual withdrawal without necessary adjustments.

6.14. One of the few studies to address employment issues across a group of people with CSN (people with hearing loss, aphasia, voice disorders, post-laryngectomy speech, dysarthia and stuttering) has suggested that most of the issues are common. Principal barriers to work re-integration include ambient noise, tasks requiring speed, having to speak to groups of people, and the attitudes of others and their knowledge about communication disabilities (Garcia, Laroche and Barrette 2002). For example, individuals whose CSN is a result of neurological difficulties such as aphasia or speech difficulties have difficulty completing tasks quickly. Employer expectations of returning to full workload were viewed as a potential barrier for these groups. All CSN groups reported speaking to other people as a barrier. However, this varied across CSN groups, for example individuals with speech difficulties or who stammered had difficulties speaking to bosses, individuals with speech difficulties and aphasia had difficulties communicating with clients, while groups with hearing impairments experienced difficulties understanding people with accents.

6.15. One aspect of employment which can have an impact on families is the employment of the main carer. It is sometimes assumed that the employment of other members of the family is not affected by the needs of people with communication support needs. In fact, there is likely to be an effect on the employment of other parties and a resulting loss of family income associated with this, especially amongst those who are self employed. In a recent submission to the Equalities Review the Disability Rights Commission reported that 39% of mothers of disabled children were in work compared to 86% in the non-disabled population, with parents of disabled children facing on average three times the costs of parents of non-disabled children in bringing up their child (DRC 2005). This is clearly also linked to the provision of childcare for the parents of disabled children (Kagan, Lewis, Heaton et al. 1999). This pressure on the employment of the parent may be particularly salient for the parents of children with autism (Blanchard, Gurka and Blackman 2006).

6.16. A study of the perspectives of 14 people with learning disabilities in employment revealed that none of the people in this sample were capable of completing their own tax forms, relying on the assistance of other employees or support staff. In 2 of the 14 cases the families of the employee with learning difficulties took over management of their finances (Reid and Bray 1998).

6.17. A survey carried out by Disability Agenda Scotland (2000) found that many disabled applicants complained about the time it took the benefits agency to deal with claims. Secondly, there appears to be inconsistency in the decision making process. This is illustrated in the following comment from the Disability Information Service:

> *The majority of first time applicants for DLA* [Disability Living Allowance] *are being turned down – which means going through the review/appeals process. We find that most appeals are then successful, indicating that the way DLA applications are dealt with is flawed.*
>
> Disability Agenda Scotland 2000

6.18. Many people reported problems in accessing advice regarding welfare rights and there appeared to be a lack of interpretive services available, for example in the case of users who required sign language. Furthermore, 97.3% of disabled people applying for Disability Living Allowance (DLA) reported that they had found the application form difficult to use and 82.9% required assistance completing the form. Respondents described the form as *"confusing and contradictory" (Disability Agenda Scotland 2003).*

Attitudes

6.19. There is more in the literature about the response of people with communication support needs to the lack of employment possibilities, and correspondingly less on what the employers feel they are able to do. In part, this is because it is difficult for employers to indicate that they would not employ individuals with disabilities given the current legislation. Nevertheless employers agreed that stammering decreases employability and interferes with promotion possibilities, even though they felt that it had no bearing on job performance (Hurst and Cooper 1983). One innovative approach to working with those with disabilities to help them get back into employment is the "Ticket to Work" programme in the US, which is used by people with disabilities to obtain vocational rehabilitation services with the goal of returning to work. Such a scheme depends on the capacity of the employer to respond effectively. Examining the performance of the scheme for those with visual impairment, Capella-McDonnall reported that many employers raised a wide range of concerns about employing people with visual impairments (Capella-McDonnall 2005). Interestingly, employers seemed to have started to focus on people with specific disabilities, and, while they might take on people with mental health or developmental problems, they would not necessarily do the same for people with visual impairments. One perspective on the role of employers is the employment discrimination experience of Americans who are deaf or hard of hearing (Bowe, McMahon, Chang et al. 2005). The majority of allegations of employment discrimination were filed against large employers with over 500 workers, and the most common grounds for dispute were initial hiring, provision of reasonable accommodation and discharge.

6.20. In terms of attitudes the study referred to earlier in the chapter reports that “a lack of respect and a tendency for others to assume that their intelligence and mental skills were affected” may be a reflection of society’s lack of awareness and understanding of CSN (Garcia, Laroche and Barrette 2002). In this study some employers had concerns that this may mask the individual’s capacity for work

6.21. Benefits are a major concern for people with communication support needs, as they are for people with other disabilities, but in many ways their communication difficulties make the benefits system very difficult to understand and negotiate. For example, in a recent survey in Scotland of the needs of people with autism very few people with autism and over a third of their carers said that they did not understand the benefits system (Broach 2003). With regards to accessing advice concerning benefit entitlement many disabled people have encountered problems with staff who do not understand the complexity of their needs, although there are indicators that some areas within the benefits agency are taking measures to implement staff training.

Transitions

6.22. Difficulty in finding or difficulty returning to work after an incident, such as a stroke, which affects communication inevitably has a knock-on effect on the financial status needs of the individual. There is also the added burden of then negotiating the services which are available to support people in financial difficulties.

6.23. Concerns have been raised regarding the transition phases, such as going on work training. For example:

> *“When someone comes off Training for Work there is a long waiting time before the benefits are re-instated despite being told that this is a quick process”.*
>
> Disability Agenda Scotland (2000), p11.

Secondly, individuals receiving benefits are usually expected to submit renewal claims 6 months before the existing award runs out. In some cases claimants rush to submit their renewal claim too early and their current benefit is withdrawn (Disability Agenda Scotland 2003).

Potential improvements

6.24. While most of the foregoing discussion has focussed on the experience of individuals, recent developments have started to stress the role of social networks as a means of facilitating person centred planning for both obtaining work and supporting an individual in employment. This has been shown to be a key feature of the way in which people use augmentative and alternative forms of communication (Carey, Potts, Bryen et al. 2004). An experimental intervention to ascertain the effect of specific modifications to facilitate the inclusion of people using AAC demonstrated that a range of supports, including job coach social facilitation training and eliciting co-worker support for social integration, were necessary to help people using AAC to integrate effectively into the workforce (Mautz, Storey and Certo 2001). There may also be value in using "communication books" as a way of reflecting the distinct needs of the individual (Storey and Provost 1996). Communication books contain pictures and photos of the individual, their families and friends to help people with CSN to initiate conversations or to answer questions. The books can be used in communication by combining spoken words and phrases with the pictures depicted in the book.

6.25. Services for the blind and visually impaired people are already in place to provide work placements for those concerned, and there is extensive legislation to support people with visual impairment into employment. This process is under constant review and new ways are being developed to ensure that appropriate modifications are available in the work place (Gamble, Dowler and Hirsch 2004) and to maximise the uptake of these services (Kirchner and Johnson 1997). Such "rehabilitation providers" act as mediators between the people with visual impairment and the employers, and are in a good position to articulate the needs of both groups (Crudden, Sansen and Butler 2005). For example, Crudden and colleagues have identified a number of positive innovations that these providers can put in place to address the four main barriers experienced by people with visual impairment, namely attitudes, transportation, access to print and the administrative and consumer barriers. One of the identified themes in this research was the need to further develop skills training related to literacy especially with regard to Braille, large type, computers with varied outputs and closed-circuit TVs. Finally, the blind community has also explored the value of "social networks" as a way of supporting people with visual impairment into the workplace (Roy, Dimigen and Taylor 1998). There is a case for considering how these successful developments can be adapted and rolled out for others with Communication Support Needs and used as a model of employment access for individuals with CSN.

6.26. In considering employment barriers common to all groups, Garcia et al. suggest that:

> "*When taken separately, most of the barriers in the workplace can be eliminated fairly easily by most organisations. Noise can be reduced, employees can be given access to e-mail to reduce the number of tasks requiring the use of the telephone, employees can be "eased into" and trained with groups of increasing size and in-services can be given to colleagues to help them become aware of the nature of different communication disabilities*"
>
> Garcia et al. (2002), p206.

6.27. Nonetheless, whether such adaptations are effective depends on the awareness and responsiveness of the employer and of the ability of the person with the communication disability to manage with the modifications that are made. Superficially it would be reasonable to assume that people with more severe difficulties would find it more difficult to make the necessary adaptations. It is important to recognise, however, that adults with mild acquired difficulties following, for example a mild stroke, may be particularly at risk because they are not themselves aware of the impact that their difficulties may be having on their performance at work. Additionally it may be equally difficult for the employer to recognise that adaptations are merited.

6.28. It is important to stress that there are already a number of mechanisms to help people with disabilities to get into the workplace in Scotland, and these have recently been reviewed in some detail (Riddell, Banks and Tinklin 2005). Although they cover a wide range of mechanisms and report on a range of policy impacts we were not able to find any which specifically address the needs of people with communication support needs. Lastly, when individuals are temporarily or permanently out of work and are relying on benefits there needs to be more clarity in the decision making process. The length of time for decision making regarding benefits should be reduced and monitored. Disability awareness training should be provided to benefit agency staff. Welfare advice and interpretation should be more accessible. This could be improved by a mapping exercise to identify services and gaps. (Disability Agenda Scotland 2000, 2003).

EMPLOYMENT AND FINANCIAL SERVICES- KEY POINTS

Problems identified

- Although employers may report positive attitudes towards employing people with CSN, these individuals are still more likely to be unemployed or employed at levels below their education status, and may be at a disadvantage for promotion opportunities.
- Even supportive employers may lack understanding of CSN and make only limited adjustments, leading to a gradual withdrawal of people with CSN from the workforce.
- Common employment barriers for people with CSN are noise, tasks requiring speed, speaking to groups of people, attitudes of others and their knowledge about communication difficulties.
- Employment experiences of families and carers of people with CSN may also be affected, e.g. parents of children with CSN may have difficulty in finding suitable childcare which allows them to work.

Potential for improvement

- The mechanisms and policies which are already in place to help people with disabilities get into the workplace could be extended to address the specific needs of people with CSN.
- The use of “social networks” may be useful in helping some groups of people with CSN into employment.
- Many of the barriers mentioned above can be removed through the use of relatively straightforward adaptations.

CHAPTER SEVEN: CRIMINAL JUSTICE

Background

7.1. The challenges for people with CSN within the criminal justice system is an area which has only recently received attention in the literature. This applies to people with communication support needs both as witnesses/victims and as offenders.

7. 2. There is good evidence that a higher proportion of people in juvenile offenders' institutions and prisons have communication support needs than in the general population, although the proportion varies from study to study. Bryan reported that over 40% of a group of young offenders had scores significantly below average for their naming ability and 23% below average for their comprehension (Bryan 2004). In a recent annual review of speech and language therapy provision in a young offenders institution, 18% of young offenders were identified as having communication difficulties (Robson 2006). This can be compared with the 7-8 % which would be likely to be identified in the general population (Tomblin et al. 1997). Similar discrepancies have been observed for people who stammer in the prison population. The clear message is that many offenders have histories of poor speech, language and literacy skills and this is likely to be manifested in any prison population. The difficulties that these individuals experience are likely to impact on their earlier school performance and on their ability to access employment and some rehabilitation services.

7.3. The reverse has also been demonstrated. People with disabilities are also much more likely to be the victims of crime than those without disabilities (Petersilia 2001). There are no directly comparable figures for people with communication support needs, but given the considerable overlap between developmental difficulties and communication difficulties the same is likely to be true. It may be that the difficulties that individuals may experience can increase the risk of crime, and of course their difficulties are likely to affect their ability to report a crime. The suggestion is that rates of crime are likely to be of the order of 3 or 4 times higher in the population with intellectual disabilities. The details are provided in Table 7.1 below.

Table 7.1 Victimisation risk by intellectual disability (in percentages) cited in Petersilia 2001

	Intellectually Disabled?		
Crime	**Yes**	**No**	**Relative Risk**
Assault	11.4	4.0	2.8
Sexual Assault	3.2	0.3	10.7
Robbery	5.1	0.4	12.8
Total Personal	19.7	4.7	4.2
Auto Theft	0.6	0.7	0.9
Theft	7.6	6.4	1.2
Burglary	11.4	6.4	1.8
Household Theft	4.4	3.7	1.2
Total Property	24.0	17.2	1.4

(Data From Wilson and Brewer 1992)

Barriers

7.4. People with communication support needs are likely to have difficulty interacting with those involved in the criminal justice system. The verbal nature of the proceedings and the highly formulaic procedures involved are challenging for the public as a whole to negotiate, but for those who have difficulty in understanding what is being said to them or expressing themselves these problems are exacerbated. This group may also have their credibility as a reliable witness questioned due to common misconceptions regarding individuals with communication difficulty. For example, a man with cerebral palsy's report of abuse was not followed up, because in the eyes of the police he was not deemed a credible witness due to his reliance on AAC (Togher, Balandin, Young, et al. 2006). Even with the growing acceptance of sign language, it would appear that this group may still be judged intellectually incompetent or incapable of communicating reliable evidence.

7.5. Similar to other groups of people with disabilities, such as those with learning disability, individuals who use AAC are also vulnerable to crime and abuse (Lever, Lightholder, Bryen et al. 2003). One of the common barriers to reporting crime in this group is that AAC technology does not enable them to provide full and coherent evidence. For example often AAC technology does not have the vocabulary to adequately describe experiences of sexual abuse (Lever 2003).

7.6. In a recent review of the practice in the Children's Hearings System in Scotland a series of recommendations were made for helping young children to understand the process (Scottish Executive 2006). A number of children between 5 and 18 years of age were interviewed, none of whom were explicitly identified as having communication support needs. However, the recommendations in terms of improving the participation of those concerned were similar to those identified for individuals with specific support needs. The emphasis was on participation within the process, which is a hallmark of the children's panel approach, with greater emphasis placed on the ability of the child to understand what is being said and express their own views. And this can be as relevant for the paperwork around the process as it is in the discussions themselves, as described in the following quotation:

> "*The first thing I knew of the date of my hearing was when a recorded envelope came and on the back was a stamp 'Report to the Children's Panel'. It made me feel ashamed and I couldn't understand the language on the letter they sent me.*"
>
> Milne 1992: 14 cited in SE 2006 p.61

7.7. One of the key problems identified in the literature is the tendency for young offenders to have poor oral language competence (Snow and Powell 2004). This is likely to have an impact on their ability to make sense of any involvement with the criminal justice system.

7.8. One aspect of this involvement is the ability of people with poor communication skills and moderate learning disabilities to provide adequate testimony during the legal process (Gudjonsson 1993). In particular, concern has been expressed that courts may now be able to take evidence, especially by way of false confession, from certain types of defendants (those with mental health problems or learning disabilities tible). Although the courts are able to pay due regard to this there remains a risk that such vulnerable adults may be more at risk of self incrimination.

7.9. The Newcastle (UK) report described above gives a number of examples of people finding it difficult to get their needs met in the criminal justice system (Knight, Sked and Garrill 2003), for example:

> "*I was originally told that I would not have to give evidence, but then I was called to do so at very short notice. The court interpreter was off sick and no-one had thought to find out what I needed to be able to communicate. When the police realised that I needed help they asked me if I knew any court experienced interpreters! In the end I got a friend to help me. As a consequence, I felt that my case was not presented well and I lost the case.*"
>
> Knight, Sked and Garrill 2003 p.18

7.10. The same report also cites the specific example of people with a laryngectomy.

> *"Laryngectomees (and other neck breathers) cannot be effectively breathalysed, for that reason they may need to be arrested and taken to a police station for samples of body fluid to be tested. One man was detained for some considerable time, as the police were unwilling to allow his wife to communicate for him. Because of the stress his alternative speech had deserted him".*
>
> Knight, Sked and Garrill 2003

7.11. Recent guidance related to the Vulnerable Witnesses (Scotland) Act 2004 has specifically identified the requirements of people with special needs. Although the target group is obviously wide it includes people with significant social or learning disability or physical disability or impairment which could affect the giving of evidence (Scottish Executive 2005). This document recognises that the service may have difficulty recognising the needs in the first place and specifically warns against over or under estimating people's abilities.

Attitudes

7.12. No published evidence was identified related to the attitudes of professionals in the criminal justice system to involving people with CSN.

Transitions

7.13. There is no published evidence specifically related to the transition between different aspects of the criminal justice service although by definition the process is marked by a series of steps through which the individual must pass.

Potential improvements

7.14. Guidance has been issued regarding the management of people with communication support needs in the criminal justice system. The main messages tend to focus on sensitivity to the needs of those involved but such general recommendations are supplemented with specific techniques which have been shown to be useful with specific groups. For example, the Nova Scotia Public Prosecution Service (Nova Scotia Public Prosecution Service 2002) updated a document related to practice concerning both investigation and prosecution of cases involving people with special communication needs. This includes assessing the victim or witness' ability to communicate their needs and their ability to understand oaths etc. and allows for the provision of specialised equipment or interpretation services. The witness intermediaries scheme in England has specifically focussed on the support needs of people with communication disability (HMSO 2006a, 2006b) In Scotland, the Vulnerable Witness (Scotland) Act (2004) has made recommendations for appropriate procedures for managing children and groups of people with disabilities who are called upon to be witnesses in court. Although these recommendations are not specifically associated with communication support needs they have the potential to have a direct effect on their involvement in the judicial process. There is a suggestion that it would be helpful to have meetings prior to the discussion of a given case to ascertain the level of the individual's ability to understand and engage in the legal process (Scottish Executive 2005). The same document provides a specific set of recommendations as to the identification of vulnerable witnesses and suggests a series of strategies for facilitating the giving of evidence in open court (ie. using TV, symbol systems, Picture Exchange System (PECS) etc.). Similarly, seating and lighting may be key issues for people using alternative and augmentative systems (Balandin 2000). Preliminary findings from a study using "Talking Mats" with young offenders has also demonstrated promise (Robson 2005). This is a visual technique which utilises picture symbols to aid comprehension and responsiveness for individuals with varying degrees of CSN. The talking mat is a textured mat used to display and organise the picture symbols. The picture symbols can be attached to the map with velcro, this allows the individual with CSN to organise their thoughts. Talking mats can be used in a variety of contexts to discuss a variety of topics such as likes/dislikes, relationships and emotions, providing that the relevant pictorial system containing appropriate vocabulary is used.

7.15. Specific skills are needed when interviewing people with CSN (Snow and Powell 2004, Agnew, Powell and Snow, 2006). For example, Snow and Powell (2004) recommend that professionals dealing with young offenders with oral language difficulties should be aware of the following:

- The communication needs of young offenders may not be easily identifiable and may manifest as boredom or resistance to participation in the interview.
- Young people with oral language difficulties may be able to communicate effectively during informal communicative exchanges, however they will have difficulties in formulating coherent responses to formal questions that contain non literal language.
- Interviewers will need to modify their language to meet the needs of the interviewee.
- Interviewers should verify the interviewee's level of comprehension by asking the same question in different ways to ensure consistency in responses.

- Interviewers need to allocate more time for the individual to answer questions and they should indicate clearly which aspects of responses are incoherent or lacking in detail.
- Legal practitioners would benefit from specialised training in the identification of language difficulties in young offenders and the use of effective strategies to overcome these difficulties during formal communicative exchanges.

7.16. The Appropriate Adult Scheme in England and Wales (not yet statutory in Scotland) ensures that an 'appropriate adult' can provide assistance to someone who is deemed 'mentally disordered' in legal affairs, such as police interviews and court trials, to help them fully understand the process. Individuals with CSN such as language disorder would benefit from assistance of this kind from professionals such as speech and language therapists (AAC 2000).

7.17. There has been interest in recent years in offering speech and language therapy services to support the communication needs of people who are in young offenders institutions or prison. A well established example of this is the speech and language therapy service to Polmont Young Offenders Institution in Scotland. To date the main emphasis has been on establishing the need, and the nature of that need, in the population concerned. Clearly this is only the starting point for the provision of such services and there are plans for establishing close liaison with the mental health team within the institution and the provision of direct services to the individuals within the institution. Initial results suggest that the young people find the service helpful and accessible, but there are many obstacles to the delivery of the services, and there has yet to be a formal evaluation of the intervention provided. Other specific multi-media training packages have been developed to help those working with the criminal justice system to improve their dealings with people with CSN (Togher, Balandin, Young et al. 2006).

7.18. However, it is one thing to provide guidelines or even a service, and another to implement them and detect changes in the participants. In a study introducing a Communication Rehabilitation Regimen for youths in a residential treatment centre (Traynelis-Yurek and Giacobbe 1998), those in receipt of the package of intervention for more than fourteen months showed positive gains for their communication. Interestingly the younger members of this group of 130 young people made the greatest gains in terms of their communication skills.

CRIMINAL JUSTICE - KEY POINTS

Problems identified

- A high proportion of individuals in young offenders' institutions have communication difficulties.
- Individuals with disabilities are more likely to be victims of crime.
- The court tradition of oral argument automatically places individuals with CSN at a disadvantage.
- The formality and complexity of language used in interview and court contexts may place excessive demands on people with CSN. As a result, they may be unable to provide necessary information and/or be misrepresented as uncooperative.

Potential for improvement

- Individuals with CSN can provide reliable testimonies if suitable adaptations can be made. Professionals need specialised training in recognising and meeting the needs of people with CSN in order to communicate appropriately and to avoid underestimating or overestimating their capabilities.
- Some people with CSN may benefit from the 'Appropriate Adult Scheme', where a professional such as a speech and language therapist facilitates communication at each stage of the legal process.
- Preliminary reports indicate potential benefits of speech and language therapy provision for young offenders

CHAPTER EIGHT: EXPERIENCES OF OTHER SERVICES

8.1. This chapter summarises some additional literature relating to a range of service provision. In no case was there sufficient information in any one area to warrant a separate chapter. Each section emphasises the specific barriers experienced.

Housing

8.2. There are still a large number of adults dependent on AAC technology living in residential care institutions (AAC 2000). Likewise recent literature concerning adults with learning disabilities in England shows that 50% of adults were living with their parents, 12% were living with other relatives while 7% were living on their own or with a partner. Of those adults living in supported accommodation the vast majority reported having no choice over either who they lived with or where they lived. Furthermore, 39% of this group reported a lack of privacy. Those individuals living alone were more likely to live in socially deprived areas, and 32% of this group reported not feeling safe in their home, local area and using public transport (Emerson, Malam, Davies and Spencer 2003/4). Broach (2003) documented similar experiences in accommodation among adults with autism. Those adults living independently were more vulnerable to abuse and exploitation. One individual reported being mugged four times shortly after moving to their home. Another individual reported constantly changing electricity suppliers every time another sales representative visited.

8.3. A minority of carers reported having a discussion with a professional concerning current or future housing options. Only 7% of individuals with a diagnosis of high functioning autism had been contacted by professionals to discuss housing. This would imply that suitable accommodation is still not a priority in transition planning (Broach 2003).

Travel

8.4. Travel can be of the routine day to day variety or can relate to travel abroad for holidays. In the former category it is clear that, for many, their employment prospects are at least in part, determined by their ability to use public transport or to drive. This is particularly true of those with visual impairments but is also true of those who have to negotiate their way on public transport:

> *"I live in a rural area and since I can't drive, I face a much tighter job market because of my inability to travel long distance easily"*
> (22 year old man, unemployed, partially sighted)
>
> Salomone and Paige 1984 p.151

8.5. The increasing number of people with learning disabilities in the workforce means a higher level of demand for transport services carrying people with severe difficulties to and from work. For some this means obtaining a driving license, for others it is a question of learning how to negotiate the public transport system, which can prove frustrating (Reid and Bray 1998). In a recent survey of services to autistic people in Scotland well over half of carers said that public transport was a problem and a quarter indicated that it was very difficult to manage (Broach 2003). There was a general lack of public transport options, especially away from the main population areas. Individuals in this group experience a range of difficulties in using public transport, including: bullying, understanding timetables, and low confidence in their communication skills. Many people found accessing this service stressful, so tended to avoid travelling especially at peak times. Crowds were the biggest problem for many. Carers reported that public transport triggered behavioural difficulties or anxiety/panic attacks, and that this exacerbated the social exclusion these families experienced. For example, extreme anxiety can be created by queuing, by having the right change available and negotiating payment with a queue behind, by delays in the service, by overcrowding and excess proximity and finally how to make the bus stop and where to get off. Of those individuals with Autistic Spectrum Disorder that could cope with public transport, very few received discount fares, with only 21% reporting that the person in their care had a freedom pass or other concession.

8.6. The following example illustrates the impact of employee attitudes towards CSN, on this group's experiences of public sector services, in particular a lack of awareness on the part of service staff of the varied nature of communication difficulties.

> In this example a man with a laryngectomy went to get some information (at a railway station) and had to use a Servox to amplify his speech. The operator started laughing and said to someone to come and listen to this.
>
> Knight, Sked and Garrill, 2003 p.17/18.

8.7. One area which has become especially salient with the increase in on-line booking is the accessibility of websites. This has led to a number of ground breaking cases in the US about the extent to which company websites are compliant with disability legislation. In one recent paper the issue has been taken up with regard to the visually impaired population (Mills 2006). The paper reports a law suit against Southwestern Airlines in the US in which the plaintiff maintained that the airlines site was inaccessible because it was incompatible with his screen reader. The case was lost but there is every likelihood that other cases will proceed as the software available to individuals becomes more sophisticated.

Leisure

8.8. There is relatively little in the literature about the leisure needs of people with communication support needs. It may well be that these types of activities prove less of a problem because people find their own ways of engaging with such activities and choose activities which do not challenge their needs. For example, Hayhow and colleagues (1999), writing about the experiences of people who stammer, found that social lives were less affected by their communication disabilities than employment, school etc and other contexts in which the individual engages with the expectations of another element of society.

8.9. Of the limited literature available regarding the leisure activities of individuals with CSN, parents and carers of individuals with autism reported that the person they care for could access play/leisure facilities, however 18% of this group reported that this access was restricted to disability/autism specific groups. There was one example where a parent reported that their child was excluded from the local sports club for disabled people as this disability was not physical (Broach, 2003).

8.10. In Hayhow's study (2002), adults who stammer avoided leisure activities that involved social interaction e.g. one person reported not going to night school classes and specifically choosing activities that do not involve talking. However, some individuals felt that this aspect of their life have been more affected in their early years and that they began to be more involved in leisure activities as they get older.

8.11. "Talking mats" have been used as a means of eliciting the views of a variety of different groups of people with communication support needs about their environment and aspects of their life. In one study specifically targeting the frail elderly Murphy and colleagues successfully elicited the opinions of a group of people living in care homes to their environment, in particular how they like to spend their time (Murphy et al. 2005). The people involved in this study had CSN as a result of Parkinson's disease, stroke and dementia. They expressed an interest in a range of leisure activities such as shopping, concerts, bingo, listening to music and reading.

8.12. Much of the material reviewed refers to people with CSN's experiences of barriers to access across areas such as employment and healthcare. However, individuals with CSN may experience barriers in other areas at a personal and interpersonal level. One study reports on people with aphasia experiencing barriers to maintaining social relationships with friends as a result of their communication needs. Individuals who participated in this study also reported a loss of self identity and that they could no longer fully participate in groups that they belonged to previously such as their religion, culture or peer group (Parr, 2007). Evidently these barriers to participating in these areas will prevent the person fully accessing social and recreational services within the community and leading a social life.

EXPERIENCES OF OTHER SERVICES – KEY POINTS

Problems identified

- ❑ Clearly the difficulties experienced identified in the earlier sections are repeated across a range of services. Indeed there is probably less understanding in services which have less of an emphasis on communication skills
- ❑ No one study has addressed the experiences of the range of CSN across different services. In the main the reporting reflects the experiences of specific groups with specific services
- ❑ Nevertheless it is clear that the experience of having a communication support need has far reaching implications for accessing a whole range of services
- ❑ Many of the experiences reported are associated with the experiences of disability more generally and may be mediated by but are not confined to the individual's communication.

Potential for improvement

- ❑ There is little evidence from the literature that those providing the services identified have identified people with communication support needs as being of concern.
- ❑ There are probably some fairly straightforward modifications that can be made to the way in which materials are produced which would help people with communication support needs. For example having information available in a variety of formats would be relatively easy to achieve.
- ❑ There will undoubtedly be some implications for most of these services from the Disability Discrimination Act but as far as it is possible to ascertain from the literature the implications of this legislation have yet to be felt, at least in so far as it has a bearing on people with Communication Support Needs.

CHAPTER NINE: CONCLUSIONS AND RECOMMENDATIONS

9.1. Communication support needs must be seen within the broader disability rights framework. Under the Disability Discrimination Act (1995) all service providers have a duty to provide a “reasonable adjustment” to enable a disabled person to access their services. This refers not only to making changes to the physical environment (producing ramps etc.) but also to adapting the ways that services are delivered. The latter has a direct consequence for people with CSN who, as the literature indicates, experience considerable difficulties in accessing the services that they need.

9.2. CSN covers a wide range of people with different levels of need at different points in their lifetime. Despite this many of the needs identified in this review are similar. There are more similarities than there are differences across CSN groups, in so far as their communication needs and the way that these needs are addressed are concerned.

9.3. Although some people with CSN only have difficulties with communication, for many their difficulties are part of an overall profile of different conditions, some of which may cause difficulties with communication while others may exacerbate these difficulties. For a person with a stammer or a voice problem their difficulties may be confined to speech, while a person with autism may have both a communication problem and other learning disabilities which may affect their quality of life.

9.4. The complex demands on people’s communication skills, particularly in the sphere of public services, increase the risk of exclusion. In many arenas, such as employment, this may well be getting worse, as expectations of communication skills in the workplace increase (Ruben, 2000).

9.5. Despite the wide range of publications dealing with the needs of specific groups of people with communication support needs it is clear that their needs as a group are not being recognised by the public and by those responsible for public services. Despite, or perhaps because of, the fact that communication is such a pervasive feature of our everyday life there is little public understanding of what it means to have difficulty with communication. Communication disabilities are invisible and often unrecognised. The public seem to be clearer about a small number of higher profile groups (such as those with hearing or visual impairment) and then often focus on the nature of the disability more than society’s response to it. That is, they describe the barriers at the individual level of disability. Very few publications have proposed and discussed adjustments that society can make to improve the experience of service provision for people with a range of disabilities.

9.6. To date environmental adaptations to increase access and inclusion associated with disability have tended to be physical and spatial in nature. There is a need to go beyond physical modification, towards the development of methods of facilitating communication. Such methods, skills and resources are comparable to the ramps and rails used by people with physical impairments.

9.7. At the root of the problem is the need for providers of services to engage with the concept of “person centred care” and to be able to be sensitive to the very different needs of people with CSN. Indeed it might be said that the ability to respond effectively to people with CSN could be a litmus test of the adaptability of those services. The provision of relevant equipment to help the inclusion of people with communication support needs is clearly important, whether this refers to better signage, visual displays, braille, hearing loops or augmentative and alternative forms of communication. The responsibility for using such equipment once it is available rests with the person with communication support needs but there remains a need for a strong facilitative environment to promote the use of this equipment.

9.8. There is also a need to change societal attitudes towards individuals with CSN. However, it is much easier to introduce physical modifications to the environment than it is to change the attitudes and knowledge of other members of society, employers, friends or those providing services etc.

9.9. There are a number of prominent gaps in the literature. Discussion with the project reference group identified a number of key areas where there is very limited literature:

- ☐ Public awareness and understanding of communication disability and public attitudes towards people with communication support needs;
- ☐ The costs of communication support needs to the individual and to society as a whole;
- ☐ The relative value of an enhanced "communication accessible" model of service delivery across sectors;
- ☐ Specific gaps in the evidence base related to aspects of service delivery include:
    - Children and young people's experience of CSN within the educational context;
    - Transition periods and attitudes of criminal justice professionals;
    - Housing (problems identified include limited choice, lack of privacy, abuse and exploitation, increased probability of social deprivation);
    - Travel (problems identified include difficulty accessing and understanding information, negative attitudes, anxiety associated with crowding);
    - Leisure (problems identified include communication demands of some leisure activities inhibit involvement by people with CSN, limited availability of appropriate group activities);
    - Financial services (problems identified include communication demands associated with complex documentation when accessing services/benefits, lack appropriate training).

9.10. It has proved relatively easy to identify factors which are thought to improve the engagement of people with communication support needs. Many of the issues which affect people with communication support needs also apply to the wider public, albeit not to the same extent. For example, relatively simple concepts such as the ability to listen and show respect are central to the discussion of what is needed. The Communication Access Toolkit project described previously provides a useful illustration of how techniques, skills and resources that promote communication access can be learned and adopted by service providers. There are other examples of such training programmes, although no one training programme deals with all the groups with communication support needs and those that exist tend to focus on one scenario – i.e. vulnerable witness training or training around access to health and social services. However it is difficult to know whether the introduction of the guidelines really makes a difference to those concerned. There are very few intervention studies aiming to demonstrate the effects of particular regimes associated with communication access.

9.11. It is important to recognise that communication impairment can have very real consequences for the individual concerned and that the way that the individual responds to his or her circumstances is likely to play a part in the extent to which they are included in society. It is not simply a matter of manipulating external factors. The internal and the extrinsic factors are obviously closely linked together and due attention needs to be paid to the carers and the extended family as well as the individual with CSN.

RECOMMENDATIONS FOR FURTHER RESEARCH

9.12. We conclude that there are three lines of enquiry or "research strands" which have the potential to make a substantive contribution to the field and fill gaps in the overall knowledge base associated with CSN. In each case it is proposed that a group of people with communication support needs be instrumental in setting up and monitoring the project. There is a strong case for adopting an inclusive approach to this, using what has come to be known as "co-production" (Boyle, Clark and Burns 2006), paying due attention to the type of operational matters, such as engagement, specific research expertise and physical considerations such as location of meetings, raised in the London Region primary care exercise involving people with disabilities in research (Wyatt, Carter, Mahtani et al. (submitted).

Study 1. Expectations and improvements for service users with communication support needs

The literature, by its nature, reports specific aspects of the experiences of subgroups of people with CSN, for example the health needs of people with aphasia following stroke. It is proposed that a study be set up to obtain a comprehensive picture of experiences of the full range of services of the range of people with CSN. In order to map different levels of need across groups it is proposed that such a study should make use of a single scale of "need" which would help provide a snapshot of current need in Scotland. The aim of such a study would be to go beyond the identification of barriers towards establishing key directions for policy makers and other agencies in making living with a communication support need easier. Such a project might also have an economic dimension, capturing the financial impact of their difficulties on people with CSN and on society as a whole. Such a study would be likely to make use of questionnaire and qualitative interview data.

Study 2. Public attitudes to and understanding of people with communication support needs

The literature clearly indicates that there are concerns regarding public knowledge about, and attitudes towards, people with CSN. It is proposed that a study be set up to obtain a comprehensive picture of public experience of and attitudes towards CSN across Scotland and address issues of ignorance and prejudice associated with CSN. Such a study would be designed in two parts. In the first part a national representative survey would be taken of the public experiences of CSN in their own lives and in the public domain. This would include an element designed to establish what could be done to meet the needs of people with CSN. The aim of this study would be to address some of the prejudice and lack of awareness surrounding CSN, which were identified as significant barriers in this review.

Study 3. Developing and evaluating a communication friendly environment across local services

Much is already known about what is required of services in improving the opportunities for people with CSN, and a number of training packages aimed at promoting communication access are already available. It is proposed that these be developed for the range of people with CSN and introduced and evaluated in a coherent fashion across the full range of services in the public and private sectors within a given geographical area. This would include publicity, training and the availability of support workers related to specific aspects of services for example employment and criminal justice. The results of such an evaluation would be reported in terms of uptake and performance amongst the professional groups concerned and in terms of improvements to the experience of people with CSN. Such a project would require the "buy in" of a forward looking local authority which wanted to act as a beacon for social inclusion and which is already well integrated with local health, education and social services. Such an evaluation would be likely to adopt a mixed methodology, making use of survey and quantitative audit data coupled with nested interview and diary studies.

REFERENCES

A Simple Cure. A National Report into Deaf and Hard of Hearing People's Experiences of the National Health Service.

AAC (2000) Practical Approaches to Augmentative and Alternative Communication. Collected Papers from Augmentative Communication in Practie: Scotland Tenth Annual Study Day. CALL Centre.

Afasic Scotland (2002) Exploring Participation. Outcomes of AFASIC's enquiry into participation by children and young people with speech and language impairments in the process of formal decision-making concerning their education.

Afasic Scotland. New Voices – New Language, Improving Provision for Children With Speech and Language Impairments in Secondary Education. Towards An Action Plan.

Afasic Parent's Survey (1993). Alone and Anxious. Parents' Experience of the Services Offered to Children with Speech and Language Impairments

Agnew, S., Powell, M. and Snow, P. (2006) An examination of the questioning styles of police officers and caregivers when interviewing children with intellectual disabilities. *Legal Criminological Psychology*, 11: 35-53.

Ainscow, M. (1997) Towards Inclusive Schooling British Journal of Special Education, 24, 3-6.

Aitken, S and Millar, S. (2002) *Are we listening? Book 1 of Listening to children with Communication Support Needs* Glasgow**:** Sense Scotland, CALL Centre and Scottish Executive Education Department

Anderson, J. (2005) *Shout it to the top! People Who Stammer Find Their Voices In Scottish Parliament.*

Archie, R., Dimigen, G. and Taylor, M. (1998) The Relationship Between Social Networks And The Employment of Visually Impaired College Graduate. *Journal of Visual Impairment and Blindness*, 92 (7).

Augmentative Communication in Practice: Scotland (1998) Augmentative Communication in Practice: An Introduction. Edinburgh: CALL Centre Edinburgh University

Baker, R. and Child, D. (1993) Communication Approaches Used in Schools for the Deaf in the UK-A Follow-Up Study. *Journal of the British Association of the Teachers of the Deaf*, 17 (2): 36-47.

Balandin, S. (2000) Witnessing without Words. In T. Shaddock and M. Bond and K. Hales (Eds), Intellectual Disability and the Law: Contemporary Autstralian Issues (pp.31-40). Newcastle: ASSID Inc, Banks, P. and Pearson, C. (2002) *Are services meeting the needs of young stroke survivors in scotland? Final report*. Glasgow: Strathclyde Centre for Disability Research.

Beck, A., Thompson, J.R., Clay, S.L., Hutchins, M., Vogt, W.P., Romaniak, B. and Sokolowski, B. (2001) Pre-service Professionals' Attitudes Toward Children Who Use Augmentative/Alternative Communication. *Education and Training In Mental Retardation and Developmental Disabilities*, 36 (3): 255-271.

Beck, A. R., Bock, S., Thompson, J. R., Bowman, L., and Robbins, S. (2006) Is Awesome Really Awesome? How the Inclusion of Informal Terms on an AAC Device Influences Children's Attitudes toward Peers Who Use AAC. *Research in Developmental Disabilities: A Multidisciplinary Journal*, 27 (1): 56-69.

Beck, A. R. and Fritz-Verticchio, H. (2003) The influence of information and role-playing experiences on children's attitudes toward peers who use AAC. *Am J Speech Lang Pathol*. 12 (1): 51-60.

Brown, M. and MacArthur, J. (2006) A new research agenda: improving healthcare in general hospitals. *Journal of Clinical Nursing* 15, 1361-1369.

Bryan, K. *Stammering In Prison*. (The British Stammering Association – Website).

Bryan, K. (2004). Prevalence of speech and language difficulties in young offenders. *International Journal of Language and Communication Disorders*. 39, 391-400.

Blanchard, L. T. G. M. J. and Blackman, J. A. 2006, "Emotional, Developmental, and Behavioral Health of American Children and Their Families: A Report From the 2003 National Survey of Children's Health", *Pediatrics Official Journal of The American Academy of Pediatrics*, 117: 1202-1212.

Boyle, D., Clark, S and Burns, S. (2006) *Hidden work: co-production by people outside paid employment*. York: Joseph Rowntree Foundation.

Bowe, F.G., McMahon, B.T., Chang, T. and Louvi, I. (2005) Workplace Discrimination, Deafness and Hearing Impairment: The National EEOC ADA Research Project. *Work* 25: 19-15.

Broach, S., Heather, C., Mustapha, S., Potter,D., Prior, A. (2003) Autism: Rights In Reality. How People With Autism and Their Families Are Still Missing Out On Their Rights and Entitlements.

Capella-McDonnall, M. E. (2005) The Ticket to Work Program: Employment Networks' Views on Serving Beneficiaries Who Are Blind or Visually Impaired. *Journal of Visual Impairment and Blindness*, 99 (6): 336-344.

Carey, A. C., Potts, B. B., Bryen, D. N., and Shankar, J. (2004) Networking towards employment: Experiences of people who use augmentative and alternative communication. *Research and Practice for Persons with Severe Disabilities*, 29 (1): 40-52.

Carlin, J. (2005) Including Me: Managing Complex Health Needs In Schools and Early Years Settings.

Charles, C. Gafni, A. and Whelan, T. (2000) How to improve communication between doctors and patients: Learning more about the decision making context is important. *British Medical Journal* 320, 1220-1221.

Christie, E. The Primary Healthcare Workers Project. A Summary Report.

City of Edinburgh Council (2004) *In on the act; Draft guidance on the Education (Additional Support for Learning) (Scotland) Act 2004*. City of Edinburgh education department

Clarke, M., McConachie, H., Price, K., and Wood, P. (2001) Views of young people using augmentative and alternative communication systems. *Int J Lang Commun Disord*. 36 (1): 107-115.

Clark-Carter, D. D. (1983) The Nottingham survey of visually handicapped people. *International Journal of Rehabilitation Research*, 6 (4): 495-497.

Contact a Family (2005) *Post-16 transition in Scotland* London: Contact a family.

Contact a Family (2006) *Additional Support for Learning* – Scotland: Contact a family.

Conti-Ramsden, G., Durkin, K. and Simkin, Z. (forthcoming) "Hw r u?": interpersonal and education uses of ICT among adolescents with specific language impairment (SLI).

Cottrell, S. & Davies, A. (2006) *Stroke Talk: a communication resource for hospital care.* London Connect Press.

Craig, A., Hancock, K., Tran, Y., Craig, M., Peters, K. (2002). Epidemiology of stuttering in the community across the entire lifespan. *Journal of Speech, Language and Hearing Research,* 45, 1097-1105.

Crichton-Smith, I. (2002) Communicating in the Real World: Accounts from People Who Stammer. *Journal of Fluency Disorders* 27: 333-352.

Crudden, A. and McBroom, L. W. (1999) Barriers to employment: A survey of employed persons who are visually impaired. *Journal of Visual Impairment and Blindness*, 93 (6): 341-350.

Crudden, A., Sansing, W., and Butler, S. (2005) Overcoming Barriers to Employment: Strategies of Rehabilitation Providers. *Journal of Visual Impairment and Blindness*, 99 (6): 325-335.

Cruice, M., Worall, L., Hickson, L. and Murison, R. (2005) Measuring quality of life: Comparing family members' and friends' ratings with those of their aphasic partners. *Aphasiology*, 19 (2): 111-129

Dare Foundation (2005) *Greater Glasgow NHS Communication Impairment Workshop report*. Kirkcaldy: The Dare Foundation.

Dattilo, J. and And, O. (1995) Parents' Perspectives on Leisure Patterns of Youth Using Augmentative and Alternative Communication Systems. *Therapeutic Recreation Journal*, 29 (1): 8-17.

DFES (1999) *The Moser Report. A Fresh Start: Improving Literacy and Numeracy* ref CMBS1. Nottingham: DfEE publications.

Department for Education and Skills (2003) *Every child matters.* Nottingham: DFES.

Department for Education and Skills (2004) *Removing barriers to achievement*. Nottingham: Department for Education and Skills Publications.

Department for Education and Skills (2006) *National audit of support, services and provision for children with low incidence needs (RR729*) Nottingham: Department for Education and Skills Publications.

Disability Agenda Scotland (2000) *Battling for Benefits Disabled People's Experiences of the Benefits System.* Disability Agenda Scotland - Action On Benefits.

Disability Agenda Scotland (2003) *The Struggle for Disability Living Allowance*. Disability Agenda. Scotland - Action On Benefits.

Disability Rights Commission (2004a) *The Web: access and inclusion for disabled people.* London: Disability Rights Commission.

Disability Rights Commission (2004b) *You can make a difference: improving hospital services for disabled people* London: Disability Rights Commission.

Disability Rights Commission (2005) Disability rights commission submission to the Equalities Review http://www.drcgb.org/library/policy/other_issues/disability_rights_commission_s.aspx Accessed 05.03.07

Disability Rights Commission (2006a) *Achieving fair access: Improving NHS services for disabled people : Postive access- real change* London: Disability Rights Commission http:www.dfc.org.uk/fair4all/achievingfair access/ Accessed 05/02/07

Disability Rights Commission (2006b) *Equal treatment: closing the gap: A formal investigation in physical, health and inequalities experienced by people with learning disabilities and/ or mental health problems.* London: Disability Rights Commission

Disability Rights Commission (2006c) *Report of the DRC formal inquiry panel to the CRD's formal investigation.* London: Disability Rights Commission.

Disability Rights Commission (2006d) Practical guidance to NHS Scotland in mainstream disability equality and access to service delivery Edinburgh: Disability Rights Commission.

Elder, G. H. (1998). The life course as developmental theory. *Child Development,* 69**,** 1-12.

Enderby, P. and Davies, P. (1989) Communication Disorders: Planning A Service To Meet The Needs. *Journal of Disorders of Communication*, 24: 301-331

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.

Emerson, E., Malam, S., Davies, I. and Spencer, K. (2005) Adults with Learning Difficulties in England 2003/4. Full Report

Enquire The Scottish Advice service for Additional Support for Learning (2005) *The parents' guide to additional support for learning.* Edinburgh: Enquire

Ferguson, A. (2005) The epidemiology of communication and swallowing disorders. *Advances in Speech-Language Pathology*, Seminar Issue.

Fichten, C. S., Schipper, F., and Cutler, N. (2005) Does volunteering with children affect attitudes toward adults with disabilities? A prospective study of unequal contact. *Rehabilitation Psychology*, 50 (2): 164-173.

Finkelstein,V. (1980) *Attitudes and disabled people.* New York: World Rehabilitation Fund.

Foley, B.E. and Staples, A.H. (2003) Developing Augmentative and Alternative Communication (AAC) and literacy interventions in a supported employment setting. *Topics in Language Disorders,* 23 (4): 325-343.

Foster, S. (1989) Social alienation and peer identification: A study of the social construction of deafness. *Human Organization*, 48 (3): 226-235.

Fox, A. and Pring, T. (2005) The Cognitive Competence of Speakers with Acquired Dysarthria: Judgements by Doctors and Speech and Language Therapists. *Disability and Rehabilitation*, 27 (23): 1399-1403.

Fundamental Facts: All The Latest Facts and Figures on Learning Disabilities. Foundation for People with Learning Disabilities, 2000.

Garcia, L. J., Larouche, C., and Barrette, J. (2002) Work integration issues go beyond the nature of the communication disorder, *Journal of Communication Disorders*, 35 (2): 187-211.

Gamble, M.J.; Dowler, D.L.; Hirsh, A. E. (2004) Informed decision making on assistive technology workplace accommodations for people with visual impairments. *Work: Journal of Prevention, Assessment & Rehabilitation*, 23 (2): 123-130.

Gascoigne, M. (2006) Supporting Children with Speech, Language and Communication Needs within Integrated Children's Services*: Position paper*. London: Royal College of Speech and Language Therapists.

Gudjonsson, G. (1993) Confession evidence, psychological vulnerability and expert testimony. *Journal of Community and Applied Social Psychology*, 3, 117-129.

Hamilton, J. Speech and Language Communication Therapy. A Perspective From HMYOI Polmont (1999), Annual Review (1998-1999).

Harasty, J. and McCooey, R. (1994) The prevalence of communication impairment in adults: A summary and critical evaluation of the literature. *Australian Journal of Communication Disorders*, 22 (1): 81-95

Hartley, K. (2003) Better Health Through Better Communication Project. A Pilot Project Aimed At Improving Access to Primary Care Services for People with Communication Difficulties.

Hartshorne, M. (2006) *The cost to the Nation of Children's Poor communication.* London: ICAN.

Hayhow, R., Gray, A.M. and Enderby, P. (2002) Stammering and therapy views of people who stammer. *Journal of Fluency Disorders*, 27: 1-17.

Henderson, J. and Weston, J. (2004) *"We're Still Waiting". Deaf People's Experiences of the Struggle to Improve their Health and Wellbeing.* Scottish Human Services Trust.

Hilari, K., Byng, S., Lamping, D.L. & Smith, S.C. (2003) Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39): Evaluation of Acceptability, Reliability and Validity. *Stroke*, 34 (8): 1944-1950.

HMSO (2005) *The Disability Discrimation Act* London: HMSO

HMSO (2006a) Better communication, better justice - new campaign for Witness Intermediaries http://www.cjsonline.gov.uk/the_cjs/whats_new/news-3265.html Accessed 30.05.06

HMSO (2006b) Code of practice for intermediaries http://www.homeoffice.gov.uk/documents/intermediary-registration-2006/intermediary-code-of-practice?view=Binary Accessed 30.05.06

Huer, M.B., Parette, H.P. and Saenz, T.I. (2001) Conversations with Mexican Americans Regarding Children with Disabilities and Augmentative and Alternative Communication. *Communication Disorders Quarterly*, 22 (4): 197-206.

Huer, M. B., Saenz, T. I., and Doan, J. H. D. (2001) Understanding the Vietnamese American Community: Implications for Training Educational Personnel Providing Services to Children with Disabilities", *Communication Disorders Quarterly*, 23 (1): 27-39.

Hunt-Berg, M. (2005) The Bridge School: Educational Inclusion Outcomes over 15 Years. *Augmentative and Alternative Communication*, 1 (2): 116-131.

Hurst, M.A. and Cooper, E.B. (1983) Vocational Rehabilitation Counsellors' Attitudes Toward Stuttering. *Journal of Fluency Disorders* 8: 13-27.

Hurst, M.I. and Cooper, E.B. (1983) Employer Attitudes Toward Stuttering. *Journal of Fluency Disorders* 8: 1-12.

IDEA (2004) The Individuals with Disabilities Education Improvement Act (2004) http://www.copaa.org/pdf/IDEACOMP.pdf Accessed 06.03.07

Information Services Division Scotland (2006) AHPS: *Preliminary results from the census* Edinburgh: National Services Scotland.

Jones, S. D., Angelo, D. H., and Kokoska, S. M. (1998) Stressors and Family Supports: Families with Children Using Augmentative and Alternative Communication Technology. *Journal of Children's Communicative Development*, vol. 20, no. 2, pp. 37-44.

Joseph Rowntree Foundation (2005) *User involvement in research: building on experience and developing standards.* York:JRF

Jordan, L. and Bryan, K. (2001) Seeing The Person? Disability Theories and Speech and Language Therapy. *International Journal of Language and Communication Disorders/ Royal College of Speech and Language Therapists,* 36, Supplement, 453-8.

Kagan, C., Lewis, S., Heaton, P., and Cranshaw, M. (1999) Enabled or disabled? Working parents of disabled children and the provision of child-care, *Journal of Community and Applied Social Psychology* 9 (5): 369-381

Kent, B. A. (2003) Identity Issues for Hard-of-Hearing Adolescents Aged 11, 13, and 15 in Mainstream Setting. *Journal of Deaf Studies and Deaf Education*, 8 (3): 315-324.

Kent-Walsh, J. E. and Light, J. C. (2003) General education teachers' experiences with inclusion of students who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 19 (2): 104-124.

Kirchner, C., Johnson, G., and Harkins, D. (1997) Research to improve vocational rehabilitation: Employment barriers and strategies for clients who are blind or visually impaired. *Journal of Visual Impairment and Blindness*, 91 (4): 377-392.

Klein, J.F. and Hood, S.B. (2004) The Impact of Stuttering On Employment Opportunities and Job Performance *Journal of Fluency Disorders* 29: 255-273

Knight, B., Sked, A. & Garrill, J. (2003) Breaking the Silence. Identification of the communication and support needs of adults with speech disabilities in Newcastle.

Knox, E. and 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.

Kyle, J., Reilly, A.M., Allsop, L., Clark, M., Dury, A. (2005) Investigation of Access to Public Services In Scotland Using British Sign Language.

La Grow, S. J. (2004) Factors that Affect the Employment Status of Working-Age Adults with Visual Impairments in New Zealand, *Journal of Visual Impairment and Blindness*, 98 (9): 546-559.

Larcher, J. (1995) Leaving School – Crisis or Opportunity: Which Is It For AAC Users? in Widening The Perspective – Augmentative Communication in Practice: Scotland.

Law, J., Lindsay, G., Peacey, N., Gascoigne, M., Soloff, N., Radford, J.,and Band, S. (2000). *Provision For Children With Speech And Language Needs In England And Wales: Facilitating communication between education and health services.* London: DfEE/DoH.

Law, J., Lindsay, G., Peacey, N., Gascoigne, M., Soloff, N., Radford, J., and Band, S. (2002).Consultation as a model for providing speech and language therapy in schools: a panacea or one step too far. *Child Language Teaching and Therapy.*_18, 2, 145-165.

Law, J., Bunning, K., Byng, S., Farrelly, S.,and Heyman, B., (2005) Making sense in primary care: levelling the playing field for people with communication disabilities. *Disability and Society* 20, 169-185

Law, J**.** Van der Gaag, A. Symon, S. (2005) Improving communication in primary care: an examination of the feasibility of introducing Health Talk: Count me in in two primary care practices. Report to Forth Valley and Ayrshire and Arran Primary care Trusts. Available from the first author c/o Centre for Integrated Healthcare Research, Queen Margaret University, Edinburgh EH12 8TS

Law, J. Pringle, A-M, Irving, A-M, Conachie, D. Huby, G. and Haworth, C. (forthcoming) *The Aphasia in Scotland Project*. Edinburgh: NHS Quality Improvement Scotland.

Lennox, N.G., Diggens, J.N. and Ugoni, A.M. (1997) The general practice care of people with intellectual disability: barriers and solution. *Journal of Intellectual Disability Research.* 41, 380-390.

Lewis, A. (2004) 'And when did you last see your father?' Exploring the views of children with learning difficulties/disabilities. *British Journal of Special Education*, 31 (1): 3-9

Lewis, A. and Porter, J. (2004) Interviewing children and young people with learning disabilities*: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities*, 32: 191-197.

Lever, S. (2003) Speaking Out: Access to Vocabulary. *Alternatively Speaking*, 6, 3, 4-5.

Lever, S.E., Lightholder, L., Bryen, D.N. and Carey, A.C. (2003) Speaking Out Against Abuse. *Alternatively Speaking*, 6 (3): 1-2, 8.

Light, J., Stoltz, B., and McNaughton, D. (1996) Community-based employment: Experiences of adults who use AAC. *AAC: Augmentative and Alternative Communication*, 12 (4): 215-228.

Light, J.C., Beukelman, D.R., and Reichle, J. (2003). Communicative competence for individuals who use AAC: From research to effective practice. Baltimore: Paul H. Brookes Publishing Co.

Lothian Inclusive Communication Strategy (LInC). (2006) An Effective and Appropriate Communication Approach Across Lothian will Help to Tackle Inequality and Remove One of the Biggest Barriers to Services.

MacDonald, L. and Ritchie, A. (2005) Bridging The Gap: Improving Access to Primary Healthcare Services for Disabled People.

Markham, C. and Dean, T. (2006) Parents' and Professionals' Perceptions of Quality of Life In Children With Speech and Language Difficulty. *International Journal of Language and Communication Disorders*, 41 (2): 182-212.

Mautz, D., Storey, K., Certo, N. (2001) Increasing Integrated Workplace Social Interactions: The Effects of Job Modification, Natural Supports, Adaptive Communication Instruction, and Job Coach Traning. JASH, 26 (4): 257-269

McEntee, M.K. (1993) Accessibility of Mental Health Services and Crisis Intervention to the Deaf. *American Annals of the Deaf.* 138 (1): 26-30.

McPake, J., Johnstone, R., Bianco, J.L., McColl, H., Klompas, M. and Ross, E. (2004) Life Experiences of People who Stutter, and the Perceived Impact of Stuttering On Quality of Life: Personal Accounts of South African Individuals. *Journal of Fluency Disorders*, 29: 275-305.

McPake, J., Johnstone, R., Lo Bianco, J., McColl, H., Prieto, G.R., and Speake, E. (2002) Translating, Interpreting and Communication Support Services Across the Public Sector in Scotland.

Meadow-Orlans, K. P., Mertens, D. M., Sass-Lehrer, M. A., and Scott-Olson, K. (1997) Support services for parents and their children who are deaf or hard of hearing: a national survey. *American Annals of the Deaf*, 142 (4): 278-293.

Mencap (2004) *Treat me right: Better healthcare for people with learning disability.* London: Mencap.

Midlothain Council (2004) Midlothian: Education for all – The education (Additional Support for Learning) (Scotland) Act 2004 – Practitioners' Guidance. Midlothian Education department.

Millar, S. (2001) Supporting children using augmentative and alternative communication in school pp103-124 in H. Cockerill, L. Carroll-Few *Communication without speech: Practical augmentative and alternative communication*. Oxford: Mackeith Press.

Millar, S. & Aitken, S. (2005) *FE and Complex needs: Views of children and young people*. Edinburgh: Call Centre University of Edinburgh

Mills, J.E. (2006) Is your tourism website ADA-compliant? Proceedings of the Travel Distribution Summit, Europe Research Conference 2006.

Mitchell, V. Smith, C. and Stevens, J. (2005) *The Lothian Child concern model.* Unpublished report.

Morton, D., Chandler, R., and Kiff, P. (2002) Looking for a simple school communication policy and procedure", *Deafness and Education International*, 4 (1): 41-58.

Murphy, J., Tester, S., Hubbard, G., Downs, M., and MacDonald, C. (2005) Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats as an interview tool. *Health and Social Care In The Community*,13 (2): 95-107.

Murphy, J. (2006) Perceptions of Communication Between People With Communication Disability and General Practice Staff. *Health Expectations*, 9: 1-12.

National Association of Paediatric Occupational Therapists (2000) *Guidelines for good practice*. NAPOT, 65, Prestbury Road, Wilmslow, Cheshire SK9 2LL.

Nicholas, J.G. and Geers, A.E. (2003) Personal, Social and Family Adjustment in School Aged Children with a Cochlear Implant. *Ear and Hearing*, 24: 69-81.

NHS Forth Valley (2007) *Improving equity of access to healthcare for people with communication difficulties after stroke January 2004-December 2006.* Stirling: NHS Forth Valley Speech and Language Therapy Service.

NHS Health Scotland (2004) *People with learning disabilities in Scotland.* Glasgow: NHS Health Scotland.

NHS QIS (2006) *Promoting access to healthcare for people with learning disability – a guide for frontline NHS staff.* Edinburgh: Quality Improvement Scotland.

Nova Scotia Public Prosecution Service September 2002.Investigation and Prosecution of Cases Involving Persons with Special Communication Needs.

O'Day, B. (1999) Employment Barriers for People With Visual Impairments. *Journal of Visual Impairment and Blindness*, 93 (10).

Oliver, S., Clarke-Jones, L. Rees,R. Milne, R. Buchanan, P. Gabbay, J. Gyte, G., Oakley, A. and Stein, K. (2004) Involving consumers in research and development agenda setting for the NHS: developing the evidence base. *Health Technology Assessment*, 8. 15.

Orr, K.S., Leven, T., Bryan, R. and Wilson, E. (2006) Community Care and Mental Health Services For Adults with Sensory Impairment in Scotland.

Parr, S. Byng, S. Woolf, C. and Summers, S. (1997) Living with communication impairment: A study commissioned by the Communications Forum. London: City University

Parr, S., Byng, S. and Gilpin, S. (1997) *Talking about aphasia.* Buckingham, OUP**.**

Parr, S. (2006) *Review of communication access within Connect and beyond* Draft report submitted to The King's Fund.

Parr, S. (2007) Living with severe aphasia: Tracking social exclusion. *Aphasiology*, 21 (1): 98-123.

Parr, S., Pound, C. and Hewitt, A. (2006) Communication Access to Health and Social Services. *Topics In Language Disorders* 26 (3): 189-198.

Parette, H.P., Brotherson, M.J., Huer, M.B. (2000) Giving Families A Voice In Augmentative and Alternative Communication Decision-Making. *Education and Training in Mental Retardation and Developmental Disabilities*, 35 (2): 177-190.

Parrette, H.P., Chuang, S.L. and Huer, M.B. (2004) First-Generation Chinese American Families' Attitudes Regarding Disabilities and Educational Interventions. *Focus On Autism and Other Developmental Disabilities, 19* (2) 114-123.

Parette, P. and Huer, M.B. (2002) Working with Asian American Families Whose Children Have Augmentative and Alternative Communication Needs. *Journal of Special Education Technology*, 17 (4): 5-13

Parette, H.P., Huer, M.B. and Brotherson, M.J. (2001) Related Service Personnel Perceptions of Team AAC Decision-Making Across Cultures. *Education and Training in Mental Retardation and Developmental Disabilities*, 36 (1): 69-82.

Parrette, H.P. and Marr, D.D. (1997) Assisting children and families who use augmentative and alternative communication (AAC) devices: Best practices for school psychologists. *Psychology in the Schools* 34 (4): 337-346.

Perry, A., Reilly, S., Cotton, S., Bloomberg, K. and Johnson, H. (2004) A Demographic Survey of People Who Have A Disability and Complex Communication Needs in Victoria, Australia. *Asia Pacific Journal of Speech, Language and Hearing*, 9: 259-271.

Perez, I.A., Wilson, C.W.L., King, C., and Pagnier, C., (2006) Translating, Interpreting and Communication Support: A Review of Provision In Public Services In Scotland.

Petersilia, J.R. (2001) Crime victims with developmental disabilities: A review essay. Criminal Justice and Behavior 28 (6): 655-694.

Pirrie, A., Head, G. and Brna, P. (2005) Mainstreaming Pupils with Special Educational Needs: An Evaluation.

Plester, B. and Wood, C. (2006) Cognitive factors in text messaging and literacy links. Poster presentation at the British Psychological Society Developmental Section Annual Conference, Royal Holloway University of London, September 2006.

Public Health Institute of Scotland (2003) Needs assessment report on child and adolescent mental health – www.phis.org.uk/pdf.pl?file=publications/CAMH1.pdf

Raney, C. and Silverman, F. H. (1992) Attitudes toward non-speaking individuals who use communication boards. *Journal of Speech and Hearing Research* 35 (6): 1269-1271.

Reid, P. M. and Bray, A. (1998) Real jobs: The perspectives of workers with learning difficulties. *Disability and Society* 13 (2): 229-239.

Rescorla, L. & Roberts J (2002) Nominal Versus Verbal Morpheme Use in Late Talkers at Ages 3 and 4 Journal of Speech Language Hearing Research, 45: 1219 - 1231.

Riddell, S. and Banks, P. (2001) Disability In Scotland: A Baseline Study. Disability Rights Commission.

Riddell, S., Tinklin, T. and Banks, P. (2005) Disability and Employment in Scotland: A Review of the Evidence Base.

Ridsdale, J. and Thompson, D. (2002) Perceptions of Social Adjustment of Hearing-Impaired Pupils in an Integrated Secondary School Unit. *Educational Psychology in Practice*,18 (1): 21-34.

Robson, T. (2005) Using Talking Mats with Young Offenders. RCSLT Bulletin.

Robson, T. (2006) Speech and Language Therapy Service At HMYOI Polmont. Annual Review.

Roy, A.W.N., Dimigen, G. and Taylor, M. (1998) The relationship between social networks and the employment of visually impaired college graduates. *Journal of visual impairment and blindness*, 92 (7): 423-432.

Royal College of Speech and Language Therapists (2005) *RCSLT Clinical Guidelines.* Bicester, Speechmark Publishing.

Royal College of Speech and Language Therapists (2006) *Communicating Quality 3: Information, standards and guidance to support the provision of quality Speech and Language Services in the U.K.* London: RCSLT.

Ruben, R.J. (2000) Redefining the survival of the fittest: Communication disorders in the 21st Century. *Laryngoscope* 110.

Salomone, P. R. and Paige, R. E. (1984) Employment problems and solutions: Perceptions of blind and visually impaired adults. *Vocational Guidance Quarterly*, 33 (2): 147-156.

SCOPE (2002) *The good practice guide for support workers and personal assistants working with disabled people with communication impairments* London: SCOPE

Scottish Council Foundation (2005) *Disability in Scotland 2005-2020): A state of the nation report.* Edinburgh: Scottish Council Foundation.

Scottish Executive (1999) Report into the Education of Children with Severe Low Incidence Disabilities. Edinburgh: Scottish Executive.

Scottish Executive (2000) *The Adults with Incapacity (Scotland) Act* Edinburgh: Scottish Executive

Scottish Executive (2001) *For Scotland's Children: Better Integrated Children's Services* www.Scotland.gov.uk/library3/education/fcsr-00.asp Accessed 01/03/07.

Scottish Executive (2002) *Building on Success: Future directions for the Allied health professions in Scotland.* Edinburgh: NHS Scotland.

Scottish Executive (2003a) *A Scottish Executive Review of Speech and Language therapy, Physiotherapy and Occupational therapy for children and speech and language therapy for adults with learning disability and autistic spectrum disorder.* Edinburgh: Scottish Executive.

Scottish Executive (2003b) *Talking matters: developing the communication skills of doctors.* Edinburgh: Scottish Executive.

Scottish Executive (2004a) *Social Focus on Disability* Edinburgh: Scottish Executive.

Scottish Executive (2004b) *The education (Additional Support for Learning) (Scotland)* Act Edinburgh: Scottish Executive.

Scottish Executive (2004c) People with learning disabilities in Scotland: Health needs summary report Glasgow: NHS Health Scotland.

Scottish Executive (2004d) *Vulnerable Witnesses (Scotland) Act 2004* Edinburgh: Scottish Executive.

Scottish Executive (2005a) *Further and Higher Education (Scotland) Act 2005* Edinburgh: Scottish Executive.

Scottish Executive (2005b) *Health for all children 4: Guidance on implementation in Scotland: Getting it right for Scotland's children*. Edinburgh: Scottish Executive.

Scottish Executive (2005c) *The mental health of children and young people: A framework for promotion, prevention and care.* Edinburgh: Scottish Executive.

Scottish Executive (2005d) *Supporting Children's Learning*. Edinburgh: Scottish Executive.

Scottish Executive (2006) *Focusing in inclusion and the Education (Additional Support for Learning) (Scotland) 2004 act: A paper for professional reflection*. Edinburgh: Scottish Executive.

Scottish Executive (2007) *A strategy for Scotland's Languages: Draft version for consultation* Edinburgh: Scottish Executive. http://www.scotland.gov.uk/Publications2007/01/24130746/2 Accessed 16.02.07

Scottish Funding Council (2006) *Consultation: developing and implementing a Needs-led Model for funding the Activity of students with additional Support needs for Learning in Colleges*. Edinburgh: Scottish Funding Council

Scottish Qualifications Authority Promote effective communication for and about individuals Edinburgh SQA. http://www.sqa.org.uk/files_ccc/CL1.doc Accessed 16.02.07

Sense (2006) Filling in the Gaps. A toolkit for professionals working with older deafblind people. http://www.sense.org.uk/ Accessed 26.02.07

Simmons-Mackie, N.N., Kagan, A., Christie, C.O., Huijbregts, M., McEwen, S. and Willems, J. (2007). Communicative access and decision making for people with aphasia: Implementing sustainable healthcare systems change. *Aphasiology*, 21 (1): 39-66.

Sivanesan, N. (2003) The Journey of a Visually Impaired Student Becoming an Occupational Therapist. *British Journal of Occupational Therapy* 66 (12): 568-570.

Snow, P. and Powell, M. (2004) Interviewing juvenile offenders: The importance of oral language competence. *Journal of the Institute of Criminology*, 16 (2): 220-225.

Smart, J.F. and Smart, D.W. (2006) Models of Disability: Implications for the Counselling Profession. *Journal of Counselling and Development*, Winter, 84 pp. 29-40.

Stone, E. (1992) A follow-up study of ex-pupils from a speech and language unit. *Child Language Teaching and Therapy*, 8 (3): 285-313.

Storey, K. and Provost, O. (1996) The Effect of Communication Skills Instruction On The Integration of Workers with Severe Disabilities in Supported Employment Settings.

Education and Training in Mental Retardation and Developmental Disabilities. 2 (31): 123-141.

Tarleton, B., Ward, L. and Howarth, J. (2006) *Finding the Right Support? A Review of Issues and Positive Practice in Supporting Parents with Learning Difficulties and Their Children.* The Baring Foundation.

The Equality and Human Rights Group (2004). Guidance On Developing Local Communication Support Services And Strategies. Department of Health.

The Rehabilitation Act (1973) http://www.ed.gov/policy/speced/reg/narrative.html Accessed 06.03.07

Thomson, G.O.B., Stewart, M.E. and Ward, K. (1996) Criteria for Opening Records of Needs. *SOEID Interchange 40*. Edinburgh Scottish Council for Research in Education. http://www.scotland.gov.uk/edru Accessed 01.03.07

Togher, L., Balandin, S. Young, K., Given, F. and Canty, M. (2006) Development of a Communication Training Program to Improve Access to Legal Services for People With Complex Communication Needs. *Topics In Language Disorders*. 26 (3): 199-209.

Tomblin, J.B., Records, N.L., Buckwalter, P., Zhang, X., Smith, E. and O'Brien, M. (1997) Prevalence of specific language impairment in kindergarten children. *Journal of Speech, Language and Hearing Research*, 40: 1245-1260.

Traynelis-Yurek, E. and Giacobbe, G.A. (1998) A communication rehabilitation regimen for incarcerated youth: Positive peer culture. *Journal of Offender Rehabilitation*, 26 (3/4): 157-167.

Turnbull, M., Mackintosh, S., Edmonstone, A., Malcom, C., Little, N., and Hartley, K. *The Case For Action: A Strategy For People With Communication Impairment.* Communication Impairment Action Group

UNESCO (1994)*The Salamanca Statement and Framework For Action on Special Needs Education.* UNESCO: Paris.

United States of America in Congress (2004) *Individuals with Disabilities Education Improvement Act of 2004.* Washington: United States Congress

Whigham, B. R. and Mattson, B. D. (1969) Attitudes influencing employment of the handicapped. *Journal of Employment Counselling*, 6 (2): 72-78.

Whyatt, K., Carter, M. Mahtani, V. Hawton, A. and Britten , N. (submitted) *The impact of consumer involvement in research: an evaluation of consumer involvement in eleven primary care research studies.*

Wood, B. (2006) *The sustainability of a Speech and Language Therapy Service for Stroke Patients in a Remote and Rural Community: report for Managed Clinical Network* *for Stroke in NHS Highland.* Edinburgh: Chest, Heart and Stroke Association, Scotland.

Woolley, H., Armitage, M., Bishop, J., Curtis, M., and Ginsborg, J. (2005) *Inclusion of Disabled Children in Primary School Playgrounds.* Joseph Rowntree Foundation.

Wright, J.A. and Kersner, M. (1998) Collaborative working practices in schools for children with physical disabilities. *International Journal of Language and Communication Disorders*, 33 (supplement): 626 – 631.

APPENDIX

1. **Indicative Level of Needs Table**
2. **Search strategies**
3. **Search results**
4. **Selection Criteria**

APPENDIX 1: INDICATIVE LEVEL OF NEEDS TABLE

Operational definition of level of need as applied to children using augmentative and alternative communication.

Needs relating to:	**Level I Needs**	**Level II Needs**	**Level III Needs**	**Level IV Needs**
The physical environment	The ordinary nursery/class/school is appropriate.	The child/pupil's needs are such that some special features are required in the nursery, class or school accommodation. For example, access to a resource base may be required for the delivery of structured programmes etc for some of the time. The child may require ramps and other aids.	A specialist facility may be required, eg a resource base/unit within a mainstream setting, for a substantial portion of the child/pupil's time in nursery, primary or secondary school.	A highly specialised environment, eg a special unit/school or nursery, is required for all the time the child/pupil is in the setting dealing with a combination of profound sensory loss, physical disability and/or disruptive behaviour.
The curriculum and how it is delivered	Ordinary curriculum with minor features of differentiation in relation to '5-14' guidelines, such as specific objectives for reading, listening, etc. Alternative methods of presentation within the group.	Significant differentiation is needed in **one** or some areas of the '5-14' curriculum requiring structured and clearly targetted programmes in learning and/or behaviour which are subject to termly review.	Very substantial and specialised differentiation is needed in a wide area of the '5-14' curriculum such as requires weekly review and con-sultation with agent(s) external to the school on an individualised teaching plan.	The curriculum which the child follows is radically different from that provided in the mainstream in that it requires daily review and consultation with agent(s) external to the school in order to establish the pre-requisites for learning, eg cognitive, sensory development.
The level of child/pupil support required	Levels of child/pupil support/ contact in individual/group settings which are normally available, with short periods with the classroom aide in small groups.	Direct individual support by Learning Support staff in small group. Use of scribe/reader. Short-term behaviour support to avoid causing stress to self/others.	Enhanced level of individual child/pupil/aide contact required for some of the time, eg primary care needs (soiling, catheterisation etc); behaviour support.	Child/pupil requires enhanced level of teacher and/or aide contact continuously. Extended primary care needs; continuous behaviour support; longer term life plan of total care needs.
The level of specialised resources, facilities and technologies required	Ordinarily available resources, facilities and/or technology shared with groups of children/pupils on a time-limited basis, eg word processors/personal computers.	Ordinarily available resources, facilities and/or technology required by the child/pupil individually on a time-limited basis, eg word pro-cessors/personal computers.	Highly specialised resources, facilities or technology not normally available and deployed/designed for the child/pupil's specific use on a time-limited basis.	Highly specialised resources, facilities or technology not normally available and deployed/designed for the child/pupil's specific use on a continuous basis.
The level of specialised support agent(s) involvement	Needs identified and monitored by class teacher and within-school support staff, eg Learning Support in mainstream setting. Advice only from other external agent(s), eg RAPS*, speech and language therapy, behaviour support, service for the sensory impaired etc.	Agreed and monitored support and advice from agent(s) cited in Level I, with clear objectives delivered by teacher and support staff deployed to support/teach child/pupil.	Agreed, monitored and delivered support on a regular basis to small groups of children/pupils by specialist agent(s), over and above learning support, and engaging one or all of external agent(s) cited in Level I.	Agreed, monitored and delivered support on an intensive basis on an individualised basis in a specialised setting, eg special unit, base or school, by specialist agent(s) as cited in Level I.
Mode of communication	Ordinary oral/aural and written with appropriate support from relevant aids.		Highly specialised methods are required by the child/pupil, eg sign language, braille etc.	

APPENDIX 2: SEARCH STRATEGIES FOR ONLINE BIBLIOGRAPHIC DATABASES

ERIC

The following free text (KW) and thesaurus terms (DE) were entered into the ERIC search engine.

#1 Communication Disorders in DE
#2 Language Impairments in DE
#3 Speech Impairments in DE
#4 Aphasia in DE
#5 Disabilities in DE
#6 Multiple Disabilities in DE
#7 Learning Disabilities in DE
#8 Hearing Impairments in DE
#9 Visual Impairments in DE
#10 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9
#11 Inclusive Schools in DE
#12 Special Education in DE
#13 Environmental Communication Support in KW
#14 Employment in KW
#15 Healthcare in KW
#16 Social Inclusion in KW
#17 Policy in KW
#18 #11 or #12 or #13 or #14 or #15 or #16 or #17
#19 Disability Identification in DE
#20 Daily Living Skills in DE
#21 Communication Aids for Disabled in DE
#22 Augmentative and Alternative Communication in DE
#23 #19 or #20 or #21 or #22
#24 #10 and #18 and #23

Medline

The following free text (KW) and thesaurus terms (DE) were entered into the Medline search engine.

#1 Communication Disorders in DE
#2 Language Disorders in DE
#3 Speech Disorders in DE
#4 Aphasia in DE
#5 Learning Disorders in DE
#6 Hearing Disorders in De
#7 Vision Disoders in DE
#8 #1 or #2 or #3 or #4 or #5 or #6 or #7
#9 Communication Aids for Disabled in DE
#10 Communication Support in KW
#11 Communication Needs in KW
#12 Augmentative Communication in KW
#13 Alternative Communication in KW
#14 #9 or #10 or #11 or #12 or #13
#15 Social Inclusion in KW

#16 Education in KW
#17 Health in KW
#18 Employment in KW
#19 Policy
#20 #15 or #16 or #17 or #18 or #19
#21 #8 and #14 and #20

Psychinfo

The following free text (KW) and thesaurus terms (DE) were entered into the Psychinfo search engine.

#1 Communication Disorders in DE
#2 Hearing Disorders in DE
#3 Language Disorders in DE
#4 Speech Disorders in DE
#5 Aphasia in DE
#6 Vision Disorders in DE
#7 Learning Disorders in DE
#8 Communication Needs in KW
#9 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8
#10 Home Environment in DE
#11 School Environment in DE
#12 Social Inclusion in KW
#13 Employment in KW
#14 Healthcare in KW
#15 #10 or #11 or #12 or #13 or #14
#20 #9 and #15

Cinahl

The following free text (KW) and thesaurus terms (DE) were entered into the Cinahl search engine.

#1 Communication Impairment (Saba CCC) in DE
#2 Impaired Verbal Communication (NANDA) in DE
#3 Communicative Disorders in DE
#4 Speech Disorders in DE
#5 Learning Disorders in DE
#5 Language Disorders in DE
#6 Visually Impaired in KW
#7 Hearing Impaired in KW
#8 Aphasia in KW
#9 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8
#10 Communication Aids for Disabled in DE
#11 Alternative and Augmentative Communication in DE
#12 Hearing Aids in DE
#13 Assistive Listening Systems in DE
#14 Rehabilitation of Hearing Impaired in DE
#15 Communication Support in KW
#16 Communication Needs in KW

#17 Communication Technolog* in KW
#18 #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17
#19 Aphasia/ED in DE
#20 Home Environment in DE
#21 Work Environment in DE
#22 Deaf Education in DE
#23 Education Special in DE
#24 #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23
#25 #9 and #18 and #24

LLBA

The following free text (KW) and thesaurus terms (DE) were searched for in the LLBA search engine.

#1 Learning Disabilities in DE
#2 Aphasia in DE
#3 Language Pathology in DE
#4 Vision Disorders in DE
#5 Hearing Disorders in DE
#6 Speech Pathology in DE
#7 #1 or #2 or #3 or #4 or #5 or #6
#8 Sign Language in DE
#9 Hearing Aids in DE
#10 Communication Aids in DE
#11 Augmentative and Alternative Communication in DE
#12 Augmentative Communication Technolog* in KW
#13 #8 or #9 or #10 or #11 or #12
#14 Special Education Handicapped in DE
#15 Education in DE
#16 Employment in KW
#17 Healthcare in KW
#18 Environmental Communication Support in KW
#19 Social Inclusion in KW
#20 Policy in KW
#21 #14 or #15 or #16 or #17 or #18 or #19 or #20
#22 #7 and #13 and #21

SCOPUS

The following free text terms where entered into the SCOPUS search engine.

#1 communication impair*
#2 communication disorder*
#3 speech disorder*
#4 language disorder*
#5 hearing disorder*
#6 visual impair*
#7 aphasia

#8 learning disorder*
#9 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8
#10 communication support
#11 communication needs
#12 augmentative communication
#13 alternative communication
#14 communication technologies
#15 #10 or #11 or #12 or #13 or #14
#16 supportive communication environment
#17 social inclusion
#18 education
#19 society
#20 health
#21 employment
#22 policy
#23 #16 or #17 or #18 or #19 or #20 or #21 or #22
#24 #9 and #15 and #23

APPENDIX 3: SEARCH RESULTS

Results of the search strategy from each database

Electronic Resource	**Found**
Cinahl	92
Psychinfo	238
Scopus	28
Linguistics and Language Behaviour Abstracts (LLBA)	158
ERIC	316
Medline	76
Total	**908**

APPENDIX 4: SELECTION CRITERIA

Inclusion

- Must be a document concerning individuals with CSN.
- The experience of CSN individuals use or non use of services in both the mainstream and more specialist services (education, health, justice etc.).
- Documents that identify and draw out core difficulties/barriers to access and engagement with services for individuals with CSN.
- Documents identifying attitudes of the general population to individuals with CSN as from the viewpoint of how discrimination or lack of awareness and understanding of CSN affects the experiences of accessing and engaging with services.
- Documents that identify and draw out themes of good practice in terms of what helps people with CSN move through services (egg. successful transition through school, educational attainment).
- Document must be a research based, this can include any of the following:
    - Case studies
    - Studies that due to varied nature of CSN e.g. type/severity interpret the experience of use or non use of services by individuals with CSN via carers, family members, service providers, specialist therapists, special needs teacher etc.
- Documents that provide an indication of prevalence and scale of CSN in Scotland.
- Documents with a Scottish/UK focus or relevant international literature (e.g. English speaking countries).

Exclusion

- Document not concerned with CSN
- Document does not focus on the experiences of CSN individuals in their use or non use of both mainstream and specialist services (education, health, justice etc.)
- Non-research document (e.g. internet blogs, TV broadcast material, anecdotal reports or books written by individuals with CSN)
- Intervention studies that measure individuals' performance without reference to the individual's beliefs and attitudes regarding access and engagement with services
- Material focusing on training assistants or other professionals about some of CSN such as alternative and augmentative communication
- Literature describing interventions, skills and symptoms of specific conditions characterised by CSN
- Document does not have a Scottish/UK focus or relevant international perspective

ISSN 0950 2254
ISBN 978 0 7559 6635 6
Price £5.00

www.scotland.gov.uk/socialresearch

The text pages of this document are produced from 100% Elemental Chlorine-Free material.
The paper carries the Nordic Ecolabel for low emissions during production, and is 100% recyclable.

RR Donnelley B51924 6/07

GSR
GOVERNMENT SOCIAL RESEARCH
Analysis for Policy

ISBN 978-0-7559-6635-6
9 780755 966356