



# Resource Manual for Commissioning and Planning Services for SLCN

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## Resource Manual for Commissioning and Planning Services for SLCN

### CONTEXT

The aim of this section is to set out the context for this resource. This work forms part of a range of tools which can support leaders with service planning and delivery, in line with both government and local priorities.

**It is essential for service providers to demonstrate quality and productivity and to:**

- show value for money
- be able to provide a strong financial argument for the need to invest in services for people with speech, language, communication and swallowing needs
- demonstrate improvements in outcomes for individuals, families and society

Value for money is not about being the cheapest option but about delivering the most return (impact, best outcomes) for a given investment over time.

The key drivers for change to services include:

1. The broad context, which can be divided according to the following factors:
  - **P**olitical and **L**egislative factors
  - **E**conomic factors
  - **S**ocial factors
  - **T**echnological factors
2. The near or local context, including:
  - Localised policies
  - Addressing local needs
  - Service provision
  - Workforce
  - The evidence base

### THE BROAD CONTEXT (MACRO-ENVIRONMENTAL ANALYSIS): FACTORS FROM THE WIDER WORLD

The Macro-environmental analysis commonly takes the form of a PEST analysis:

**P**olitical and legislative factors

**E**conomic factors

**S**ocial factors

**T**echnological factors

#### *Political and legislative drivers*

Devolution has resulted in changes to the powers of the different institutions across the UK.

The government in power at Westminster maintains responsibility for policy and legislation in relation to key areas including: tax, benefits, foreign affairs, international development,

trade and defence for the four countries of the UK. Government in Westminster is also responsible for health, social care and education in England, but these areas are devolved for Northern Ireland, Scotland and Wales.

As a result of devolution, each country of the UK may have different parties in power, with the possibility of increasing powers in the future. The impact of this is the diversification of policy and direction of travel.

### *Legislative drivers*

The main areas of UK-wide legislation that are relevant include the following themes:

- Human Rights
- Disability Discrimination
- Equality

Though there is different local interpretation, these far-reaching legal instruments define the rights and responsibilities of people and those commissioning and providing services for them.

Public protection has also been strengthened through the introduction of registration of professionals, for example, through the Health Professions Council.

There is separate legislation relating to health, education and social services in each of the devolved administrations in England, Northern Ireland, Scotland and Wales.

### *Economic*

The current challenging economic backdrop will have a significant impact on the financing of public services, with local planners and commissioners prioritising services which are value for money, evidence based and releasing cash through innovation.

### *Social*

In order to plan and deliver services, it is essential to identify the demographic factors relevant to speech and language therapy (SLT) and the challenges that these bring.

- The population is aging: people are living longer.
- The birth rate is falling: most families are having fewer children
- The infant mortality rate is also falling, with more children surviving premature birth or health problems or injury in infancy.
- The urban population is growing.
- The proportion of the population in employment is falling.
- The proportion of the population with English as an additional language is increasing, particularly in urban areas.

## THE NEAR OR LOCAL CONTEXT

### *Localised policies*

Central to the new reforms is the emphasis on local decision-making within a national framework. Across the four countries of the UK there are requirements to provide services to accord with local need and influence. In England there is a particular focus on increasing the range of potential providers (plurality of provision) with commissioners having a role to stimulate the market.

For each country, arrangements have been established to assess whether commissioners are achieving better health outcomes for the local population. Part of this process will be an assessment of how well commissioners are performing against specified competencies/indicators/targets. For example, in Northern Ireland these targets are based upon high-level outcomes linked to local strategies.

With the devolution of power to local levels, there is a focus on developing more robust accountability. There is an emphasis on joint working to support integrated commissioning, service planning and provision across health, social care and education.

There are different approaches to this development with different structures and commissioning and performance management arrangements being established across the UK. The dominant theme in strengthening accountability is “putting service users at the centre” with respect to:

- Access and self-referral
- User voice at strategic to operational to individual case management
- Population/local engagement
- Information and advice for users, parents/ carers
- Patient Rights
- Self management of conditions

Some localities will be commissioning or planning speech and language therapy services as a single service whilst others will be commissioning integrated services, cutting across traditional boundaries, with health services integrated with education or social services. In many areas, this has already happened for children's services.

It is recognised that, often, no single agency can deliver best outcomes for their service users by working in isolation. Joint commissioning is advocated wherever the meeting the needs of individuals requires contributions from a number of agencies.

Similarly, some service planners or commissioners will be organising services around disease groups, such as services for persons who have survived a stroke. In either case, it will be important for speech and language therapy managers to liaise with other services to ensure that SLT provision is incorporated in their service plans.

Special arrangements are in place for commissioning services for unusual, low incidence or costly interventions. Speech and language therapy managers should identify the specialist commissioning procedures that may be required for individuals requiring

particular interventions such as costly augmentative communication aids, protracted or intensive interventions.

### *Addressing local needs*

In general terms, the UK is experiencing a number of long-term demographic changes (some of which are identified above).

There is significant local variation within these general trends. It is important to understand what these changes and variations imply in relation to the provision of local SLT services. Other local factors to be taken into consideration include: employment, cost of living, housing, transport and, particularly, levels of deprivation.

There are information resources available online from which planners, commissioners and providers can find out more about local and regional demographic factors. Some of these can be found signposted on the RCSLT website [www.rcslt.org](http://www.rcslt.org).

Local public health teams will also be able to sign-post local services to relevant data and information for their area.

There will also be learning from data collected by services. The RCSLT has developed an online tool called Q-SET, the Quality Self- Evaluation Tool to help you collate local SLT service derived information <http://www.rcslt.org/resources/qset>. Q-SET should be used alongside national and local data to support service planning and evaluation of service delivery.

Through completing Q-SET, provider services can:

- use the resource every 9-12 months to review progress in meeting action plans and to demonstrate service enhancement
- compare their service with other similar service types e.g. urban, rural, acute, community, adult, paediatric, education, 3rd sector
- demonstrate that their service meets the needs of the service users
- identify areas of strength and generate action plans relating to areas of development.
- submit the results as part of the evidence for a clinical audit
- retain ownership of the monitoring and development of services ensuring that strong professional standards are maintained in the context of multi-agency teams

Service providers completing Q-SET will support commissioners to:

- reduce the 'postcode lottery' of service availability and quality
- have high quality information that is relevant and accessible
- have an overview of developments, trends and initiatives within the service
- have accurate and timely statistics to support performance management and monitoring
- collect data to contribute to the debates on benchmarking. Where benchmarks do not yet exist Q-SET will enable Commissioners to contribute to this in the future
- collect examples of good practice to inform other pieces of work and the development of services as a whole.

Locally derived information will help SLT services to illustrate:

- the numbers of patients/clients seen
- sources of referral
- amount of resource used in providing a service to the client e.g. number of sessions and skill mix
- nature and severity of the disorder, disability, psychosocial impact at the onset of intervention
- nature and severity of the disorder, disability, psychosocial impact at the completion of intervention.
- level of satisfaction with the service.

### *Service provision*

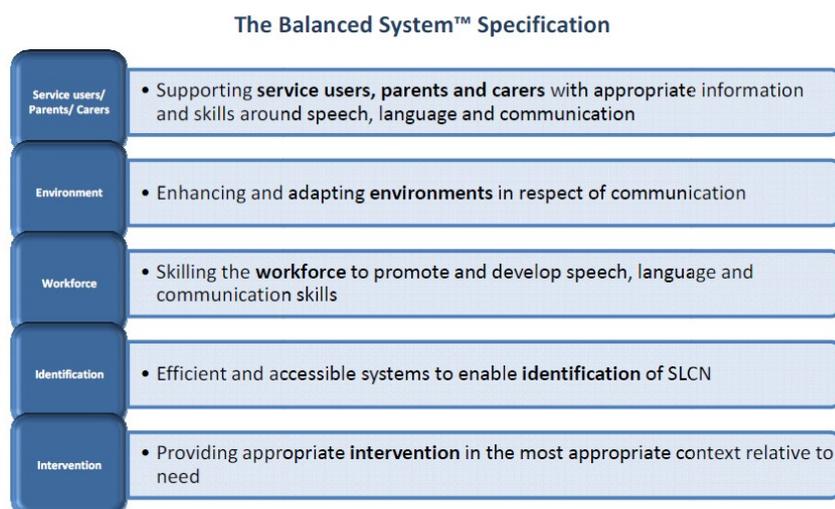
Speech and language therapists have a role in delivering specialist and targeted support to clients, carers and their families. Speech and language therapists can also reduce long-term demands on services by addressing immediate needs that arise from circumstance rather than underlying impairment. Providing training for the wider workforce is integral to the speech and language therapists core role, as outcomes for people with speech, language and communication needs SLCN are improved when the whole workforce is able to contribute appropriately to care pathways.

SLTs also work with the wider workforce contributing to the public health agenda, promoting health and well-being in respect of communication and swallowing. There is little awareness outside the profession of the role of speech and language therapists in preventing the development of speech and language impairments and the further impact and consequences of different speech, language and communication disorders upon health, education, social integration and employment.

The challenges of meeting the speech, language and communication needs (SLCN) of a given population are best understood through a social (participative) model. Key elements of a total service specification will start with:

- identifying the needs of the service user, parent or carer for support and information
- identifying/assessing and diagnosing specific SLCN and providing appropriate intervention.
- considering needs of service users within the environments they encounter
- training the wider workforce that interfaces with them to maximise opportunities for positive outcomes.

The balanced system (diagram 1) below illustrates the wider context for how SLTs contribute to this range of activities. The needs of service users should be considered in service specifications. The role of SLTs in supporting the active participation of service users in service planning, adapting the environment and enskilling the workforce is as relevant as the SLT role in identification and intervention.



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### *Workforce*

Careful planning of services, including joint commissioning, will help to shape the workforce and inform the skill mix required to deliver high quality services, improve outcomes and support value for money. Because the commissioning and planning of services relies on the evidence base for a given type of SLCN or model of practice, it is essential that clinical and managerial expertise from speech and language therapists is available to support innovation and quality of service design.

Speech and Language Therapists, as part of the wider workforce, may be employed by a range of organisations, including the third sector, social care and education or be working as private practitioners.

Equal Access to services is of importance to local decision makers. Local demographic profiling will inform workforce requirements. For example, bilingual staff and support workers are required in most areas to meet the needs of diverse communities. The appropriate skill mix should enable services to be family-centred and be culturally and linguistically appropriate and responsive. It may be necessary to consider increasing home delivered services or providing services in unusual locations.

The RCSLT also acknowledges the important role that Assistants and Support Workers have in the delivery of effective speech and language therapy services. Assistants and Support Workers are integral members of both speech and language therapy and multi-disciplinary teams, engaged in a wide range of clinical settings with diverse client groups, duties and responsibilities. [http://www.rcslt.org/aboutslts/rcslt\\_statement\\_v3.pdf](http://www.rcslt.org/aboutslts/rcslt_statement_v3.pdf)

In order to support more effective use of skill mix, SLT services also need to provide education and training of the wider workforce and not be focussed solely on direct patient / client care. For all services, this is critical to secure the appropriate balance of cost-effective universal, targeted and specialist services.



## PRACTICAL CONSIDERATIONS

Many people involved in strategic planning, commissioning or reviewing services will not be familiar with speech and language therapy, its objectives, the needs of clients requiring speech and language therapy, the principles driving the profession, or the evidence base and the following points may support people.

- Where possible, draw on the evidence base.
- Communicate clearly and succinctly.
- Avoid using acronyms and provide a glossary of terms.
- Do not assume knowledge of local arrangements or the requirement to interface with other agencies
- Set your service in the context of local priorities.

The RCSLT's Communicating Quality 3 (CQ3) provides clear guidance on care pathways, clinical standards and issues related to quality assurance. This information should be used in submissions to support commissioning quality services.

The following guiding principles have been adopted and apply to all client groups. Services are to:

- be family centred and culturally and linguistically appropriate and responsive
- be comprehensive, coordinated and team based
- work with and communicate effectively with other services meeting the needs of the client
- be evidence based
- ensure equal access
- involve the family and carers
- include training and education of co-workers
- ensure practitioners continuing professional development and appropriate support.

Evidence of the impact of the service will be important to commissioners and providers. Providers will need to demonstrate the impact of their service, particularly when services are being reviewed. Determining the objectives of the service will support the process of outcome measurement. SLT services will need to provide information on outcomes achieved and levels of client satisfaction. Some of this information can be gathered through use of the RCSLT's Q-SET tool, as detailed above.

Managers of speech and language therapy services will need to equip themselves to engage effectively and positively with those who are commissioning or monitoring services. They will need to:

- identify who is commissioning or responsible for overseeing different services. For example, health commissioners may be working with commissioners for education/head teachers. It is important to identify who is taking the lead for each aspect of the service delivery in the locality.
- establish good working relationships and effective communication with those commissioners and planners for their area of responsibility.
- be aware of local priorities and commissioning plans and strategies.
- have a good understanding of the commissioning/planning/monitoring framework for the locality
- be equipped with local data, knowledge and evidence to the tendering process
- be clear of the unique contribution of the service to improving health, employment, education and social outcomes
- be able to clarify and demonstrate local working partnerships and collaborations
- provide data describing the service provided, (numbers and types of patients, numbers of attendances, health and social outcomes etc).

The RCSLT has developed a range of resources to support its members with Continuing Professional Development. CPD is a regulatory requirement for all SLTs and this requires all HPC Registrants to demonstrate how the CPD they have undertaken has sought to enhance service delivery and to be of benefit to service users. The RCSLT has endorsed this requirement through its own CPD standards. <http://www.rcslt.org/cpd/resources>

## THE EVIDENCE BASE

The commissioning and planning of services must be informed by the evidence base of effective practices.

This Resource Manual SLCN is based on a synthesis of existing published research. The threshold for inclusion in the syntheses has favoured the most scientifically robust research methodologies which have often reflected medical (impairment) rather than social (participative) models of care.

In the section summaries, emerging practices that have not been included in the evidence synthesis, are referred to and should be considered alongside the syntheses. This tension between empirical evidence resulting from robust research, which by definition is retrospective, and the needs to encourage innovation and service re-design to support improvements in outcomes for people with speech, language, communication and swallowing difficulties is natural and unavoidable. Emerging practice will not have the same evidence base and therefore less empirically stringent measures of evidence need to be taken into account for these areas including professional consensus and measures of service user, parent or carer experience. However, because of the value of some emerging innovative practice, they have been included in this resource.

An overview of the methodologies employed in identifying practices that are included in this resource accompanies this document.

### *Using these resources*

Speech and language therapy managers can assist commissioners by understanding their agenda and the objectives that they are to be assessed on.

The Royal College of Speech and Language Therapists is providing these resources to assist speech and language therapists in gathering the core data required to support service tendering agreements, service planning, monitoring arrangements and/or where services require specification.

Each part of these resources is focused on a specific area.

The resources provide:

- *The Contextual Synthesis.* This includes definitions, information on the incidence and prevalence of the disorder, key contribution of speech and language therapists, consideration of the implications and broader consequences of the disorder.
- *The Synthesis of Key Literature.* This summarises the evidence of the impact of speech and language therapy.

Each section within these resources gives succinct information to inform the factual content for any service planning activity. These include:

- Key points
- Topic –What is [the condition]?
- How many people have [the condition]?

- What causes [the condition]?
- How does this condition affect individuals?
- What are the aims/objectives of speech and Language therapy interventions for [this condition]?
- What is the management for people with [this condition]?
- What is the evidence for Speech and language therapy interventions in [this condition]?
- Studies
- Assessment methods
- Speech and language therapy interventions
- Summary
- References

This information will need to be put into context, using local information.

### **Other guidance and resource materials**

It is recognised that service managers may wish to amplify or clarify, an aspect of their service by providing reference to other national or local research of relevance.

The RCSLT has a range of resources which can be used to further support and inform the commissioning, planning and provision of services for people with speech, language, communication and swallowing needs. These can be found on the RCSLT website: [www.rcslt.org](http://www.rcslt.org)

**The RCSLT is grateful to the experts from within the SLT community who contributed to the evidence published in this document.**

## METHODOLOGY FOR SYNTHESIS OF LITERATURE

### *Introduction*

The focus of the interventional synthesis within these briefings is to provide a synopsis on the effectiveness of speech and language therapy interventions for each specific condition.

The interventional syntheses are produced by reviewers within the Information Resources Section (within the Health Economic and Decision Science Section) at the School of Health and Related Research (SchARR). Information specialists/reviewers for this bulletin were Diana Papaioannou and Anna Cantrell.

### *Methodology*

The interventional syntheses are not intended to be a full systematic review within each topic area. However, they draw upon systematic review techniques to ensure that the syntheses are developed according to systematic, explicit and transparent methods. The intention of the syntheses is to consolidate twenty articles which represent some of the best research for each topic area.

### *Literature searching*

Systematic literature searches were undertaken to identify a range of evidence for each interventional synthesis. The interventional syntheses do not attempt to consolidate all research within a particular topic area; rather they aim to present a careful selection of the most current research within that field. Therefore, the approach adopted for the literature search aims to be comprehensive reflecting this systematic and explicit approach.

Firstly, search terms were selected within the project team drawing on the expertise of four speech language professionals. This involved listing all possible synonyms describing the condition or population (for e.g. children/infant, stuttering/stammering) and combining those with terms to describe speech and language therapy. Terms were used in both free text and thesaurus searching. The following databases were used:

- ASSIA
- CINAHL
- The Cochrane Library (which includes the Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled trials, Database of Abstracts of Reviews of Effects, Health Technology Assessment Database and NHS Economic Evaluations Database).
- Linguistics and Language Behaviour Abstracts
- MEDLINE
- PsycInfo

All references retrieved from the literature searches were entered onto a Reference Manager Version 11 database using appropriate keywords.

### *Selecting and obtaining relevant articles*

Articles for inclusion were selected to illustrate the range of good quality evidence within each topic area. An initial screening of articles was undertaken by the Information specialists/reviewers who adopted the following principles:

- Articles must be empirical research evaluating the effectiveness of a particular speech and language therapy intervention
- Only articles published in English language are included.
- In general, only the most current (1998-present) literature is included. However, exceptions were made to this if a particular article was felt to be important to include.
- Where possible higher level evidence was included (systematic reviews, randomised controlled trials). However, this research did not always exist in every topic area.
- Efforts were also made to seek out literature that provided a range of perspectives on interventions for each topic area, i.e. both quantitative and qualitative research.

Following initial screening, the remaining articles were examined by two members of the team; each having considerable speech and language therapy knowledge and experience. Approximately, twenty articles were selected by the two reviewers with disagreements being resolved by a third reviewer.

### *Assessing the quality of relevant articles*

Formal quality assessment of the articles was not undertaken. Instead, quality assessment involved using checklists as a guide to give an indication of the overall quality of studies and highlight the main good and bad aspects of each study. For each interventional synthesis, the included study designs are listed and the problems with each study design noted. General observations on study quality are made and common errors within the studies, where appropriate, are specifically noted. The checklists used are one for quantitative and one for qualitative studies from the Alberta Heritage Foundation for Medical Research.<sup>1</sup> Additionally, when an identifiable study design was used, the appropriate Critical Appraisal Skills Programme (CASP) checklist was selected.<sup>2</sup>

### *Syntheses of the twenty articles*

Each article was read in turn by one of the Information Specialists/reviewers. The key points were summarised including the objective of the study, the participants' characteristics, the methodology, the intervention, results and limitations. From this, articles were grouped into themes according to the factor being investigated (for e.g., length of intervention, personnel carrying out intervention, family involvement in treatment, nature of disorder). Results were summarised and drawn together within each particular theme and a summary paragraph provided at the end.

These syntheses first went out for review by selected individuals, identified by the research team, with particular expertise in the delivery or management of services to the

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<sup>1</sup> LM Kmet, RC Lee, LS Cook (2004) Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields. Accessed at <http://www.ihe.ca/documents/hta/HTA-FR13.pdf> (Accessed on 25<sup>th</sup> September 2008, now no longer available)

<sup>2</sup> Critical Appraisal Skills Programme (2007) Appraisal Tools. Accessed at <http://www.phru.nhs.uk/Pages/PHD/resources.htm> on 9<sup>th</sup> January 2009.

specific client group. Comments were included in the second draft, which was then dispatched to those selected by the Royal College Speech and Language Therapists who were invited to attend a focus group day. These therapists gave detailed consideration to their specialist area and contributed to the more general discussion of one further area. Issues to be captured in the key points were also identified within the focus groups. These comments contributed to the third draft of the syntheses, which again went out to reviewers. In some cases, further work was required in order to modify the wording and reflect discussion.

#### **Checklist for service managers involved in commissioning services**

Have you presented incidence and prevalence figures and local demographic trends for the conditions in your area?

Have you provided information on local access and use of services in the context of the number expected and highlighted your approaches to inequalities?

Have you consulted systematically with users to inform development of this commissioning proposal?

Does your proposal fit/link with local cross agency priorities?

Have you outlined the range of services provided including training?

Have you made clear how this fits with future planning for your service over the next 3-5 years?

Have you stated the assumptions which underpin your thinking in the plan and for future developments?

Have you offered predictions about the likely impact of investment in the proposal?

Have you made clear where the risks are and what contingency plans you have put in place?

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# **RCSLT RESOURCE MANUAL FOR COMMISSIONING AND PLANNING SERVICES FOR SLCN**

## **LEARNING DISABILITY**

## Learning Disability

### 1. Key Points

1. Learning difficulty is a lifelong condition, which impacts on the individuals, educational, social, economic, and life choices. There is a high prevalence of communication and swallowing disabilities occurring in this population.
2. Service providers need to be aware of demographic factors associated with an increase in the numbers of individuals with learning difficulties, requiring support and treatment
3. Speech and language therapists have a unique role in identifying the social communication characteristics of importance to diagnosis, contributing to differential diagnosis and facilitating identification of retained abilities and comorbidities e.g. hearing loss
4. Difficulties with social communication is a predominant feature in reducing access to education, employment and social integration.
5. Communication difficulties are associated with increased prevalence of challenging behaviour.
6. Swallowing disorders associated with increased ill health, chest infections and reduced survival
7. Speech and language therapists should be integral members of the multidisciplinary team supporting children and adults with learning difficulties, their families and carers.
8. Interventions by speech and language therapists are set within a social model driven by principles detailed in Valuing People
9. Speech and language therapists have a key role in educating/training others involved in the care of those with learning difficulties including the family, health, education and social care staff. There is research evidence of the positive impact of speech and language therapists conducting training packages on the behaviour of others in promoting communication with persons with learning difficulty
10. There are critical periods in the life of a person with a learning difficulty, where additional speech and language therapy intervention may be needed. For example, primary to secondary school, death of a member of the family etc
11. There is evidence that the use of augmentative and alternative methods of communication are effective in facilitating communication and do not reduce speech production capabilities.
12. As part of all service delivery there is emerging practice and developing roles. Within Learning Disability this might include building capacity in other services and the wider community and helping services to make reasonable adjustments.

## 2. What is learning disability?

Learning disability is a lifelong condition, and not an illness as such, although it may be accompanied by physical, psychological and psychiatric illness and disability. The term encompasses a range of conditions and levels of severity, and many people with learning disabilities can be integrated into, and make a positive contribution to, wider society. Acceptance of the condition, and assisting individuals to reach their personal potential is the aim of intervention with this group.

Learning disability has had many different labels over time and continues to be referred to by different terms. These include, mental retardation, special needs, mental handicap and intellectual impairment (Kelly, 2002). The Department of Health in England and Wales has agreed on the term 'people with learning disabilities', and this term will be used throughout this synthesis, except where citing literature that uses a different term. Learning disability is diagnosed when an individual has a significant impairment of intelligence, social functioning that is acquired before adulthood (DoH,1998).

Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- a lasting effect on development.

This definition encompasses people with a broad range of disabilities, which can include for example, global delay and Down's Syndrome. An intelligent quotient below 70 is one way in which need is identified, but an assessment of social functioning and communication skills will also inform a decision about health and social care needs (Department of Health, 2001).

There are also a group of patients described as having 'profound and multiple learning disabilities' (PMLD). This group is characterised by a complex range of severe physical and learning disabilities with an IQ below 25, and a lack of functional skills (Kelly, 2002).

'Learning disability' is not interchangeable with the term 'learning difficulty', which is an educational term and includes, for example, dyslexia.

## 3. How many people have learning disability?

Learning disability persists from childhood into adulthood. An ageing population and better medical and social care, means that people with learning difficulties are living longer (British Institute of Learning Disabilities, 2008).

There are an estimated 985,000 people with learning disabilities in England (Primary Care Trust Network, 2009). Incidence figures tend to be cited for the most common causes of learning disability, Down's Syndrome and Fragile X syndrome, are shown below.



Table 2: Incidence and Prevalence

Incidence	Prevalence
Down's Syndrome is diagnosed in 1 per 700 live births (Wellcome Trust 2009).	1.5 million people in the UK have a learning disability (Mencap, 2008).
Fragile X syndrome is diagnosed in 1/4000 male live births, and 1/6000 female live births (FRAXA 2009).	1-2% of population have learning disability (British Institute of Learning Disabilities, 2008).
	0.35% of population have profound to moderate learning disabilities (British Institute of Learning Disabilities, 2008).
	20 per 1000 have mild learning disability (Department of Health 1995, cited in Kelly, 2002).

People with learning disabilities will often have communication difficulties, either because of the learning disability itself, or due to an associated physical or sensory impairment:

- 50%-90% of the learning disabled population have communication difficulties (Enderby and Davies 1989, RCSLT, 2006)
- 80% of people with severe learning disabilities do not acquire effective communication (RCSLT, 2006)
- One third of all Speech and Language Therapy service in the UK is directed at the learning disabled population (RCSLT, 2006)
- 89% of people with learning difficulties need speech and language therapy intervention (Bradshaw, 2007).
- 45% of people with learning difficulties have serious communication problems (Bradshaw, 2007).
- 50% of people with intellectual disability have significant communication problems and up to 80% have some communication problems (Scottish Executive, 2000).

Dysphagia (swallowing disorder) is also a common associated condition for people with learning disabilities. It is difficult to ascertain the prevalence rate for dysphagia in children with learning disabilities, due to the way dysphagia is reported as part of other health conditions. However, Chadwick et al 2003 (cited in RCSLT, 2006), found that 5.27% of all adults with learning disability were referred for advice regarding dysphagia. For more information on the impact of dysphagia (which includes malnutrition and the risk of death from asphyxiation) and the role of the SLT in diagnosing and treating dysphagia, please refer to the dysphagia synthesis within this guide.

Services for people with learning disabilities, including Speech and Language Therapy, will come under increasing demand due to:

- decreased mortality among people with learning disabilities,
- increases in adults with learning disabilities requiring services when parents become too frail to care
- changing expectations in families with people with learning disabilities
- the rights of a person with learning difficulty to an independent life (Emerson and Hatton, 2008).



#### 4. Factors contributing towards learning disability?

A learning disability is caused by problems during brain development before, during or after birth.

Before birth, damage to central nervous system e.g.:

- accident or illness of mother while pregnant (malnutrition, drugs, alcohol, diseases)
- genetic syndromes (Down's syndrome; Fragile X)

During birth e.g.:

- born prematurely
- not enough oxygen during birth-hypoxia
- birth difficulties
- infections in the womb

After birth e.g.:

- illness or accident during early childhood (head injury, epilepsy, meningitis)
- environmental factors (lead/mercury poisoning, malnutrition, social deprivation) (Mencap 2008a)

The most common causes of learning disability are associated with inherited conditions such as chromosomal abnormalities. Down's Syndrome and Fragile X Syndrome are not learning disabilities in themselves, but people with these conditions are likely to have an accompanying learning disability (Mencap, 2008a). In about 50% of people with a mild learning disability, no cause is identified. In this group it is thought that environmental factors could contribute.

#### 5. How does learning disability affect individuals?

A learning disability will impact on all areas of an individual's life, for the duration of their life, and the challenges faced will change throughout their lifespan.

People with learning disabilities may face challenges in learning, understanding and communicating. People with profound and multiple learning disabilities (PMLD) are likely to need help with all activities of daily living (Mencap, 2008).

##### *Health*

Life expectancy is lower than for the rest of the population and is shortest for people with Learning Disability who are least able. Disease patterns are different than that found in the normal population and there are frequent complications of co-morbidity with other conditions. The leading cause of death in people with Learning Disability is respiratory disease which relates to pneumonia and aspiration and abnormal posture (NHS Health Scotland, 2004).

People with learning disabilities have a higher incidence than the general population of:

- Epilepsy
- Visual Impairment
- Hearing Impairment
- Swallowing problems

There are also health problems associated with the overall condition of the person with learning disability, for example, children with Down's Syndrome have increased risk of congenital malformations, and in developing early onset dementia.

Many individuals with learning difficulties also experience dysphagia, which can result in dehydration, malnutrition and chest infections. Any of the four stages of swallowing can be affected, and it is important that the speech and language therapist assesses swallowing competence and intervenes appropriately given the complexity of the disorders and additional barriers to overcoming these. (Darren et al, 2005) Further information, speech and language therapy management of dysphagia is provided within that section.

In more general terms it is important to promote a healthy lifestyle for people with learning disabilities, as it is for the general population, as well as encouraging health screening and dealing effectively with health needs which arise from associated conditions.

Attention needs to be paid to promoting choice and independence in these matters, which includes accessible information and advocacy.

A report by Mencap (2007) highlighted a growing concern that people with Learning Disabilities were not having their needs met by mainstream NHS services, emphasising the need for the above.

### *Social*

People with learning disabilities have the need for a fulfilling social life, as much as the general population. However, their opportunities for this are limited, and they may face difficulties in their interaction with other people. 65% of people with learning disabilities claim to have been bullied with 38% saying it happens regularly (Scottish Executive, 2000). They are frequently more vulnerable than the general population with having a higher risk of being victims of crime and being involved in the criminal justice system as potential perpetrators of crime.

### *Education, Work and Income*

Throughout their lifespan people with learning disabilities can face disadvantages in education, work and income. The parents of children with learning disabilities are likely to act as full time carer for their child and therefore not work, and half of all families with children with a learning disability live in poverty (Mencap, 2008d).

Opportunities for work and education are limited. Emerson and Hatton (2008) estimate that:

- **28%** of people with mild/moderate learning disabilities that are known to services are in paid employment. (70% of these people work for 16 or more hours a week).
- **10%** of people with severe learning disabilities that are known to services are in employment. (57% of these people work for 16 or more hours a week).
- **36%** of people with learning disabilities are undertaking some form of education.

People with learning difficulties often have low incomes and few personal possessions (Enderby & Davies, 1989).

### *Family and Housing*

At least half of adults with a learning disability remain with their parents, lessening their chance for independence and meaning that the parents often continue to act as carer into their old age (Mencap, 2008d). 6 out of 10 people with learning disability live in residential care or supported housing in which they have had no choice (Mencap, 2008d). In all situations, people with learning disabilities may well have limited privacy in their living situation (Mencap, 2008d)

### *Vulnerability and risk*

People with learning disabilities are at a higher risk of sexual and physical abuse, and of being victims of crime.

### *Challenging behaviour*

The communication challenges faced by people with learning disabilities, identifies them as a vulnerable population. They have increased risk of developing challenging behaviour, which is often used as a mode of communication. This can include physical aggression directed at themselves or others, damage to the environment, and sexually inappropriate behaviour.

People with learning disabilities have an increased risk of developing psychological problems, and many adults with learning disabilities will have a dual diagnosis of a psychiatric disorder.

There is some evidence that people with learning disabilities are over represented in the criminal justice system (Scottish Executive, 2000).

### *Transitions*

As the needs of people with learning disability continue and change throughout the lifespan, services should be aware of periods of transition in the person's life and able to offer tailored support at these times, to make transition as smooth as possible (Scottish Executive, 2000). This includes:

- The transferral from children's to adult services
- Starting and changing schools
- The death of a parent

### *Communication*

Up to 80% of people with learning disability have communication difficulties, with 50% having significant difficulties, and many people with PMLD have extremely limited communication ability which may be restricted to eye gaze and changes in facial expression. Whilst communication difficulties vary greatly from person to person, the following areas are commonly found to be of difficulty with this group:

- understanding speech, writing and symbols, and interpreting environmental sounds,
- having a sufficient vocabulary to express a range of needs, ideas or emotions
- being able to construct a sentence
- maintaining focus and concentration in order to communicate
- fluency, e.g. stammering
- being able to articulate clearly which may be due to related physical factors
- social skills, a lack of which may prevent positive interactions with people

(Kelly A 2002)

**Risks of non-intervention**

The potentially far reaching and long term effects of having a communication problem associated with a learning disability mean that it needs to be taken into consideration throughout the individual’s lifespan. If this does not happen it is likely to have a highly detrimental effect on patient’s health and social well being, at an ultimate cost to health and social care.

If appropriate communication support is not available it may contribute to problems in:

- social interaction
- restricted ability to choose and control environment
- development of language skills
- initiating communication
- learning
- developing life skills
- participating in education and employment

This in turn may lead to:

- lack of or loss of identity
- depression
- passivity/learned helplessness
- reduced learning opportunities
- isolation
- challenging behaviour
- risk of harm or abuse
- failure to reach potential in life

(Communicating Quality 3, 2006)

Table 3: International classification of functioning (ICF): dimensions and impact

<b>ICF Dimension</b>	<b>Impact</b>
Impairment	Impaired communication, cognition and function causing: <ul style="list-style-type: none"> <li><input type="checkbox"/> Understanding language and expressing ideas</li> <li><input type="checkbox"/> Limited attention span</li> <li><input type="checkbox"/> Limited memory span</li> <li><input type="checkbox"/> Limited vocabulary</li> <li><input type="checkbox"/> Dysfluency</li> <li><input type="checkbox"/> Control speech musculature for sound production</li> <li><input type="checkbox"/> Limitations in understanding or showing appropriate communicative intent</li> <li><input type="checkbox"/> Limitations in understanding social use of language</li> <li><input type="checkbox"/> Difficulties with feeding and drinking</li> </ul>
Activity	Performance ability and behaviours can involve the following difficulties: <ul style="list-style-type: none"> <li><input type="checkbox"/> Ability to use language to communicate</li> <li><input type="checkbox"/> Speak intelligibly</li> <li><input type="checkbox"/> Follow instructions or learn through verbal teaching</li> <li><input type="checkbox"/> Express needs, choices and opinions</li> </ul>



ICF Dimension	Impact
	<ul style="list-style-type: none"> <li><input type="checkbox"/> Use appropriate behaviour in social situations</li> <li><input type="checkbox"/> Take appropriate nutrition and hydration</li> <li><input type="checkbox"/> Considering options and coming to informed decisions.</li> </ul>
Participation	<p>Communication and intellectual difficulties can limit ability to:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Function appropriately in social settings</li> <li><input type="checkbox"/> Access education and work opportunities</li> <li><input type="checkbox"/> Be autonomous in life, may need life-long support</li> <li><input type="checkbox"/> Interact socially with peers and in wider society</li> <li><input type="checkbox"/> Socialise in other than 'safe' environments.</li> </ul>
Well-being	<ul style="list-style-type: none"> <li><input type="checkbox"/> Anger and frustration may result from an inability to express needs effectively or understand the world around them</li> <li><input type="checkbox"/> Depression, low self-esteem, low self-confidence</li> <li><input type="checkbox"/> Challenging behaviour</li> </ul>

**6. What are the aims/objectives of Speech and Language Therapy interventions for learning disability?**

Communication skills are essential for being able to express needs and preferences and ultimately to making choices and leading an independent life. Therefore, the involvement of the Speech and Language Therapist in the care and management of the person with a learning difficulty is essential (van der Gaag & Dormandy, 2008).

It is the right of the person with learning disabilities to communicate in the way they choose, and all methods of communication should be valued.

Money (2002) developed the Means, Reasons and Opportunities model for working on communication with people with learning disabilities. This is the principle that intervention needs to tackle:

- the means of communication, that is, ensuring that the client has a way of expressing themselves and understanding when people communicate with them
- reasons to communicate, which is focusing on the autonomy of the individual with learning disabilities to make choice, express likes and dislikes etc.
- opportunities to communicate, which means ensuring that the individual has access to communicative partners and situations in which to express themselves and interact

The starting point for intervention with a new client will begin with assessment. This will include formal and informal speech, language and communication assessments, talking to key people involved with the clients care, and observing the person in their everyday environment. The environment itself will also be assessed, as many interventions involve altering the communicative environment, including both physical and human factors (Kelly, 2002).



For a person with severe learning disabilities, the goal might simply be to have some degree of consistent expression of communication intent or to find non-speech based alternatives (Enderby & Emerson, 1995).

The focus for SLT intervention would be about what the client's needs rather than assuming the SLT knows from their assessment what is required and what the person or their carers is hoping for. E.g. Help to feel less anxious about a blood test, help to understand sexuality issues, support to use public transport, where communication difficulty plays a central role.

Communication strategies need to be able to be applied across service and within various life situations. Accessible means of communication need to be developed and updated according to need (strategies include signs, symbols, objects and photographs). The use of a communication profile can be useful in order for the communication abilities, strengths and weaknesses to be understood by those supporting the individual.

The key principles of the RCSLT position paper on Speech and Language Therapy Provision for Adults with Learning Disabilities are:

1. Speech and Language Therapy service delivery is committed to the promotion of independence, choice, inclusion and civil rights.
2. Speech and Language Therapy service delivery considers communication needs in the context of a social model of disability.
3. Speech and Language therapists are committed to delivering their services in line with the personalisation agenda.
4. The practical delivery of Speech and Language Therapy services to adults with learning disabilities is in line and in partnership with local policies, resources, and priorities.
5. All modalities of communication are valued, respected and promoted by Speech and Language Therapists.
6. Speech and Language Therapy service delivery maximises service user involvement at all levels.
7. A collaborative approach to service delivery across agencies, professional groups and also across the lifespan of the people with learning difficulties is essential.

### **Assistive and Augmentative Communication**

People with learning disabilities are especially likely to benefit from Augmentative and Alternative Communication (AAC) due to the complex intellectual and physical impairments which will often accompany the communication impairment. AAC refers to any system of communication that is used to supplement or replace speech, to help people with oral communication impairments to communicate. AAC covers a range of high technology and low technology systems, including those involving no

equipment, such as eye pointing, to high tech voice output communication aids. AAC is used with this client group to promote increased participation.

The principle that “everyone can communicate” is the basis for AAC intervention. AAC utilises the diverse ways in which symbols can be interpreted, on their own and in combination with others, within human interaction. (Bornman, 2006). The theoretical basis of AAC is this ability to have access to different modes of communication. AAC tends to exploit the natural ability we have to use multiple modes to communicate, and systematize it. The use of Talking Mats (Murphy and Cameron, 2008) to support and extend communication with persons with learning difficulties has been found to be successful in clinical trials and has been adopted broadly.

Speech and Language Therapists are very much part of the multi-disciplinary team when working with people with learning disabilities. They may well be intervening in issues which are not strictly ‘communication problems’, but communication is considered one component for resolving the issue. For example SLT’s are often involved in the teaching of non-verbal communication skills, such as eye contact and turn taking, as part of a wider concern with social skills (Enderby & Emerson, 1995).

Speech and Language Therapists have a key role in working with carers of people with learning disabilities. Training in this area is key, considering the relationship between language understanding and challenging behaviour.

A communication strategy requires a multi-agency plan to develop a consistent and coherent approach to meeting the communication needs of people with learning disabilities, within both their daily environments and wider contexts. This includes facilitating the use and understanding of a range of different means and opportunities for communication. A successful strategy has to involve the key elements of management support, training, and networks, and be underpinned by agreed and adequate resources. (Money et al, 1997)

## **7. What is the management for learning disability?**

Learning disability requires different interventions throughout the life span. Many of the issues faced by people with learning disability will be the same as those faced by the general population, but may require more help and support to successfully navigate, this includes communication support. Points of life transitions are critical times, e.g. starting and changing schools, puberty and transition to adulthood, and key events such as the death of parents needs careful management.

In order for Speech and Language Therapists to maximise address the communication barriers faced by people with learning disabilities, they must deliver their services within a broad context and work closely with other health, education and social care professionals. A variety of approaches are likely to be used, and these may include one or more of the following

- Assessment and evaluation
- Producing a formulation based on this evaluation and devising a plan with clear objectives
- Advice/consultation/ co-working with others
- Training/ teaching/ transmitting information

- Coaching/ enabling/ resourcing
- Change management
- Service development

These approaches can be used at different levels, and are not mutually exclusive

- Person** – where the focus of intervention will be the individual's communication
- Environment** – where there are changes in people, processes or settings within a person's (or group of people's) environment, which will increase the individual's inclusion in social networks. This will often be needed to support work at the 'person' level
- Community** – where the communication for adults with learning disabilities is enhanced through influencing attitudes, cultures or practices within the local community

Whatever approach is used, and at whatever level, it must always be person centred, and must involve working in partnership with others. The Speech and Language Therapist has to combine assessment, planning, facilitating, training and service development, in order to maximise the person with learning disabilities' effective communication (Money, 1997; Jones, 2000, Bradshaw, 1998; Thurman, 1997; Purcell et. al, 2000).

<sup>1</sup>All processes used can take place at one or more of person, environment or community level and include

1. Specialist clinical and therapeutic skills
  - Assessment and evaluation
  - Working holistically
2. Facilitation of others
  - Accessible Information
  - Training and development
3. Service Development
  - Working with Speech and Language Therapy colleagues
  - Working with Learning disability services
  - Working with welfare and other services

The Speech and Language Therapist will be working as part of multidisciplinary team, including people from health, social, and education services, along with those in voluntary organisations. Essentially, SLTs will include the individual's family members and others in their communication environment. There are time implications for the education and training that SLT's provide to other professionals and family members. Working as part of a multidisciplinary team necessitates taking on team roles, and attending meetings, which have time and cost implications.

### ***Cultural diversity***

Many individuals and families who have English as a second language, or are from a culture which have particular beliefs and customs will require specialist and sensitive consideration by the speech and

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<sup>1</sup> These ideas have been further developed in the RCSLT ALD Position Paper which adapts the model of specialist health care services tiered model and applied this to the role and scope to the SLT in ALD.

language therapist. These individuals may have more difficulty in accessing services and participating in life, if these special needs and preferences are not understood and taken into account. An interpreter may be required to assist the SLT assessment, to ensure it is both accurate and reliable and to facilitate understanding of therapy and implementation of treatment strategies. There is a time and cost implication when working with interpreters/co-workers, for example, in taking a case history, completing a full assessment in all languages spoken by the individual (if appropriate) and their family. Timings of services need to be culturally sensitive, for example, not offering appointment times which coincide with religious observations (Communicating Quality 3, 2006).

## 8. *What is the evidence for SLT interventions?*

### Studies

All studies were published in English, with the earliest being published in 1996. Nine studies were conducted in the UK, five in the USA, one in Ireland and one in Spain. One study synthesised results from studies worldwide. The number of individuals who took part in the studies ranged from 4 to 51. The studies investigated the effects of speech language therapists training other staff members who worked with individuals with learning difficulties, prelinguistic milieu training and parent responsive education, augmentative and alternative communication and other speech language therapy techniques.

### Study Quality

The populations varied greatly between studies including children and adults who experienced learning difficulties as part of a variety of different syndromes. Often the exact nature or severity of the learning difficulties was not stated or explained in any great detail. The four randomised controlled trials were of good quality and this study design is the preferred method of determining an effect of treatment however, it is recognised that this design is particularly challenging and may not be desirable for research, incorporating subjects who have complex and multiple difficulties. Overall, the methodological quality and study designs used were weak. The most frequent study design was that of an interventional study in which a group of individuals received some form of intervention, of which the treatment effect is gauged by recording appropriate pre- and post-intervention measurements. The problem with this study design is that it is difficult to attribute effects to the treatment since they could be due to other variable factors. By including a comparison group with similar characteristics that does not receive the intervention being tested, evidence of treatment effects can be determined, but may raise ethical issues.

As well as problems with study design features, there were other weaknesses. The number of participants who took part in the studies was small making generalising results to the wider population difficult. Descriptions of the intervention being studied often lacked detail. Where measures were used to record effects of a treatment programme, they were usually unvalidated measures. A number of studies were published in the late 1990s and this limits the currency of information.

### Speech Language Therapists as Training Providers

Several studies evaluated the effects of speech language therapists training other professionals involved in working with individuals with learning disabilities. This included staff from day services, residential

homes, physiotherapists, occupational therapists, teachers, special needs assistants and learning disability nurses.

Money, D (1997) compared three different approaches of delivering a speech language therapy intervention to people with learning difficulties. Thirty-six staff from day services (both health and social service providers) chose a service user they worked with regularly. The staff/service user pair was videoed working together during a familiar activity. The pairs were randomly allocated to three groups. One group received a direct intervention in which the staff/service user pair had six contacts with a speech language therapist over a four month period. Sessions lasted one hour and were delivered every three weeks with a focus on discussing and assessing the specific communication strengths and needs of the service user and staff. Goals were discussed and worked towards in between contacts. The second group received an indirect intervention in which staff members took part in a course called 'Talkabout.' Over a period of four days (one day per week), staff completed a strength and needs assessment in order to develop a communication plan for a particular service user. A further day acted as a follow-up session six weeks later. The third group received both the indirect and direct interventions. Each pair was re-videoed at the end of the treatment programme to assess communication skills. In terms of quantity, service user responses and staff initiations remained unchanged after the interventions. However, in terms of form of initiations, there was a significant increase in the number of open-ended questions by staff within the indirect and combination therapy groups. There was a decrease in staff use of 'do/get/give' something statements in the combination therapy group. Changes were also seen in the form of service user responses. Service users in the combination therapy group increased their use of Yes/No and action responses whilst decreasing their use of nil response. Use of modalities to augment communication increased in the direct and combination therapy groups. This was more pronounced for formal modalities (e.g. signs, symbols) than informal modalities (facial expression).

O'Toole (2007) measured the effectiveness of training professionals working with children with language delay. The programme was based on the Hanen 'Learning Language and Loving it' (LLLI) which includes workshops to target child-orientated, interaction-promoting and language modelling strategies. The study participants were 16 staff, aged 21-47 (mean 28 years, 9 months), working in preschools and primary schools with children with mild/moderate/severe and profound learning difficulties. This included five health professionals (physiotherapists, occupational therapists and learning disability nurses), three teachers and eight special needs assistants. The programme was delivered over a ten-week period by two Hanen-certified speech and language therapists. This included eight after school workshops lasting 2 ½ hours. Each participant was videoed six times interacting with a child or children in a classroom activity e.g. reading, play; the first and last video session acting as a pre and post-programme assessment. Four of these video sessions were used within the workshops as feedback sessions where each participant received individual feedback from the speech language therapist. Attendance at the workshop was high; all attended 60-100% of the sessions. Participants perceived their skills and confidence in working with children to have improved significantly. Prior to the programme, participants indicated they valued collaborative working practices with speech language therapists and this remained unchanged after the programme. Participants significantly improved on eight of the 11 language and interaction promoting strategies that were rated from the video samples. This included 'wait and listen', 'follow the child's lead',

'join in and play', 'be face-to-face', 'use a variety of questions', 'encourage turn-taking', 'use a variety of labels', 'extend'.

McConkey (1999) investigated the nature of staff-client interactions in a residential and day care service setting. Forty-three staff from services for people with intellectual disabilities chose to take part in the study. Each staff member was asked to select one client with whom they worked. Each staff/client pair was videotaped for 15 minutes undertaking a chosen activity (e.g. making tea, and craft) in a familiar setting. The videotapes were analysed by two experienced speech and language therapists to count the number of communicative acts by staff and clients and to rate each interaction as appropriate or inappropriate. The results showed clients had few opportunities to participate in conversations equally and few attempts were made by staff to adjust their language according to the client's level of understanding. Staff tended to rely on verbal interaction, even if clients communicated non-verbally. In terms of types of interactions, directives and questions were used more frequently. Recommendations from the speech and language therapist included use of simpler sentences and words, increase the use of non-verbal signals and open-ended questions, provide more opportunities for clients to initiate topics, and to increase responsiveness to clients' non-verbal signals.

Chatterton (1999) investigated the efficacy of a combination of direct speech and language therapy intervention and staff training for individuals who have a severe learning difficulty and challenging behaviour. Thirteen staff from a residential care home (four nurses, four support workers and four assistant support workers) took part. Speech and language therapists (SLTs) firstly assessed the strengths of the four residents identified as exhibiting challenging behaviour and the communication environment. All staff attended a one-day workshop which covered how and why communication problems occur and their relationship with challenging behaviour and identifying environmental factors to promote effective communication. Finally, the SLTs worked with staff to develop individualised realistic and workable strategies to improve communication with the four residents that could be incorporated into the daily routine. Video analysis of staff/service user interaction was undertaken pre- and post-workshop. Post workshop, results on a questionnaire demonstrated a significant increase in staff knowledge and continued difference in opinion between staff and SLTs regarding residents' communication skills. Video analysis showed significant increases in direction of interactions, use of non-verbal communication, social interaction and immediacy of response by staff when interacting with residents. Following the study, the authors note that the use of communication strategies is being audited and monitored by staff at the residential home; hence this type of intervention is cyclical rather undertaken once only.

Jenkins (1998) assessed the effectiveness of a training workshop for staff working with people who have severe physical and learning disabilities who need extensive support with eating and drinking. Training was delivered by SLTs, dieticians, occupational therapists and physiotherapists to a group of 20 from a small group home and a day centre. The one day interactive workshop was divided into nine sessions. The first four sessions described normal eating and drinking, positioning, nutrition and environmental considerations. Three sessions focused on how to meet special needs in these areas. The final session was practical and involved role play exercises. Participant evaluation was overwhelming positive with an 89.3% overall satisfaction rating. Knowledge scores improved pre- to post-course from 65.5% to 82%. Six months after the workshop, this knowledge gain remained. Pre- and post-workshop videos of staff members feeding a client did not demonstrate any change in behaviour or practice by staff. This could

indicate that the checklist used to record changes in practice was not sufficiently sensitive or changes in behaviour are harder to achieve than knowledge gains following staff training.

Sutton (1998) described a project designed to equip care workers with the knowledge and skills to address communication with people with learning disabilities who challenge services. Training was delivered to small staff teams focusing on selected service users. Staff completed a communication profile on a particular service user. Two days training followed which incorporated addressing the nature of the specific challenge that particular service user posed, for example approaches to managing the challenging behaviour, challenging communication and, reasons and opportunities for communication. The end result was an action plan for a particular client which may have included approaches such as a picture menu to support service users' choices. Six to eight weeks later, a half day follow up provided opportunity for staff to discuss the results of implementing their action plan. Formal analysis of this programme was not provided. However anecdotally, positive outcomes were noted for service users, care works, manager and speech and language therapists.

Graves (2007) undertook a study to gain insight into the perceptions of speech and language therapists and their trainees by undertaking a series of semi-structured interviews. Twelve carers (who had experience of indirect interventions) and five speech and language therapists (SLTs) took part in the study. From the SLTs' perspective doubts were expressed about the outcome of indirect interventions; one difficulty cited was the belief that carers did not share information between each other. SLTs were critical about the carers' focus on task-based activities with interaction with clients being less valued. SLTs felt the mode of training was often too formal and knowledge could be better imparted by training by example and modelling desired behaviour. Carers described their core role as revolving around 'day-to-day care' with their time taken up with personal care tasks such as mealtimes and medications. Carers cited their own personal life experiences and values as strongly influencing their roles. Most carers felt positive about the outcome of SLT intervention and felt they had sufficient support to implement strategies with clients. These findings have implications for provision of indirect intervention that both staff groups need to take into account. Carer providers are not uniform in terms of capacity and resources to carry out tasks prescribed by SLTs and share information. This may explain why unsuccessful rather than successful experiences were recalled more easily by SLTs. There appears to be a need to clarify and agree on respective responsibilities and roles at the beginning of the SLT/carer relationship so that each can understand what is may be feasibly achieved. It was speculated that training provided by SLTs could perhaps be more successful if it emphasised the importance of the relationship between client well-being and communication so that communication is valued more highly, and by using modelling approaches and training by example.

### **Prelinguistic Milieu Teaching and Responsive Education**

Three studies investigated the use of prelinguistic milieu teaching (PMT) and responsive education. It is suggested that PMT works best when parents are more responsive to their child's communicative acts, hence the use of these techniques in tandem. PMT takes the approach of using child-centred play in order to teach vocal and gestural communication.



Yoder (2002) investigated the efficacy of prelinguistic milieu teaching for children and a responsive education intervention for parents (RPMT). Thirty-nine prelinguistic toddlers with intellectual disabilities and their primary care-givers were randomly assigned to one of two groups: a PMT and responsive parent education intervention or no treatment group. The PMT intervention was delivered by 20 minute sessions, three to four times per week over a six month period. During one-to-one sessions, the therapist established play routines with the child. When the child appeared highly motivated to communicate, the therapist used the least intrusive communication prompts to facilitate requests for an object or actions by the child. The children's parents received up to 12 responsive education sessions that used both one-to-one and group small group teaching methods. Parents were taught how to respond to their children's communication acts. Parent-child and examiner-children play sessions were analysed according to specific scales and measures prior to the intervention, six, nine and 12 months later. The parents responsiveness to the child's communicative acts increased significantly post-intervention. The effect of the RPMT on the children differed according to other variables. RPMT accelerated growth in communication and early productive language in children who started treatment with low frequency of comments and canonical vocal communication and who did not have Down's syndrome. However, if children began treatment with a high frequency of comments and canonical vocal communication had Down's syndrome, RPMT could decelerate growth in language.

Fey (2006) undertook a study evaluating the efficacy of a six-month programme of responsive education intervention for parents (RPMT) for children with developmental delay. Fifty-one children with mild to moderate developmental disabilities took part in the study along with 51 parents (50 mothers and one father). The parent-child pairs were randomly allocated to receive RPMT or no treatment. Parents received eight one-hour individual sessions of responsivity education (RE). The SLT used videotapes of the child and parent interacting. Parents were asked to pause the tape when they identified opportunities to respond in a positive manner according to the principles taught in RE. Children received four PMT sessions per week, each lasting 20 minutes at their home or in day care facilities, over a six month period. PMT focused on targeting non-verbal communication, for e.g. gestures, vocalisations and eye gaze shifting. There were significant treatment effects for the RPMT group in terms of child-examiner (adult who was not a primary caregiver) interactions demonstrated by the increased rate of intentional communication acts. Measures of parent-child interaction did not change for either group pre- and post-treatment, and no effects were seen on parenting stress. Warren (2008) evaluated the long-term effects of RPMT for the same 51 children in the study by Fey (2006). Following the RPMT intervention, further data was collected at six and 12 months after treatment completion. All children, despite group allocation in the original study, received standard SLT for one hour per week. Additionally, all children 6-12 months post-intervention received a 'booster intervention' of RPMT which was less intense and of reduced duration than the original programme in Fey, M (2006). Parents received six one hour responsive education sessions and children received one PMT session per week, each lasting 45 minutes. Six and 12 months after the original study, no effects of treatment were recorded on the parent-child and child-examiner interaction measures.

### **Alternative and Augmentative Communication**

Two studies investigated the use of alternative and augmentative communication (AAC). One study attempted to summarise the effects of AAC on speech production. One study investigated the efficacy of

using a standard set of objects of references within a group of individuals with profound and multiple learning difficulties.

Millar (2006) undertook a systematic review to determine the effects of Augmentative and Alternative Communication (AAC) on speech production in individuals with developmental disabilities. Searches on electronic databases searching and key journals identified 23 studies. Six of the 23 studies were selected according to criteria specifying that inclusion of only those studies that established a comparison no treatment or alternative treatment group. Five studies investigated the effects of unaided AAC interventions, most specifically instruction in manual signs whilst the remaining study looked at an aided AAC system without speech output. 78% of the AAC interventions were highly structured and led by the speech and language therapist; the remainder were child-centred play activities. In total, the studies included 17 participants; four with autism and thirteen with mental retardation, Down's Syndrome or developmental delay. The mean number of sessions was 42. In 89% of cases speech production increased with the mean number of words gained being 13. More importantly, no cases demonstrated a decrease in speech production post AAC intervention, indicating that AAC is not harmful to the speech production in individuals with developmental disabilities.

Jones (2002) investigated the effectiveness of using a standard set of objects of reference with 13 adults with profound and multiple learning difficulties. With the aid of the researchers, nine day centre staff who worked with the clients chose a set of 14 objects that represented 14 different activities at the centres. For example: a paintbrush was used to symbolise art, toilet by a piece of blue towel and physiotherapy by a soft yellow ball. Day centre staff received six months of training, during which a scoring scheme was designed to record clients' use of the objects. The objects were then introduced and their use monitored for 20 weeks following an initial baseline measure period. Each day, a different client was chosen to collect the appropriate object after some form of gesture, sign or spoken word by a staff member. The way clients approached, collected and reacted to objects was recorded and this was completed for each client at least once a week. The use of the set objects of reference was increased over the 4 month period of use. Most of this improvement occurred within the first 10 weeks, after which there was no further improvement in some clients since they had reached a 'maximum' use of the objects. Other clients, whilst still progressing, made limited use of the objects. Some clients responded better to certain types of objects for e.g. objects that gave sensory feedback. This could indicate whilst for the majority of clients, a set of standard objects produced promising results, other clients require more individualised objects.

### **Other Treatment Techniques**

There appears to be a great deal of variation in treatment techniques used by speech and language therapists with individuals with learning difficulties, which perhaps reflects the differing populations of individuals with learning difficulties. The following studies evaluate training via computer games, pragmatic based language interventions, naturalistic language interventions, the fast-mapping technique and the treatment of children exhibiting language problems as well as behavioural, social and emotional difficulties.

Merzenich (1996) undertook two small studies in which children completed training on two computer games designed to improve temporal processing in children with language-based learning impairments. The aim of the first game was to correctly reproduce the order of two non-verbal sound stimuli (in the sweep frequency and speed range for English consonants). The second game was a phonetic element recognition exercise in which two consonant-vowel stimuli with contrasting consonants (e.g. [be] vs. [de]) were spoken. Children had to identify the sequence position of one of the consonant-vowel pairs. Within both tests, there was the facility to alter the stimuli adaptively to increase the level of difficulty. Correct responses were identified by a points accumulator and points were awarded which could be exchanged for prizes. The first trial involved seven 5.9-9.1 year olds with learning difficulties who used the computer games for 19-28 sessions over a four-week period, each session lasting 20 minutes. Five children progressed on the first game to achieve higher performance levels at the end of the trial, with 2 children exceeding normal performance levels. A similar improvement was seen in the second computer game. Benchmark tests, before and after training, demonstrated significant improvement in all the children in temporal event recognition, sequencing abilities and phoneme element identification. The latter improvement translated to an increase in language development age of 1.5 years. The second trial involved a further 11 children who trained on a modified version of the computer games which had been improved for consistency and maintaining the children's attention. Ten of the eleven children improved their performances on Game 1 and eight did so for Game 2. Performance gains were also seen in the benchmark tests. It is important to note the level of detail and quality of write-up is very poor for this study and the results should be interpreted with caution.

Richardson (2000) measured the effects of a treatment programme designed to improve pragmatic language skills in 20 children with learning difficulties. The children, aged between 6-10 years, attended a private school for individuals with learning difficulties. Each underwent a criterion-based reference test to assess their language in terms of social skills and language use. Following this test, a six-week treatment programme was established for the 20 subjects, focusing on three areas of identified weakness: Conversation (starting, maintaining and ending), internal responses (identification of emotion), and qualitative and quantitative description of objects. During each therapy session, each of these three areas were targeted and reviewed via posters, blackboards, picture cards, acting out short scenarios etc. All participants improved across all three target areas following the programme. However, caution must be applied when interpreting the results of this study. Whilst improvements were documented, no tests for statistical significance were undertaken and it was unclear how each of the three target areas were measured.

Wilkinson (1998) undertook a study investigating the use of the fast-mapping technique in increasing the vocabulary in individuals with moderate to severe learning difficulties. In this technique, children acquire an initial understanding of a new word's meaning after brief exposure to the word. Typically, one or more known, labelled items are presented to the child, along with one item the child is not expected to know. Fast-mapping works on the premise that when the child hears a new label spoken, they point to the unknown item. Following a test to determine known and unknown words, ten participants were presented with a series of line drawings of known items and auditory stimuli on a computer. New items were also introduced in this way. The majority of participants who had some receptive language skills were able to learn multiple words receptively. There is some evidence that this technique is best suited to individuals who demonstrate comparable expressive and receptive language skills.

Gracia (1999) undertook a small study investigating the use of a naturalistic language intervention to improve communication between children with learning difficulties and their mothers. Four children with Down's Syndrome (aged 3-8 years) were videoed playing with their mothers once a week for 6 months. After the first two weeks, mothers were involved in analysis of the video and discussed aspects of mother-child interaction and how it could be improved. Strategies implemented included observing how a child communicates before starting a conversation and then following the child's lead; interpreting and imitating the child's gestures. The mother-child interactions were analysed and coded according to interaction analysis categories. Following the intervention, mothers listened to their children more, followed the child's lead and reduced the use of requests when communicating. Overall, the frequency of utterances was decreased in mothers whilst this increased in their children.

Heneker (2005) undertook a pilot study investigating the prevalence of learning difficulties within children with behavioural, emotional and social difficulties (BESD) at a Pupil's referral Unit, and the effects of subsequent speech and language therapy. Formal assessment via standard tests and informal assessment by class teachers and teaching assistants revealed ten out of the 11 children with BESD had speech and language difficulties. Six of these children had difficulties significant enough to warrant intervention and were offered SLT for one term. The SLT consisted of working on understanding and using vocabulary. All pupils who received SLT made considerable progress in the areas targeted by their individual treatment programmes and gained confidence in communication. The results from this study need to be treated with caution as the research was undertaken as a pilot and lacks rigour in its methodology. Nevertheless, the outcomes of the study resulted in securing funding for a SLT service within the Unit for one day per week.

### **Summary**

There is significant literature documenting the effectiveness of speech and language therapists providing training to professionals who work with individuals with learning disabilities. Generally training was very well received by other professionals and led to significant improvement in staff-client communication. Outcomes were particularly positive when staff taking part in the training programmes were able to select service users to produce individual communication action plans as part of the intervention. One qualitative study highlighted the need for speech and language therapists and other professionals to understand each others roles and resources available to facilitate communication strategies.

There appears to be inconclusive evidence for the effectiveness of prelinguistic milieu teaching and responsive parent education (RPMT) interventions. It appears RPMT does not have long term effects. RPMT appears to be effective in accelerating language growth in some individuals but has the potential to decelerate language growth in other individuals. Augmentative and alternative methods appear to be effective in facilitating communication and do not reduce speech production capabilities. There are a range of other interventions and techniques which are represented by single studies, making it difficult to draw conclusion from the limited evidence available. Finally, it is important to point out that overall the methodological quality of the studies included in this synthesis was poor.

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Table 6: Studies identified in evidence search for consideration

Study	Country	Study design	Subjects	Intervention
Chatteron, S (1999)	UK	Interventional study	13 residential home staff (4 nurses, 4 support workers, 4 assistant support workers) and 4 residents who had a severe learning disability and challenging behaviour	Small-scale training consisting of one day workshop and individualised communication strategies for each resident
Fey, M (2006)	UK	Randomised controlled trial	51 children with mild/moderate developmental disabilities, aged 24-33 months (mean=26 months) and 51 parents (50 mothers and 1 father)	Prelinguistic milieu teaching and parent responsivity education
Gracia, M (1999)	Spain	Interventional study	4 mothers and their Down's Syndrome children aged 3-8 years.	Naturalistic language intervention
Graves, J (2007)	UK	Qualitative study	5 speech language therapists and 12 carers from residential and day	Perceptions of indirect interventions delivered by speech



Study	Country	Study design	Subjects	Intervention
			care services	language therapists explored for these two staff groups.
Heneker, S (2005)	UK	Interventional (pilot) study	11 children (age 5-11 years) with behaviour, emotional and social difficulties	Short period of speech language therapy (one school term)
Jenkins, C (1998)	UK	Interventional study	20 staff who support people with severe and multiple learning difficulties: seven from a small group home and 13 from a special needs unit of a day centre	Staff training workshop
Jones, F (2002)	UK	Interventional study	13 adults (aged 20-55 years) with profound and multiple learning difficulties	Standard set of 14 objects of reference representing 14 different activities at a day centre.
McConkey (1999)	UK	Observational study	43 staff members from day services and their chosen client	Two speech and language therapists rated communication and made suggestions for improvement
Merzenich, M (1996)	USA	Interventional study	First trial: seven 5.9-9.1 year olds Second trial- 11 children, age not specified	Computer games incorporating training exercises to improve temporal processing
Millar, D (2006)	Worldwide	Systematic review	6 studies (clinical trials or randomised controlled trials)	Alternative and augmentative effects on speech production
Money, D (1997)	UK	Randomised controlled trial	36 staff/service user pairs from day services	Direct therapy vs. indirect therapy vs. combination of direct and indirect therapies
O'Toole, C (2007)	Ireland	Interventional study	16 professionals working with children with learning difficulties. Included teachers, special needs assistants learning disability nurses, physiotherapists and	Hanan 'Learning Language and Loving It' programme delivered by two speech and language therapists

Study	Country	Study design	Subjects	Intervention
			occupational therapists	
Richardson, K (2000)	USA	Interventional study	20 children with learning difficulties attending a private school	Treatment programme designed to improve pragmatic language skills.
Sutton, K (1998)	UK	Programme evaluation	Care workers for people with learning disabilities	Small group staff training to create an individualised communication action plan for a particular service user
Warren, SF (2008)	USA	Randomised controlled trial (long term follow-up of Fey et al, 2006)	51 children with mild/moderate developmental disabilities, aged 24-33 months (mean=26 months) and 51 parents (50 mothers and 1 father)	Prelinguistic milieu teaching and parent responsivity education
Wilkinson, K M (1998)	USA	Interventional study	10 individuals with moderate to severe mental retardation. Mean age 16.1 years (Range 5.1-22.0)	Fast-mapping technique
Yoder, PJ (2002)	USA	Randomised controlled trial	39 prelinguistic toddlers with intellectual disabilities and their primary caregiver	Prelinguistic milieu teaching and parent responsivity education

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