

# Adults with learning disabilities (ALD)

## Position Paper

RCSLT  
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## Referencing

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The paper was developed and written by the ALD Position Paper Steering Group, which comprised of Viki Baker, Louise Oldnall, Elenor Birkett, Geraldine McCluskey and Jo Morris.

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## Executive summary

This document identifies the role of speech and language therapists (SLTs) in adult learning disability services across the UK. This information should support SLTs, speech and language therapy managers, speech and language therapy educators and other organisations that support people with learning disabilities in their role. This document aims to define the best practice for SLTs in learning disability services within the context of national policy frameworks. The paper has been written in consultation with the speech and language therapy workforce and other key stakeholders. It is recognised that any future development to this work should include more collaboration with service users and carers.

The ALD Position Paper defines the existing speech and language therapy workforce and reinforces some key messages for speech and language therapy educators in relation to preparing SLTs for working in ALD services.

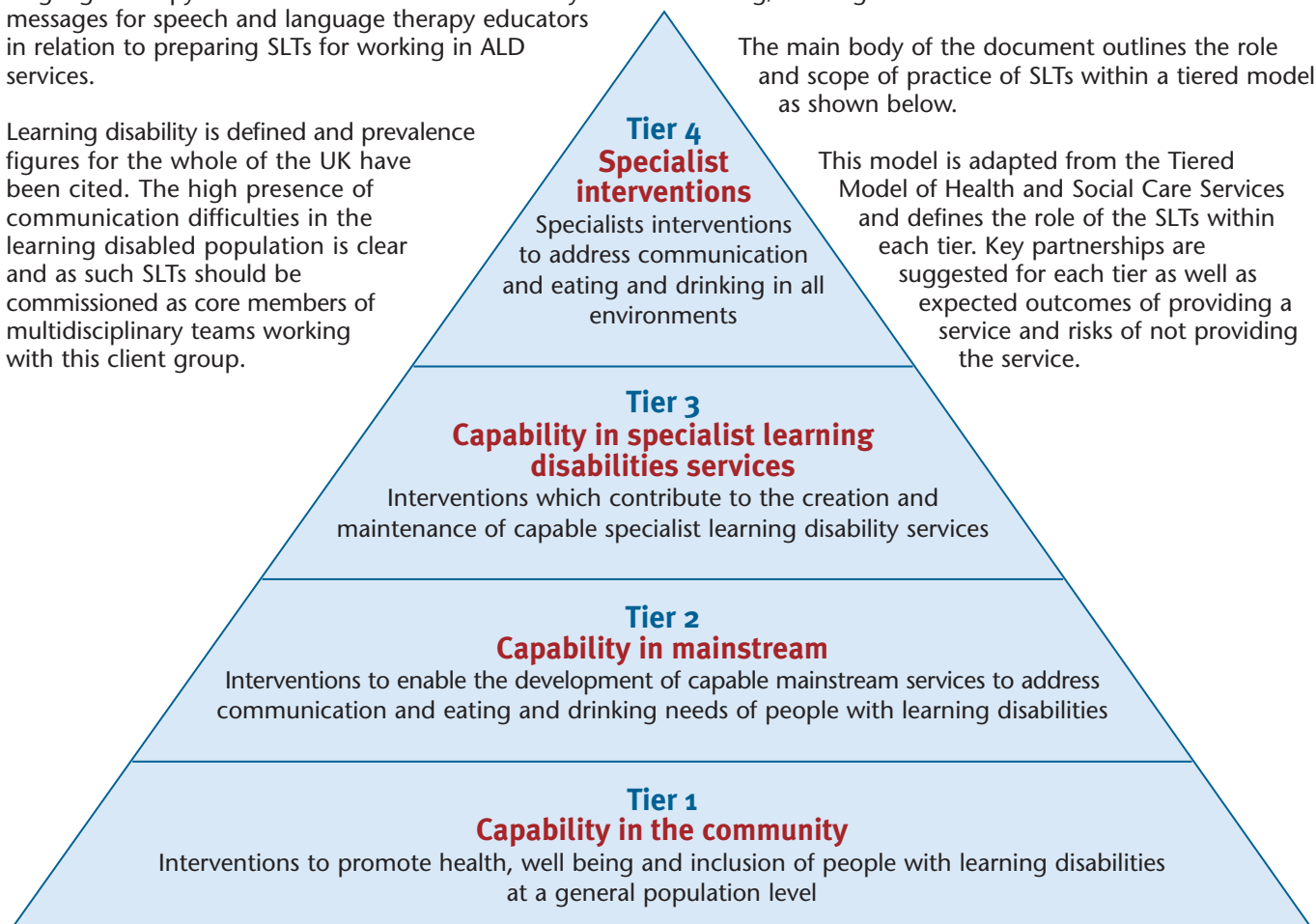
Learning disability is defined and prevalence figures for the whole of the UK have been cited. The high presence of communication difficulties in the learning disabled population is clear and as such SLTs should be commissioned as core members of multidisciplinary teams working with this client group.

Speech and language therapy services should work within and be defined by current policy frameworks and key policy drivers are given for each country it is envisaged that all SLTs will be familiar with these documents and so be able to translate national strategy and ideology into best practice.

The visions and values that should underpin every speech and language therapy service are discussed within the context of the social model of disability. Speech and language therapists should place the service user at the centre of their intervention and work in partnership with them and their significant others to address their communication barriers and/or eating/drinking difficulties.

The main body of the document outlines the role and scope of practice of SLTs within a tiered model as shown below.

This model is adapted from the Tiered Model of Health and Social Care Services and defines the role of the SLTs within each tier. Key partnerships are suggested for each tier as well as expected outcomes of providing a service and risks of not providing the service.



Throughout each tier there are examples of best practice that clearly show the role of an SLT. The key messages behind this model are:

- Speech and language therapy should work at all tiers. This will range from providing a service that promotes the health, well being and inclusion of people with learning disabilities through to direct specialist interventions that address a person's individual communication or eating and drinking needs.
- Speech and language therapists need to develop partnership working with others at each tier.
- Speech and language therapists should work within a person-centred framework.
- Local commissioning arrangements and service capacity will determine to what extent particular SLTs can work within the model. However, the model should be seen as a conceptual framework for good practice within speech and language therapy and can be used to support local service development and delivery.

The Position Paper addresses the role of the SLT in producing accessible information and emphasises the importance of this work being developed and carried forward in partnership with other agencies.

The importance of a competence-based workforce is identified. Speech and language therapists need to be open to workforce re-design and put the needs of the service user before professional boundaries. The speech and language therapy assistant practitioner should be seen as an integral member of the team and should support SLTs to provide a person-centred service.

This document recommends that the speech and language therapy workforce (through the national ALD leads network) address certain key points that have arisen during the development of the Paper. These workforce and performance issues will be relevant to all services and require consideration from the profession as a whole.

Full references are given and this document should be read in conjunction with other key documents produced by the Royal College of Speech and Language Therapists.



# 1. Introduction

The political and social climate for speech and language therapists (SLTs) working with people with a learning disability continues to change and develop at pace. Since the original Royal College of Speech and Language Therapists' (RCSLT) position paper, Speech and Language Therapy Provision for Adults with Learning Disabilities (2003) there has been significant change and growth within this area. For example, the Speech and language therapy profession within adult learning disability has seen a development of posts and clinical specialisms, the development of a progressive national network and considerable innovative practice across the UK.

The majority of SLTs are based in learning disability teams. These teams, however, are organised and structured differently across regions and countries of the UK. Some SLTs in England are seconded to, or employed by the local authority, some are employed by the independent and voluntary sector, while most remain directly employed by the NHS.

Whereas 10 years ago speech and language therapy work in adult learning disabilities could have been described as having a low profile within the profession, and often within multidisciplinary teams, now the picture is very different. Speech and language therapists are seen as a

core profession working in adult learning disability services, and the profession itself is recognising that much work with adults with learning disabilities is cutting edge, characterised by progressive strategic thinking, partnership working, and embracing the social model of disability. The speech and language therapy profession needs to ensure there is a greater awareness of communication as a basic human right and that this should be recognised at a strategic level by commissioners. It is fundamental that people with learning disabilities themselves, alongside SLTs, lead the work and campaign for communication rights.

The authors of this document recognise people with a learning disability are themselves experts in communication due to their having first-hand experience of living with communication barriers. Perhaps it is a limitation of this paper that it has been written by professionals working in the field and national organisations that represent user groups with little user voice.

We would, however, both hope and envisage that future work stemming from this paper will be developed in partnership, where possible, with people with learning disabilities and their families as partners. It is this group that should be at the heart of speech and language therapy service planning and redesign.

## 2. Purpose and intention

What has become evident in the process of consultation with the profession for the purposes of writing this paper is the overwhelming passion, energy and commitment for people with learning disabilities to be included as valued members of society, and the core role SLTs have in enabling inclusion to happen.

This paper aims to offer guidance to SLTs and speech and language therapy managers in order to influence commissioning arrangements and higher education (for the purposes of speech and language therapy education and academic research). It is hoped the paper will also be useful for other organisations committed to supporting the rights of people with learning disabilities. It includes:

- Key strategic and policy drivers influencing practice.
- Values embedded within speech and language therapy practice.
- Role and scope of speech and language therapy practice.
- Advice on service models and structures.
- Evolving roles and workforce issues for the profession.
- Questions for future consideration and discussion.
- Key research and evidence base.

This paper should be used in conjunction with the following key publications produced by the RCSLT:

The Quality Self-Evaluation Tool (Q-SET) demonstrates how speech and language therapy services meet the need of service users. It provides evidence of the effectiveness of activities and this is useful in communicating the value of learning disability services to commissioners and helps to identify areas for improvement. It can also be used as a national benchmarking tool and it is recommended that all services complete Q-SET to develop a body of evidence to enable comparison.

The Resource Manual for Commissioning and Planning Services for SLCN (Speech, Language and Communications Needs) (RCSLT, 2009) supports RCSLT members to communicate more effectively with commissioners. It includes a synthesis of the evidence about speech, language and communication needs to inform commissioning based on systematic searching and expert review. The document includes:

- Incidence and prevalence figures.
- Range of interventions available.
- Effectiveness of interventions available.
- Relative cost effectiveness of those interventions (where evidence exists).
- A prioritisation process which manages health gain across the population as a whole.



### 3. Process for consensus and method of analysis

The process to gain consensus regarding the content of this position paper has been the following:

- Election of a steering group from within the national network. All members of the group have a considerable background in working with people with a learning disability and are all lead SLTs or senior speech and language therapy service managers in the UK.
- Holding a series of seven consultation events across the UK in London (two events), the south west of England, the north west of England, the Midlands, Scotland and Northern Ireland.
- Each of the events followed the same format, using discussion groups working to a service model (described later in the paper). Issues raised were discussed and debated where necessary and results collated by the steering group. All events have been led by members of the steering group to ensure consistency between them.
- In addition to these seven events, there has been a range of special interest group meetings and regional leads meetings that have also focused on the paper.
- The paper itself was produced in draft form and circulated broadly within the profession and, in its final draft to key stakeholders, for example, organisations representing service user groups. Consensus regarding its content and necessary changes was made using SurveyMonkey as a tool.
- Advisers have been invited to all consultation events, and their comments and recommendations included in redrafts.
- Comments from consultation have been analysed in depth and included or discussed in the re-write.



Linda Clark, a service user who is employed as a speech and language therapy assistant, provided signing training for Charlton Community Trust Football coaches

## 4. The speech and language therapy workforce

Speech and language therapy is a degree level entry profession and all practising SLTs are required to be registered with Health Professions Council (HPC). Membership of the RCSLT is recommended. The HPC and RCSLT have codes of practice, conduct and standards which govern speech and language therapy practice.

Speech and language therapists are the lead experts regarding communication and eating and drinking/dysphagia. The level of pre-registration education and later experience enables SLTs to lead on the assessment, differential diagnosis, intervention with and management of individuals with communication and eating and drinking difficulties/dysphagia. It is recognised that SLTs will liaise and work closely with other agencies and other professions.

Speech and language therapy assistants are integral members of the speech and language therapy team employed to act in a supporting role under the direction of a professionally qualified SLT. (Further guidance on the specialist ALD speech and language therapy workforce is discussed later in the document.)

### 4.1 Pre-registration education of student SLTs

The national ALD Network completed and circulated a set of recommended 'core messages' by consensus in 2007 for universities and colleges providing speech and language therapy education training, in relation to work in adult learning disability services. These are:

- Students will have knowledge of the values and philosophy of the Social Model of Disability.

- Students will understand the need for delivery of speech and language therapy, employing various models at the level of the individual, environment and population. This is now superseded by the Tiered Model of Health and Social Care services adapted for speech and language therapy ALD service delivery model (described later in the paper).
- Students will have knowledge of relevant government legislation and strategy relating to LD in that country.
- Students will have insight into the importance of training others as fundamental in underpinning speech and language therapy work.
- Students will have awareness of the variety of work within the area of ALD: forensic, dysphagia, profound and multiple learning disabilities, challenging behaviour, autistic spectrum disorder, mental health.

As each course is varied in terms of the time and teaching methods/placements and so on, this paper recommends local speech and language therapy teams in adult learning disability services form a close working relationship with their local university to ensure the messages above are included in the courses/education training in the most efficient way for that particular course.

It is important here to note that all students, regardless of future specialism, should have the above as a baseline of knowledge so that any SLTs can work more effectively with people with a learning disability.

## 5. Definitions

### Learning disability

There are several ways in which the term 'learning disability' can be defined; however, for the purposes of this paper we are using the following:

Central UK Government and the regional and devolved governments within Valuing People 2001 (England), Equal Lives 2005 (Northern Ireland), Same as You 2000 (Scotland) and Fulfilling the Promises 2001 (Wales), give a definition which includes three elements all of which much be present:

- A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence).
- A reduced ability to cope independently (impaired social functioning).
- These are in evidence before adulthood and have a lasting effect on development.

This paper in line with MENCAP and the World Health Organisation, amongst others, adopts the social model of disability as the overarching model.

The two key areas of assessment and intervention for SLTs are communication impairment and eating and drinking difficulties/dysphagia.

### Communication difficulty

Up to 90% of people with learning disability have communication difficulties; with half having significant difficulties. Many people with profound and multiple learning disabilities have extremely limited communication ability which may be restricted to behaviours such as eye gaze and changes in facial expression. Whilst communication difficulties vary greatly from person to person, it is acknowledged that barriers to successful communication are often social ones, eg a focus on written information questionnaires to obtain people's views. Communication difficulties that people with learning disabilities may experience include:

- 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.
- Dysfluency, eg 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.

(From Working with adults with a learning disability, A Kelly, 2002)

### Eating and drinking/dysphagia

In 2004, the National Patient Safety Agency (NPSA) identified dysphagia as one of the five key areas of risk for people with learning disabilities.

Dysphagia refers to difficulty in eating, drinking or swallowing. It can lead to malnutrition, dehydration, reduced quality of life and choking. Asphyxia and respiratory-related mortality are known to be disproportionately high in people with learning disabilities.

"Dysphagia can occur as a result of either a single medical problem, eg stroke, progressive neurological condition, or as a result of:

- Oropharyngeal structural problems.
- Motor processing difficulties.
- Central nervous system disorders.
- Pharyngo-oesophageal problems.
- Poor oral health.
- The psychological effects of institutionalisation.
- Mental health problems.
- The effects of medication."

(NPSA, Dysphagia (2008))

## 6. Prevalence

It is estimated in **England** that:

- 169,000 people aged 20 or over (0.46% of the adult population) are known users of learning disability services in England. Of these, 26,000 are aged 60 or over.
- There will be a sustained growth in the numbers of people with learning disabilities known to services over the next 10 to 20 years:
  - 11% over 2001-2011
  - 14% over 2001-2021
- The estimated number of people with learning disabilities in England will therefore also increase:
  - 15% over 2001-2011
  - 20% over 2001-2021
- In common with general life trends there will be marked increases in the numbers of people with learning disabilities known to specialist services aged 50+:
  - 28% over 2001-2011
  - 48% over 2001-2021
- More people with mild to moderate learning disabilities will become known to and start using services. Therefore, the total numbers of people using services is set to increase:
  - By more than 50% to 223,000 by 2018

(Healthcare Commission, 2007; DOH, 2009)

In **Scotland** it is estimated that:

- 20 people for every 1,000 have a mild or moderate learning disability.
- Three to four people for every 1,000 have a profound or multiple disability.
- Approx 120,000 people with learning disability in Scotland.
- These figures will grow by 1% per year.

(Same as You, 2000)

In **Wales** it is estimated that:

- There are 10,450 people with learning disabilities over the age of 16.
- 360-380 per 100 000 total population have severe learning disabilities.

(Statement on Policy and Practice for Adults with a Learning Disability, 2007)

In **Northern Ireland** it is estimated that:

- A combined prevalence of all people with learning disabilities has been reported as 9.7 people per 1,000 people in the population.
- There are an estimated 8,200 people aged 20+ who present with learning disabilities. This figure is derived from those known to services and there is likely to be an unrecognised population of people with mild learning disabilities of approximately 16,000 who are not known to services.
- It is predicted that these figures will grow by 1% per year. However, this may be slightly higher in NI due to demographic trends.

(Equal Lives, 2005)

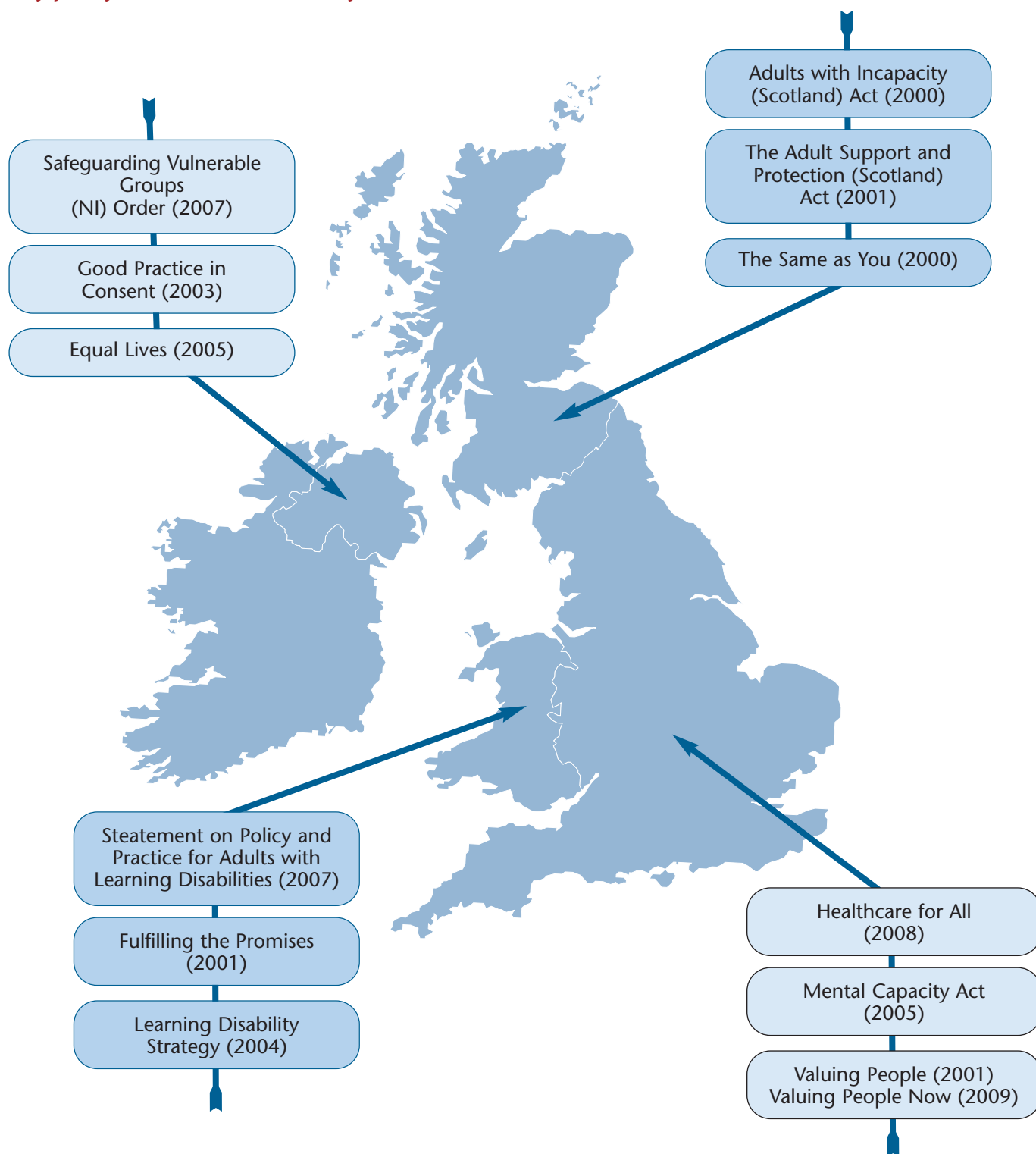
Enderby et al (2009) reported:

- 50%-90% of the learning disabled population have communication difficulties (Enderby and Davies, 1989; RCSLT.CQ3, 2006).
- 80% of people with severe learning disabilities do not acquire effective communication (RCSLT, CQ3, 2006).
- One third of all speech and language therapy services in the UK are directed at the learning disabled population (RCSLT, CQ3, 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).
- Half of people with intellectual disability have significant communication problems and up to 80% have some communication problems (Scottish Government 2000).

There are no reliable figures on the prevalence of dysphagia in people with learning disabilities. Figures range from 36% based on general speech and language therapy caseloads to 73% based on inpatient populations (Leslie, Crawford and Wilkinson, 2008). What is accepted is that the ALD population has a higher incidence of health problems including dysphagia than the general population (RCSLT CQ3, 2006; Death by Indifference, 2007; Valuing People Now, 2009).

Chadwick et al 2003 (cited in RCSLT, CQ3 2006), found that 5.27% of all adults with learning disability were referred for advice regarding dysphagia.

## Key policy drivers for the delivery of ALD services



For other influential policies/reports see reference list.



## 7. Vision and values

People with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services (United Nations, 1994).

**This statement has been selected as it encapsulates the vision and values of all UK regional and devolved governments' strategies**

The **social model of disability** proposes that barriers and prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognises that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal' (BILD, 2006).

The social model of disability "sees disability as created by social barriers rather than individual impairment" (Walmsley, 2001) p195.

The overall aim for SLTs is to work in the context of the social model of disability by:

- Enabling others to address the barriers to communication that adults with a learning disability experience.
- Maximising the opportunities for positive interactions, participation and choice for people with learning disabilities.
- Working as part of a multidisciplinary team to ensure that adults with learning disabilities can eat and drink as safely and enjoyably as possible.

The specific objectives of speech and language therapy interventions is to work in partnership with individuals with learning disabilities, their carers, other significant people and the wider community to enable people to:

- Understand and express the choices available to them
- Express their views.
- Access services.
- Be included and involved.
- Maintain health and well being.
- Develop personalised services.

These roles can be applied to any area of an individual's life. This may include, for example, health, education, leisure or employment. These will depend upon:

- The individual's needs.
- Local priorities.
- Circumstances influencing effectiveness of intervention.

This can be represented diagrammatically as shown on the next page.

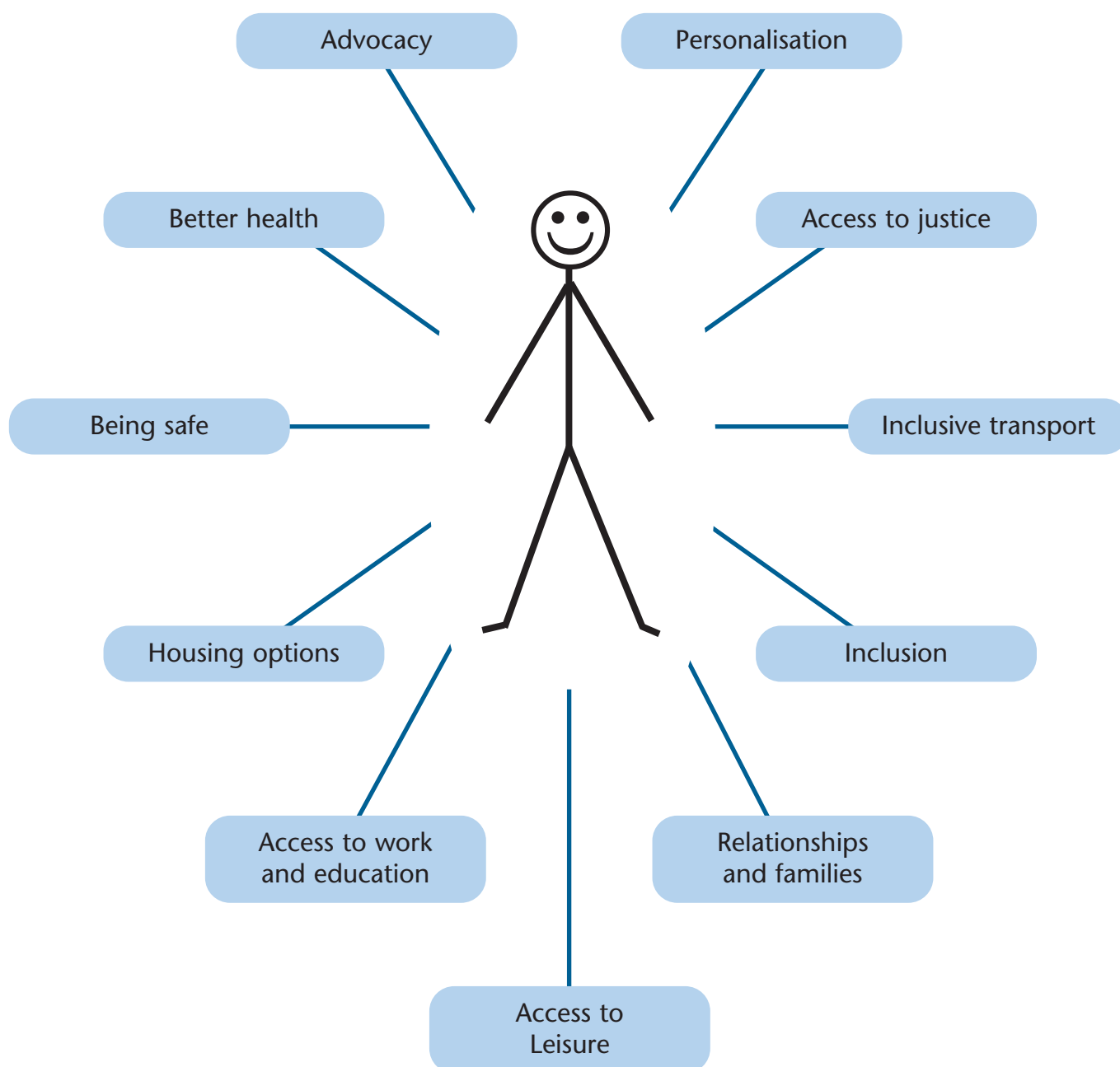
### 7.1 Service delivery principles

- Speech and language therapy service delivery is committed to the promotion of independence, choice, inclusion and civil rights.
  - Speech and language therapy service delivery considers communication and eating and drinking needs in the context of a social model of disability.
  - Speech and language therapists are committed to delivering their services in line with the personalisation agenda. Interventions are linked to the life aims and identified priorities of individuals.
  - Speech and language therapy service delivery to adults with learning disabilities is in line and in partnership with local policies, resources, and priorities.
  - Speech and language therapists value, respect and promote all modalities of communication.
  - Speech and language therapy service delivery maximises service user involvement at all levels.
  - A collaborative approach to service delivery across agencies, professional groups and also across the lifespan of the people with learning disabilities is essential.

(Adapted from the first RCSLT ALD Position Paper, 2003)

## 7.2 Person-centred values

(adapted from Valuing People, Valuing Employment Now, Equal Lives, Same as You and Fulfilling the Promises)





## 8. Role and scope of practice

The following model was used as a guide at the position paper consultation events as a way to gain consensus about the role and scope of practice of SLTs.

Using a triangle to describe tiers of health and social care is a widely utilised conceptual framework. Tiers can be interpreted differently between agencies and care groups. However, it is widely recognised that services can be mapped out usefully in this way, eg NHS and Social Care model for long-term conditions (2006), Learning Disability Services Commissioning Partnership Wales (2008).

Through this paper, reference is made to Mansell's (2007) work, which describes capable teams as consisting of a skilled learning disability workforce.

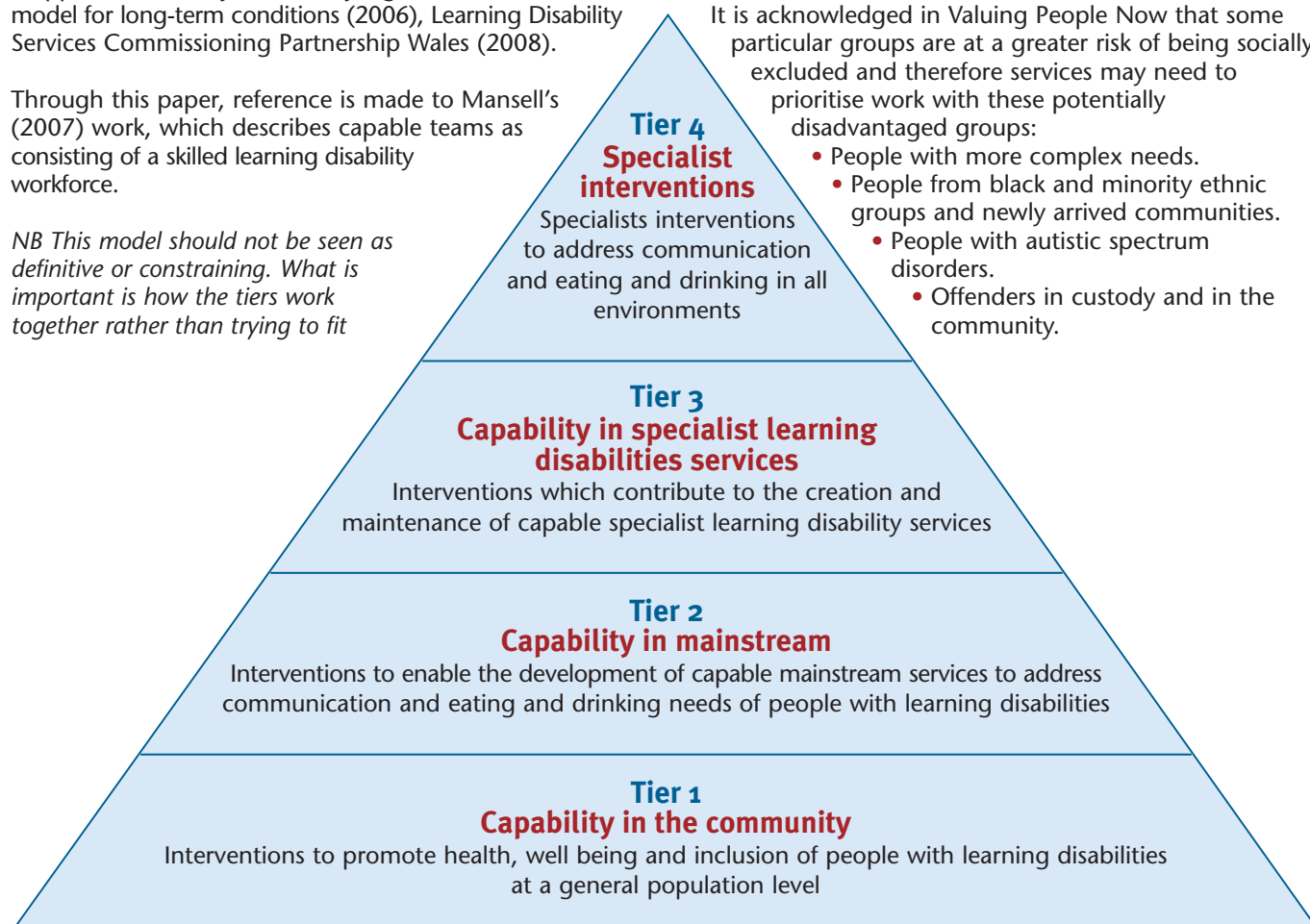
*NB This model should not be seen as definitive or constraining. What is important is how the tiers work together rather than trying to fit*

*services into each tier. Also, people can be in need of more than one tier at one time depending on their circumstances at a particular time and individual needs.*

*The position paper acknowledges that the way speech and language therapy resources are allocated across the tiers will vary according to local priorities and commissioning arrangements and service capacity.*

It is acknowledged in Valuing People Now that some particular groups are at a greater risk of being socially excluded and therefore services may need to prioritise work with these potentially disadvantaged groups:

- People with more complex needs.
- People from black and minority ethnic groups and newly arrived communities.
- People with autistic spectrum disorders.
- Offenders in custody and in the community.



### Tiered Model of Health and Social Care Services

Adapted for speech and language therapy service delivery in adult learning disability services

Adapted from Specialist healthcare services – a tiered view.

Department of Health commissioning guidance – Tiered model of UK H&S Services p.185 CQ3 (2006)

## 8.1 Capability in the community

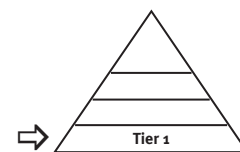
Communication disability is cited in all key strategic drivers across the UK (Valuing People Now, 2008; Equal Lives, 2005; Same as You, 2000; Fulfilling the Promises, 2001), as a reason why people with a learning disability can be socially excluded or marginalised from their own communities. Disability, Equality and Human Rights legislation (Disability Discrimination Act (DDA) 2005; Human Rights Act, 1998; Section 75 of the Northern Ireland Act, DDO, 2006; A Life Like No Other, 2007) has meant universal services must not be discriminatory in their practices (DDA, 2005). Valuing People Now (2009) as well as the aforementioned UK strategic drivers, cite the key areas of 'having a life' as being:

- Better health.
- Housing.
- Work and education.
- Relationships and having a family.

Working with universal service partners to improve awareness and knowledge of ways to overcome communication difficulties should therefore be a core role of SLTs.

There has been considerable work carried out nationally regarding this tier. Unfortunately very little research has been published which demonstrates the value of speech and language therapy intervention in improving social inclusion. However, there is considerable consensus and anecdotal evidence from projects across the UK that suggest that this work is considered as offering significant benefit.

This tier of the model describes the role of speech and language therapy in improving knowledge and skills at a community level to understand and best support the



communication needs of people with a learning disability. It also includes work to raise understanding of the needs of people with a learning disability who require modified diets, eg modified diet choices in local cafes.

Depending on local need and resources, partnerships will vary. However, key priority partnerships agreed by consensus nationally include:

- Police and emergency services.
- Transport agencies.
- Leisure industries.
- Retail industries.
- Restaurants and cafes.
- Further education.
- Employment and housing.
- Substance misuse services.
- Religious and faith organisations.

Speech and language therapists in England should be aware that Valuing People Now (2009) cites the importance of working with transport providers, leisure services and social activities to ensure these services take into account the needs of people with learning disabilities.

In Scotland an informal alliance called Communication Forum Scotland has been set up representing people of all ages with varied communication support needs. Its aims are to highlight the diverse range of communication support needs and promote ways of meeting these needs.

### Tier 1 – Capability in the community – expected outcomes and risks Communication and eating/drinking/dysphagia

#### Expected outcomes of providing a specialist speech and language therapy service include:

- Increased positive regard for people with learning disability.
- Increased awareness and examples of Total Communication practice.
- Increased examples of positive experiences by people with learning disability in accessing everyday activities and places, eg library, cafe, shops.
- Feeling safe and valued in the community, eg safer places where people can access help.
- Increased job opportunities.

#### Risks of not providing a specialist speech and language therapy service include:

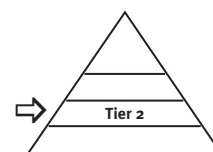
- Increased stigma.
- Increased vulnerability to abuse and hate crime.
- Withdrawal from community life, eg not eating out.
- Failure to meet legal requirements of:
  - Mental Capacity Act
  - Human Rights Act
  - Disability Discrimination Act

Reasonable adjustments not made in the community, eg pureed food not provided  
People with communication and learning disabilities are unable to access job opportunities.

In South Devon and Torbay SLTs have been very involved in an innovative community project regarding a safer place to live scheme.

- Interagency and multidisciplinary working between Devon and Cornwall Police, other emergency services and the Learning Disability partnership and provider services agreed to produce an update to Hertfordshire's "People in Partnership (PiP) Pack. Rebranding and expanding the pack to include wider issues of "keeping safe".
- This resulted in the "Keeping Safe Pack" which is being produced through Pluss, a social firm training and employing people with a learning disability. They have produced a website about the pack [www.keeping-safe.org.uk](http://www.keeping-safe.org.uk)
- During the work, a local chamber of commerce group approached the steering group to ask how they could support people in their community who were being bullied or became victims of hate crime. The "safe place" scheme was born from this request, with speech and language therapy designing shop window stickers, simple cards for people to carry reading "I need help" and a help sheet for shop keepers, using pictures to help bridge the communication gap when trying to explain what happened and who needs to be called. This scheme is being rolled out across Devon and Cornwall by the Police Community Support Officers. Other areas have expressed an interest in the scheme.

In the Abertawe Bro Morgannwg NHS Trust the SLT has worked jointly with local housing associations to develop an accessible tenancy agreement for service users to understand their tenancy rights and to enable them to express their opinions in relation to their accommodation.



## 8.2 Capability in mainstream

Work at this tier focuses on interventions to support mainstream services, eg hospitals, primary care, to make reasonable adjustments in relation to communication as required by DDA (2005) and as recommended in key documents, eg Healthcare for All (2008), Equalities (2005). Key partnerships at this tier would include primary and secondary healthcare staff, criminal justice workers, child and family services, further education colleagues.

Whilst this tier includes all 'mainstream' services, eg criminal justice system, family courts, the position paper would suggest that SLTs have a fundamental role to play in partnership with others, to address healthcare inequalities as a national priority.

Speech and language therapists have a role to improve the awareness and understanding of primary and secondary healthcare staff of the needs of people with a learning disability and communication/dysphagia needs and working with them to improve access. For example, training GPs, ward staff, community palliative care teams, community rehabilitation teams, health promotion staff, family and childcare teams, mental health teams.

If a person with a learning disability develops communication problems relating to a neurological or other medical condition, they should have access to the speech and language therapy services that specialise in that condition.

This is in line with all UK governments' policies that people should be receiving mainstream provision where possible, with specialist advice sought if necessary.

Key factors to be considered regarding how people with a learning disability would access mainstream adult speech and language therapy services will include:

- The complexity of the person's learning disability.
- The impact of this on their ability to access the service.
- The capability and capacity of the service.

The specialist adult learning disability SLT's role will vary from no involvement through to advice, training and supervision, partnership working or working alongside the mainstream speech and language therapy service.

Specialist adult learning disability therapists have a core role to play (as with other mainstream health services) in developing the understanding, capability and competencies of mainstream SLTs in working with people with a learning disability.

In Portsmouth City PCT Specialist ALD speech and language therapy services are fully integrated with mainstream speech and language therapy. Each person is considered at the time of his or her referral. Both communication and dysphagia are triaged and cases allocated to mainstream or specialist ALD speech and language therapy based on clinical need.

In addition, the education of undergraduate and post-graduate staff is a recommendation from Healthcare for All (2008). SLTs are in a key position to offer and advise on training that develops the awareness of the communication and eating and drinking needs of people with learning disabilities.

The SLTs working in the Northern Trust, Northern Ireland have developed a joint project with A&E staff. "Come & See A & E" SLTs provided training to A&E medical and nursing staff in communicating with adults with learning disabilities. Training sessions included the use of practical strategies such as signs and visual cues when working with ALD in order to assist with difficulties that may arise such as establishing the nature of the medical complaint and pain location. They also co-ordinated visits to the A&E department for service users so that they could experience the environment and procedures, eg having casts fitted to limbs, in a relaxed and supportive environment.

The learning disability speech and language therapy team in Eastern Kent and Coastal PCT have a collaborative project with the radiographers at the Breast Screening Unit at the Kent and Canterbury Hospital. In order to improve the uptake of breast screening amongst women with a learning disability they have:

- Changed the policy of the breast screening unit so women with learning disabilities are offered appointments at the hospital instead of the mobile units. They are also allocated a half hour appointment instead of the six minutes offered to most women.
- Produced a 'user friendly' leaflet with photographs of the unit.
- All unit staff, from receptionist to senior radiologist have been trained in communication strategies and the relevant Makaton signs.
- Made photographic resources available in each room and mobile unit detailing the breast screening process.
- Raised staff awareness of consent issues.

They are currently developing photographic resources describing the process of investigation, should an abnormality be detected.

In addition to more general services, speech and language therapy work has successfully been targeted to known high risk/common health issues for people with a learning disability, eg videofluoroscopy clinics, audiology and ENT.

All primary and secondary health care work should be delivered in partnership with health care providers. Key priority partnerships agreed by consensus nationally include: audiology, gastroenterology, GPs, practice nurses, hospital liaison staff, maternity services, ophthalmology, patient advice and liaison services, mainstream speech and language therapy, complementary therapies, mental health, dental and oral hygiene staff.

In the Camden Learning Disability Service the SLT has developed an accessible Care Programme Approach (CPA) tool kit with a multidisciplinary steering group to support users to participate and understand the CPA process.

An SLT working in Oxleas NHS Foundation Trust has developed a protocol between community ALD speech and language therapy and acute hospital speech and language therapy for joined up working regarding videofluoroscopy/percutaneous endoscopic gastrostomy. The protocol outlines the steps that speech and language therapy services will take when working with individuals with severe/profound dysphagia. It ensures consistent experiences for the service users and informs carers/staff what to expect at each stage.

The way resources are allocated at this tier will be dependent on local speech and language therapy resources and commissioning priorities.

## Tier 2 – Capability in mainstream – expected outcomes and risks

### Communication and eating/drinking/dysphagia

#### Expected outcomes of providing a specialist speech and language therapy service include:

- Reduced healthcare inequalities.
- Evidence of mainstream services being adapted to include people with learning disability, eg audiology and vision services; videofluoroscopy; criminal justice system.
- Improved patients' understanding, choice and control through a care-pathway.
- A positive experience for people with learning disability and their carers.
- People with learning disabilities have their needs met by primary and secondary healthcare services, with specialist support where necessary.
- Improved health and life expectancy.
- Prevention of unnecessary hospital admissions.

#### Risks of not providing a specialist speech and language therapy service include:

- Increased anxiety and distress for people with learning disability and their families/carers during hospital admissions.
- Lower standard of healthcare received as communication and eating and drinking/dysphagia needs are not adequately addressed.
- Overuse of specialist learning disability services when mainstream services should provide adequate care.
- Failure to meet legal requirements of:
  - Mental Capacity Act (England)/Incapacity Act (Scotland)/Good Practice in Consent (Northern Ireland)
  - Human Rights Act
  - Disability Discrimination Act
- People not making informed decisions, eg lack information in understandable formats.
- Increased vulnerability of abuse.
- Preventable death, eg undiagnosed dysphagia.

### 8.3 Capability in specialist learning disability services

National guidance, eg Valuing People Now (2009), Equal Lives (2005), The Same As You (2000) and Fulfilling the Promises (2001), suggests that it is a fundamental role of learning disability teams and therefore SLTs, to work with partner agencies to improve specialist services for people with a learning disability. Despite the move to more integrated and mainstream provision, currently people with a learning disability receive many of their services from specialist care providers.

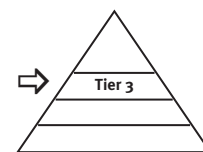
In the consultation events all SLTs agreed nationally that strategic and targeted work in this area is core business.

Work at this tier aims to:

- Improve knowledge and skill of the learning disability workforce in understanding and responding to people with a learning disability with communication difficulties.
- Improve knowledge and skill of the learning disability workforce in understanding and responding to people with a learning disability who have eating and drinking difficulties/dysphagia.
- Ensure environments focused on the needs of people with a learning disability are capable to meet the needs of people with communication difficulties and dysphagia.
- Develop responsive environments that support inclusive communication and empower individuals.

An SLT in NHS Forth Valley has championed 'SNACK':

There was a significant concern over the health needs of clients with a learning disability and eating and drinking difficulties. The role of carers in managing these issues was recognised as crucial. Similar information was being gathered by Community Learning Disability Team (CLDT) members on several occasions. It was recognised this required a more strategic and coherent approach to impact on clinical effectiveness. A multidisciplinary training package called Safe Nutritional and Chewing Knowledge (SNACK) was developed so that an SLT or dietitian could run with another trained member of the CLDT. The purpose of SNACK was to provide quality training that acknowledges the shared professional responsibilities in providing safe eating and drinking support.



Speech and language therapy provision at this tier of the model may include any one or more of the following:

- Accessible/inclusive communication environments, eg objects of reference/signing/visual timetables/promoting use of easy read resources.
- Supportive and responsive communication environments, eg Intensive Interaction.
- Training staff, eg signing/Talking Mats/communication passports.
- Consultation/non-direct advice and support, eg drop ins.
- Consultation to improve personalised care, eg person-centred planning and toolkit, direct payments/individual budgets.
- Being active members of partnership boards or equivalent to advise on communication issues, eg workforce development subgroups/person centred planning/total communication projects/transition.
- Supporting/leading development of service-wide communication and/or eating and drinking strategies.

Speech and language therapy services at this tier would be delivered in partnership with:

- People with learning disabilities (peer supporters as well as individuals who need support) and families.
- CLDT colleagues (health and social care).
- Group homes (health, social care, independent and voluntary sector).
- Day opportunities, specialist employment agencies, specialist local learning disability provisions.
- Local advocacy services.
- Independent mental capacity advocates – local IMCAs (England and Wales).
- Partnership boards and equivalents.

Speech and language therapy services would also be delivered in line with recommendations from national guidance from the following organisations and regulatory bodies – MENCAP, British Institute of Learning Disabilities (BILD), Scottish Consortium for Learning Disability (SCLD).



### **Tier 3 – Capability in specialist learning disability services expected outcomes and risks**

#### **Communication and eating/drinking/dysphagia**

##### **Expected outcomes of providing a specialist speech and language therapy service include:**

- People with learning disability will access a quality environment.
- Staff will have appropriate skills to suit the communication and eating and drinking/dysphagia needs of the service users.
- Compliance with the requirements of Valuing People Now, Same as You, Equal Lives, Fulfilling the Promise.
- Evident understanding of the communication needs of people with learning disability.
- Appropriate and timely referrals for eating and drinking/dysphagia.
- Improved quality of care provided through supervisory support.
- Evidence of Total Communication/Inclusive Communication practice.
- Non-verbal signals of distress recognised and responded to.
- Consistent, stable placements and staff team.

##### **Risks of not providing a specialist speech and language therapy service include:**

- Services fail to achieve national quality standards.
- Inadequate or incomplete specialist learning disability care-pathways.
- People's placements may break-down due to lack of staff competence in understanding and responding to communication and dysphagia.
- Increased vulnerability of abuse and safeguarding issues.
- Increase in number of incidents that need to be reported.
- Increase number of inappropriate referrals at Tier 4.
- Increase in challenging behaviour.
- Increase of injury and distress for service users, families and carers.
- Preventable illness and death.

An SLT in London has developed a bespoke communication support-training package for a housing service specifically for people with learning disability.

To increase the awareness and skills of housing support officers, working for the organisation, in appropriate communication support methods to use with the individuals whom they support.

To develop and deliver a number of practical-based communication support training sessions. These were tailored to the needs of clients supported by the housing officers within this organisation and covered topics such as:

- General communication strategies when supporting an individual with a learning disability.
- Communication strategies when supporting an individual with a learning disability and a sensory impairment.
- The use of visual supports to support communication.
- The use of keyword signs to support communication etc.

Each session was held at the organisation's office base and used practical exercises related directly to the role of the housing officers in receipt of the training.



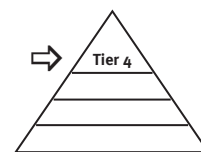
## 8.4 Specialist interventions to address the needs of individuals

This tier describes the core business of SLTs in community learning disability teams to provide assessment, information and training/advice for individuals with a learning disability and complex communication needs or dysphagia referred to the service. Eligibility criteria for the service will be decided locally. More detailed information can be found in key RCSLT guidelines eg CQ3, Clinical Guidelines, Competencies Project (2003), in relation to this area.

### Process

Adapted from the first RCSLT ALD position paper, 2003.

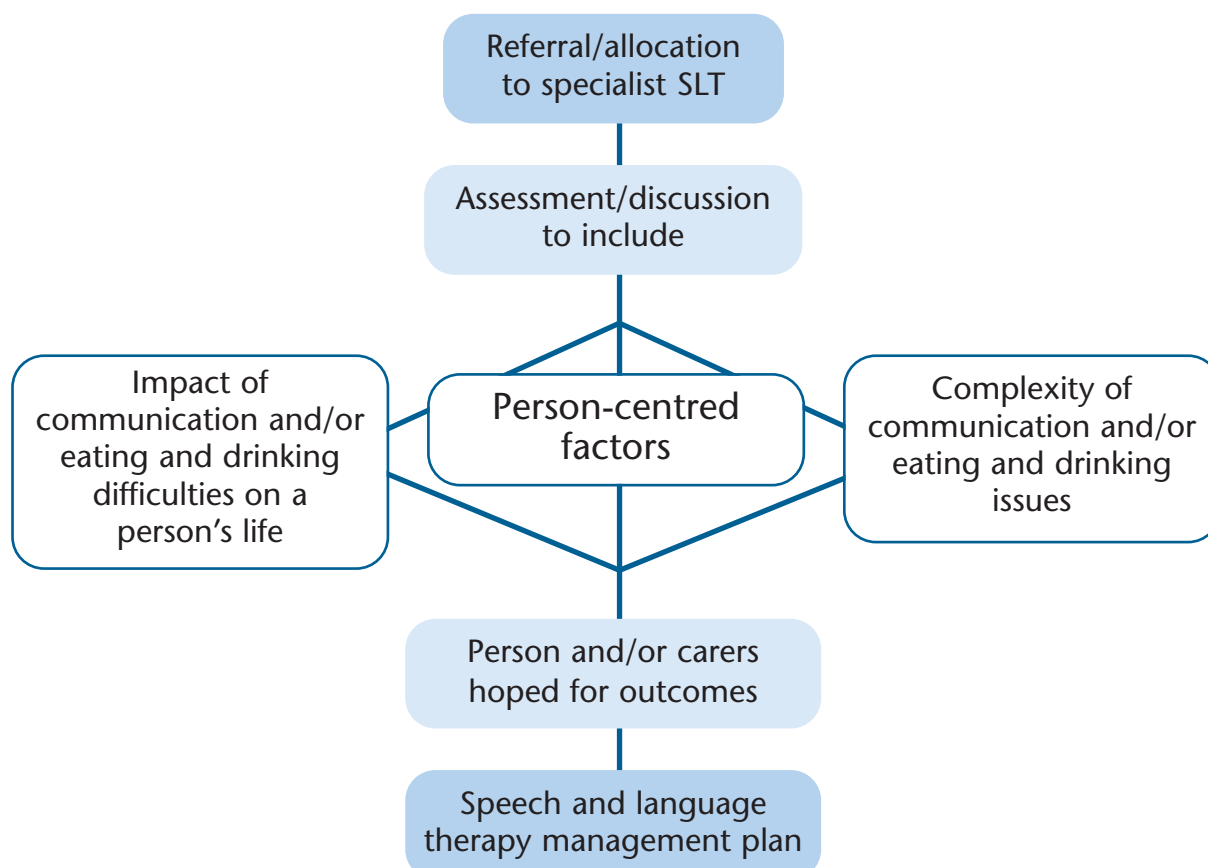
The SLT must deliver personalised services, working with the individual and their significant others.



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 including families.
- Training/teaching/transmitting information.
- Coaching/enabling/resourcing.
- Improving overall communication environments.
- Use of specialist knowledge and skills to facilitate and inform the work of other professionals.

In line with national best practice in relation to person centred outcomes, the following process should be applied to all referrals:



Being person-centred from the outset in clarifying the reason **why** a speech and language therapy referral has been made, the impact on the individual's life and the hoped for outcome(s), enables everyone concerned to determine what speech and language therapy intervention(s) will be the most useful and effective.

The following describe key areas of an individual's life that may need speech and language therapy support (agreed at the national consultation events):

- Behaviours which challenge/prevention of violence, aggression and distress.
- Safeguarding issues.
- Issues for parents who have learning disabilities.
- Differential diagnosis.
- Relationship issues.
- Social skills.
- Housing.
- Employment.
- Leisure.
- Sexuality/sexual health.
- Transition.
- Consent.
- Dysphagia.
- End of life care.
- Specific 'access' issues, eg blood tests.
- Forensic/offending behaviour.

Speech and language therapy in Leicester Partnership NHS Trust has been working within a multidisciplinary team to enable some parents with learning disabilities to engage fully in assessment of their parenting capacity, improve the communication skills of those working with them, and help them understand the child protection process. The outcome was that the child was removed from the child protection register and appropriate support given to the parents.

- A full speech and language therapy assessment was carried out with both mum and dad and this information shared.
- Speech and language therapy worked with the family aide worker around issues of weaning/feeding children appropriately and routines.
- Recommendations of the child protection case were made accessible to the parents to ensure their understanding and participation in the process.
- Joint visits were undertaken with children's social workers to give an opinion on the parent's understanding of complex verbal information.
- Joint working with the community LD nurse to develop skills, eg shopping, cooking, budgeting.

Speech and Language therapy had a major role in highlighting how the parent's communication needs impacted on the parenting assessment.

It is in line with national best practice, eg Challenging Behaviour – A Unified Approach (2007) that all speech and language therapy assessments will be part of a multidisciplinary approach.

The work at the other tiers will help to ensure the referrals we accept at this level are the ones that are appropriate for this level of intervention, for example where speech and language therapy can be effective. The work at the other tiers also allows the progress made at the individual level to be sustained and maintained across a range of settings.

In Northampton the Speech and Language Therapy in the Community Team for People with Learning Disabilities (CTPLD) describes work in relation to the need for a client to have a possible per endoscopic gastrostomy (PEG) insertion.

Speech and language therapy met with service user and his carers to discuss swallowing difficulties and possibility of PEG insertion. Speech and language therapy then liaised with GP to request referral to gastroenterologist and attended gastroenterology appointment with carer, as service user was having difficulties using his wheelchair and therefore could not attend appointment as arranged. As there were ongoing issues with service user attending hospital appointment, speech and language therapy liaised with service user and gastroenterologist in order to ensure service user understood information from gastroenterologist and that the service user's questions regarding the PEG were answered. After the service user had made the decision to go ahead with PEG insertion, speech and language therapy liaised with strategic health facilitator for the local hospital to ensure provision was made on the ward for service user's needs to be met and for his carer to stay with him during admission. Speech and language therapy also liaised with community nurse support worker who ensured that a "Helping me in hospital" book was developed prior to admission and with the dietician and nutrition nurse to ensure follow up care was in place.

## Tier 4 – Specialist interventions – expected outcomes and risks

### Communication

#### Expected outcomes of providing a specialist speech and language therapy service include:

- Specialist speech and language therapy interventions result in person-centred communication strategies tailored to meet an individual's needs and maximise their abilities and opportunities and enjoyment of rights.
- Increase in meaningful engagement and interactions.
- Improvement in emotional and mental well being.
- Improvement in inclusion of people with more severe disability and PMLD.
- Improved transition.
- Reduction in frustration and distress of individual and others.
- Crisis prevention.
- Improved access to the safeguards and protections in criminal justice system.

#### Risks of not providing a specialist speech and language therapy service include:

- Placement breakdown.
- Inpatient admission.
- Out of county placement.
- Vulnerability to breakdown in mental well being.
- Increased vulnerability and safeguarding issues.
- Exclusion.
- Offending.
- Increased challenging behaviour.
- Failure to meet legal requirements of:
  - Mental Capacity Act (England)/Incapacity Act (Scotland)/Good Practice in Consent (Northern Ireland)
  - Human Rights Act
  - Disability Discrimination Act

## Tier 4 – Specialist interventions – expected outcomes and risks

### continued Dysphagia

#### Expected outcomes of providing a specialist speech and language therapy service include:

- Specialist speech and language therapy interventions result in person-centred, individually tailored support that maximise and individual's abilities and opportunities for safe and enjoyable eating and drinking.
- Improved life expectancy.
- Improved physical health.
- Improved emotional well being.

#### Risks of not providing a specialist speech and language therapy service include:

- Choking.
- Aspiration.
- Dehydration.
- Malnutrition.
- Increased incidence of chest infection and subsequent demand on primary care resources.
- Compromised health.
- Repeated or prolonged hospital admission.
- Distressing and unnecessary medical procedures.
- Premature/preventable death.

## 9. Accessible information

The term 'accessible information' is now widely used within national documentation and it is accepted by all as an essential element of supporting the communication needs of people with learning disabilities. It is the general term used to describe making information easier to understand for people with people with learning disabilities. Over the last decade we have seen the emergence of various terminologies that are all used to describe similar methods of support such as; Inclusive Communication, Total Communication, easy read etc. Whilst all of these support the communication needs of people with learning disability, the distinction needs to be made that accessible information is aimed at supporting **receptive** communication needs. The term 'accessible information' is applicable to all levels of receptive communication from sensory information through to text based information; rather than 'easy read' which just refers to access to the written word. Accessible information can therefore be defined as:

*'A supportive process of making information easier for people with learning disabilities, that firstly involves simplifying the linguistic message and secondly conveying the simplified message in different mode(s) of communication, ie not just the written word or spoken message'*

(Mander, 2008)

It is important that accessible information is seen as a process with various stages of production and implementation, rather than just an accessible resource, as without the implementation of such resources, accessibility is not necessarily improved.

The rationale for accessible information is not only considered best practice, but within the UK it is set within a legal framework. Firstly, the Disability Discrimination Act (1995) stipulates that 'reasonable adjustments' need to be made to improve access for people with disabilities and the Human Rights Acts Article 10 (1998) sets out the right

to information as does the Communication Bill of Rights (1992). The Mental Capacity Act (1998) highlights the need for 'practicable steps' to be taken to support individual communication needs with reference to the decision making process. More recently Valuing People (DoH, 2001) and Valuing People Now (DoH, 2009) state that the government expects organisations working with learning disabled people to develop communication policies and produce and disseminate information in accessible formats.

At a practical level, one of the most important considerations is individual differences. As we know, it is not possible to neatly categorise the receptive communication needs of the population and this is the quintessential challenge in supporting their receptive communication needs through the use of accessible information. Accessibility is not absolute. What counts as accessible for one person will not necessarily be so for someone else. Extreme individual differences are just one aspect that influences the multi-faceted nature of accessible information and the unlikelihood of the production and implementation of accessible information being a straightforward process.

As stated above, accessible information is an issue for everyone and not solely the role and responsibility of speech and language therapy. When we consider our role in the production and implementation of accessible information it will depend greatly on local needs and the resources available. At a specialist clinical tier, assessing and supporting an individual's receptive communication needs through the use of tailored accessible information will be relevant to all. At the other tiers of the model, working in partnerships with other agencies is essential; this may include a wide range of learning disability services through to media and communication departments. Below you will find some suggested roles and responsibilities at each level:

### Tiers 1, 2 and 3: community, mainstream and specialist teams

When we consider accessible information at these levels, a high degree of person-centeredness is hard to achieve, in that it is not possible to produce one resource that will meet the needs of the whole learning disability population. With this in mind speech and language therapy may have a role in:

- Promoting the use of accessible information to support receptive communication needs.
- Developing written guidelines/local strategies/training about how to produce and implement accessible information.
- Reinforce the legal context of accessible information and the responsibility of accessible information.
- At a strategic level, involvement in planning/promotion of the use of accessible information.
- Acting as a consultant to organisations producing accessible information in terms of appraisal of the information.
- Signposting others to relevant materials/internet sites.

### Tier 4: Individual tier

At a specialist clinical level, accessible information should be tailored to the individual and therefore complement their communication skills and needs. At Tier 4, the SLT may have a role in:

- Identifying communication strengths and needs, to include: level of symbolic development, sensory impairments, comprehension levels etc.
- Producing or commissioning specific accessible information for the individual and supporting its implementation.
- Advising key worker/s, other professionals and carers on how to produce and implement accessible information for an individual.
- Supporting the translation of relevant information into an appropriate format, eg care plans.
- Training other professionals and care workers to tailor their communication and environment to cater specifically for the needs of individuals.
- Promoting the use of person-centred strategies and resources.

There will be forthcoming guidance from the Department of Health for people who commission or produce 'easy read' information.

## 10. Workforce development

Recent shifts in policy have required SLTs to examine their skills and competencies. The UK wide Skills for Health require the workforce to meet the needs of the service user by putting their needs before professional boundaries.

As a profession, SLTs need to develop emerging roles and be clear about the competences and skills required to meet that role. Speech and language therapists need to cross-traditional professional and agency boundaries and be open to workforce redesign.

This section will consider the evolving workforce and put forward consensus views on workforce development.

There are detailed guidelines on clinical practice in RCSLT Clinical Guidelines (2005), RCSLT Competencies Project (2003) and CQ3 (2006). This section is not intending to repeat these guidelines. It is not the remit of a position paper to discuss competencies and capability.

During consultation events held across the UK, participants were asked to consider the evolving roles and workforce issues for therapists and assistants/support workers working in the area of ALD.

Recent shifts in learning disability policy require SLTs within the field of ALD to work in innovative and creative ways. These emerging roles are not outside of the scope of core professional practice and are still considered 'core business' for ALD SLTs.

The RCSLT Policy Statement 'Evolving roles in speech and language therapy' (October 2008) provides a framework for RCSLT members whose roles may be evolving or who may be setting up new clinical initiatives. ALD is a rapidly expanding area and it is apparent that SLTs working within this clinical area are developing new roles and skills. This development should take place within a safe framework endorsed by the RCSLT and which is in the best interests of clients.

An overall policy objective in Valuing People Now (2009) is “The workforce across public services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the Valuing People Now priorities for all people with learning disabilities.”

During consultation events the following emerging roles were identified:

- Criminal justice system including intermediary and community forensic services.
- Developing role with people with dementia.
- Parents with learning disabilities (working alongside children’s services).
- Complex dysphagia management.
- Autistic spectrum disorder (including Asperger’s).
- Mental health.
- Palliative care.

The emergence of different roles or ways of working “should not be limited by the grading of the clinician and may not always be exclusively developed and carried out by advanced practitioners” (Evolving Roles in Speech and Language Therapy, RCSLT. October 2008). It is possible for all levels of the speech and language therapy workforce to work in any of the above. What needs to be considered is the level of support available, the skills needed for the role, the competencies required by the role and the capability of the speech and language therapy in that role.

### 10.1 Skill mix and the role of the speech and language therapy assistant practitioners/support workers

The speech and language therapy assistant/support worker is an integral member of the speech and language therapy team and is employed to act in a supporting role under the direction of a professionally qualified speech and language therapist (CQ3 2006). In addition to this is the developing role of the generic worker. Further information on skills and competencies for assistants/support workers can be gathered from CQ3, NHS, KSF, RCSLT Support Practitioner Core Clinical Competencies (2002) and the RCSLT Policy Statement on Education and Training for Assistants/Support Workers (2009).

The RCSLT Policy Statement ‘Education and Training for Assistants/Support Workers’ (2009) affirms there are changing demands within health, education and social care and there is increasing status, responsibility and accountability expected of assistants/support workers.

The role of the Assistant/Support Worker within ALD speech and language therapy services mirrors that of therapists in that there is a need to broaden the scope to remain inline with key national drivers. Consultation events showed there is a varied and diverse role for assistant practitioners/support workers within UK ALD speech and language therapy services (See paragraphs 10.2/10.3).

### 10.2 Existing role of assistant practitioners/support workers

- Producing client resources using advanced IT knowledge, eg to produce passports, life story book.
- Jointly running groups.
- Observational assessment.
- Participating in and supporting training.
- Supporting production and implementation of accessible information.
- Carrying out interventions, eg intensive interaction (under direction of a qualified SLT).
- Tutors for Makaton, Signalong, or other signing systems.
- Supporting the implementation of augmentative and alternative communication (AAC).
- Promotion of team, eg at exhibitions.

### 10.3 Trends in emerging and existing roles

From the UK-wide consultation events it is clear to see that there are emerging roles for the assistant/support worker population. Whilst this broadening scope in practice will be dependant on local influences, the need for robust supervision and clear lines of accountability are paramount.

- Triage.
- Eating and drinking/dysphagia monitoring.
- Screening assessment and informal assessment.
- Development of specialisms within teams, eg Intensive Interaction, signing, dysphagia.

Workforce development is an important area for all SLTs to consider. The speech and language therapy workforce needs to be aware of national trends in workforce development and how this will impact on individual services. Speech and language therapists and speech and language therapy assistants have a broad range of skills and competencies that enable them to fulfil a number of different roles and commissioners need to be aware of the unique contribution of SLTs across LD services.

### 10.4 Building capacity of people with learning disabilities to enhance their contribution to service delivery

Work towards building capacity and developing an increasing partnership with people with a learning disability and their families. This approach recognises that the people with a learning disability are the people who are experts in what it is like to live with a communication support need and therefore can support a variety of projects, eg training staff, advising on accessible information, quality assurance activities. An example of the latter is reported in Cameron and Boa (2009).



## 11. The Future

Following development of this paper, the ALD Speech and Language Therapy network should consider the following questions:

- Should there be specific outcome measures for ALD?
- What performance indicators relate to the tiered model of health and social care described in this paper?
- What is the contribution of speech and language therapy to Payment by Results in England/Tariff-based commissioning?
- What is the optimal provider context for efficiency and effectiveness of speech and language therapy services to people with learning disabilities, eg health, social care and social enterprise?
- What are emerging roles for the speech and language therapy ALD workforce, to include qualified staff and assistant practitioners?
- What is the impact of individualised healthcare budgets on the delivery of speech and language therapy services?



## 12. Review of literature and level of evidence

Throughout this consultation process and in the writing of this paper there has been a thorough overview of relevant research and literature relating to ALD. Using the electronic survey tool the profession has been asked to highlight those key papers/projects that influence clinical practice. These are included in the reference list at the end of the document.



top Comms chart

centre Richard and Chayne have taken part in an involvement project in Leicester

bottom Reema shows her communication passport



## Conclusion

This position paper aims to offer guidance to SLTs and others with a vested interest in delivering high quality services to people with a learning disability.

The paper is a collective view gained by consultation with the profession. It aims to offer a vision of the way speech and language therapy services for people with learning disabilities should be delivered.

We want to encourage SLTs and their employing organisations to embed this guidance into their policies, partnership agreements and their own working practices.



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## Notes





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