



information

## How much is enough?

### Speech and Language Therapy Provision for School Aged Children who have Down's Syndrome

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# How much is enough?

## Speech and Language Therapy Provision for School Aged Children who have Down's Syndrome

Pupils who have Down's syndrome face complicated challenges in mastering and using speech, language and communication skills. With the right opportunities and support, they can develop communication skills that help them to make relationships and socialise, communicate wishes, needs and aspirations, and use language effectively as a tool in all sorts of situations.

It's vital that pupils who have Down's syndrome, and school staff who support them, have access to specialist input from speech and language therapy services throughout their school careers.

This booklet provides information for parents, schools, service planners and speech and language therapists about appropriate speech and language therapy for pupils with Down's syndrome.

The booklet covers:

### ***Speech and language therapy for pupils with Down's syndrome:***

Professional standards for speech and language therapists, and recommendations from experts and researchers

Comments from families and schools

### ***Tackling barriers to accessing effective speech and language therapy for school aged children:***

Low expectations, out of date information, and limited resources

Securing speech and language therapy from state funded statutory services

### ***Is my child receiving the right type and amount of speech and language therapy?***

10 point checklist that you can use to evaluate the speech and language therapy that your child receives

### ***Strategies that take into account the specific learning style and impairments associated with Down's syndrome:***

Speech and language therapists can adapt this section as appropriate to suit each child's individual needs

### ***Reference list of publications:***

The list of publications at the end of this booklet is grouped according to subject area, so that you can reference them easily. Quotes from publications are referenced throughout the text, so you can use extracts from this booklet as evidence in discussion with speech and language therapy providers, and when gathering evidence to present at a Tribunal.

[Please note that throughout this text, the term "Down's syndrome" is used, except where referring to titles of publications, where the term "Down" or "Down's" is used as it appears in the title, for ease of reference].

## **What do professional standards for speech and language therapists say?**

Communicating Quality 3 (the Royal College of Speech and Language Therapists' guidance on best practice in service organisation and provision) <sup>[1]</sup>, describes the tasks that speech and language therapists address when working with school age children:

- To develop and maximise communication skills in all environments
- To promote inclusion into school and social contexts
- To promote access to curriculum
- To minimise secondary difficulties arising out of communication impairments such as emotional and behavioural difficulties and literacy difficulties
- To support parents as child's communication needs change and develop throughout childhood and adolescence.
- To maximise communication potential by skilling others in their use of facilitative strategies and/or use of augmentative communication systems.
- With regard to language impairments, "the main aim is to maximise their comprehension and production of language in both oral and written forms, and also maximise their use of those abilities so that they can reach their full potential both educationally (including literacy) and socially."
- Regarding speech impairments, "the main aim is to maximise intelligibility to reach full potential educationally and socially." <sup>[1]</sup>

This guidance highlights that **as well as working directly with pupils, speech and language therapists act as a resource that supports education providers to achieve successful inclusion and learning**. It states that speech and language therapy services should "enable education staff to incorporate the aims of speech and language therapy in the planning of an individual educational programme within the context of the broad curriculum."

"Intervention will include facilitating access to the National Curriculum and supporting staff to make environmental changes to support inclusions. This is most effective through collaborate working strategies including joint assessment, planning and working, as well as through training workshops, provided as part of the school in-service trainings (INSET) programmes." <sup>[1]</sup>

## What do the experts and researchers say?

**All pupils who have Down's syndrome are likely to require speech and language therapy input.**

Libby Kumin, Professor and Department Chair of the Speech-Language Pathology Department at Loyola College in Baltimore, states "Speech and language are complex and present many challenges to the child with Down's syndrome that need to be addressed through a comprehensive approach to speech and language treatment"<sup>[3]</sup>. Jon Miller, Mark Leddy and Lewis Leavitt of the Waisman Centre at the University of Wisconsin-Madison write, "optimal communication skills development in children with Down's syndrome require that they receive early and continuing instruction"<sup>[4]</sup>.

**People who have Down's syndrome require speech and language therapy to help them to overcome the specific impairments to speech, language and communication skills associated with Down's syndrome.** These impairments affect the ability to understand spoken language, produce speech, and use language to communicate.

The profile is summarised in more technical terms by Sue Buckley, Emeritus Professor of Developmental Disability, Department of Psychology/Sarah Duffen Centre at the University of Portsmouth, in *Speech and language development for individuals with Down syndrome - An overview* (Down Syndrome Issues and Information Series)<sup>[5]</sup>, and discussed in depth in the book *Improving the Communication of People with Down Syndrome* edited by Miller, Leddy and Leavitt, aimed at professionals<sup>[4]</sup>.

Researchers have identified specific underlying impairments that contribute to the speech, language and communication impairments experienced by people who have Down's syndrome. Sue Buckley and Patricia Le Prevost of the Sarah Duffen Centre at the University of Portsmouth, in their article making recommendations about *Speech and Language therapy for children with Down syndrome*, state that "**The needs of children with Down's syndrome tend to be different from the needs of other children with learning difficulties.** Their hearing, phonological loop impairment and speech-motor difficulties make them different, and therapists need to be skilled in auditory discrimination, oral-motor function and speech work as well as language work."<sup>[6]</sup>

**People who have Down's syndrome require direct teaching of specific aspects of speech, language and communication skills, as well as good language models and general language stimulation to support language learning.**

Writing in *Speech and language development for individuals with Down Syndrome - An overview* (Down syndrome Issues and Information Series), Sue Buckley states: “the evidence from available research does suggest that improving the quality, quantity and sensitivity of the talk to children with Down’s syndrome does help ... this type of language experience approach is not sufficient on its own but needs to be accompanied by teaching specific vocabulary and sentences, using techniques which encourage the child to imitate production.”<sup>[5]</sup>

**There are plenty of widely used speech and language therapy interventions that are effective in addressing the underlying impairments and real-life communication challenges faced by people who have Down’s syndrome.**

When describing some of these, Sue Buckley comments: “The proposals for intervention...follow logically from the available evidence from research, the profile of language development of children with Down’s syndrome and the probable causes.”<sup>[5]</sup>

**As in other areas of speech and language therapy, research studies have demonstrated the effectiveness of a few interventions, but more research is needed to scientifically demonstrate that widely used techniques produce to measurable gains.**

Sue Buckley comments: “The number of studies that have actually evaluated the effectiveness of intervention are few.”<sup>[5]</sup> This is consistent with the situation generally in speech and language therapy as described by Reilly: “In many instances there will be little or no evidence to support a particular approach.”<sup>[12]</sup> Sue Buckley presents evidence that addresses issues such as the benefits of naturalistic, language interaction intervention compared to direct teaching approaches, and the benefits of direct work on phonology.<sup>[5]</sup> As with all clients, speech and language therapists must adapt interventions to suit individual interests, learning styles and needs.

Greatest gains are usually made when intervention is started early, but **people who have Down’s syndrome can benefit from speech and language therapy throughout life.** Tracking the development of skills has indicated that people who have Down’s syndrome make progress in all areas well into adulthood, and indicates that communication skills can be further developed no matter what age intervention is initiated. Robin Chapman, Professor Emeritas - Communicative Disorders, and Linda Hesketh of the Waisman Centre at the University of Wisconsin-Madison report “language production skills do not stop with the onset of adolescence, or plateau with simple sentence structure.”<sup>[7]</sup> Sue Buckley and Patricia Le Prevost recommend: “Speech and language therapy should continue for all teenagers with the same list of key objectives and targets as for the primary age group, but should be adapted to focus on age appropriate language needs and activities.”<sup>[6]</sup>

**Enhanced communication skills support people who have Down's syndrome to maximise independence and achieve an enhanced quality of life.** Sue Buckley writes: "Since speech and language skills are central to the development of mental abilities such as thinking, reasoning and remembering as well as to social inclusion, it is essential that speech and language is a focus for parents, teachers and therapists from infancy through to adult life." [5]

**Specialist intervention is effective when provided in the context of opportunities that maximise achievement.** Professor Jean Rondal from the University of Liege in Belgium writes, "whatever the merits of a given intervention strategy, it will have only a limited effect in furthering development and functioning if the attitudes and opportunities of the inclusive educational or community setting are less than appropriate." [8]

## What do families and schools tell us?

The Royal College of Speech and Language Therapists set out some themes identified from consultation with service users regarding School Aged Children with Speech, Language and Communication Difficulties in their Clinical Guidelines [2]. These include:

- Collaborative working
  - Required between all disciplines involved, and in particular, between the Speech and Language Therapist and the class teacher
- Provision of information
  - General strategies that enhance communication
  - Specific strategies that form part of the therapeutic programmes
- Documentation of need
  - The need for, and details of, speech and language therapy provision to be included within the child's Individualised Education Plan (IEP).

Families and schools recognise the value of the specialist input that speech and language therapists provide. A survey carried out by the Down's Syndrome Association in 2004 in England and Wales found that more families were dissatisfied about speech and language therapy provision, than any other issue surrounding education. Of the 1 380 families who responded, 66% felt that the speech and language therapy provided didn't meet their child's needs. Families express dissatisfaction with the *amount* of speech and language therapy offered, and concerns about whether the speech and language therapy that they receive addresses their child's needs in an *effective way* [13]. The Down's Syndrome Association is working with speech and language therapists to implement a strategic plan to contribute to improving services that address the speech, language and communication needs of people who have Down's syndrome.

## **Tackling barriers to accessing effective speech and language therapy for school aged children- *Low expectations and out of date information***

It's vital that you and others working with your child are aware of current thinking on the sort of provision that will support our children to achieve their potential.

Professionals may simply be unaware of the achievements of people who have Down's syndrome nowadays, and lack information about effective ways of supporting our children. This may lead them to underestimate what your child can achieve and to recommend less than adequate provision for your child.

Some professionals (and other people!) base their expectations on what they know about achievements in the past, instead of recognising that each generation of people who have Down's syndrome is achieving so much more than the previous generation, due to *increased opportunities* and *better knowledge about the syndrome*. It's important that the speech and language therapist has up to date knowledge about effective speech and language therapy for people who have Down's syndrome, and high expectations for your child's achievements.

Most people who have Down's syndrome *usually* can (and do!):

- Learn to read and write
- Use hearing aids and glasses if needed
- Learn to let people know what they want, how they feel and what they think
- Communicate with friends, family, and the wider community
- Eat ordinary food in ordinary situations
- Learn to breath through the nose and keep the tongue in the mouth
- Use language to plan, make decisions and negotiate
- Use spoken language
- Speak clearly enough for others to understand ....

*...and lots of other things that professionals may tell us are unlikely!!!*

When people who have Down's syndrome don't achieve these things, it's because they haven't had the opportunity to do so, or because they have additional difficulties (such as visual impairments, physical disabilities, Autistic Spectrum Disorder), not simply because they have Down's syndrome. If your child is having great difficulty with something, the professionals must work to identify any additional challenges that your child experiences, and give advice on the impact of these difficulties and what can be done to address them, rather than "blaming" it on the diagnosis of Down's syndrome.

## **Tackling barriers to accessing effective speech and language therapy for school aged children- *Limited resources***

Many families have used a combination of service providers to ensure that their child receives appropriate speech and language therapy, making best use of locally available services. These may include:

- Health services and education services funded by the government (Statutory Services), including speech and language therapy provided at Children's Centres, in Health Centres and Community Clinics, in Mainstream Schools and Special Schools. In a few areas, the Local Education Authority (LEA) employs speech and language therapists directly but in many areas the local NHS Health Trust provides the speech and language therapy that children receive in school.
- Services that you can access through voluntary organisations, such as parent-led groups that commission speech and language therapy services. These may be free or require some payment.
- Speech and language therapists who work as independent practitioners, that you pay directly to work with your child at school, at home, or at their clinic. In some areas, the Local Education Authority may pay for some children to receive speech and language therapy from independent practitioners in schools.

Local Statutory Services often comment that they don't have enough speech and language therapy staff to meet the needs of all the children they serve, due to inadequate funding and the national shortage of speech and language therapists. If speech and language therapy posts remain vacant, there may be no service for a period of time. There may be a long waiting list and they may inform you about prioritisation and guidelines that specify the type and amount of speech and language therapy that particular groups of children will receive. For example, they may tell you that children in mainstream Primary schools receive up to three visits per school year from a speech and language therapist, and no speech and language therapy after they transfer to Secondary school, or that children in Special schools receive speech and language therapy in groups with their classmates.

## **Securing speech and language therapy from state-funded statutory services for school aged children who have Down's syndrome**

The government has put in place a framework called "The Special Educational Needs Code of Practice" to ensure that school-aged children who have additional needs receive the support that they require, based on their unique and individual requirements. Families and schools can use this to secure appropriate speech and language therapy for pupils - but it can be a lengthy process, as explained in the government's booklet for parents about the Code of Practice <sup>[10]</sup>.

The Code of Practice states: when support required by an individual child that cannot be provided from the resources available in mainstream schools, the LEA should carry out a Statutory Assessment and issue a Statement of Special Educational Needs. The Statement should describe all your child's "Special Educational Needs", and input that your child should receive in addition to what can be provided from within the school's resources, including speech and language therapy. This should normally be specified as "educational provision" in part 3 of the Statement (as described in section 8:49 of the Code of Practice <sup>[11]</sup>).

The framework directs that "the statement comes into force as soon as the LEA make it. From that time the LEA must provide your child's school with any extra resources that it needs. The school's governors must do their best to make sure that your child gets the special educational help set out in the statement." <sup>[10]</sup> Section 8:51 of the Code of Practice says that if the NHS does not provide speech and language therapy for a child whose Statement specifies such therapy as educational provision, ultimate responsibility for ensuring that the provision is made rests with the LEA, unless the child's parents have made appropriate alternative arrangements<sup>[11]</sup>. The Code of Practice specifies that the Governing Bodies of maintained schools have a statutory duty to do its best to ensure that the necessary provision is made for any pupil who has a special need. This means that if your child is not receiving appropriate speech and language therapy, the LEA and school must address the issue, even if the service is provided by another organisation.

The LEA will usually ask the speech and language therapy service at your local NHS Health Trust to provide advice about the speech and language therapy that your child requires. The rules about Statutory Assessment direct the LEA to gather information from the family, school and others who work with the child, about your child's skills, the challenges s/he faces and recommendations about the type of input your child should receive to ensure that her needs are met. Professionals must base their recommendations on up to date thinking on what best supports individual children, rather than the systems that they already have in place to deliver services. You can also arrange

for the LEA to receive additional or different advice from other agencies, including independent speech and language therapists who you can approach directly. The Code of Practice details how professionals should report on pupil's skills and needs for the purposes of statementing.

While some LEAs carry out Statutory Assessment and issue Statements for most children with additional needs, others aim to provide what each child needs without going through this process. However the Code of Practice applies across England and Wales, so that if your Local Education Authority has not issued a statement for your child, and you are unhappy about the support that your child receives, then you can request that your child's needs are assessed to identify appropriate provision.

The Code of Practice includes arrangements for resolving differences of opinion when families and LEAs cannot reach agreement, which include disagreement resolution services (designed to resolve agreements quickly and informally), and your right of appeal to the Special Educational Needs Tribunal. This independent body considers parents' appeals against decisions that LEAs have made about whether to assess, whether to issue a statement, and what is included in the statement. At a Tribunal hearing, three Tribunal members examine evidence from the LEA, and from the parents and/or their representatives, and make a decision on what is good practice and in the best interests of the child. The Tribunal can order the LEA to make changes to parts 2 (needs), 3 (provision) and 4 (placement) of the statement.

## **Is my child receiving the right type and amount of speech and language therapy?**

Speech and language therapy input for people who have Down's syndrome should focus on both *developing* new skills; and on *supporting* individuals to communicate in their everyday activities, at home, school, work and in leisure.

Areas addressed will usually need to include:

- adapting teaching to **minimise the impact of pupils communication difficulties**;
- advising others on **supporting the pupil's understanding**, including: sharing information about your child's skills at understanding language; presenting information in an accessible way; and using visual support for communication (gesture/sign, pictures and symbols);
- establishing an effective means for **expressing** ideas, which is likely to include spoken language, may include signing, and for some people, a communication book or communication aid;

- teaching **specific communication skills** that enable your child to take part and interact appropriately, such as asking for a turn at an activity or telling other people how you feel;
- developing **vocabulary** and **language** (sentences and grammar) skills, including supporting our children to learn and use a wider range of words/signs and enabling our children to communicate more effectively through use of longer sentences and more correct grammar;
- developing **speech production skills** and **speech clarity**;
- **other skills that support spoken language and communication skills**, including listening and attention skills, oral motor skills, reading skills, auditory memory skills.

Speech and language therapists also provide advice on managing difficulties with eating and drinking.

People who have Down's syndrome are likely to require speech and language therapy to address **most or all of these areas**. To plan an appropriate "package" of intervention, speech and language therapists need to take into account:

- Current skills: communication; social, emotional and behavioural; speech; language.
- Demands on communication skills: what are the communication tasks that your child needs to accomplish on a day-to-day basis?
- The extent to which others are able to address communication needs, according to other support that is in place, and the skills and experience of others who are working with your child.
- Prioritisation of your child's various needs: there may be periods when work on particular areas of communication skills become more important, or when other issues, such as health problems, mean that work on some aspects of communication skills are put on hold for a period.
- Awareness of potential for change: this depends on people having high expectations and a good knowledge of just what is possible with the right kind of intensive support!

The package of intervention should include:

- providing advice and training to school staff,
- recommending and supporting implementation of activities that can be carried out by school staff,
- sessions where the speech and language therapist and/or speech and language therapy assistant works directly with your child.

With regard to how frequently the speech and language therapist should provide support, Sue Buckley and Patricia Le Prevost recommend: “children with Down’s syndrome **should be seen at least monthly** in school, targets reviewed and activities set for parents, teachers and assistants to include in their daily routines...Some children with Down’s syndrome of school age **may need weekly individual or groups sessions** of speech and language therapy with a therapist who has the specialist knowledge and the skills to address their profile of difficulties, particularly for speech and intelligibility work” <sup>[6]</sup>. Because each pupil’s “package” of speech and language therapy should take into account individual needs and circumstances, it’s not possible to specify a format or amount of speech and language therapy that will be right for everyone who has Down’s syndrome at a particular age or in a certain situation.

However, it’s reasonable to expect that speech and language therapy input will:

- address your child’s needs,
- make effective use of support available to your child,
- have positive results.

The checklist that follows asks questions that check this out. If the answer to any question is “no”, you could work towards addressing the problem by discussing your concerns with staff at your child’s school, the named officer on your child’s Statement, the speech and language therapist, and/or the speech and language therapy service manager. If you choose to raise your concerns at your child’s Annual Review, they should be documented in the notes from the Annual Review that are sent to the Local Education Authority. You could consider whether amendments to your child’s statements will help to secure more appropriate speech and language therapy input. You have the opportunity to press for appropriate speech and language therapy provision to be specified in the Statement when the LEA amends your child’s statement (as happens when your child moves from one school to another, and may occur following an Annual Review). You and your child’s school can also ask for a new statutory assessment, provided that 6 months have passed since last statutory assessment.

## **Checklist: speech and language therapy for pupils who have Down’s syndrome**

### **1. Does the package support others to enable the child to take part, communicate and learn, as well as addressing the development of skills?**

Speech and language therapy input should address your child’s communication support needs, that is, provide guidance to others on the best ways of making sure that your child communicates

successfully, looking at both how others can communicate more effectively with your child, and at support for your child to enable him/her to communicate more effectively.

*Royal College of Speech and Language Therapists Clinical Guidelines (School aged Children with Speech, Language and Communication Difficulties) 2005 state that:*

- **The classroom environment can be modified and strategies used to enable pupils with speech, language and communication needs to access the curriculum and reach their potential.**
- **Collaborating with school staff in teaching strategies to manage communication needs will reduce the impact of the language difficulties on both the child's learning and their access to the curriculum.**
- **The Speech and Language Therapist will work with others to adapt the physical, social, sensory and linguistic components of the environment, and to look at the demands being placed on the child in order to maximise successful communication and learning.**
- **The therapist should ensure that other symbolic forms of communication (signs, objects of reference, photographs, symbols and communication aids) are used appropriately to improve comprehension and expression where necessary.**
- **The Speech and Language Therapist needs to consider the development of opportunities for the children with these needs to use signs and symbols to communicate with training and support for school staff, peers and parents and communication partners.<sup>[2]</sup>**

Speech and language therapists also provide support and advice on strategies that take into account the specific learning style and impairments associated with the syndrome, in particular, how to take account of communication impairments when teaching key skills. There are a number of strategies that are appropriate for most pupils who have Down's syndrome, described later in this booklet.

## **2. Does the package support the child to develop specific aspects of his/her speech, language and communication skills, as well as supporting the child to take part, communicate and learn?**

People who have Down's syndrome require specialist support to improve their speech, language and communication skills. Speech and language therapy input should also assist your child to develop specific aspects of his/her communication skills, looking at, for example, mastering language to use in certain situations, learning more signs, achieving clearer speech, learning more words, using longer sentences.

Because there is a wide range of variation in the skills, interests and aspirations of individuals who have Down's syndrome, it's not possible to recommend a set of activities that will be appropriate for all pupils who have Down's syndrome.

*Libby Kumin comments* **"Speech and language are complex, and present many challenges to the child with Down's syndrome that need to be addressed through a comprehensive approach to speech and language treatment".** She defines a comprehensive speech and language therapy program as: **"an individually designed program that meets all of the communication needs for a specific child."** <sup>[3]</sup>

*Sue Buckley and Patricia Le Prevost recommend:* **"Each child with Down's syndrome should receive an individualised programme.... The principles of effective practice upon which this should be based**

**are the same for all children with Down's syndrome. There is considerable agreement amongst international experts."** [6]

*Libby Kumin states: "The speech and language treatment program should be ..... based on a careful evaluation of each child's communications patterns and needs."* [3] *She gives the following categories as areas to assess and treat:*

- (a) general behavioural performance including levels of attention and play;
- (b) oromotor skills;
- (c) receptive and expressive language skills;
- (d) speech skills;
- (e) pragmatics skills. [9]

*Sue Buckley and Patricia Le Prevost recommend four principles for effective interventions:*

1. **Have separate targets for all four components of speech and language skill: communication, vocabulary, grammar, and speech work, for each child.**
2. **In addition for vocabulary and grammar, separate targets will be needed for comprehension and production.**
3. **Include use of signing and use of reading.**
4. **Language is learned all day everyday so share skills with parents (friends, carers, school staff).** [6]

*Libby Kumin comments: "Speech and language treatment is complex and can include different approaches, a variety of goals, and many different activities. The goal is to find treatment approaches and methods which will enable each child to reach his communication potential."* [3]

### **3. Has the speech and language therapist taken into account and dealt with all areas of need identified by the family and others who support the child?**

The speech and language therapist should provide input that supports your child to realise his/her aspirations and overcome the difficulties that s/he faces, rather than teaching your child to do what's expected of children of a certain age, or, worse still, to pass the bits of the tests that s/he found difficult!

The speech and language therapist must address all areas of concern, which may include speech skills, language skills, interaction skills and eating and drinking skills. Language skills includes understanding and expressing oneself, and both vocabulary and sentence skills.

The speech and language therapist must provide advice on how to support your child to overcome the difficulties s/he experiences, as well as further development of skills. If it's genuinely "not a speech and language therapy issue", then the therapist should advise you of which service is best placed to deal with the concern.

You should expect the therapist to be able to explain why it's important for your child to master the skills that s/he has selected to work on, in a way that makes sense to you.

### **4. Has the programme been designed and shared with all the people who need to know about it?**

Speech and language therapists must involve parents and school staff in identifying the *challenges* that the child faces and *strategies* to support your child and build communication skills. People who

know your child well have a vital role to play in gathering information about your child's *skills* and helping the therapist to capitalise on your child's *skills, interests and opportunities* that arise in his/her life. As well as this, families and school staff require information and advice from the speech and language therapist to gain insight into speech, language and communication difficulties, and provide expert suggestions on how to support your child.

Many school based services provide limited opportunities to work with families, so let the school and the speech and language therapist know how you'd like to be involved and negotiate a convenient and effective way of communicating about the speech and language therapy programme.

*Royal College of Speech and Language Therapists Clinical Guidelines (School aged Children with Speech, Language and Communication Difficulties) 2005 state:*

**“Where the service is school-based... the Speech and Language Therapists will seek information from, and provide information to, the family. The Therapist will also plan the child's management jointly with the education professionals.**

**Where a Statement of Special Education Needs exists, the Speech and Language Therapist will contribute to Individualised Education Plans (IEPs) and target setting, and will consider the speech, language and communication needs of the child within the context of the curriculum.”** <sup>[2]</sup>

## **5. Does the package make good use of the skills of others who work with your child?**

Families, teachers, teaching assistants, Portage workers, speech and language therapy assistants and others do fantastic work to support our children in developing speech, language and communication skills, by supporting our children in all aspects of their lives, and finding out about and implementing recommended strategies like signing and teaching our children to read through whole word recognition. They also do a great job when they carry out programmes of speech and language therapy activities set up with speech and language therapists.

Many aspects of speech and language therapy intervention are successfully carried out by other people who spend more time with your child and know your child better than the speech and language therapist. Advising school staff on activities to incorporate into your child's learning programme is often an effective way of making sure that your child gets maximum support and practice.

In order for this to work well, the speech and language therapist should identify training needs of school staff and recommend and provide training, in areas such as using signing to support communication, and carrying out activities recommended by the speech and language therapist to promote your child's communication skills.

*Royal College of Speech and Language Therapists Clinical Guidelines (School aged Children with Speech, Language and Communication Difficulties) 2005 state:*

**The Speech and Language Therapist will work collaboratively within the multi-agency/ disciplinary team, with parents and carers, recognising the skills and contribution to a child's communication development offered by the range of other agencies/options.** <sup>[2]</sup>

## **6. Is the package of speech and language therapy input designed and monitored by a qualified speech and language therapist?**

Specialist teachers and others may support you and school staff to implement strategies that help people with Down's syndrome to extend their speech, language and communication skills. If your child continues to experience difficulties with communication even when you do all of this - and we would expect this to be the case for almost all people who have Down's syndrome - then speech and language therapy *assessment* and *advice* is needed to identify further strategies that are helpful.

If it isn't overseen by a qualified, registered speech and language therapist, then it isn't speech and language therapy.

## **7. Does the speech and language therapist have knowledge of the specific speech and language therapy needs of people who have Down's syndrome, including:**

- **the profile of skills and challenges associated with the syndrome,**
- **therapy and interventions that are recommended by experts in the field?**

Speech and language therapists can work with the full range of people who have communication problems - including people who have strokes, head injury and other acquired conditions, children who have speech, language and communication difficulties ranging from babies to teenagers, including short lived problems to persistent difficulties. The training that therapists complete to gain a speech and language therapy qualification tends to include little on working with people who have learning disabilities, let alone Down's syndrome.

*Sue Buckley and Patricia Le Prevost state that "Specialist training for work with children with Down's syndrome will be helpful, and up to date knowledge of the research literature is essential" <sup>[6]</sup>, and describe knowledge and skills required:*

- **To have up to date knowledge of the specific research literature on speech and language development, working memory and effective therapies for children with Down's syndrome**
- **To understand the significance of the specific impairment in the phonological loop component of working memory for the speech and language profile associated with Down's syndrome**
- **To understand the importance of reading work to support the development of vocabulary, grammar and speech clarity, using strengths in visual memory.**
- **To understand the importance of auditory discrimination for speech sounds, phonics activities, phonological awareness training and speech work in order to improve working memory function as well as speech.** <sup>[6]</sup>

Speech and language therapists build up specialist knowledge through attending courses, reading specialist publications (such as those listed in the reference section of this booklet), and working with more experienced therapists to develop their skills. They can access resources and courses available from the Down's Syndrome Association and Down Syndrome Educational Trust. Of course we'd all prefer for our speech and language therapist to have specialist skills before s/he starts work with our child! At present, this is frequently not the case. If the therapist doesn't have specialist knowledge and skills already, it's vital that s/he recognises that this is necessary.

It's reasonable to ask the speech and language therapist who works with your child whether s/he has specialist training or knowledge about working with children who have Down's syndrome, and chatting to him/her about the Down's Syndrome Association and Down Syndrome Educational Trust, so you can check out whether s/he is familiar with these organisations and the resources they produce, and whether s/he values and follows the advice of these organisations.

Speech and language therapists work in teams, so if the therapist does not have specialist knowledge and skills, then you could ask if there is another therapist with specialist skills in the team who can contribute to planning speech and language therapy for your child.

### **8. Does the speech and language therapist have or use specialist speech and language therapy knowledge to manage all aspects of your child's needs e.g. eating and drinking difficulties, Autistic Spectrum Disorder, use of Voice Output Communication Aids, hearing impairment, being bilingual (speaking more than one language)?**

A speech and language therapist who has specialist knowledge of Down's syndrome won't necessarily have the full range of specialist skills that your child needs to access. Most speech and language therapy teams include therapists who have specialist skills in other areas. People who have Down's syndrome should receive input from these specialists when needed, just like everyone else!

### **9. Does the speech and language therapy programme work?**

Speech and language therapists are expected to state what will be achieved through the speech and language therapy programme.

*Royal College of Speech and Language Therapists Clinical Guidelines state: "Goals should be relevant to the clients, carers, and context; needs based; formulated in conjunction with client/carer/other members of the team; regularly reviewed; and discussed, agreed and evaluated with clients/carers"*  
[2]

You can expect the speech and language therapist to set SMART targets, which are:

**Specific:** objectives address the specific and individual needs of the pupil, referring to skill/function addressed in therapy.

**Measurable:** objectives describe skills that can be measured, for example, in terms of presence/absence of skills, level of difficulty experienced, frequency of successful use.

**Achievable:** in the opinion of the speech and language therapist, the objective can be achieved within the timescale.

**Realistic:** given the pupil's situation and context of intervention, it is likely that the objective will be achieved within the timescale.

**Timescaled:** a timescale is given for achieving the target.

Predicted outcomes should frequently be achieved. If they are not achieved, the speech and language therapist should explain why. Reasons might include: the programme could not be implemented consistently because of staff changes; therapist underestimated how difficult this would be; skill was no longer relevant and motivating so work was discontinued; more opportunities and time to practice are needed. If a strategy has not worked, the therapist must look for an effective way of meeting the challenge, provided that the skill is still relevant.

## **10, Does the speech and language therapist get on with your child and respect him/her and your family?**

You should expect the speech and language therapist (and everyone else who works with your child) to trust and respect you, and to earn your trust and respect. If there are difficulties in this area, it is likely that they will impact on the effectiveness of speech and language therapy. If there are problems, you could discuss how to improve relationships with people you trust, and/or report the difficulties to the service manager.

## **Speech and language therapy advice on strategies that take into account the specific learning style and impairments associated with Down's syndrome, and, how to take account of communication impairments when teaching key skills.**

### **Learning environment**

- Pupils who have Down's syndrome respond well to high expectations and clear boundaries, with clear, concise explanations of what is expected, models from other children, and a consistent approach to support.
- Pupils who have Down's syndrome should follow adapted programmes of study to facilitate access to a full curriculum.
- Pupils who have Down's syndrome benefit from placement in a mainstream setting that provides effective support for pupils with additional needs, so that good models of social interaction and language can support development.
- Pupils who have Down's syndrome require additional support to achieve successful inclusion in a mainstream setting.  
*If no local mainstream setting has the skills, experience and enthusiasm to provide what an individual requires, then placement in a special education setting may be more appropriate.*
- In a special education setting, steps must be taken to ensure that all individuals experience meaningful opportunities to make full use of their communication skills, experience high expectations relative to their current level of functioning, and are educated alongside pupils who provide good role models of behaviour and language.

### **Taking into account learning style**

- The pupil's learning style and speech, language and communication difficulties are likely to impact on participation in activities and learning situations. Learning will not be maximised simply through exposure to mainstream classroom teaching and language models.
- Staff should enable the pupil to take part in tasks through pointing at and manipulation of objects, words, pictures, and symbols, rather than requiring the pupil to use skills in areas where they may demonstrate less competence: spoken and written language.
- Staff should make effective and extensive use of visual cues including symbol timetables, instructions and labels, visual cue sheets and rewards.
- Learning is best supported through:
  - Specific, targeted, small steps teaching
  - Using visual, rather than auditory methods of teaching, that is, being shown rather than told. Use pictures, written words, demonstrate, gesture and signing to present information, capitalising on strengths in visual learning.

- Using kinaesthetic strategies: learning through doing.
  - Using a “no fail” errorless learning approach, where support is given to enable successful completion of tasks. This should include spoken prompts, modelling, and hand over hand support, as appropriate to the tasks and level of competence.
  - Reward through positive responses (facial expression, touch, enthusiasm), spoken praise, and tangible rewards (earning a privilege/certificate/sticker).
  - Plenty of practice to consolidate learning of new skills
  - Support to use new skills in a range of situations.
- Most pupils who have Down 's syndrome enjoy learning through routines and participating in familiar activities that they feel confident in attempting. They are likely to demonstrate sensitivity to perceived failure and may withdraw or refuse to attempt tasks that are perceived as too challenging or not challenging. Responses in all tasks should be monitored, and tasks adapted, to secure active participation.
  - Staff should teach, and support rehearsal and use of socially appropriate language and language scripts to enable the pupil to engage others and get their needs met.
  - Staff should use Functional Behaviour Analyses techniques to identify effective responses to inappropriate behaviour. Use a whole team approach when implementing and monitoring behaviour management plans.

## **Supporting communication**

- In order that the pupil maximises understanding of language and instruction:
  - Provide support to focus attention, giving spoken instructions or explanations.
  - Use demonstration, pictures/symbols, and modelling to support the pupil's understanding of language.
  - Use signing to support pupil's listening skills and understanding - while some pupils require extensive use of signing to support understanding in most situations, others will benefit from planned use of signing to support teaching of new concepts and vocabulary.
  - Break information down into small steps.
  - Use short, concise sentences containing few key words, in line with the pupil's language comprehension skills.
  - Make sure the pupil has plenty of time to process language, and to respond.
  - Monitor whether the pupil has understood, and provide repetition and modification where needed.
  - Teach new vocabulary, focusing on word meaning and word structure with visual support (pictures, signs), in addition to introducing new vocabulary in curriculum teaching.

The speech and language therapist should advise on how to respond to unclear speech, as appropriate to the individual.

## **Supporting literacy and language skills**

- Using signing will promote the development of expressive language, by supporting rehearsal and recall of vocabulary and words combined into sentences, as well as supporting listening and understanding.
- Using a whole word recognition approach to reading capitalises on strengths at recognising visual patterns, and overcomes challenges arising from speech impairments.
- Once reading skills are established, “language through reading” (rehearsal of sentences through reading) will support the pupil to use new vocabulary, sentences, and sentence structure.
- Pupils who have Down’s syndrome require differentiated phonics teaching that takes into account difficulties with hearing, analysing and recalling the sound-structure of words, and difficulties in producing speech sounds. Phonic awareness activities help to improve the accuracy of production of sounds in words, and speech clarity. Phonic awareness should initially focus on learning letter-sound correspondence, and syllable clapping. Many pupils who have Down’s syndrome go on to use phonics for reading and spelling, having established basic skills in these areas using a whole word approach to reading, and learning spellings by rote, alongside phonics teaching.
- The speech and language therapist and school staff should identify target vocabulary and language structures. The speech and language therapist should suggest appropriate goals and means of rehearsal for more challenging words and language structures. Activities to increase speech clarity can also be pursued in this context.
- Continued work on memory activities to extend auditory memory span will help the pupil to understand longer, more complex sentences.

## **Supporting numeracy skills**

- Pupils who have Down’s syndrome usually require specific teaching of vocabulary for number and numeracy concepts.
- Learning is best supported through use of systems such as Numicon images which capitalise on strengths in learning from action, learning from seeing, and a strong sense of pattern (rather than auditory based means such as spoken rehearsal of number bonds and times tables).

## **Reference List of Publications**

*Most of the publications referred to in this booklet are available on-line, should you wish to look at them in more detail :*

### **Royal College of Speech and Language Therapists publications**

**[1] Communicating Quality 3- RCSLT's guidance on best practice in service organisation and provision (RCSLT CQ3 Handbook)**

Royal College of Speech & Language Therapists, 2006

The Royal College of Speech and Language Therapists, 2 White Hart Yard, London SE1 1NX

Available on-line at [www.rcslt.org/resources/](http://www.rcslt.org/resources/)

**[2] Royal College of Speech & Language Therapists Clinical Guidelines**

Royal College of Speech & Language Therapists, 2005

Speechmark Publishing Ltd, Telford Road, Bicester, Oxon OX26 4LQ, UK

Available on-line at [www.rcslt.org/resources/](http://www.rcslt.org/resources/)

### **Key publications about Speech, Language and Communication skills, and Speech and language therapy, for children who have Down Syndrome**

**[3] Kumin, L (1998) Comprehensive Speech and Language Treatment for Infants, Toddlers, and Children with Down Syndrome in Down Syndrome: A Promising Future, Together,**

Edited by Terry J. Hassold and David Patterson, Wiley-Liss, Inc.

Available online at [www.ds-health.com/speech.htm](http://www.ds-health.com/speech.htm)

Libby Kumin, Professor and Department Chair of the Speech-Language Pathology Department at Loyola College in Baltimore, discusses a comprehensive approach to speech and language treatment from infancy through school, and considers the communication strengths and challenges for children with Down's syndrome, as well as the specific needs of the individual child with Down's syndrome.

**[4] Miller, J, Leddy, M, Leavitt, L (Eds) 1999 Improving the Communication of People with Down Syndrome** Paul Brookes Publishing

This book details the challenges that children, adolescents and adults with Down's syndrome face and makes suggestions on improving communication skills in a compilation of research by clinicians and researchers at the Waisman Centre at the university of Wisconsin-Madison in the US.

**[5] Buckley S. J (2000). Speech and language development for individuals with Down syndrome - An overview** Down Syndrome Issues and Information Series, Down Syndrome Educational Trust.

*Down Syndrome Issues and Information* provides about the entire range of development, health and social issues relating to individuals with Down's syndrome, from birth to old age. This module explains speech and language development, highlighting the key findings from research into the progresses and influences on speech and language development in typically developing children; the specific speech and language difficulties of children with Down's syndrome and their possible causes; and effective interventions.

[6] Buckley S. , and Le Prevost P. . (2002). **Speech and language therapy for children with Down syndrome** Down Syndrome News and Update, 2(2), 70-76.  
Available on line at [www.down-syndrome.info/library/periodicals/dsnu/02/2/070](http://www.down-syndrome.info/library/periodicals/dsnu/02/2/070)

This article by Sue Buckley and Patricia Le Prevost of the Sarah Duffen Centre at the University of Portsmouth provides guidelines for speech and language therapists based on the best evidence of the children's specific speech and language needs currently available, including:

- Summary of key facts about their speech and language profile and needs
- Recommendations for service provision
- References for further reading.

[7] Chapman, R and Hesketh, L (2001) **Language, cognition, and short-term memory in individuals with Down syndrome** Down Syndrome Research and Practice 7(1), 1-7  
Available on line at [www.down-syndrome.net/library/periodicals/dsrp/07/1/001/](http://www.down-syndrome.net/library/periodicals/dsrp/07/1/001/)

The authors refer to evidence which contradicts earlier researchers' views that adolescents who have Down's syndrome make no further progress with language skills

[8] Rondal, J, and Buckley, S (2003) **Speech and Language Intervention in Down Syndrome** Whurr Publishers

Leading experts in the field review all aspects of speech and language development in individuals with Down's syndrome in this book for speech and language therapists and language researchers.

[9] Kumin, L, Goodman, M, and Councill, C, (1996) **Comprehensive Speech and Language Intervention for School-Aged Children with Down Syndrome** Down Syndrome Quarterly, 1(1),  
Available on line at [www.denison.edu/collaborations/dsq/kumin.html](http://www.denison.edu/collaborations/dsq/kumin.html)

The authors describe in detail the skill areas they assess and interventions they use at the specialist centre at the Loyola College at the University of Maryland, USA.

### Government publications about securing support for children who have Special Educational Needs

[10] **Special Education Needs (SEN): a guide for parents and carers** Reference DfES 0800/2001, Department for Education and Skills  
Available online [www.teachernet.gov.uk/wholeschool/sen/parentcarers/](http://www.teachernet.gov.uk/wholeschool/sen/parentcarers/) or for free from DfES Publication Centre, PO Box 5050, Sherwood Park, Annersley, Nottingham, NG15 0DJ phone 0845 602 2260 e-mail [dfes@prolog.uk.com](mailto:dfes@prolog.uk.com).

[11] **Special Educational Needs Code of Practice** dfes (2001) Reference DfES 581/2001, Department for Education and Skills  
Available online [www.teachernet.gov.uk/wholeschool/sen/teacherlearningassistant/](http://www.teachernet.gov.uk/wholeschool/sen/teacherlearningassistant/) or for free from DfES Publication Centre, PO Box 5050, Sherwood Park, Annersley, Nottingham, NG15 0DJ phone 0845 602 2260 e-mail [dfes@prolog.uk.com](mailto:dfes@prolog.uk.com)

### Other publications referred to in this booklet

[12] Reilly, S (2004) in **Evidence Based Practice in Speech Pathology** Eds Reilly, S, Douglas, J, Oates, J, Whurr Publishers

November 2006

[13] **Access to Education- A report on the barriers to education for children with Down's syndrome** (2004) A Down's Syndrome Association Publication

Down's Syndrome Association National Office, The Langdon Down Centre, 2A Langdon Park, Teddington, Middlesex TW11 9PS Tel: 0845 230 0372

Available online at [www.downs-syndrome.org.uk/DSA\\_detCampaign.aspx?cam=6](http://www.downs-syndrome.org.uk/DSA_detCampaign.aspx?cam=6)

This report contains detailed information about the DSA's study into parents' experiences in accessing education and speech and language therapy for their child with Down's syndrome.

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November 2006