Guidelines for best practice based on current research

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Sue Buckley and Patricia Le Prèvost



The provision of speech and language therapy services for children with Down syndrome is a controversial issue and families receive different services depending on where they live and the knowledge and interest of local speech and language therapists in the specific needs of children with Down syndrome. This article is an attempt to provide guidelines for speech and language therapists based on the best evidence of the children's specific speech and language needs currently available. It is a summary of the key facts about their speech and language profile and needs, followed by recommendations for service provision. References to further reading are included to support the points made in this brief overview.

Parents are encouraged to draw these guidelines to the attention of their therapy providers. They may be copied for individual use.

Language is vital for mental and social development

It can be argued that speech and language therapy is the most important part of intervention services for children with Down syndrome if we wish to promote their cognitive (mental) and social development.

Cognitive development - In our view, speech and language development are absolutely central to the cognitive development of all children. First, words equal knowledge and the faster a child learns vocabulary, the faster he or she is acquiring knowledge about the world. Therefore vocabulary development is very important - the number of words that a child knows when he or she enters school at five years will have a very significant influence on progress. Secondly, language supports thinking and reasoning. The human brain has evolved a remarkable ability to learn spoken language with amazing ease and then to use that spoken language for mental activities. Thinking, reasoning and remembering, for example, are usually carried out in mind as 'silent speech'. It follows, therefore, that any child with significant delay in acquiring language will be delayed in the ability to use these cognitive processes. Although delayed, almost all children with Down syndrome will use spoken language as their main means of communication. The use of signs in early years will help them to progress but for most children signs are used as a bridge to talking, not to teach a sign language.

Social development - Language is equally important for children's social development as it enables them to negotiate their social world and to control their behaviour. For example, as children acquire language, they can ask for what they want, explain how they feel, describe what they have been doing and share thoughts and worries with friends. Children are able to begin to control their behaviour by using silent speech to instruct themselves and to plan their actions.

The more we can do to help children with Down syndrome to learn to talk, the faster they will progress in all areas of cognitive and social development.

The speech and language profile associated with Down syndrome

Specific speech and language difficulties - Children with Down syndrome usually have an uneven profile of social, cognitive and language development - they do not have a profile of equal delay in all areas, they have a profile of strengths and weaknesses. For example, social development and social understanding is typically a strength, while spoken language development is a weakness. There is now consistent evidence that these children have a profile of specific speech and language delay relative to their non-verbal mental age. There are considerable individual differences in rates of progress but the overall specific profile is usually evident for all children with Down syndrome. [1,2]

An uneven profile within the language domains - While the speech and language skills of children with Down syndrome are delayed relative to non-verbal mental abilities, different aspects of speech, language and communication skills are not equally delayed.

Communication skills are a relative strength with good understanding and use of non-verbal communication skills and good use of gesture. ^[1,2]

In language, the children show delayed development of vocabulary in infancy, with comprehension ahead of production, but by the teenage years, vocabulary is a relative strength with vocabulary 'ages' ahead of grammar 'ages'. In grammar, there is evidence of specific difficulties in both comprehension and production. ^[1-3]

In speech, there is considerable difficulty at all levels from planning to articulation and phonology. Most teenagers still have significant intelligibility problems. ^[4,5]

Individual differences are seen within the typical profile, with some children having more speech difficulties than others, relative to language comprehension and some children having larger differences between comprehension and production than others, for example. Therefore, each child with Down syndrome should receive an individualised therapy programme but the principles for effective practice upon which this should be based is the same for all children with Down syndrome.

Possible primary causes

Research is beginning to provide some useful information on the underlying causes of the speech and language profile associated with Down syndrome.

Working memory - Children with Down syndrome have specific impairment in the phonological loop component of working memory relative to their non-verbal abilities, and this is now thought to be a major cause of their speech and language difficulties.⁽⁶⁾ For all children, the phonological loop is thought to play a critical role in learning a spoken language as it holds the sound pattern of the word to enable the child to both link this with meaning and to store it to support production of the spoken word. Phonological loop difficulties will affect both vocabulary learning and grammar learning.^[see 26]

Visual short-term memory is not impaired relative to non-verbal mental abilities and is described as a relative strength. In addition, research has indicated that visual coding of verbal information may be used by children with Down syndrome in short-term memory tasks. ^[6,7]

Hearing - Most children with Down syndrome (at least 80-90%) suffer from conductive hearing loss and auditory discrimination difficulties which will compound the phonological loop difficulties. However, the phonological loop difficulties are thought to exist independently of any hearing impairment. ^[6]

Speech-motor difficulties - speech sound and word production difficulties also have physical causes. These are linked to the motor skill difficulties associated with Down syndrome and the oral-motor difficulties demonstrated from the first year of life, which affect feeding and chewing patterns. For all children, first words can be predicted from the speech sounds that they can make in babble – in other words early spoken vocabulary is influenced by existing articulation and phonological skills, not the reverse. ^[8]

Possible secondary

causes

Slow vocabulary acquisition - The development of early grammar has been shown to be linked to total productive vocabulary for typically developing children as well as for children with Down syndrome. Therefore, the very slow rate of productive vocabulary development that is typical for children with Down syndrome may mean that the development of grammar is delayed beyond the optimal period for grammatical acquisition (1-6 years) – for a full discussion of this issue see[24].

Speech-motor effects - Delayed output of first words and unintelligible utterances may reduce or change the language input to the children. Difficulties with speech production probably compound the grammar learning and grammar production difficulties.^[2]

Principles for effective interventions

There is considerable agreement among international experts on the principles that should guide speech and language therapy for children with Down syndrome, based on research into their difficulties and into effective interventions. ^[see 1-5]

Targets for all four domains

All experts identify the need to have separate targets for the four components of speech and language skill - communication, vocabulary, grammar and speech work, for each child.

Targets for comprehension and production

In addition, for vocabulary and grammar separate targets will be needed for comprehension and for production.^[3]

Use of signing - There is agreement on the use of sign systems to promote spoken language with benefits for both comprehension and production.

Use of reading - There is agreement on the importance of using reading activities to teach spoken language for those of all ages. In particular, the benefits of using early reading in preschool years as an explicit language teaching activity are recognised.

Parents are the main therapists

All experts identify that language is learned all day, every day, as children are involved in communication with their families and friends and therefore the focus of effective therapy must be to share skills with parents because they will be their child's best therapist.

Implications for a comprehensive therapy programme

Preschool services

Specialist training for work with children with Down syndrome will be helpful and up-to-date knowledge of the research literature is essential. The needs of children with Down 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.

Knowledge and skills

- 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 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 syndrome

(or in intensive care if baby is sick) for several months from birth on at least a monthly basis

• in the second to fourth years various models can be effective, including group sessions to ensure families know about speech and language development and at which individual targets can be set for them and their infant.

Group activities can be started with babies from about 18 months and they usually enjoy learning in this way, with the opportunity to copy and learn from other children. Group activities can also develop attention and the ability to take turns. In the groups, activities



- 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.

Models of delivery

• in the first year of life families should receive a service at home

can be modelled by the therapist to increase parent's confidence at carrying them on at home. Parents frequently report that children are often more willing to show what they can do in groups than when asked to do the same things at home! Groups may reduce the individual pressure on children, though sometimes children do not enjoy groups and can become resistant to group activities. Groups are a cost effective way to offer services and also provide general parent support. Parents often have effective tips to share with each other and the progress of older

children is motivating for parents of younger ones.

- parents should be able to choose the delivery models that suit them as some parents will prefer individual home visits to groups
- any model used should offer continuous support throughout this vital period for speech and language development and no family should receive less than monthly contact with a therapist

First year of life

- 1. Encourage a good communication environment at home and ensure that parents understand the speech and language needs of their child, and how speech and language develops.
- **2.** Provide support for feeding and activities for oral-motor development.
- **3.**Encourage all communication skills, eye-contact, turn-taking, pointing and joint-referencing by the end of the first year.
- **4**. Target auditory discrimination for speech sounds to improve auditory discrimination in the phonological loop.
- 5. Target auditory discrimination for speech sounds in order to support the development of babble (typical babies tune their babble to the language they are hearing by 12 months – in other words they are setting up the speech-motor skills for talking).
- **6.**Encourage the use of gesture and sign primarily to aid comprehension.

The Swedish therapist Irene Johansson has evaluated and promoted this type of programme for infants with Down syndrome for a number of years and others have stressed the need for speech as well as language work to begin early. $^{[4,5,9]}$

Second year

- 1. Encourage a good communication environment at home and ensure parents understand the speech and language needs of their child, and how speech and language develops.
- **2.**Continue with targeted work in support of hearing and producing speech sounds single sounds and reduplicated babble (for speech and for auditory

memory development). ^[4,5,12,24] Keep a record of speech sound progress.^[23]

- 3. Teach comprehension and production of early vocabulary with games using objects, pictures and actions to supplement the daily language exposure of the child. This approach is currently recommended by the Hanen programme for children with Down syndrome. ^[10,11] They recommend targeted teaching and practice of words, then two and three word constructions, as they do not believe that the quality language immersion approach is sufficient for children with Down syndrome. They advise that the words chosen for imitation are chosen with initial consonant sounds that the child can already make, highlighting the need to address speech sound production skills in advance of vocabulary and language progress. Keep a record of words understood and words signed or spoken.
- **4.** Teach two and three words constructions through play and encourage imitation by child.
- **5.**Address communication skills if necessary (3-5% have autistic spectrum difficulties).

Third to fifth years

- Encourage a good communication environment at home and ensure parents understand the speech and language needs of their child, and how speech and language develops.
- 2. Continue with targeted work in support of hearing and producing speech sounds – as single sounds and in whole words (for speech and for auditory memory development). ^[13,14] Keep a record of speech sound progress. ^[see 23]
- **3.** Continue to teach vocabulary and develop early grammar and syntax. This can be done through play and by making books with the language to be learned in print.^[see 25]

These reading activities will be an aid to parents to support the teaching and practice of vocabulary and grammar, but there is also increasing evidence that seeing words as well as hearing them is a significant aid for many children with Down syndrome. Indeed, the research evidence indicates that the most effective interventions for speech, language and working memory development for children with Down syndrome is to place them in mainstream preschools and schools, and to teach them to read. This leads to very significant gains in expressive language structure, speech intelligibility and verbal and visual short-term memory spans by the teenage years. Significant gains are seen by 10 years of age.^[15-21]

The benefits of reading may come initially from the ability to store the whole printed word image more accurately than the spoken form - and the former then supports the learning of the latter. As letter sounds are learned, auditory discrimination for speech sounds will improve and then phonological awareness - the ability to hear sounds in words. Longitudinal studies demonstrate this happening for children with Down syndrome as they learn to read and to spell. [19] All reading activities are planned to ensure the children understand, or are taught to understand, what they are reading otherwise no language benefits would be seen. If observers complain that children with Down syndrome read but do not understand what they are reading, this is the fault of the teacher not the child. [see 25]

4. Records of vocabulary comprehension and production should be kept ^[23] and therapists should be aware of the important link between productive vocabulary size and the development of grammar in production, which has been demonstrated for typically developing children and children with Down syndrome.[see ^{24]} This means that at least some of the grammar delay seen in children with Down syndrome is the result of delay in learning vocabulary. Further there is evidence of a critical period for learning grammar (to about 6 years) when the brain is maximally receptive and there is evidence that mastering grammar significantly effects phonological development in children. All these findings have significant implications for our understanding of the speech and language profile usually seen in children with Down syndrome and significant implications for early and continued therapy.



5.Address communication skills if necessary (3-5% have autistic spectrum difficulties).

Primary school years

Ideally all children with Down syndrome should receive speech and language therapy in school but access to this service will vary considerably from place to place.

Progress at five years will vary widely between children, with some having quite clear production of 3 or 4 word sentences but with grammatical markers missing, the majority at a 2 or 3 word stage in production, much of this difficult to understand, and some with very few words or signs. Most children will have significantly better comprehension than production.

Reading activities will be an important support for speech and language development throughout the school years.

Detailed information on the range of progress of children can be found in the books in the DSii series on Development and Education – see Resources.

Goals for speech and language therapists working with 5-11 year olds with Down syndrome

Knowledge and skills

- 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 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 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.

Therapy plans

- to have clear targets for 4 areas of work, speech, vocabulary, grammar and communication skills and to keep detailed records of progress
- **2.** for vocabulary and grammar, to have separate targets for comprehension and for production, as comprehension in both domains is typically significantly ahead of production
- **3.** for speech work, separate targets may be needed for articulation, phonology and intelligibility (pacing, voice etc)
- 4. to assist teachers in using reading to teach language and to incorpo-



rate speech and language targets into literacy activities

- 5. to review oral-motor function, feeding, chewing and drinking patterns and advise accordingly
 6. all targets should be shared with
- parents, teachers and assistants
 encourage a good communica-
- tion environment at home and at school, and ensure parents, teachers and learning support assistants understand the speech and language needs of their child, and how speech and language develops.
- 8.address communication skills if necessary (3-5% have autistic spectrum difficulties).

Models of delivery

- children with Down 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
- these activities should be modelled with the child by the speech and language therapist, so that parents and assistants can confidently enable the child to practice daily. Therapy sessions will not change speech and language development unless they lead to an increase in daily teaching activities and appropriate styles of communication at home and at school.
- some children with Down syndrome of primary school age may need weekly individual or group 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.

Secondary school years

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 adapted to focus on age appropriate language needs and activities.

Some teenagers with Down syndrome will be making good progress and talking in reasonable sentences, others will still have fairly limited spoken language. The range of individual differences is very wide. Many secondary school pupils with Down syndrome will have small productive vocabularies (800 words or even less) and limited productive grammar.

Reading activities will still be an important way to help all teenagers. Most will still have phonological and intelligibility difficulties that should be targeted, and the social use of language, particularly the ability to initiate and maintain conversations, may need addressing.

Goals for speech and language therapists working with 11-16 year olds with Down syndrome

Knowledge and skills

- to have up-to-date knowledge of the specific research literature on speech and language development, working memory and effective therapies for children and teenagers with Down 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 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.

Therapy plans

- to have clear targets for 4 areas of work, speech, vocabulary, grammar and communication skills and to keep detailed records of progress
- 2. for vocabulary and grammar, to have separate targets for comprehension and for production, as comprehension in both domains is typically significantly ahead of production
- **3.** for speech work, separate targets may be needed for articulation, phonology and intelligibility (pacing, voice etc)
- **4.** to assist teachers in using reading to teach language and to incorporate speech and language targets into literacy activities

- **5.** to review oral-motor function, feeding, chewing and drinking patterns and advise accordingly
- **6.** all targets should be shared with parents, teachers and assistants
- 7. encourage a good communication environment at home and at school, and ensure parents, teachers and learning support assistants understand the speech and language needs of their teenager, and how speech and language develops
- 8.address communication skills if necessary (3-5% have autistic spectrum difficulties).

Models of delivery

- teenagers with Down 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
- these activities should be modelled with the teenager by the speech and language therapist, so that parents and assistants can confidently enable the young person to practice daily. Therapy sessions will not change speech and language development unless they lead to an increase in daily teaching activities and appropriate styles of communication at home and at school.
- some teenagers with Down syndrome of secondary school age may need weekly individual or group 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.

Adult life

A recent study in the UK and work in the USA has indicated that speech and language skills can be improved with therapy during the adult years.^[2,22] However, speech and language therapy services for adults are even scarcer than those for children. This is an area for further work and an article on work with adults will be published in next year's issue of this journal written by a practitioner in this field.

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Speech and language resources

Record keeping

Six checklists to enable parents and therapists to plan activities and to keep a record of children's progress in vocabulary, grammar, speech and communication are available from The Down Syndrome Educational Trust:

Vocabulary checklists and record sheets: Checklist I - First 120 words. Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-32-1

Vocabulary checklists and record sheets: Checklist 2 - Second 330 words. Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: I-903806-33-X

Vocabulary checklists and record sheets: Checklist 3 - Third 280 words. Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-34-8

Speech sounds checklists and record sheets. Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-35-6

Interactive communication and play checklists and record sheets. Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: I-903806-36-4

Sentences and grammar checklists and record sheets. Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-37-2

Practical Activities

Three age specific guides to practical activities to encourage speech and language development are available from The Down Syndrome Educational Trust. They should be helpful to parents and classroom assistants:

Speech and language development for infants with Down syndrome (0-5). By Sue Buckley and Gillian Bird (2000). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-05-4

Speech and language development for children with Down syndrome (5-11). By Sue Buckley and Gillian Bird (2001). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-06-2

Speech and language development for teenagers with Down syndrome (11-16). By Sue Buckley and Gillian Bird (2000). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-07-0

Books

Communication skills in children with Down syndrome – A guide for parents. By Libby Kumin (1994). Bethesda: Woodbine House, MD, USA. ISBN: 0-933149-53-0.

Classroom language skills for children with Down syndrome – A guide for parents and teachers. By Libby Kumin (2001). Bethesda: Woodbine House, MD, USA. ISBN: 0-890627-11-9.

For detailed reviews of the relevant literature see the following Overview modules from the Down Syndrome Issues and Information Development and Education Series:

Reading and writing for individuals with Down syndrome – an overview. By Sue Buckley (2001). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-09-7

Speech and language for individuals with Down syndrome – an overview. By Sue Buckley (2000). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-00-3

Memory development for individuals with Down syndrome. By Sue Buckley and Gillian Bird (2001). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-08-9

Teaching Materials

Four early language games are available from The Down Syndrome Educational Trust, sold either separately or as a set, saving 15%.

DownsEd picture lotto, illustrating first words with full colour photographs.

DownsEd picture dominoes, for picture matching and teaching vocabulary.

DownsEd consonant sound cards, with picture prompts for 20 English consonant sounds to encourage toddlers to listen to and to imitate the sounds.

DownsEd language cards, with colour photographs illustrating a selected set of first words.

For details of these and specialist courses for speech and language therapists, see the websites at http://www.downsed.org

Videos

Understanding Down syndrome (1) - learning to talk. By Sue Buckley (1995) Portsmouth, UK: The Down Syndrome Educational Trust.

Understanding Down syndrome (2) - learning to read. By Sue Buckley (1995) Portsmouth, UK: The Down Syndrome Educational Trust.

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Speech and Language workshops at The Sarah Duffen Centre (autumn 2002)

Monday II November Tuesday 12 November Speech and language development for children with Down syndrome from birth to teenage years (Day I/2) Speech and language development for children with Down syndrome from birth to teenage years (Day 2/2)

See our Services brochure for details of these and other Workshops, or visit our website at: http://www.downsed.org