



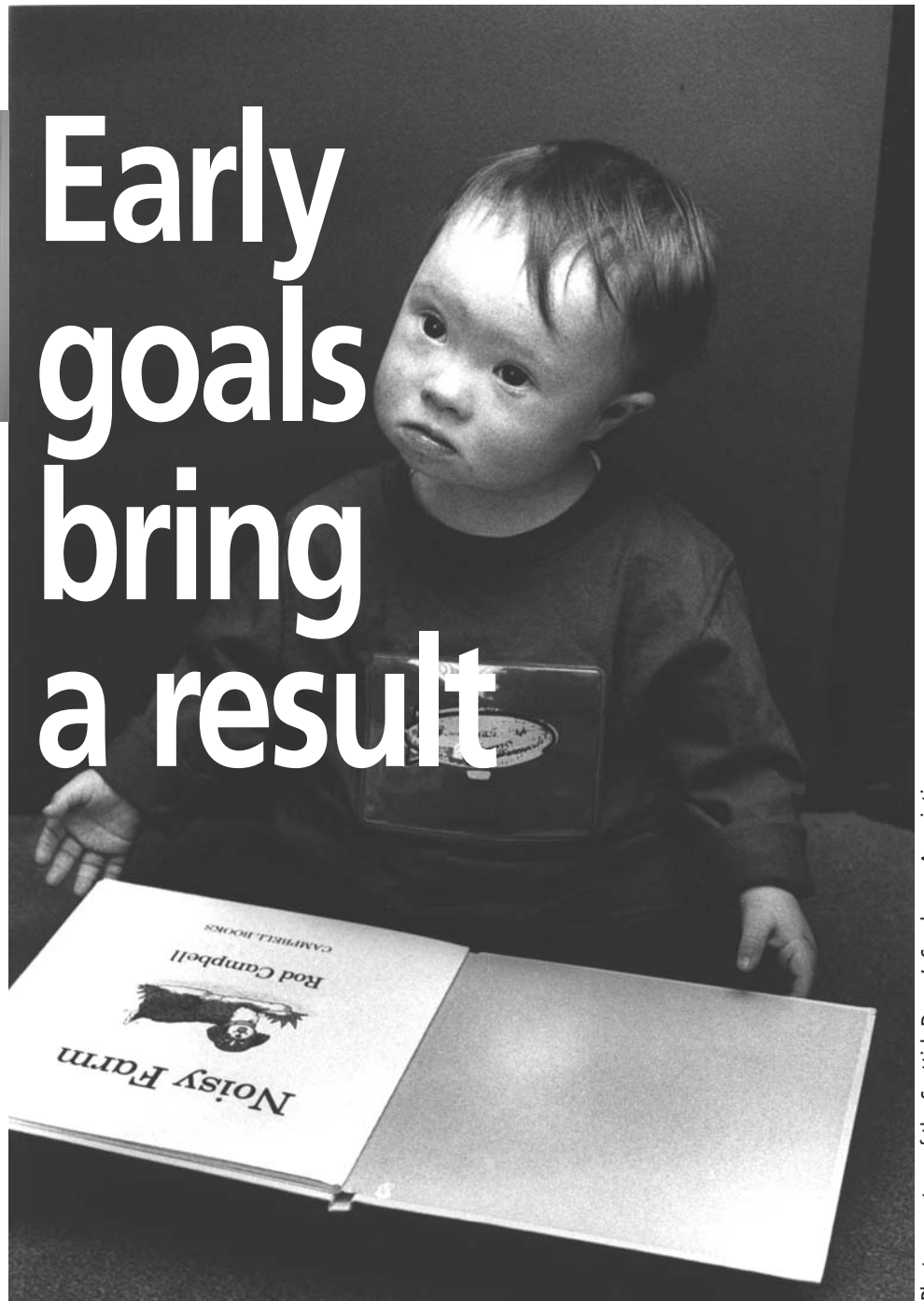
To facilitate a child's speech and language development, parents and professionals need consistent and timely information and the opportunity to share ideas.

Robert Robinson and Karen Bailey explain how the city wide referral of parents to their early intervention group programme is benefiting children with Down Syndrome.

Read this if you are interested in

- early intervention
- organising groups
- empowering carers

# Early goals bring a result



Photos courtesy of the Scottish Down's Syndrome Association

It is becoming increasingly common to offer speech and language therapy intervention very early to children with Down Syndrome to try to minimise language difficulties and their effects. A readily identifiable population from birth, the vast majority will be late starting to talk and will continue to experience language difficulties into later life. There is growing evidence that speech and language are areas of specific deficit, with these children typically performing better in non-language areas of cognitive development (Chapman, 1995).

We aim to provide a consistent, readily accessible early intervention programme to the families of preschool children with Down Syndrome in the City of Manchester. There are four key aspects to the programme's success:

#### 1. Empowering

We decided early on that the intervention should be targeted at empowering parents. The identification

of a significant developmental disability in a child at or around the time of birth can substantially affect parents' confidence in their own parenting abilities. It is important to mitigate this effect.

#### 2. Informing

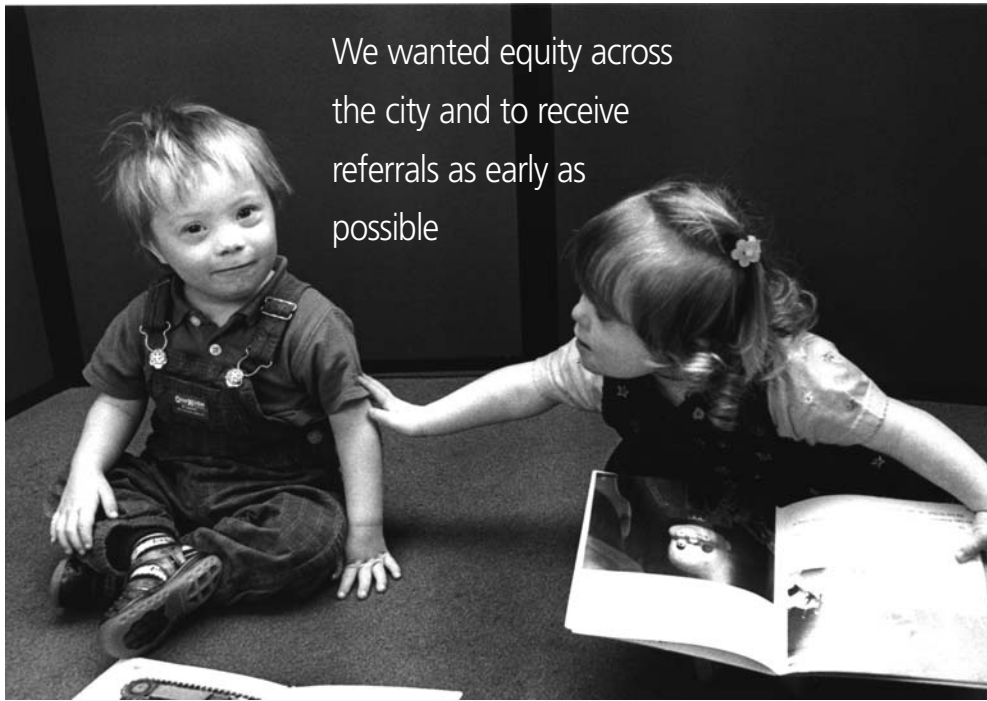
We share information with parents. This includes knowledge of typical developmental sequences to help them appreciate where their own child is developmentally, and to be aware of the next step. It also helps them see how professionals arrive at judgements about developmental progress and enables them to take a more active role in these judgements.

#### 3. Teaching

We enhance parents' skill levels so they are better able to facilitate speech and language development.

#### 4. Explaining

We explain the role of the speech and language therapist in their child's development. We are



We wanted equity across the city and to receive referrals as early as possible



keen to stress the advisory and facilitative aspects to make our relationship with parents more honest and equal. This helps establish realistic expectations of what the speech and language therapist can or should do, and places parents in the primary position as language facilitators.

### Equity

We decided to deliver our early intervention in a group format for a number of reasons. The existing situation in Manchester meant that the service offered to each child with Down Syndrome varied according to time and location of referral. Speech and language therapists waited for the children to be referred - rather than actively seeking them - then made individual decisions on management. We wanted equity across the city and to receive referrals as early as possible so we could commence intervention in the first year. The recent

merging of three district speech and language therapy services into one community trust also meant we had a population large enough to offer us viable group numbers.

We knew of a number of studies showing the value of group based intervention for the parents of children with special needs, and wanted to provide a forum in which parents could meet, share experiences and information and support each other. As professionals, we knew we would learn a lot from the families in a group situation, and wanted the opportunity to provide consistent and evidence-based information to parents and other professionals.

Community paediatricians are notified by their hospital colleagues when a baby with Down Syndrome is born. They then refer to other community services including preschool special needs. Before the group was started, we actively sought

referrals on a city wide basis. We informed all relevant professionals - consultant community paediatricians, health visitors, preschool special needs services - of our intentions. There is now a highly effective referral system, with some babies coming to us as young as three months.

### Surprised

Parents have differing reactions to early referral. Most anticipate contact with a speech and language therapist but are surprised at how soon we become involved. However, some parents, having looked into intervention for children with Down Syndrome, request early input.

Each family is visited at home, twice, before a group begins. This is to introduce our service, engage the parents, and answer any immediate questions. We explain the benefits of early intervention, and also introduce the concept of signing as part of total communication. Substantial research evidence suggests the introduction of a transitional alternative and augmentative communication (AAC) system such as signs for this population (Fowler, 1990).

The group consists of six sessions, on a monthly basis, with families attending a central location within the Trust area. The format of the sessions is consistent throughout (lasting 1-1½ hours) starting with a general discussion or recap of previous information.

We then spend time discussing a particular language related topic, encouraging parents to focus on their child's development. At the end of this section we ask the parents to choose a specific objective to work on in the coming month. Next, we teach the parents a small number of basic signs. These are largely social signs which fit in with a small child's daily routine. The choice of signs has been modified in the light of discussion with parents. The current list is "all gone, hello, more, no, please, thank you, good, give, drink/cup, wash, sleep/bed, eat, go, look, car, telephone". We re-visit these at each session, with the aim of incorporating signs consistently into the home routine, rather than amassing a large but unused vocabulary.

### Opportunity

The group finishes with tea and coffee where the parents have an opportunity to share their own experiences - we deliberately take a less active role in this part of the group.

Over the six sessions we focus on a variety of speech and language topics:-

- Group 1 - general principles of interaction and intervention
- Group 2 - play
- Group 3 - listening
- Group 4 - turn-taking
- Group 5 - speech sounds and feeding
- Group 6 - recap - parents' choice of topics and discussion of future intervention.

There is a handout for each subject and, although this section of the group is essentially

Figure 1 - Examples of monthly topics discussed and goals set

## Group 1 - General Principles

### Pacing

Remember that it takes your child longer to work out what sounds and words mean.

- Try to speak
  - in short sentences
  - slower
  - a little louder
- Have lots of tune in your voice
- Allow plenty of time for him to react.

#### Parent Goal

*I know I speak too fast to Jasmin so I will try to slow down and give her the chance to respond.*

## Group 2 - Play

### Relating 2 objects together

The child will relate 2 objects.

- eg. banging them together  
piling on top of each other  
placing in a container

#### Parent Goal

*Sam is good at holding things but not at letting go. I will work on getting him to drop objects into a pan so that they make a noise.*

## Group 3 - Listening

### Meaningful Noises

Here your child starts to relate a particular sound to:-

- an object eg. keys, phone
- part of his daily routine eg. meal time, bath time

#### Parent Goal

*I am going to see if Joe will learn that the noise of the microwave means dinner time.*

## Group 4 - Turntaking

### Set the scene

Each day, choose a time when your child is in a good mood, turn off the television, remove as many distractions as possible, so that he can concentrate fully on the activity you're sharing.

#### Parent Goal

*I am going to try to remember to switch the radio off more.*

## Group 5 - Making Sounds

### Sound Making

The more fun your child gets from making sounds and noises of all sorts, the more she will make them. This means she gets lots of valuable practice in before the time for 'real speech' comes.

- copy the sounds and add new ones  
eg. if she says "mama" say "mama, meme" back

#### Parent Goal

*Ahmed babbles a lot but he tends to only use "dedede". We will try to encourage different types of babble sounds.*



Photos courtesy of the Scottish Down's Syndrome Association

led by the therapists, there is plenty of opportunity to discuss and learn from each other.

We have a small range of resources related to children with Down Syndrome that parents are free to loan and use at home; for example, the MAKATON nursery rhymes video; books on general development of children with Down Syndrome; specific texts on language development (Kumin, 1996). We also encourage parents to use the Down's Syndrome Association and the DOWNSed as resources, and some are members of local and national support groups.

### Consistency

Although the group is for parents, we have welcomed the variety of professionals asking to join us. This is especially helpful when nursery staff working with a particular child attend because it means we can develop consistency in development and knowledge. We have also built up our own professional relationships as a result of the group with increased collaboration and information sharing.

At present we are involved in our fifth early intervention group, but each group has been altered in some way. As a result of our observations, professional liaison and parental suggestion, we now have a structure in which we are confident:

#### a. Two home visits

Contact with families prior to a group starting ensures a clearer perception of the aims of the

group and therefore a higher attendance.

#### b. Group size and age limitations

Our first group included all preschool children with Down Syndrome from Manchester. This huge range of age and ability did not prove successful, so we now have smaller groups (depend-

## Reflections

- Am I proactive in seeking early referral where it has been shown to be effective?
- Do I emphasise quality over quantity to make goals more realistic?
- Do I give carers sufficient opportunity to discuss topics in general before asking them to set specific goals?



We explain the benefits of early intervention, and also introduce the concept of signing as part of total communication.

ing on numbers referred) of children under the age of 18 months.

**c. Delivery and amount of information**

We are now much more informal in our presentation and we try to limit information to quality not quantity.

**d. Signs**

Initially we were too enthusiastic and presented too many signs. Now we have approximately 20 basic signs that we use throughout the six month period.

**e. Handouts**

Our first set of handouts have been re-written with the assistance of speech and language therapy colleagues.

**f. Goal-setting**

When we have discussed the topic of the month, we ask each family to identify one specific goal for themselves to work on over the coming months. Parents are usually very accurate at identifying the next developmental step following our discussion of the topic. We explicitly discuss how this aim can be addressed in a practical way in the context of the particular family's daily routine. (For excerpts from our handouts which trigger discussions and examples of the goals families have set themselves, see figure 1.) We return to these goals next time and together we talk about the degree of success experienced. We have found that parents are very supportive of each other and often offer each other practical ideas.

These changes suit the present group but we anticipate alterations in the future.

At the end of each six months we ask the parents to complete a questionnaire to provide us with qualitative data about their perceptions of the group. We have been encouraged by suggestions and comments, including "Very reassuring - I know I am doing the right things"; "We have got some idea of what to expect, and when"; "I learned how to sign and help my child to try and sign. The signs related quite well to things he does at home."

As a result of the success of the first group we decided to run a second group. This was for children aged 18 months - 2½ years who were show-

ing potential for more structured language and signing input. We have now completed two cycles of this group with successful outcomes.

We have also provided training sessions for our own speech and language therapy department so that all members of staff are aware of early information given to parents. Other professionals are also aware of the advice we provide and support our approach in their contact with parents.

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**References**

Chapman, R. (1995) Language Development in Children and Adolescents with Down's Syndrome. In Fletcher, P. and MacWhinney, B. (Eds) *The Handbook of Child Language*. Oxford Blackwell.

Fowler, A. (1990) Language Abilities in Children with Down's Syndrome:- Evidence for Specific Syntactic Delay. In Cicchetti, D. and Beeghly, M. (Eds) *Children with Down's Syndrome*. Cambridge University Press.

Kumin, L. (1996) Speech and Language Skills in Children with Down's Syndrome. *Mental Retardation and Development Disabilities Research Reviews*. 2; 109-115.

**Resources**

- MAKATON nursery rhymes video from the Makaton Vocabulary Development Project, www. (£10 & £3.50 p+p), tel. 01276 61390.
- Libby Kumin (1994) *Communication Skills in Children with Down Syndrome - A Guide for Parents*. Woodbine House. ISBN 0933 149530, £12.50.
- Down's Syndrome Association, www.dsa-uk.com, tel. 020 8682 4001.
- Scottish Down's Syndrome Association, www.sdsa.org.uk, tel. 0131 313 4225.
- DOWNSed (The Down Syndrome Educational Trust), www.downsed.org. Prefer contact by e-mail, but tel. 023 9282 4261. □

**...RESOURCES...RESOURCES...**

**Paediatric dysphagia assessment**

Two speech and language therapists have developed an observational dysphagia assessment for children over two years.

Judi Hibberd and Jeanne Taylor believe they have "achieved a package that facilitates thorough, efficient, flexible and accurately documented assessments". They stress only those trained in paediatric dysphagia should use the assessment and only those with further training in the use of cervical auscultation should use that section. The assessment's 11 sections include non-oral, oro-aversion and meal observation, and there are summary sheets for other professionals.

*Jays Observational Assessment of Paediatric Dysphagia - information from Judi Hibberd, tel. 01203 422977, e-mail MJJ.Hibberd@btinternet.com*

**Bad back?**

A new leaflet timed to coincide with European week for Safety and Health gives advice on managing back pain in the workplace.

*'Back to Work' from Health & Safety Executive, tel. 020 7717 6000.*

**Last chance?**

The book *Aphasia - A Social Approach* may be put out of print at the end of the year.

For now, it can be ordered through book shops or from *Customer Services, Stanley Thornes Publishers FREEPOST SWC0506, Cheltenham GL50 1BR.*

**Kids on the net**

Many internet sites now provide interactive educational material suitable for young children. These include:

- www.funwithspot.com - based on Eric Hill's Spot the dog and aimed at children aged from 2-6 years. Includes an area for parents and teachers.
- www.peterrabbit.com - celebrating the works of Beatrix Potter.

**Clear speech**

A booklet explains a technique hearing people can use to enable hard of hearing people to follow conversations more easily.

The Clear Speech guide from Cubex, an independent hearing aid audiologist, emphasises the need to talk in a clear and concise manner to maximise the benefits of a hearing aid. Rather than suggesting you speak more loudly or slowly, the message is to speak clearly and precisely, producing each word as accurately as possible without missing parts or endings. Exercises are included to help people learn the technique which is used routinely by the company's staff as part of their patient care service. *For a copy of the Clear Speech guide, send an SAE to Cubex Hearing Centre, 25 New Cavendish Street, London W1M 8LP, tel. 020 7247 0367.*