

Autism and Down syndrome

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How many children with Down syndrome also have autism and how do we meet their needs?

Introduction

In recent years, there has been an increase in the number of children with Down syndrome who are being diagnosed as having autism or autistic spectrum disorder. These children are then referred to as having a 'dual diagnosis' i.e. two co-existing conditions. However, it is not easy to diagnose autism in children who already have a learning disability and there is not clear agreement on the numbers of children with Down syndrome who do have autism or features of autism. Some authors^[1] argue that the diagnosis is missed because children with Down syndrome are thought to be sociable and, if this is true, some children and their families could be missing out on treatment and serv-

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ices they might benefit from. Others, including myself, are concerned that there may be a tendency to over-diagnose autism in children with Down syndrome. This could lead to changed and lowered expectations for children's progress as well as distress for families.

I recently put out a call to families for photographs and developmental histories if their children had a diagnosis of Down syndrome and autism, and many parents responded. The histories of Conner and Daniel, (see boxes) give us some idea of the needs of this group of children. With colleagues, I am planning further research and we will be collecting information from as many families as possible using a survey in the initial stages, as we need to know much more about the profiles of these children if we are to improve the accuracy of diagnosis and provide as much effective help as we can as early as possible.

Difficulties with diagnosis

There is no objective test for autism such as a blood test or a brain scan at the present time. The diagnosis is made on the basis of having a par-

ticular *pattern* of development and behaviours, described below. However, many of the *individual* behaviours are not indicative of autism on their own. Many of these behaviours are seen in typically developing children at early stages in their development and may be seen for longer in children who are delayed in their progress. Children with delays in communication, children with hearing and vision impairments, children with brain damage and children with severe learning difficulties are all more likely to show behaviours that are on the autistic symptom list. This means that there is plenty of room for different opinions and for mistakes in diagnosis.

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What is autism?

Autism is essentially a social impairment, affecting children's ability to communicate with and to socialise with other children and adults.

There are three main clusters of symptoms recognised as important for diagnosis:-

1. Social impairments
2. Communication impairments
3. Repetitive stereotyped behaviours

A diagnosis of autism requires significant impairment in all three areas (see ICD-10 criteria in box on page 116) but a child who shows some but not all the difficulties may be described as having autistic spectrum disorder (ASD) not full autism. In the USA, autistic spectrum disorder is described as pervasive developmental disorder (PDD). The pattern



My wife Denise and I are parents of five children, three of whom have Down syndrome. Our middle child, Charlie (sitting on my knee), has dual diagnosis of Down syndrome/Autism. He clearly functions and learns at a different level than his siblings, who have "typical" Down syndrome. Mike Allshouse

Conner's Story

Conner is 5½ years old. He has red hair and green eyes, along with Down syndrome, autism, Celiac Disease and asthma. He's very mischievous, cunning and resourceful when he wants something. Conner just finished his first year of kindergarten. He was in a fully inclusive preschool program, taught by special education teachers, and supported by occupational, physical and speech therapy before he started kindergarten. We also had early intervention services from the time he was 4 months old until he was 3 years old.

This year, Conner has learned all of his ABC's and is able to recognize numerous sight words. We aren't sure how many he knows, as he does not talk, but uses signs, gestures and an augmentative communication device to communicate with us. He can also match lower case letters with upper case letters. He has been learning to count to 20 and match the number to the corresponding correct number of objects. He knows shapes and colors, and is able to recognize some objects by their descriptors or location (such as small, big, yellow, next to). These concepts are still a bit difficult and his mastery at this point is hard to pinpoint. He has an incredible memory (not usually associated with Down syndrome), but only for those things that are of intense interest to him.

At home, Conner helps with some household chores, such as sorting laundry by color and putting it in the washing machine or dryer, putting away silverware, making his bed, putting clothes in the hamper, picking up his toys, etc. He even has begun to assist with caring for his 2-month-old baby sister (with close parental supervision of course). He has taught himself how work the VCR, turn on the computer, open and close the games on the computer that he likes – we did not show nor teach him any of those things. He is able to follow 2-3 step commands, especially if they are familiar, such as “put the comb in the drawer and your clothes in the hamper” after his bath.

As Conner's mother, I've known he had a dual diagnosis of Down syndrome and autism since he was 1½ - 2 years old. We just got an official diagnosis of autism last week however. Our family doctor is very uneducated and inexperienced with

autism so he was not a good resource for us, though he is supportive. Conner's therapists from early intervention program (birth to 3 years) did not believe he had autism – they said he was ‘too social’ because he would give them hugs and us. His teacher and therapists (occupational, physical, and speech) in his fully inclusive preschool class also did not believe he had autism because they did not see in their highly structured environment the repetitive behaviors we encountered at home such as spinning himself or objects, dangling objects, looking at the TV up close and from all angles, watching the music come out of speakers, avoiding other people (esp. children), sensory defensiveness (auditory and tactile), and numerous other things. They did observe he did not particularly like his classmates nor interact with them, but they attributed that to immaturity or mental retardation associated with Down syndrome. In fact, when I requested an autism assessment at the end of the first year of preschool, the principal called me in for a meeting to ask why I wanted the assessment. After the meeting, one of the diagnosticians from the school district came to observe Conner and review his records. She said she did not see any signs of autism, and really did not think a full evaluation would be beneficial. The principal did listen to our concerns, and they sent an in-home trainer to us for 5 visits to assist us with some of the issues at home.

By the end of his second year in preschool however, his teacher did agree that he probably had autism, as some of the behaviors we saw were more pronounced at school. Since he was very ‘a-social’, we (parents, teacher and speech therapist) decided that he should go to kindergarten where he would go to school for a whole day, rather than a half-day. Because of his birth date, he could have stayed in preschool one more year. We thought it would be more beneficial to him to have a whole day with more structure than we could provide at home rather than a half-day that preschool provided.

This year, we were scheduled to have another Full Individual Evaluation (FIE) for Conner. Every 3 years one must be completed if a student is receiving special education services. We again requested the autism assessment and the school



agreed. The assessment was conducted last week, and the doctor, therapists, and diagnostician (the same one who said she did not see any signs 2 years ago) all agreed that Conner was in the unique minority of having both Down syndrome and autism.

It has been a relief to have that actually ‘officially’ diagnosed. It now helps us to be able to explain to extended family members why he has some of the quirky behaviors, and they seem to understand better. The diagnosis does not change who Conner is. Nor is it going to change much in his Individualized Education Plan next year because his father and I have already advocated for the things he needs to be successful in school, in a regular kindergarten class. We have agreed, that because of his age (he won't be 6 until after school starts next year), that repeating kindergarten is a good idea, though academically he could be successful if he went on to 1st grade. It is also comforting as a parent to be validated and vindicated to some degree – to know that the paid professionals now see what we've known for years, and that we are not crazy. I feel like I can take a deep sigh of relief because his teachers and I will ‘officially’ be on the same page when discussing what he needs to be successful in school by addressing some of his unique needs.

Kelly Theriault

ICD-10 criteria for a diagnosis of autism

A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:

- (1) receptive or expressive language as used in social communication
 - (2) development of selective social attachments or of reciprocal social interaction
 - (3) functional or symbolic play
- and

B. A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3):

(1) *Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas.*

- (a) failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction
- (b) failure to develop (*in a manner appropriate with mental age, and despite ample opportunities*) peer relationships that involve mutual interests, activities and emotions
- (c) lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional, and communicative behaviours
- (d) lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. lack of showing, bringing or pointing out to other people objects of interest to the individual).

(2) *Qualitative abnormalities in communication are manifest in at least one of the following areas:*

- (a) delay in, or total lack of, development of spoken language that is *not* accompanied by an attempt to compensate using gesture or mime as an alternative mode of communication (often preceded by a lack of communicative babbling)
- (b) relative failure to initiate or sustain conversational interchange (*at whatever level of language skills is present*) in which there is reciprocal responsiveness to the communications of the other person
- (c) stereotyped and repetitive use of language or idiosyncratic use of words or phrases
- (d) lack of varied spontaneous make-believe or (when young) social initiative play

(3) *Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities are manifested in at least one of the following areas:*

- (a) an encompassing preoccupation with one or more stereotyped patterns of interest that are abnormal in their intensity and circumscribed in nature though not in content or focus
- (b) apparently compulsive adherence to specific, non-functional routines or rituals
- (c) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements
- (d) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration they generate).

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For 'atypical' autism the impairment can be identified after 3 years of age

and severity of symptoms can vary from child to child.

How is autism diagnosed?

The diagnosis of autism or autistic spectrum disorder is usually made by a psychiatrist. The psychiatrist will use the diagnostic criteria set down in one of the two major diagnostic guides, the ICD 10 (International Classification of Diseases,^[2] World Health Organisation) or the DSM IV in use in the USA. The psychiatrist may use clinical experience to make a diagnosis based on the ICD 10 or DSM IV criteria but increasingly one of two standard diagnostic tests will also be used. These are the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview (ADI). The use of these measures, for which specialised training is required, improves the reliability of diagnosis. However, a child may need to be seen in familiar environments at home and in nursery or school – not just in the clinic – to obtain a full picture of their

behaviours and difficulties (as Conner's story indicates).

At what age can autism be diagnosed?

There is now general agreement that an experienced professional can reliably diagnose autism by 3 years of age in the general child population. There is also evidence that some children may be identified earlier on screening tools,^[3] relying on early indicators such as differences in eye-contact, joint attention, pointing, imitation and play behaviours.

What causes autism?

While autism can be recognised and described, the causes of autism are not understood and for the past 20 years there has been an enormous amount of research into the condition. Researchers are investigating the genetics, the brain development and the biology of autism and some progress has been made.^[4] The suggested link with MMR jabs has been

discredited^[5] but there have been no major breakthroughs. There is evidence of a genetic pattern and a tendency for autistic profiles and/or communication difficulties to run in families.

Psychologists have been investigating the differences in social and emotional development, in behaviour and in cognitive development. Some of this work has led to awareness of some early social behaviours which may be important indicators of autism but not to any breakthrough in understanding causes. Readers may be interested to know that in many of these research projects, the performance of children with Down syndrome and children with autism, matched for IQ and age, has been compared. The majority of children with Down syndrome do not show the deficits in social and emotional understanding that are shown by the autistic children.

Autism and Down syndrome**How common is autism?**

There are quite widely varying estimates in the UK and USA because there are no objective measures of autistic spectrum disorders. In the 1970s the estimates of the incidence of autism were 4-5 autistic children per 10,000 children. Currently estimates vary from 18.7 per 10,000 to 91 per 10,000. Since the 1970s, there has been an increased recognition of 'milder' social impairments such as Asperger syndrome, which are now part of the autistic spectrum disorders and this accounts for some increases but not all. There does seem to be evidence for a genuine increase in the numbers of children now having autism and autistic spectrum disorders.^[5] Of all individuals with a diagnosis of autistic spectrum disorder, some 50% have learning disabilities.

How does learning disability affect autism?

Surveys show that the incidence of autism increases as the severity of learning disability increases. In a recently published article looking at autistic spectrum disorders (pervasive developmental disorder) in the total population of individuals with learning disabilities in an area of The Netherlands they report the following figures.^[6] In a total group of 1436 children between 4 and 18 years, 9.3% of those with mild learning disabilities were diagnosed as having autistic spectrum disorder, 16.8% of those with moderate learning disabilities and some 43.4% of those with severe or profound learning disabilities. This study gives an overall incidence of 16.7% for the total group of children with learning disabilities (IQ of 70 and below) or 26.1% (IQ of 50 and below). Similar figures have been reported from studies in Sweden and in the UK. These studies use IQ measures to group children by degree of learning disability as shown in the side box.

Most children with Down syndrome are within the range of mild to moderate learning disability – with about 10% in the severe/profound range. We might predict that the expected rates for autism and Down syndrome would be the same as those for the learning disabled population as a whole given above,

but we will see below that they are probably significantly lower.

What do we know about Down syndrome and autism?**How common is it?**

Over the past 25 years, some dozen papers have reported cases of children and adults with Down syndrome and autism. There have also been some surveys in the UK^[7] and Sweden^[8] which suggest that about 5-7% of children with Down syndrome have autistic spectrum disorders. A recent study of a sample of young children in the USA found 2 children in a group of 20, giving a 10% incidence.^[9] These all suggest that the rate is considerably lower than the 16.7% that would be expected for children with IQs across the mild/moderate/severe range. In fact, it could be argued that children with Down syndrome have some inbuilt social strengths that reduce the likelihood of having autism despite their delayed language and intellectual development.

A link with level of disability

The published case reports do not always include information on degree of learning disability but in those that have this information, a substantial number of the individuals described with Down syndrome and autism have severe to profound levels of disability. In 19 cases where the information is given, 12 (63%) have severe to profound levels of disability, 6 (32%) have moderate learning disability and 1 (5%) has a mild learning disability. In other words, most young people with this dual diagnosis were in the most delayed and cognitively impaired group of children with Down syndrome.

Family and health factors

Some studies have identified that a history of autism spectrum disorder was present in the families of some of the children with Down syndrome who were diagnosed as autistic.^[8,10] Like other children, they are being affected by a genetic predisposition in their families.

Several studies note that many children with a dual-diagnosis had serious health problems that do not affect all children with Down syn-

drome. Children may be at increased risk of being diagnosed as autistic when they have experienced significant illnesses in early life including conditions such as infantile spasms, epilepsy, brain injury after complicated heart surgery, severe hearing or visual impairments and severe persistent infections. Not all children with Down syndrome who have these medical problems will become autistic but sometimes brain damage or serious sensory deprivation does lead to severe to profound levels of learning disability and autistic like profiles of development.

Degree of learning disability

Mild = IQ 51-70

Moderate = IQ 36-50

Severe = IQ 21-35

Profound = IQ below 20

Risk of over-diagnosis

The data in several studies provide evidence for the real risk of over diagnosis. For example, in a UK population study of 33 2-16 year olds with Down syndrome, 4 were diagnosed as having autism and a further 11 scored highly on items relating to 'obsessional' behaviours, such as liking routines, engaging in repetitive behaviours and disliking change.^[7] These scores put them at risk of scoring in the autistic spectrum range even though they were not showing social or emotional impairments. Similarly, in the USA study of 20 children aged 2-3 years, 2 were diagnosed as having autism but a further 9 met some of the criteria – all of these demonstrated limited play, repetitive motor behaviours (particularly hand flapping) and were non-verbal at the time but none demonstrated a core difficulty in social relatedness.^[9]

Many autism spectrum disorder questionnaires in common use include items covering language delay, motor 'clumsiness' and friendships which, if the user is not familiar with the development of children with Down syndrome, would lead to them scoring highly and being wrongly diagnosed.

Regression at 2-4 years

In the USA there are specialised Down Syndrome Clinics in number of major cities led by specialist pae-

Daniel's story



My son Daniel has both Down syndrome and autism. He was not officially diagnosed with autism till he was almost five years old. The delay with the diagnosis was not due to the lack of him having almost all of the symptoms for an Autism diagnosis, but due to the fact that he already had

the diagnosis of Down syndrome and history of infantile spasms.

Daniel spoke his first word at ten months, and by two years old he had a vocabulary of twenty words. Then at two and a half he just stopped speaking; he did not even make vowel or consonant sounds. At first the doctor thought it could be seizure, like Landau-Kleffner, though Daniel still responded to us, he just did not speak. He had hearing tests, an EEG and multiple other tests but nothing was noted. Finally, after they took everything else out of the equation, it was determined that his lack of eye contact, his over sensitivity to stimuli, his self-stimuli body movements (rocking and flapping his arms), his odd play habits, and his lack of wanting any physical touch may be just what it suggests - Autism.

It is very hard to describe the problems of having the physical things associated with Down syndrome and the behavioral things associated with autism. I belong to both a Down Syndrome Association and the Autism Association, go to conferences and read all the books I can get my hands on, but we do not fit well into either group. I even had a Neurologist ask me why I would bother having the autism diagnosis added to the Down syndrome. The answer for that is what the school system offers for our kids. I had to fight to get them to use PECS with my child till they started to think of him as autistic. I am glad that someone has brought this subject up, since there are more children out there just like Daniel.

Laura Fontenot

diatricians who see many children with Down syndrome. Two of these centres^[11] are making special studies of children with Down syndrome and autism. Both report that they see a number of children whose early development does not give any cause for concern but that they seem to 'regress' and lose some skills such as some early words or signs and then progress seems to stop and a serious autistic profile emerges. A vivid example of this pattern can be found in the case study of Andy written by his mother Joan Medlen on the *Disability Solutions* website.^[12] Cases which seem to indicate regression from an earlier 'normal' pattern of development are also seen in the general population of children with autism.^[5]

What conclusions can we draw?

At this stage, I am speculating based on my experience of children and what we learn from the published research. I think that it is probable that there are at least two groups of children with Down syndrome who are receiving the correct diagnosis of autism and Down syndrome, and another group who are wrongly diagnosed or may be 'at risk' for social withdrawal.

The two correctly diagnosed autistic groups do show deficits in social and emotional impairments in relating to and communicating with other children and adults. In one group, this autistic social impairment is seen in children who are otherwise functioning within the moderate to mild range of learning disability i.e. the typical range of IQ for children with Down syndrome. The second group have severe or profound levels of disability probably resulting from additional brain damage and are seriously impaired in most areas of their development.

The wrongly diagnosed group show a range of 'obsessional', repetitive behaviours, may do some hand-flapping, may have limited play and dislike change and have limited communication skills but they relate affectionately to those around them. As their communication and play skills improve, the 'autistic' like behaviours will reduce though a tendency to cling to routines and show some 'obsessional' behaviours

especially when anxious is very common among children with Down syndrome right through childhood years. However, if their communication and play skills do not improve, then children in this group may well withdraw and become more 'autistic'.

Risk factors for social withdrawal

When children's play and communication skills are developing very slowly due to learning disability, there is a risk that their development becomes arrested, or 'stuck'.

For example, a child may sit and just roll a car back and forward, or line up bricks or sit and flap an object because he or she does not know how to play more creatively. Progress will only be made if someone – parent or sibling or teacher – plays with the child and shows him or her how to play in more rewarding and advanced ways. Even if play is not more advanced, if someone plays with the child, taking turns in a simple activity such as rolling a ball or running balls down a runway, this will prevent the child developing the habit of engaging in a repetitive activity that does not lead to any learning or progress.

A child who is not yet able to use some signs or words to communicate, and is of a shy temperament, may retreat into his or her own world and not seek out others to play with or communicate with. Sometimes such a child is making some efforts to communicate by reaching for something or by looking – and these small communicative signs need to be encouraged. We need to be alert to *any* ways in which children are trying to communicate and to be sure we are giving them a chance to communicate and make choices. We should not fall into the pattern of doing everything for them and thinking for them so that they have no need to communicate. Most importantly, we need to be sure that every child with Down syndrome is receiving a service from a home-teacher or a speech and language therapist which focuses on helping parents to teach their child to progress in their use of signs and speech.

To diagnose autism in children with a learning disability you need:

1. A detailed assessment of cognitive level (verbal and non-verbal) and of receptive and expressive language abilities
2. A developmental history covering progress from infancy onwards, preferably obtained with a standardised interview such as the Autism Diagnostic Interview
3. Observations of the child in both structured and non-structured settings (again a standardised instrument such as the Autism Diagnostic Observation Schedule Generic can be very informative)
4. Routine screening for medical/genetic conditions
5. Consideration of other relevant psychosocial factors

Guidelines from Patricia Howlin 2000 ^[13]

Autism and Down syndrome

What can we do to improve diagnosis?

At present, we can draw attention to the guidelines already available from experts in autism such as Pat Howlin – see box on facing page. Her guidelines emphasise the need to consider the child's level of cognitive and language functioning in order to be able to interpret behaviours in the context of the child's current developmental level.

In adapting these excellent guidelines to be specific for children with Down syndrome, I would want to be sure that anyone assessing the child was aware that possible symptoms considered 'autistic' such as 'obsessional' repetitive behaviours, sensitivity to sensory stimulation and a dislike of change are common and not usually associated with any social or emotional deficits.

I would highlight the need to take a medical history *first* to identify any reasons to suppose the child has additional brain damage and also to screen for any existing conditions such as severe hearing loss or hypothyroidism or any conditions causing pain which have not been detected.

I would also encourage parents and professionals to wait until children are 5-6 years old to be sure about the diagnosis. They also need to be aware that most standardised autism assessments have not been evaluated for use with children with Down syndrome and should therefore be interpreted with caution. I would also encourage professionals to take parent's concerns seriously as several recent studies highlight the fact that parents knew that their child was somehow different from other children with Down syndrome – but often no-one listened to them.

What treatments are effective for autistic children?

Despite the fact that the number of children with autism in the general population is increasing and that people have been looking for effective treatments for more than 20 years, there is no evidence that any treatment can 'cure' the underlying cause of the social impairment. There is some evidence that

educational and management strategies may help children to progress, to adapt to their difficulties and to reduce the incidence of behaviour difficulties that they may show. The advice of Pat Howlin, based on many years of work in this field, is again a good starting point (see side box)

Each of these recommendations can be developed in more detail with examples of how they might apply to children with Down syndrome and autism. Space does not allow this here but more detailed practical information is contained in the forthcoming book on Atypical Development in the *Dsiv* series.

In order of priority, the key messages for families are

1. Discuss your child's additional needs in the family and recognise the extra demands that they make. Be sure to ask for the extra services you need including respite care. It may be helpful to link up with other parents in the same situation.
2. Develop a daily routine and a visual timetable to provide a structure, to allow the child to anticipate what is to be expected, and to reduce anxiety
3. Focus on encouraging communication skills – however small the steps more communication will help. Remember to offer choices and respond to all attempts to communicate.
4. Focus on teaching independence and self-help skills as this will improve the child's quality of life now and later
5. Encourage participation in meaningful activities – such as helping with household chores. Children who have very limited abilities in play or self-occupation may be able to help with these, reducing the time they may spend in repetitive or 'self-stimulating' activities such as hand flapping or twiddling objects.
6. Engage children in play and activities with partners as much as possible – recognising that left alone they will not be able to make progress
7. Try to limit the time spent in repetitive activities so that they do not 'take over'
8. As part of the daily routines,

Features of successful intervention strategies for children with autism

- A combination of behaviourally oriented strategies with developmental and educational approaches relevant to the individual child's profile of skills and deficits
- Recognition of the need for structured teaching programmes, with a particular emphasis on visually based cues; these provide the child with a predictable and readily understandable environment, which helps to limit confusion and distress
- A focus on the development of social-communication and play activities, especially with peers, and if possible the implementation of specialist training programmes
- Acknowledgement that many so called undesirable behaviours are a reflection of the child's limited behavioural repertoire or poor communication skills; a focus on skill enhancement is therefore often the most effective means of reducing difficult and disruptive behaviours
- Understanding of the importance of obsessions and rituals, not just as an underlying cause of many behaviour problems, but also as having a vital role in reducing anxiety and as powerful sources of motivation and reinforcement
- Treatment approaches that are family centred rather than exclusively child oriented
- Management strategies that can be implemented consistently without excessive sacrifice of time, money and other aspects of family life.

Guidelines from Patricia Howlin 2000 ^[13]



Peter

set clear expectations for behaviour

9. Use simple, clear and consistent language to maximise learning and understanding
10. Be calm in all your interactions – keep emotional expressions to a low intensity as displays of emotions that they sense but do not understand will increase children's anxiety

A child with Down syndrome and autism should receive services from autism specialists who can help to address their extra needs.

The future

An intervention programme developed in Manchester which focuses on teaching social communication skills to autistic children at an early age has actually been shown to reduce the autistic symptoms of the children.^[14] The team that developed this programme now have a large grant to extend their work. If we can identify the children with Down syndrome who have autistic difficulties early in their preschool years then similar approaches may help us to reduce their difficulties. We may have to accept that this may help the children in our first group most, those with autism within the typical ability range for children with Down syndrome. The children with severe or profound levels of disability, for whom an autistic profile is part of severe delays in most areas of their development, may benefit but will also need more help to develop their skills in all areas.

We need more research to enable us to collect detailed information on the ages at which the key social indicators of early social engagement with others such as pointing, following eye-gaze to both look at an object or action and to imitate actions, emerge in children with Down syndrome. This might enable those with a real social impairment to be identified and supported as early as possible. We also need more detailed information on the ages at which communication skills develop so that we can spot the children with unusual difficulties.

We also need to know how moderate to severe hearing loss influences the progress in social relationships and communication in children with Down syndrome. I have seen children

with Down syndrome and persistent losses of 40-60dB from 'glue ear' who have struggled with communication and had significant difficulties relating to those around them.

At The Down Syndrome Educational Trust, we plan to begin to collect preliminary data on these issues in the autumn on a representative group of preschool children attending our services, linked to the work we are doing on the Early Support Developmental Protocol (see page 138). We plan to apply for grant funding to support the full research programme needed to provide information on which to develop more effective support for this group of children and their families.

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The next issue of *Down Syndrome News and Update* will include an article by Joan Guthrie Medlen about teaching resources that she has created for her son Andy, who has autism. See Disability Solutions website.^[12]