

Dealing with **AUTISM**

Autism is on the increase and is often a misunderstood disorder. Autism expert **Kelly Lynn Redden** explains the condition and some possible interventions that may help a child with autism to reach their full potential.

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Autism is one of a group of serious neurobiological disorders that are recognised by parents in early childhood — usually before age three.

According to health expert Fred Volkmar, the age of diagnosis is more appropriately called the age of recognition and should not be assumed to be the real age of onset.

The symptoms and severity vary, but nearly all autistic spectrum disorders affect a child's ability to communicate and interact with others. There is, at present, no cure for autism, but intensive, early treatment can make an enormous difference in the lives of many children with the disorder.

Children with autism generally have problems in three crucial areas of development, commonly referred to as the 'triad of impairments', which include: difficulties in social interaction; language; and behaviour. But because the symptoms of autism vary greatly, two children with the same diagnosis may behave quite differently and have strikingly different skills.

In most cases, however, the most severe form of autism is marked by an inability to communicate or interact with other people. Young children with autism also have a hard time sharing experiences with others. For example, when they are read to, they're unlikely to point at pictures in the book, referred to as 'joint attention'. This early-developing social skill is crucial to later language and social development.

Common behavioural characteristics that many children with autism display may include: insistence on sameness, repetitive or ritualistic behaviours, echolalia, problems with pragmatic communication, difficulties with functional play, and difficulty making eye contact with others.

Approximately 70 per cent of children diagnosed with autism have some form of developmental delay; other children may have normal to higher intelligence. An extremely small number of children (approximately 10 per cent) with autism are "autistic savants" and have exceptional skills in a specific area, such as art, maths or music.

Possible causes

Autism has no single known cause. Given the complexity of the condition, the range of autistic spectrum disorders and the fact that no two children with autism are alike, it's probable that there are many causes. It could be a genetic disorder; researchers have discovered a number of genes that appear to be involved in autism. Some may make a child more susceptible to the disorder; others affect brain development or the manner in which brain cells communicate. Genetic errors seem to be inherited, though others occur spontaneously.

However, according to Wing and Potter, genetic factors alone are very unlikely to account for a real rise in rates that appears to have occurred so rapidly and continuously year-on-year. It is believed environmental factors are involved. Many suggestions have been made concerning possible causes, including constituents of the diet, environmental pollutants, antibiotics, allergies etc.

Autism affects children of all nationalities and socio-economic levels, but some factors are known to increase a child's risk. Studies show that boys are three to four times more likely to develop autism than girls are, and families who have one child with autism have an increased risk of having another child with the disorder. In some cases, the parents or relatives of an autistic child also have minor problems with social or communication skills themselves or engage in certain autistic behaviours.

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Diagnosis and treatment

If your child shows some signs of autism, you may be referred to a specialist. This person works with a team of experienced professionals that are familiar with autism and can perform a formal evaluation for the disorder. A complete medical and developmental history is required, in addition to pre- and post-natal information. A member of the diagnostic team should also observe the child in natural settings such as at home, at school, and use some type of standardised assessments in addition to the diagnostic criteria stipulated in the Diagnostic and Statistical Manual (DSM IV, American Psychological Association, 1994) or the International Classification of Diseases (ICD-10, WHO, 2007).

As autism varies widely in severity and manifestations, making a diagnosis may be difficult. There isn't a specific medical test to pinpoint the disorder. Instead, a formal evaluation consists of an expert observing your child and talking to you about how your child's social skills, language skills and behaviour have developed and changed over time. To help reach a diagnosis, your child may undergo a number of developmental tests covering speech, language and psychological issues.

Specialist interventions

guidelines for parents in search of intervention options

There is no "one-size-fits-all" treatment for autism. The intervention choices can be difficult and may include home-based or school-based treatments. Your doctor can recommend specialists. Treatment options may include behaviour and communication therapies to address the range of social, language and behavioural difficulties associated with autism. Some programmes focus on reducing problem behaviours and teaching new skills, while others focus on teaching children how to act in social situations or how to communicate better with other people. Though children don't outgrow autism, they may learn to function well with the disorder.

POSSIBLE SIGNALS

Babies don't follow exact timelines in their development. But children with autism usually show some signs of delayed development by 18 months. Your doctor may recommend further evaluation if your child doesn't babble or coo by 12 months, doesn't gesture — such as point or wave — by 12 months, doesn't say single words by 16 months, or doesn't say two-word phrases by 24 months, or loses previously acquired language or social skills at any age. If you suspect that your child may have autism, discuss your concerns with your doctor. The earlier treatment begins, the more effective it will be.



Prevalence rates

Prevalence rates range from:
2-5 to 60 per 10,000 for
Autism and 13-48 per 10,000
for Asperger's.

This range has been derived
from several published
scientific journal studies.

Of the 4 million young
people (up to age 20)
living in the Netherlands, a
minimum of 11,000 children
have some form of autism.

Source: Trimbos Institute www.trimbos.nl

THE AUTISM SOCIETY OF AMERICA RECOMMENDS SOME QUESTIONS FOR PARENTS TO ASK:

- Will the treatment result in harm to my child?
- Has the treatment been validated scientifically?
- Are there assessment procedures specified?
- How will the treatment be integrated into my child's current programme?

THE NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) ALSO SUGGESTS QUESTIONS FOR PARENTS TO ASK:

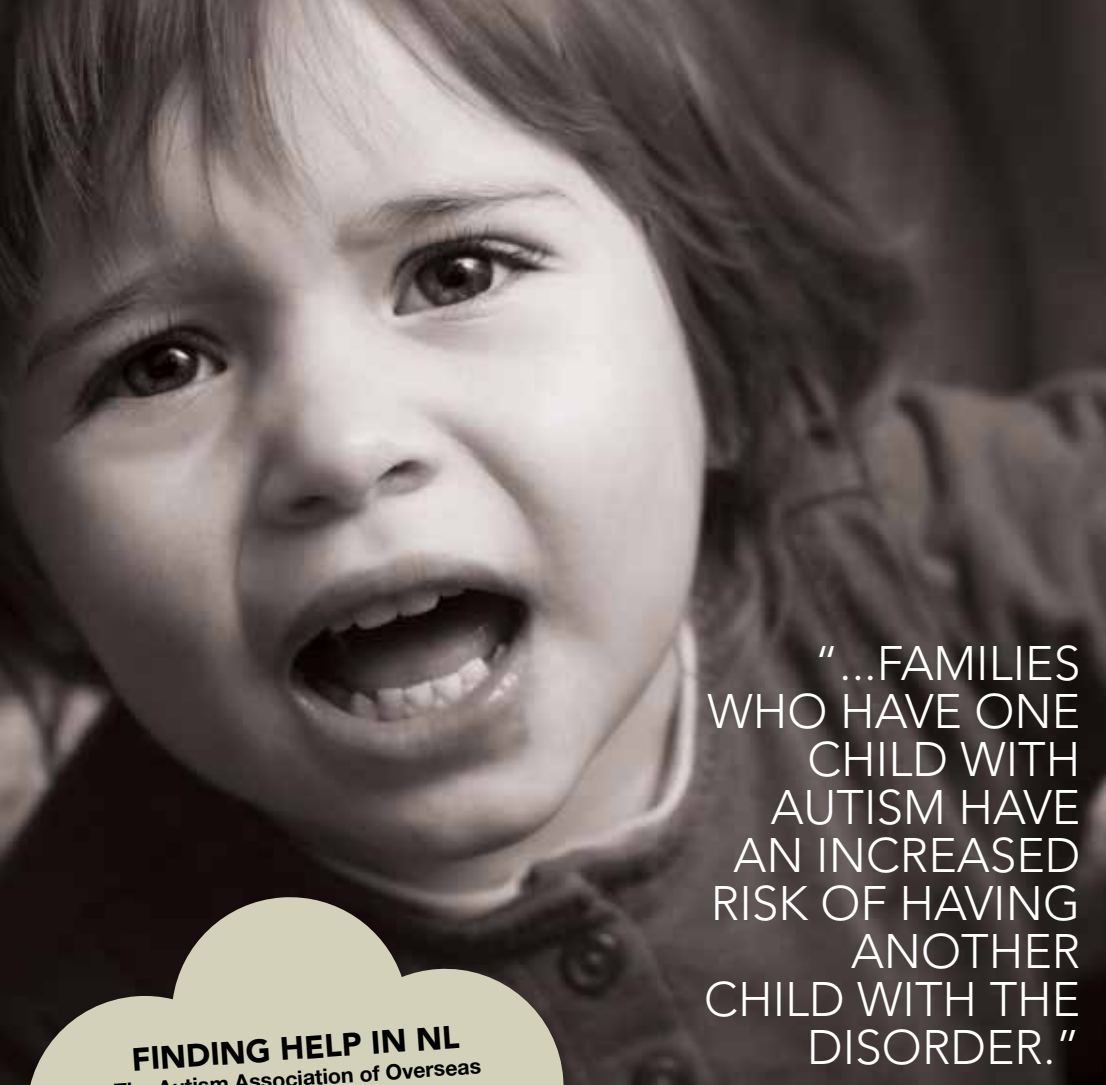
- How successful has the programme been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organised?
- Are there predictable daily schedules and routines?
- How is progress measured? Will my child's behaviour be closely observed and recorded?
- Is the environment designed to minimise distractions?
- What is the cost, time commitment, and location of the programme?



POSSIBLE RED FLAGS FOR AUTISM SPECTRUM DISORDERS CHILDREN AND ADULTS WITH AN AUTISM SPECTRUM DISORDER MIGHT:

- not play "pretend" games (pretend to "feed" a doll)
- not point at objects to show interest (point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds
- be very interested in people, but not know how to talk to, play with, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions repeat actions over and over again
- have trouble adapting to changes in routine
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had (for instance, stop saying words they were once using)

Source: Centre for Disease Control
www.cdc.org



“...FAMILIES WHO HAVE ONE CHILD WITH AUTISM HAVE AN INCREASED RISK OF HAVING ANOTHER CHILD WITH THE DISORDER.”

FINDING HELP IN NL

The Autism Association of Overseas Families living in the Netherlands provides a network of information on professional treatments, where to apply for PDB financial benefits for medical costs, publications, parent support groups, events and more. Informal parent's coffee mornings and evenings are held regularly in The Hague, Amsterdam and Rotterdam areas. www.aeof.info

Children with autism often respond well to highly-structured education programmes. Successful programmes often include a team of specialists and a variety of activities to improve social skills, communication and behaviour. Preschool children who receive intensive, individualised behavioural interventions show good progress.

Applied Behavioural Analysis (ABA) uses educational techniques to change certain behaviours in autistic children. By working on a one-on-one, weekly basis, therapists can increase children's skills in language, play and social interaction. They can also help them get over behaviour that interferes with learning. ABA has over 30 years of clinical research behind it and is very effective not only with children with autism but with other disabilities as well. Pivotal Response Treatment (PRT) addresses these issues by working in a more natural environment using shared control techniques and increas-

ing motivation by allowing the child the choice of which resources to work with. Although some children do require a great deal more therapy, 20 hours per week is practical and is just as effective. In the Netherlands, treatment costs are paid by applying for 'PersoonsGebondenBudget' (PGD). ■

USEFUL WEBSITES FOR FURTHER INFORMATION:

- www.autismspeaks.org
- www.autism-society.org
- www.nas.org.uk
- www.nih.org
- www.autismresearchcentre.com
- www.cdc.org
- www.aeof.info

SAS has recently expanded its list of services to include: Workshops, in-service training, and seminars designed specifically for the needs of special needs schools, international and Dutch schools, KDC's, stichtings, and other organisations involved with special needs children. The workshops, in-service training and seminars can be individually designed to meet the needs of each organisation, and are targeted at professionals and para-professionals. SAS also has a special workshop on offer for parents, siblings, and caregivers.

About the author

Kelly Lynn Redden received her Post Graduate Diploma in Analysis and Intervention in Learning Disabilities at the University of Kent, Canterbury UK. She has also attended a 180-hour course in Autism at the National Autistic Society. She holds certificates in PRT and PECS. Redden plans to continue to expand her knowledge about autism by enrolling in higher education courses, as well as becoming the only therapist in Holland trained in the SCERTS (Social Communication, Emotional Regulation, and Transactional Supports) model in the UK.

She specialises in working with children with autism and has over eight years of direct intervention experience. She has worked in Dakar, Senegal; and Varna, Bulgaria. Her approach includes the design and implementation of individualised in-home ABA programmes, utilising cutting-edge educational therapy such as Pivotal Response Treatment (PRT), in addition to Discrete Trial Training (DTT) and Picture Exchange Communication System (PECS). *Upcoming workshop: Inside Autism, June 20, 2009 at the ABC Treehut in The Hague. For details, contact Specialized Autism Services www.specializedautismservices.com.*

Personal note from the author:

“Unfortunately, early intervention is not stressed here in the Netherlands, and parents have had to fight with members of the medical community to get their children screened. It has been my experience that the knowledge of treatment options and autism here is outdated. Shockingly, institutionalizing the child is recommended at times, clearly an easy out. I treated a four-year-old whose parents were appalled at the thought of putting him away. Today, three years later, thanks to intense treatment, he is now attending an international school and is reaching his full potential. There is a complete lack of knowledge about behavioural analysis and modification in schools as well as in KDCs (Children's Day Care). Oftentimes, the schools and KDCs are not equipped to deal with difficult behaviour, nor do the workers receive any type of training. This is a dangerous situation as it leads to staff burn out and endangers both the children and the people who work at these places. We need to work on quality and focus more on prescreening and working with professionals, including paediatricians, to explain and dispel the myths about autism and ABA. For a child with autism, the potential is unlimited. One should not think of certain ranges or in terms of limitations. When you work with a child, you discover their potential. I go all out for every child I work with.”



Credit: Jose Mendoza