

WHAT IS AUTISM ?

Films like 'Rainman' have done much to raise the awareness of autism with the general public. Unfortunately, they have also led to a number of misunderstandings, for example that all people with autism had unique and special abilities – referred to as 'savant' skills. Autism is in fact the core condition of a spectrum of disorders, which all share common characteristics but which are manifested in very different ways within each individual.

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Autism is a significant disability, affecting communication and interaction with other people, but also with the world. The degree of autism varies along a dimension of severe to mild, although the effect is always serious. Thus someone with autism may have severe autism with severe additional learning difficulties and thus be maximally disabled, or they may have mild degrees of autism with normal or high levels of intelligence. The majority have learning disabilities. Language development varies greatly in autism, some have very good speech, but still lack full understanding and have difficulties with conversation, while a significant portion of those with core autism will have no spoken language. Many may be oversensitive to noise, light, touch, smell, and under-react to pain.

WHAT CAUSES AUTISM ?

Although the precise causes of autism are not known, we do know that it is a biologically based disorder that affects the

Autism is a biological disorder that affects the brain. Parents are not the problem.

developing brain. It is not diagnosable at birth, because the patterns of behaviour do not emerge until the child is between 18 months and 3 years. Sometimes there is a period of apparently normal development and then, between 18 months and 3 years, the child appears to withdraw and lose skills.

We now know that parents are not to blame for autism, but, in contrast, are the child's greatest resource.

WHAT ARE THE COMMON SIGNS OF AUTISM ?

There is no single characteristic that on its own typifies autism but it is difficulty in three areas that is characteristic of the condition.

SOCIAL INTERACTION PROBLEMS are the most evident characteristic of autism. Children with autism may fail to respond to their names and often avoid looking at

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people. They often have difficulty understanding gestures, tone of voice or facial expressions and emotions. They appear unaware of others' feelings toward them and of the negative impact of their behaviour on other people. Some people with autism tend to be aggressive at times,

mainly when they are in a strange or overwhelming environment, or when angry, frustrated or painfully stressed by their over-sensitivity to sensations.

COMMUNICATION PROBLEMS: More than half the people with autism will remain mute throughout their lives. Those who do speak will tend to start late and may refer to themselves by name instead of "I" or "me". They often use language in unusual ways. Some speak only single words, some repeat the same phrase no matter what the situation. Some speak in a singsong voice about a narrow range of favourite topics, with little regard for the interests of the person to whom they are speaking.

Children with autism are mute or use language in unusual ways. All have problems in understanding language

Independent of any ability to speak, all people with autism will have problems in understanding communication.

BEHAVIOURAL PROBLEMS: Although people with autism usually appear physically normal and have good muscle control, many engage in odd repetitive motions, like

Many engage in repetitive motions or repeat actions. Changes to routines may be upsetting

rocking and hair twirling, or self-injurious behaviour such as biting or banging their heads. These often arise from communication difficulties or problems in understanding their social environment and the social meaning of behaviour or painful

sensitivity to sensory stimulation. An unusual sensitivity to touch may contribute to behavioural symptoms such as resistance to being cuddled. Some people with autism also tend to repeat certain actions over and over again. Any minor change to their routine may be particularly upsetting for them. Children with autism rarely engage in pretend play.



Autism - Europe a.i.s.b.l.

Awareness of AUTISM

"People's knowledge of Autism is still vague, full of prejudices, if not altogether non-existent"

It is therefore important to increase public awareness of what autism entails, of autistic people's rights, of their difficulties in adapting to an inflexible society that does not provide for their different and specific needs.

At a political level, action has been urged towards more inclusive policies for people with disabilities in areas as broad as healthcare, education, employment, ageing and life-long needs. It is absolutely essential that these policies are adopted and that children and older people with autism are not denied their fundamental right to live full, worthwhile lives, within their unique possibilities.

"Being autistic is one way of being. Even if it is not the "normal" way, an autistic person's life can be as fulfilling and happy as anyone else's" (Angel Rivière)



AUTISM-EUROPE is a European network regrouping nearly 85 associations of parents of persons with autism in 31 countries. Its principal objective is to promote and defend the rights of people with autism and their families and to improve their quality of life.

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HOW IS AUTISM DIAGNOSED ?

Because it varies widely in its severity and symptoms, autism may go unrecognised. There is no single test that can be applied to make the diagnosis. Autism spectrum disorder is best diagnosed by a multidisciplinary team of professionals using well validated instruments. Yet early detection and recognition are of great importance as early intervention can make a big difference to quality of life. The level of intellectual functioning in people with autism is difficult to assess because their social and language impairments interfere with testing.

The majority in fact function at a level of mild to moderate learning disability. An impressive minority known as savants display extraordinary skills in areas like mathematics, music, drawing and memorising far beyond their general capabilities. The term Asperger Syndrome is sometimes used to describe people with autistic behaviour but well-developed language skills.

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WHAT CAN BE DONE TO IMPROVE THIS CONDITION ?

Though there is to date no cure for autism, much can be done to foster their development and improve the day-to-day lives of children and adults with autism. The best-studied therapies include educational/behavioural and medical interventions. Many other interventions are available, but few, if any, scientific studies support their use.

Therapies include educational/behavioural and medical intervention

EDUCATIONAL/BEHAVIOURAL INTERVENTIONS: These strategies emphasise skill-oriented training within a well-structured environment and time schedule. Individualised educational programmes (IEP), including the teaching and training of the skills necessary for the child's well-being and future can enhance their capacity to learn, communicate and relate to others, while reducing the severity and frequency of disruptive behaviours. Personal interests provide a strong incentive to learn. Education should begin as early as possible and not end with adolescence and adulthood. Higher functioning people who handle academic work need help to organise tasks and avoid distractions.

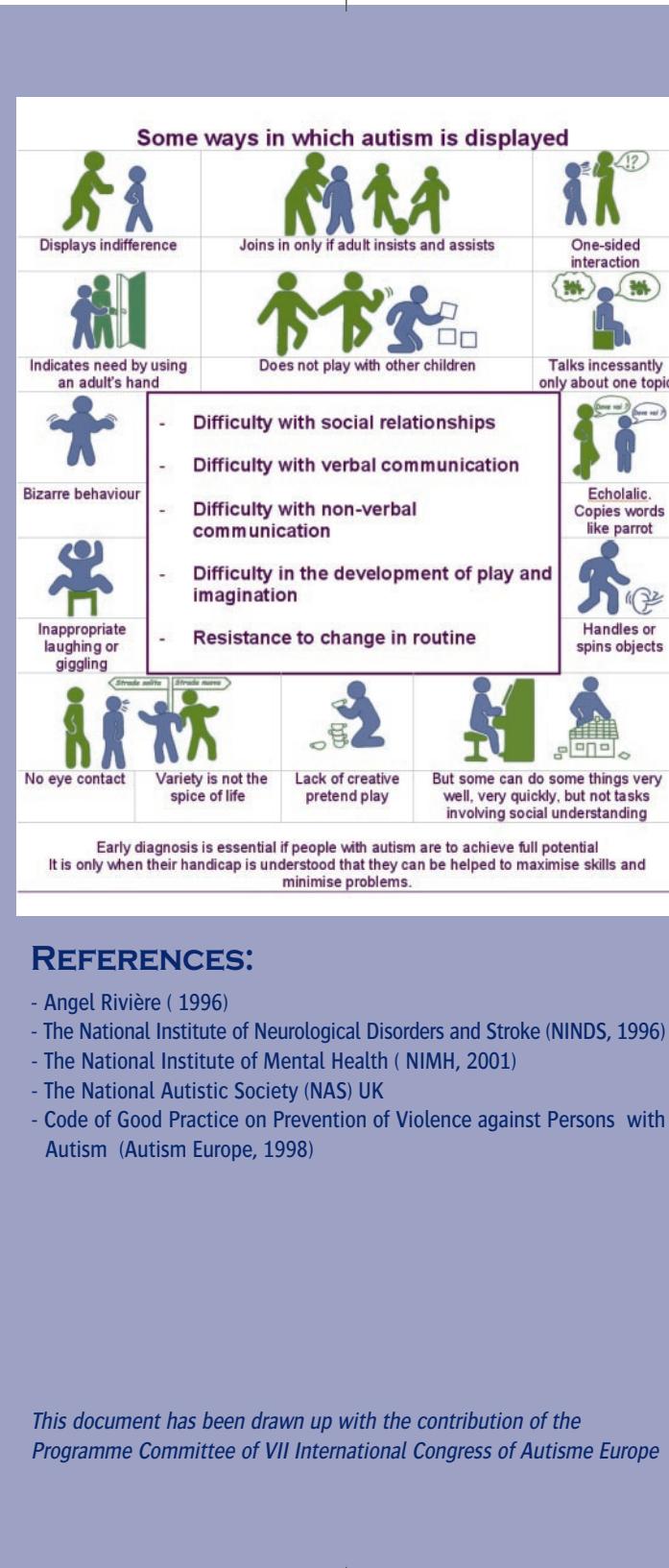
Educational training can enhance skills, well-being and independence

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MEDICATION: there are no drugs that can cure autism but pres-

Medication can not cure autism, but can improve symptoms

scribing appropriate medication can enhance attention and reduce troublesome symptoms such as self-injurious behaviour.



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EUROPEAN INCLUSION POLICIES

It is absolutely essential that more inclusive policies for people with disabilities be adopted, in areas as broad as health-care, education, employment, ageing and life-long needs, and that children and older people with autism are not denied their fundamental right to live full, worthwhile lives within their unique possibilities.

People with autism need the same care, love and respect as "normal" human beings

The majority of adults with autism need lifelong training, ongoing supervision and reinforcement of skills. These needs are best met in sheltered housing and by working within the community rather than in segregated environments. At present, thanks to lifelong support and adapted care services, about one third of all people with autism can live and work in the community to different degrees of independence.

People with autism have normal life expectancy but ageing brings further problems. The ongoing vulnerability of older people with autism is a challenge that will have to be addressed in order to find optimal solutions for supporting their condition and services tailored to their future needs.

COLLABORATION WITH PARENTS

As all individuals with autism are unique in their way of being and how they react, families should be acknowledged for their invaluable knowledge of their relative. Their views should be taken into account both during the diagnostic procedure, the tailoring of the intervention programmes and the evaluations.

The parents of children with autism encounter, on a daily basis, the difficulties of inaccurate diagnoses, inadequate care settings, shortage and/or lack of well-trained staff and general unwillingness to engage with autism. Meeting their own needs (risk of social isolation, disregard for the needs of siblings...) should be a serious issue in any comprehensive treatment and guidance plan.

However, it is parents, in their everyday encounters, who are in a position to help other people overcome their preconceptions and fears, accept their own social responsibilities and explore the potential of viewing life from another perspective, the perspective of a person with autism.