
Summary

Health Council of the Netherlands. Autism Spectrum Disorders: a lifetime of difference. The Hague: Health Council of the Netherlands, 2009; publication no. 2009/09

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are developmental disorders characterised by limitations in social interaction, communication and imagination. They are often associated with stereotypical or rigid behaviour patterns. The term 'spectrum' is used to reflect the fact that the disorder takes different forms in each individual with ASD. Most ASD cases can be classified into one of the following three groups: childhood autism, PDD-NOS (pervasive developmental disorder - not otherwise specified) and Asperger's disorder. In childhood autism, depending on their age, affected individuals make little or no contact with the outside world. Conversely, those with PDD-NOS or Asperger's disorder are characterised not so much by a lack of contact, but more by dysfunctional interactions with those around them.

The causes of ASD are unknown. What is clear, however, is that ASD is largely hereditary, with a higher incidence among boys/men than among girls/women. Environmental factors also appear to be implicated in these disorders, but the exact mechanism involved has yet to be elucidated. Approximately half of those with ASD also suffer from some form of intellectual disability.

Request for advice

In recent years, there appears to have been an increase in the number of children diagnosed with ASD. This is mainly reflected in an increase in the number of applications for care under the terms of the Exceptional Medical Expenses Act (AWBZ)/client-linked budgets (PGB), or indications for special education/pupil-specific funding (LGF) associated with the diagnosis of ASD. There has also been an increase in the number of claims for incapacity benefit for young people with ASD.

In response to this development, the Minister of Youth and Families, together with his counterparts at the ministries of Health, Welfare and Sport; Social Affairs and Employment; and Education, Culture and Science, formally requested the Health Council of the Netherlands to produce an advisory report on autism spectrum disorders. They asked the Council to address issues relating to: the occurrence of ASD; the possible relationship between the observed increase in occurrence and indication processes for care and funding; the problems encountered by those with ASD; and the integrated approach required to enable children and adults to participate in society and to function as effectively as possible in everyday life.

Detection

Autism is not something that can be detected by a simple blood test or scan. A diagnosis of ASD is made on the basis of behavioural characteristics. A good diagnosis includes two important factors. The first is a classification in which the core symptoms (limitations in social interactions and communication, together with rigidly stereotypical behaviour) are scored according to the Diagnostic and Statistical Manual of Mental Disorders (DSM). The second involves a dimensional diagnosis, which addresses the subject's context, as well as their individual potential and limitations. Together, these separate aspects of the overall diagnosis form the basis for the action-oriented diagnosis, which indicates the treatment and counselling needs of the individual in question, taking into account their potential and limitations. The classification will remain the same throughout the life of the individual in question. This is not true of the dimensional diagnosis and the action-oriented diagnosis, however, as they are partially dependent on the development of the individual and their social context. Accordingly, the latter two types of diagnosis must be repeated at regular intervals.

Childhood autism can be detected before the second year of life, on the basis of developmental characteristics. PDD-NOS and Asperger's disorder often do not cause problems until children are of school-going age, sometimes not even until they reach adolescence or adulthood.

While there are a sufficient number of valid tools for detecting these conditions in young children, this is not the case for older children, young adults, and older age groups. Diagnostic tools are available for very young children and for children of school-going age. As yet, there are few such tools for young adults and older age groups, but this situation is expected to improve in the not-too-distant future.

One difficulty with identifying ASD is that generalists such as GPs, physicians at post-natal clinics, occupational health physicians and insurance physicians lack the equipment needed to detect these disorders. This also applies to professionals in other 'lookout' positions (teachers and youth-care workers, for example). Even professionals working in the mental health care service (GGZ) cannot automatically be assumed to have a knowledge of autism.

Treatment

ASD is incurable. While various therapies are used to treat the effects of the disorder, their effectiveness is still somewhat limited. Presently, the most effective form of treatment involves early, intensive behavioural interventions. As yet, however, there is only limited evidence to support the effectiveness of this approach.

In the Netherlands, there is consensus about which elements must be included in the treatment and supervision of individuals with ASD. One is psycho-education and the dissemination of information about the disorder, and about how it affects ASD sufferers' ability to function as well as other aspects of their lives. A second element involves treating the somatic symptoms presented by such individuals (such as visual and hearing problems). Then there is the treatment of comorbidity, such as ADHD and motor problems. Finally there are psychosocial interventions such as behavioural interventions and family support, as well as support in education and employment.

Prevalence

There are no figures for the prevalence of ASD in the Netherlands. According to estimates published in the international scientific literature, the prevalence of ASD is currently 60 to 100 per 10,000. No differences have been found between

ethnic groups or between groups with a different socio-economic status. Accordingly, there is no reason to suppose that prevalence in the Netherlands differs from that found elsewhere in the world. Well over thirty years ago, the reported prevalence was 2 to 5 per 10,000. The observed increase can be attributed to a number of factors. In the 1980s and 1990s not only were the criteria for classic autism broadened, but Asperger's disorder and PDD-NOS were included as classifications in the autism spectrum. Effectively, therefore, the diagnosis of autism was expanded. Another important factor is a society that places much greater demands on social and communicative skills, flexibility, and independence than was the case thirty years ago. As a result, the disorder causes problems more often now than it did at that time. In other words, people with this condition have always been with us, but improved diagnosis and the greater demands being placed on individuals are now making them much more noticeable. One factor that might be involved in the Netherlands in particular is that anyone wishing to apply for care funding or educational assistance must first obtain a classification.

Problems encountered

From the initial suspicion that something is wrong with a child, youth or young adult, the route to diagnosis and, ultimately, appropriate treatment and support is an excessively long and complicated one. A wide range of professionals working in many different domains (families, school, work) encounter people with ASD. If treatment and rehabilitation are to be successful, then thorough consultation and effective cooperation are of pivotal importance. The current funding system for the many and varied types of care does not always provide sufficient incentive, or adequate facilities, for cooperation. As a result, these children and their parents are all too often repeatedly sent from pillar to post.

Within the families concerned, life often centres around the child with ASD. This generally imposes a heavy burden on the parents, so much so that working mothers often feel compelled to give up their jobs. Given that autism has a pronounced genetic component, other family members are also likely to exhibit autistic characteristics or to suffer from a disorder. This affects the family's ability to maintain financial independence and the type of treatment/counselling being offered, as well as support measures both for the family and for childrearing.

In the area of education, their anomalous methods of information processing and language acquisition mean that ASD sufferers are unable to study 'normally'. Furthermore, their social and communicative constraints and rigid behaviour patterns make it difficult for them to work and collaborate with others.

These same constraints at the social and communicative level make it very difficult for those with ASD to work in our modern, service-oriented economy.

In general, people suffering from ASD find it difficult to cope with changing circumstances (transitions) that affect their lives. Examples of such circumstances include: starting school, the transition to secondary education, or the transition to work. Transitions involve the disruption of an existing equilibrium, resulting from the sudden introduction of different, possibly more demanding tasks. A new equilibrium has to be found, which always involves the risk that the specific characteristics of the individual disorder in question will make it impossible to meet the new requirements. This in turn further aggravates the symptoms. Assistance given to children, adolescents or young adults with ASD can, to some extent, help to prepare them for such situations. All that remains then is to wait and see how they handle these transitions in practice.

Integrated approach

It is not enough simply to explore the specific, individual characteristics of the disorder and how it affects the ability to function of those with ASD. When assisting or collaborating with these individuals, it is also important to examine their social and functional context. This requires a tailored approach that is focused on the individual's specific phase of life. Furthermore, wherever possible, an attempt must be made to anticipate possible future changes (transitions).

The Committee calls for a uniform procedure to be adopted for the early detection of ASD in children aged 0-4 and in children of school-going age. Tools should be developed to enable these conditions to be detected in adults. Research is needed into ways of effectively treating and supervising the disorder from childhood to adulthood. Furthermore, with regard to the general research effort, an effective balance has to be achieved between supply and demand. The Committee takes the view that, in the area of education, tailor-made procedures are vital. Education has an important part to play in preparing individuals as effectively as possible for the transitions that they will encounter before, during and after their years spent in the educational system. The aim here is to restrict the adverse effects of the disorder as much as possible. Measures to facilitate entry to the labour market are required, and these must be implemented in good time. A job coach will be needed to provide guidance in the workplace. This individual should always be available to deal with any problems that may arise. With regard to continuity of care, the Committee would like to see permanent arrangements put in place to provide the services of life coaches. Such people would be capable of providing guidance in the areas of health, education, employment and

municipal services, and possibly direct practical assistance for short periods of time (MEE social workers are already performing this role to some extent, and the Youth and Families Centres are assigned similar tasks). Cooperation between those offering treatment and those providing guidance should be encouraged and rewarded. The autism covenant can contribute to this, provided that the national coordinating effort is given an adequate mandate and sufficient resources, at least until such time as the regional organisations are up and running.

People with an ASD are different. They stay that way throughout their lives. Some individuals with ASD will need very intensive care, in institutions for example. Others are capable of living independently, without assistance. Given the right facilities, a significant proportion of the remaining individuals with ASD are capable of participating and performing fairly well (in some cases, very well indeed) in contemporary society.