
The request for advice

Date of request: 12 July 2008

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Several psychiatric disorders manifest themselves in childhood. In recent years there has been an increase in the demand for care from the parents of children with a psychiatric disorder. This has resulted from an increased focus on early detection and from redoubled efforts in the area of diagnosis and treatment. Pervasive Developmental Disorders, also known as Autism Spectrum Disorders (ASDs), have recently attracted a great deal of interest. These disorders are characterised by limitations in the field of social interaction, communication and imagination, and are often associated with stereotypical or rigid behaviour patterns. ASD has serious variants, such as childhood autism, in which the child has little or no contact with the outside world; but it also has milder variants, such as PDD-NOS ('pervasive developmental disorder – not otherwise specified') and Asperger's syndrome, which are characterised not so much by a lack of contact, but more by dysfunctional interactions and communications with those around them.

In recent years there appears to have been an increase in the number of children diagnosed with an autistic spectrum disorder. There has also been a clear increase in the number of claims for client-linked budgets or benefits under the Invalidity Insurance (Young Disabled Persons) Act (*Wajong*) that are associated with a diagnosis of ASD. Similarly, there has been an increase in the number of children / young people with ASD who rely on special-needs (secondary) education and / or pupil-specific funding.

The exact prevalence of ASD, however, is unclear. On the basis of data obtained from studies in other countries, the prevalence of ASD in the Netherlands has been estimated as at least 4 per 1000 children and young people up to the age of twenty.

A diagnosis of ASD requires specific expertise, as the diagnostic criteria for some behavioural traits within the spectrum are less clearly described than others, and this can mean that genuine cases can be overlooked while others are incorrectly diagnosed as having an ASD. Two distinct and highly important tasks are the identification of problems by non-professionals and the diagnosis of ASD by behavioural specialists. A complicating factor in this regard is that children with an ASD often exhibit other (mental) health problems such as ADHD or intellectual disabilities.

All in all, then, ASDs present a complex problem. Since it concerns children and young people, there is an obvious need for early detection, effective treatment and counselling; after all, the quality of their entire life is at stake. At the same time, it is important that unnecessary stigmatisation and faulty diagnosis are both prevented as much as possible. For this reason, we request that you advise us on this problem, and to provide answers to the following questions:

- 1 What is known about the prevalence of ASD in children, adolescents and young adults? How many children, adolescents and young adults are involved? What is the relative prevalence of serious and less serious forms (such as PDD-NOS)? What is the prevalence of comorbidity? How is ASD distributed between different social groups, and between the sexes?
 - 2 What are the possible causes for the observed increase in the prevalence (incidence) of ASD? To what extent is this growth related to indication processes themselves? Are ASDs subject to over-indication or under-indication? With this in mind, what is the best response to the rising demand within this group for specialist care? For instance, does this group invariably need 'care', or could other effective solutions be put forward?
 - 3 What problems do children, adolescents and young adults with an ASD encounter within the family, at educational institutions, and at work?
 - 4 In terms of the early detection, treatment and counselling of children, adolescents and young adults with ASD, what proven methods (both clinical and social) are available?
 - 5 What type of comprehensive approach is required to ensure the earliest possible detection of the most debilitating forms of ASD in children and young people, while simultaneously minimising the risk of overdiagnosis?
 - 6 What type of comprehensive approach best equips children, adolescents and young adults with an ASD to perform effectively within their social environments, at educational institutions, and at work?
 - 7 In the light of the answers to the above questions, what part could most usefully be played by each of the various professional groups involved?
 - 8 What substantive and organisational conditions must such a comprehensive approach meet in order for it to succeed?
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This research already forms part of the Health Council's working programme for 2008 (section 2.2), as laid down on 18 September 2007.

We would very much like to receive your advice no later than the spring of 2009.

The Minister for Youth and Families, A. Rouvoet

The Minister of Health, Welfare and Sport, Dr. A. Klink

The State Secretary of Health, Welfare and Sport, Dr. M. Bussemaker

The Minister for Social Affairs and Employment, Dr. J.P.H. Donner

The State Secretary of Education, Culture and Science, S.A.M. Dijkma