Autism spectrum disorders:
A lifetime of difference

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to:

the Minister for Youth and Families
the Minister of Health, Welfare and Sport
the State Secretary of Health, Welfare and Sport
the Minister of Social Affairs and Employment
the State Secretary of Education, Culture and Science

No. 2009/09E, The Hague, June 23, 2009

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Gezondheidsraad
Health Council of the Netherlands

To the Minister for Youth and Families
To the Minister of Health, Welfare and Sport
the State Secretary of Health, Welfare and Sport
the Minister of Social Affairs and Employment
the State Secretary of Education, Culture and Science

Subject	: Presentation of advisory report *Autism spectrum disorders: a lifetime of difference*
Your ref.	: DJenG/SenS-2842811
Our ref.	: I-350/08/VR/db/839-F
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Dear ministers and state secretaries,

I hereby present the advisory document Autism spectrum disorders: a lifetime of difference.

The document gives an overview of the state of current scientific knowledge on the prevention, treatment and supervision of autism spectrum disorders, and examines the problems encountered in providing the comprehensive approach that is needed to give people with these disorders the best opportunities for participating fully in society.

The committee concludes that effective detection and diagnosis are essential to the successful treatment and counselling of children, young people and adults with an autism spectrum disorder. Help for these people should be available at all times and throughout life, because the need for care and counselling changes continually in nature and intensity throughout their lives. The 'life coach' proposed by the committee can play an important coordinating role in providing this care, thus preventing problems from escalating.

A new research agenda can also streamline research towards new and effective treatment methods.

I endorse the committee’s conclusions.

Yours sincerely,
(Signed)
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Summary

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 individuals. 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 individuals. 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.

Chapter 1

Introduction

1.1 Background

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 (ASD), have recently attracted a great deal of interest. These disorders are characterised by limitations in the field of social interaction, communication and imagination. They are often associated with stereotypical or rigid behaviour patterns. ASD incorporate a wide range of different variants. In childhood autism, depending on their age, affected individuals make little or no contact with the outside world. Conversely, those with PDD-NOS *(pervasive developmental disorder – not otherwise specified)* or Asperger's disorder are characterised not so much by a lack of contact, but more by dysfunctional interactions 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 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.

There are no clear details concerning the exact prevalence of ASD. The prevalence of ASD in the Netherlands has previously been estimated mainly on the basis of data obtained from studies in other countries. This gives a figure of at least 4 per 1000, in an age group consisting of 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. 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 health problems (mainly mental health problems) such as ADHD. In addition, ASD are often associated with intellectual disabilities.

1.2 Request for advice

On 12 July 2008, 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 draft an advisory report on autism spectrum disorders (Annex A). They asked the Council to address the following eight questions:

1 What is known about the prevalence of ASD in children, adolescents and young adults?
2 What are the possible causes for the observed increase in the prevalence (incidence) of ASD?
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 evidence based methods (both clinical and social) are available?
5 What type of comprehensive approach is required for the early detection of ASD? What type of comprehensive approach could resolve the conflicting needs of identifying children and young people with ASD at the earliest possible age while avoiding a tendency towards overdiagnosis?
6 What type of comprehensive approach best equips children, adolescents and young adults with an ASD to perform effectively within the family (social environment), 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 conditions must a comprehensive approach meet in order for it to be considered successful?

1.3 Methodology

In order to answer these questions, the Vice President of the Health Council appointed a multidisciplinary committee of experts from the fields of care (including youth care), education, employment, and research, and others representing parent and patient organisations (Annex B). The Committee has met on six occasions. Various other experts have also been consulted (Annex C).

The literature on this topic has been searched and analysed as systematically as possible (for full details see Annex D). Unfortunately, in the field of autism spectrum disorders, too little of the available literature (and medical literature) meets the most demanding criteria in terms of experimental rigour. Accordingly, this advisory report also makes use of so-called ‘grey’ literature: reports, advisory reports and other documentation from the relevant ministries, from advisory councils (e.g.: the Social Economic Council, the Scientific Council for Government Policy, the Council for Social Development), research institutes (e.g. TNO), knowledge centres and centres of excellence (e.g. Knowledge Centre for Autism, National Autism Network), the Dr Leo Kanner House and the Dutch Association for Autism.

The advisory report focuses on individuals up to the age of 27. In theory, the advisory report covers the entire spectrum of autistic disorders. However, most of its conclusions and recommendations are aimed at the group with PDD-NOS and those with Asperger’s disorder. This is because, together, these represent over 75% of those with an ASD, and that, given sufficient assistance and support, these individuals generally have a better chance of performing fairly well in society. People with childhood autism are more frequently dependent on institutional care.

Given the scope of the request for advice and the limited time available in which to prepare this advisory report, the decision was taken to omit both the forensic aspects and the economic aspects of the issues in question. Examination of the forensic aspects would require an entirely different approach. In the case of the economic aspects, the scientific literature is too limited and any calculations concerning the Dutch situation would be outside the scope of the questions that this report is required to answer, and beyond the expertise of the Committee.

1.4 Structure of the advisory report

A multi-pronged approach based on several different domains proved to be the most practical way of answering the questions posed by the various ministries. Chapters 2 to 7 contain the arguments for chapter 8, where the questions set out in the request for advice are individually addressed, and in which the integrated conclusions and recommendations are formulated.

Chapter 2 contains a detailed examination of the ASD variants and the way in which they manifest themselves. There is also an outline sketch of the specific conditions of everyday life for ASD sufferers. Next, chapter 3 explores the identification and diagnosis of ASD, and discusses the prevalence of this disorder. In chapter 4, the current level of knowledge is presented, in terms of the treatment and counselling options for individuals with ASD. Chapters 5, 6 and 7 respectively focus on family life, education and employment. Chapter 8 contains the answers to the questions posed in the request for advice, in the form of this advisory report's conclusions and recommendations.

Chapter

2

The basic elements of this advisory report

This chapter commences with a brief explanation of what is meant by ‘autism spectrum disorders’. It goes on to outline both the range of clinical pictures and the common characteristics of these disorders, as well as their impact on the activities of daily life. As autism spectrum disorders are permanent, the next section briefly summarises the specific conditions of everyday life for ASD sufferers. It also addresses the conflicting demands associated with respecting these individuals’ personal development while restricting their independent participation in society.

2.1 What are autism spectrum disorders?

To the best of our knowledge, the term ‘autism’ (Greek for ‘self’) has been used in the Netherlands for more than seventy years. Records show that the Paedological Institute at Nijmegen was using this term in the period from 1937 to 1940 to designate children who were excessively self-involved. Such children were mainly distinguished by stereotypical behaviour patterns, extreme anxieties, and a pronounced resistance to change. The first scientific articles to extensively characterise children with autistic disorder (and to classify them in relation to other mental ‘diseases’) were published by the Austrian-American child psychiatrist Leo Kanner in 1943, and by the Austrian paediatrician Hans Asperger in 1944.[1,2] Kanner described a group of children with striking behavioural characteristics: from birth onwards they exhibited autistic solitude, no eye contact, stereotypical behaviour patterns, impaired language development, and an obsessive fear of change, in the absence of any obvious physical abnormalities. Kanner suggested that these children suffered from an ‘autistic disturbance of affective contact’. Asperger described a group of children with contact disorders. While such children were able to engage with their parents, they operated very much on their own, displaying little or no interest in interacting with others. In terms of language development, these children were clearly superior to those in Kanner’s group. Their speech, however, was often characterised by a loud and monotonous tone. In addition, for these children, speech was not primarily used for purposes of communication.

In 1994, the syndromes described above were incorporated into the DSM-IV classification, under the name of *pervasive developmental disorders*. In Dutch, they are described as *autismespectrumstoornissen* (autism spectrum disorders or ASD), to reflect the fact that there is clearly an entire spectrum of such disorders. This spectrum spans a wide range of disorders. At one extreme, there are individuals with severe intellectual disabilities and an impairment affecting socio-affective relating, plus many associated defects such as disorders of speech, language and motor skills. At the other end of the range are cognitively competent, intelligent individuals who are only deficient in terms of socio-affective relating.[3] Childhood autism is situated at the ‘serious’ end of the spectrum, while Asperger’s disorder is in a ‘more moderate’ region. In addition, there can be varying degrees of severity within a single classification.

DSM-IV defines three core symptoms for the spectrum. These are limitations in social interactions (especially in terms of social reciprocity), qualitative limitations in terms of communication (both verbal and non-verbal), and rigid, stereotypical behaviour. These core symptoms provide a basis for classification and diagnosis. Autism spectrum disorders occur more frequently in boys and men than in girls and women (the ratio is approximately 4:1). While the three core symptoms mentioned above are characteristic of autism spectrum disorders, they do not cover the entire range. There are many instances of comorbidity (e.g. ADHD or anxiety disorders), and about half those with an autism spectrum disorder also exhibit intellectual disabilities.

2.2 A lifetime of diversity and unity

ASD can manifest themselves in a wide variety of ways. Such differences can be related to the individual’s age and gender, as well as to their relationships with friends and family. The symptoms change throughout childhood and adolescence. The extent to which someone's ability to function is restricted by their autistic disorder is determined by their own personal development and by environmental factors. Indeed, it would not be too far from the truth to state that there are almost as many forms of autism as there are people with the disorder.

A large proportion of children with childhood autism exhibit little or no speech development. Furthermore, they do not compensate for this by means of nonverbal communication, such as establishing eye contact and the use of gestures. Those ASD sufferers who do exhibit speech development find it extremely difficult to express themselves in spoken language, and are often unable to understand non-literal language. They are generally better at written language. They are unable to answer open questions and the meaning of rhetorical questions escapes them entirely. They also continue to experience great difficulties in understanding other people's body language, facial expressions, and gestures, nor do they use appropriate body language to support their own spoken language. They are unable to appreciate jokes and irony, nor are they aware of things that are left unsaid. They are generally unable to engage in everyday social conversations. When collaborating with others, they often avoid any informal contacts. They can be excessively polite, expressing themselves in solemn, formal terms. However, they can also pose unexpected and inappropriate (unconventional) questions that others find embarrassing.

ASD sufferers have limited imagination, which makes it difficult for them to plan and organise things. They may become obsessed with specific issues. If they are drawn to a given topic they may gather enormous amounts of information on that subject, familiarising themselves with all the facts, and talking about it at great length. However, the essence of the matter escapes them. These individuals struggle to cope with unexpected situations and changes. They may panic if their routines are disrupted or if they are called upon to do several things at the same time. People with ASD often have trouble regulating emotion, both spontaneous and stress-related. As a result, some people with ASD can become enraged when told to 'wait until it is your turn'.

The movements of ASD sufferers are often stiff and awkward, and may be associated with rhythmical and/or stereotypical motions. Such individuals may find loud sounds, bright lights, certain colours, smells and tastes unbearable.

Furthermore, ASD sufferers are unable to integrate acquired knowledge effectively, and are seldom able to generalise acquired skills. They are poor at collating information into a meaningful whole. Autistic children in a maths class who are taught that two elephants plus one elephant equals three elephants may have the greatest difficulty in seeing that the same principle also applies to other animals and objects.[4] Their lack of an ability to generalise makes it difficult for them to apply what they have learned to new situations and to structure their knowledge in a meaningful way. The same may apply to acquired skills. While some children might be capable of travelling to school alone, it cannot be assumed that they can also manage the trip to the sports club, for example. It might be possible to show them how to shop in a given supermarket, but that does not mean that they would then be able to shop in a different supermarket, or in a shop where customers are served by sales assistants.

The above examples are no justification for adopting a stereotyped view of ASD sufferers. Some ASD sufferers go on to develop exceptional talents and make major achievements. Some famous writers, athletes, scientists and entrepreneurs are known to have a form of ASD.[5]

One factor that all ASD sufferers have in common is that the disorder will always be with them, and that they will always be deficient in some areas. In such people, acquired skills or abilities can be compared to a prosthesis that is only effective in exactly the same situation as that in which the skill was learned. A few metaphors might serve to clarify matters: Reading glasses are of no use if you need to see distant objects. A hearing aid may be a useful device at home, but you will not be able to enjoy a concert unless the concert hall is equipped with an induction loop system. Moreover, prostheses are generally something that you have for life. They need to be monitored at regular intervals to ensure that they still meet the requirements.

A combined approach is needed to enable ASD sufferers to participate in ‘everyday life’ as much as possible. This involves augmenting their abilities in terms of social adaptation as much as possible, as well as getting their family and friends to adapt to the limitations imposed by ASD.

2.3 The first step: a diagnosis

When an adult is placed in the company of a three-month-old baby, regardless of country or culture, the same type of communication – known as ‘proto conversation’ always ensues. They take turns in taking the initiative (which may involve sound, movement, or eye contact), in responding to each other’s initiatives, and in prompting further responses. It seems as if the child’s presence alone is enough to elicit certain spontaneous behaviour patterns in the adult. The adults’ behaviour is primarily aimed at triggering certain behaviour in the child, however, the behaviour triggered in the child elicits appropriate rearing behaviour by the adult.[6] If there is persistent awkwardness in this interaction, many parents will become intuitively aware of this at an early stage. They will then approach their GP, the staff of their post-natal clinic, or a paediatrician for advice on what might be the matter with their child. Any stagnation of early development can also be initially detected by the GP or at the post-natal clinic. In the classic form of autism (childhood autism), a diagnosis can be made at an early stage. However, this is not the case for many children with an ASD. The symptoms are either not yet recognised or they are not sufficiently pronounced to be recognised. As a result, diagnosis will be delayed until a later point in time. This might take place, for example, when the child first goes to a crèche or to primary school. One of the supervisors or teachers may notice that the child's intellectual and/or social development is not in line with expectations. Sometimes a diagnosis is not made until the individual has reached adolescence or adulthood, and sometimes not at all, even though they may be suffering from a form of autism. If the individual's development duing childhood and adolescence is in line with expectations, then a late diagnosis (or none at all) need not be an insurmountable problem. If problems occur in the absence of an early diagnosis, however, this represents a missed opportunity.

2.4 En route, but where to?

Even at an early age, children grow up in a number of different settings (institutional frameworks). Family, friends, school, care institutions – they each make their own contribution to the socialisation of children. Each of these settings plays a substantial role, and there is no specific hegemony.[6] Everyone has a part to play, and this collective aspect of childrearing is generally sufficient to enable children to become independent adults. The parents remain at the heart of this process, in addition to bearing the bulk of the responsibility. However, if their child has a developmental disorder, then they become partially dependant on the expertise, commitment and personal skills of various professionals and facilities.

Studies have shown that there is only a small probability that a child with an ASD will go on to lead a fully independent adult life.[44] However, once the diagnosis has been made, one of the main goals is to provide the affected individual with guidance that will enable them to live as independently as possible and to achieve their maximum potential. The right to an independent life is based on respect for an individual's autonomy, which is one of the pillars of our society.

How can respect for autonomy be interpreted in the case of ASD sufferers? Firstly, the individual in question is entitled to live his or her life as they see fit, without interference from others. Secondly, the aim is to enhance the freedom of action and choice of ASD sufferers.[7-9] Achieving what is important for them demands an active and supportive attitude. Autonomy is not an immutable factor. It continuously evolves over time, shaped by the process of growing up, by education and by the acquisition of experience. The fact that many cases involve an unpredictable outcome in no way detracts from the importance of trying to achieve autonomy.

Initially, those charged with counselling these individuals have to focus on intermediate goals. Step by step, each of these goals help such young people to live as independently as possible, while making full use of their talents.

'Matching short-term goals to the long-term goal of living as independently as possible' sounds inspiring, but actions speak louder than words. Treatment and training can often produce dramatic improvements in specific situations, provided that this is appropriate (see also chapter 4).[10,11] This creates a temporary equilibrium between the performance of an ASD sufferer and the actual situation. As change is inevitable, any such equilibrium will only be temporary in nature. This primarily involves the major transitions in life, such as the transition from the protected environment of the family to the larger world of primary school. Then there are the transitions to secondary school and higher education, then to work, and – if possible – to full independence. Of course, this route to independence is only applicable to those who, by virtue of their intellectual and social abilities, are eligible to make use of it.

The situations encountered within each of these different stages of life are rarely stable. Families themselves are not always stable, and parents often require help from outside the family. Teachers and caregivers come and go, and our changing society means that social structures too are continually in a state of flux. Whenever changes occur, the situation will have to be examined to determine whether there is still an equilibrium or whether certain re-adjustments are needed.

As stated, children grow up in a number of different settings and adults are constantly switching from one life domain to another: home life, work, leisure, friendships, relationships and care arrangements. The disruption of one of these domains may affect the stability of another domain. Even if an ASD sufferer has been performing reasonably well for many years, a seemingly small change in just one of these domains can still upset the applecart. What had been a seemingly stable situation only remained that way as long as an entire series of conditions were met. The individual in question is generally unable to analyse the problem or to indicate exactly what it is that has disrupted their routine.

Life's transitions must be repeatedly managed at the level of the individual, in order to reduce the impact of such changes on ASD sufferers as far as possible. The key elements are proactive supervision and careful monitoring. This means that the continuity of what has been achieved to date is safeguarded as far as possible. Furthermore, treatment and counselling must also remain available (or 'on call' at any rate) for situations that are currently in equilibrium.

2.5 Conflicting demands

In an ideal world, ASD sufferers would be free and autonomous individuals capable of achieving their full potential in terms of freedom and autonomy. It is also important to be aware of those aspects of life that are peculiar to children, adolescents and adults with an ASD. After all, it is by no means certain that they will actually be capable of achieving such autonomy, freedom and rights. The extent of an affected individual's limitations may vary, depending on the nature and severity of the ASD in question. Whatever the case, ASD sufferers require lifelong support from society if they are to achieve autonomy.

Any approach that focuses solely on either the 'opportunities' or the 'limitations' paradigm will be inadequate in this respect. In many cases, ASD sufferers will not take the initiative and request support. Generally, however, they will not reject unsolicited offers of support. It is not inconceivable, however, that such support could be imposed on them, nor indeed that a degree of compulsion might be involved. Any such approach would represent a threat to the individual's right to autonomy. The dilemma of finding an acceptable balance between 'the right to care and support' and 'pressure and compulsion' is not exclusive to ASD sufferers. Given our growing understanding of the nature of the disorder, the increased range of counselling options, and the pressure to participate in society, this target group may be faced with this dilemma more often than was the case in the past.

Chapter

3

Detection, diagnosis and prevalence

This chapter starts by focusing on the detection, classification and diagnosis of autism spectrum disorders. It then goes on to address the most common types of comorbidity. Another topic addressed here is the increased prevalence of this disorder that has been observed in recent years, and possible explanations for this. Finally, it sets out what is currently known about the possible causes of developmental disorders of this type. The final part of this chapter is devoted to conclusions and recommendations.

3.1 Detection

In the case of autism spectrum disorders, it has been found that many parents of children with an ASD that closely resembles childhood autism get the feeling that something is wrong with their child at a very early stage. Ideally, such parents will be able to put their concerns to their family doctor or to some other generalist (e.g. a physician at a post-natal clinic). The physician in question can then use a short questionnaire to assess whether the child has autism, or whether some other developmental or behavioural disorder is involved. If that does indeed prove to be the case, then the family doctor or post-natal clinic physician can refer the child for further diagnosis.

The problem with ASD is that these disorders are not all detectable at a very early stage (in pre-school children). Only in the case of childhood autism is it possible to reliably detect the disorder before the second year of life. PDD-NOS and Asperger's disorder generally take much longer to produce recognisable problems. These can manifest themselves in primary school, during the transition to secondary education or work, or when the nature of the individual's work changes.

A 2008 survey conducted among the members of the Dutch Association for Autism (NVA) revealed that the younger members were 5.3 years of age, on average, when it was first suspected that they suffered from autism.[12] This initial suspicion usually emerges following a period (often spanning many years) during which the parents intuitively feel that all is not well with their child, a period that is characterised by all manner of problems that are not easy to place. The respondents' average age at diagnosis was seven, which means that an average period of well over 18 months elapsed between the initial suspicion of autism and actual diagnosis. Data provided by the adult respondents indicated that they were 19.1 years of age, on average, when they were first suspected of having autism, and 20.7 on average when the diagnosis was made.

This section addresses the issue of detecting the disorder at various stages of life.

3.1.1 *Early detection before the second year of life*

The objective underpinning the early detection of autism spectrum disorders is to identify children with an ASD at as early an age as possible – preferably before they start school. This enables the child's treatment and care (and that of their family) to commence as soon as possible, to prevent further aggravation of the problem, and to promote the child's development.[13,227] Accordingly, it should be possible for the staff of post-natal clinics (youth healthcare) and family doctors to identify such children.

In the Netherlands, two research projects have been carried out on the detection of autism before the second year of life. These were the SOSO project (Screening Of Social Development) and the DIANE project (Diagnostic and Intervention study on Autism in the Netherlands).[14,15]

The SOSO project was conducted by the University Medical Center Utrecht (UMCU) in the late 1990s. It was a population-wide screening programme involving 30,000 children who were born in the province of Utrecht over a period of two years. This project employed a tiered screening method. First, four items from the ESAT (Early Screening of Autistic Traits) questionnaire, were completed at post-natal clinics for all children aged around 14 months. The parents of any child scoring positive for autism in one of the four questions were then offered a house call, during which the child was observed by a UMCU employee. If the suspicion of ASD was confirmed, then the final step would be an examination at the UMCU, for further diagnosis. While many cases were indeed diagnosed as disorders in the autistic spectrum, a variety of other disorders were also diagnosed.

An interesting spin-off from this project was that the participating post-natal clinic physicians proved to be much more alert to early signs of ASD. Under their own initiative, they later referred a number of older children to specialists. Following further examination, two thirds of these children were diagnosed with an ASD.

The SOSO project – like the studies carried out by Filipek (2000) and Wetherby (2004) – led to the formulation of a number of ‘red flags’ or warning signals (validated in the US) that can alert care providers/researchers to ASD (see box 1).[13,16] These signals occur in the areas of social reciprocity; language and communication; and stereotypical, rigid behaviour patterns.[15,17] The ‘red flags’ are useful for general practitioners as an initial “gut feeling” instrument, in combination with training on developmental disorders.

The findings of the SOSO project served as a basis for the DIANE project, which commenced in 2003. The above-mentioned warning signals were incorporated into the training of post-natal clinic staff and IHV teams (integrated early assistance) in the province of Gelderland and in large parts of Limburg, North Brabant and Overijssel. Rather than systematically screening all children of a certain age, this project relied on the alertness of trained professionals. Children who, on the basis of the 'red flags', were suspected of having a developmental disorder, were referred to a team of behavioural scientists, child psychiatrists, and adolescent psychiatrists, who carried out further diagnostic work. The effectiveness of this approach is illustrated by a five-fold increase in the number of references. Two-thirds of these were found to have an autism spectrum disorder, while most of the rest had another serious disorder. In the course of the next few years, the knowledge and experience gained in this way will be disseminated throughout the Netherlands. In a parallel development, the effectiveness of this approach will be tested in a project to be conducted by the Netherlands Organisation for Health Research and Development (ZonMw).[18]

Other post-natal clinics are also showing increasing interest in the early detection of ASD. Post-natal clinics in the Leiden region are making use of the PDDST-II-N (*Pervasive Developmental Disorder Screening Test-II-N*).[19] On Curaçao (white-yellow cross) a number of items from the M-CHAT questionnaire and AUTI scale have been added to the Van Wiechen schedule. The latter system has also been adopted by the University of Leiden. The above-mentioned ‘red flags’ should serve as an additional control.

- Not babbling by 12 months
- No interest in other people at 12 months
- Failure to smile back at other people at 12 months
- No reaction to being spoken to at 12 months
- No use of gestures at 12 months (pointing, waving)
- No functional use of single words at 18 months
- No two-word spontaneous (non-echolalia) phrases by 24 months
- Some loss of language or social skills at all ages
- At 24 months, no imaginative play

Box 1. ‘Red flags’ for the detection of possible autism.[17]

3.1.2 Detection in children of school-going age

If the problems occur at primary school or during secondary education, then the parents and teachers can complete a questionnaire, which – after interpretation by a psychologist or remedial educationalist – can be used to chart the pupil’s behaviour patterns. Some examples are the TRF (Teacher’s Report Form, ages 6-18) or the socio-emotional questionnaire (SEV, which is based on DSM-IV). These detection instruments can also be used by the youth care services. If there is a suspicion of ASD, more specific instruments can be used, such as the Social Communication Questionnaire (SCQ; Berument *et al.*, 1999) and the Children’s Social Behaviour Assessment Questionnaire (VISK, Hartman *et al.*, 2007).[20,21]

Where there is a strong suspicion of impairment, school social workers will refer pupils to the youth care agency, which then gives an indication for the mental health care service so that a diagnosis can be made. This is the official route. In practice, long waiting lists or long throughput times at youth care agencies often prompt schools to ask parents (depending on the region) to consult an independent psychologist (via their GP). In addition, a child’s GP can directly refer them to the youth mental health care service, or for child and adolescent psychiatric treatment.

If the child appears to be suffering from an ASD, then – at this age – it will usually be either PDD-NOS or Asperger’s disorder.

3.1.3 *Detection during adulthood*

In the case of adults, the task of detecting these disorders falls to the GP, occupational health physician, insurance physician or primary mental health carer, together with the individual concerned and their partner or family. There are no general detection instruments for developmental disorders in adults. If the primary carer already suspects ASD, then the AQ (Autism spectrum Quotient) test can be used to confirm these suspicions. The test was originally developed in Britain. It was translated into Dutch and validated by Hoekstra *et al.*[22,23] Two other tests that are increasingly being used are the EQ (empathy quotient) and SQ (systemising quotient), both of which were developed by Baron-Cohen's group in Cambridge.[24,25] Finally, there is a counterpart of the VISK test for adults, the VIS-V.[26]

When working with adults, professionals and generalists (even those specialising in psychiatry) often spend a long time exploring other avenues before they consider the possibility of an autistic disorder. For this reason, and because today's ASD sufferers encountered fewer problems in their youth (society in those days was more predictable and structured), there are probably many adults with an ASD who are, as yet, undiagnosed.

Recent years have been marked by a greater awareness for ASD within adult psychiatry, and the first teams specifically targeting adults with an ASD have now been established.

3.2 Classification and diagnosis

3.2.1 *Classification*

In the official classification systems (DSM-IV and ICD-10) the Pervasive Developmental Disorders section currently contains five classifications, the most important of which are autistic disorder, Asperger's disorder, and PDD-NOS. Rett's disorder and childhood disintegrative disorder are rare, serious conditions that fall outside the scope of this advisory report* (see the DSM-IV classification criteria for pervasive developmental disorders, Annex E).

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* In terms of their nature and etiology, these disorders differ from childhood autism, Asperger's disorder and PDD-NOS. On this basis, as part of the pervasive developmental disorder, they are the subject of debate. For this reason, these two disorders have been disregarded for the purposes of this advisory report.

In the clinical field, the term ‘autism spectrum disorder’ is increasingly replacing ‘pervasive developmental disorder’. The notion of a spectrum was conceived by Dr Lorna Wing (UK).[27] The concept initially involved a continuum, but that word suggests that there is a sliding scale of severity, both in terms of the symptoms involved and of the resulting limitations. The word ‘spectrum’ reflects the fact that these disorders occupy a range of domains, and that each of these disorders can vary in severity. An individual’s ability (or inability) to function, or the scope of their capacities, are only partially reflected by the severity of their ASD. The term ‘autism’ is better established than the term ‘pervasive’. The latter term indicates that the disorder interferes with development at a fundamental level.

The classification of autism is primarily dichotomous in nature. The disorder is either present or it is not, depending on the observed behaviour patterns. The three dimensions that the DSM lists as core problems are: problems in social interactions; problems in communication; and repetitive, stereotypical patterns of behaviour (see Annex E). Per domain, the criteria are worded in such a way that the disorder in question is always depicted as being serious in nature.

Cases that meet all of the criteria can be diagnosed as childhood autism. One way to classify less serious types of ASD is to reduce the number of requisite criteria.[28] Another approach is to examine less serious problems, per domain, which no longer reflect the severity of the individual criteria, but which still involve the above-mentioned triangle of issues and problems which adversely influence the development of behaviour and social abilities. If this is indeed the case, then PDD-NOS is involved. One problem is that, in the DSM, the ‘lower limit’ (the minimum level of severity) is not well defined. As yet, there is still no effective, clinically useful instrument to support a diagnosis of PDD-NOS. In the classification of Asperger's disorder, the main characteristics that distinguish this disorder from childhood autism and PDD-NOS is that there are no significant general shortcomings in terms of language development nor of cognitive development that started prior to the third year of life.

Of the three core problems, the criterion of stereotypical behaviour patterns is also seen as a result of shortcomings in imagination. This represents a step from the behavioural level to the cognitive level, thereby opening the debate for a more dimensional approach to ASD, in addition to a categorical one. Dimensional components (i.e. a focus on the individual capabilities and limitations) can serve as indicators that provide a better understanding of the disorder itself. However, it might also be possible to use them as an endophenotype (see section 3.5). In addition to the categorical approach, DSM-V (which is expected to be published in 2012) will also incorporate the dimensional approach.

3.2.2 *Diagnosis*

A diagnosis within the autistic spectrum can only be made by a multidisciplinary team led by a child and adolescent psychiatrist who is registered under the Individual Health Care Professions Act (BIG), a health care psychologist, a child and adolescent psychiatrist or an REG (remedial educationalist – generalist) specialised educationalist. Diagnosis takes place in the youth mental health care service (secondary health care), in university outpatient clinics (secondary and tertiary health care), and in autism teams (tertiary health care).

The use of a questionnaire as the sole diagnostic instrument is insufficient for a reliable diagnosis. The central pillar of the diagnostic process involves gathering information from various informants and details of a range of situations normally encountered by the patient in question. A diagnosis results from the collaborative efforts of a team of experienced professionals, who sift through and weigh up of the available information. This reflects the fact that the presentation of ASD is the result of a complex interaction between susceptibility and environment.

The diagnostic path consists of an extensive interview with the parents. This is based on diagnostic instruments such as the widely used ADOS (Autism Diagnostic Observation Schedule), the ADI-R (Autism Diagnostic Interview-Revised) and the DISCO (Diagnostic Interview for Social and Communication Disorders). In the case of an adolescent or an adult, the individual in question is also interviewed. Depending on the setting in which the diagnosis is made, the individual in question is observed at home, at school or at work or the school is contacted (this includes a written report by one of the teachers who are directly involved or by a member of the school's management team). Finally – in the light of further care – the specific capabilities and limitations of the individual in question are identified, including any co-morbidity. A psychiatric family case history is also taken, to check for a possible genetic component for their autism.

As part of the diagnostic process, the professionals now have access to sufficient, good quality, standardised diagnostic instruments with which to diagnose children of school-going age. In addition, advances in our knowledge of autism spectrum disorders mean that these instruments are continuously being upgraded and improved. For an overview of this situation, see the Guideline on Autism Spectrum Disorders (*Richtlijn Autismespectrumstoornissen*) by the Dutch Association for Psychiatry and the website of the National Expertise Centre for Child and

Adolescent Psychiatry.[29,30] However, there are still only a limited number of instruments available for use with adults and with children aged from two to four.

The enormous amount of diversity spanned by the spectrum means that specific knowledge and experience in diagnosing autism are at a premium.

3.3 Bottlenecks in detection and diagnosis

With regard to detection, generalists such as GPs, physicians at post-natal clinics and at child health clinics, occupational health physicians and insurance physicians, as well as professionals working in the youth care services, generally have too little knowledge of autism spectrum disorders and of appropriate instruments (questionnaires, or short checklists) that could be used to verify any suspicions that they might have. This situation is further complicated by the fact that adults in particular do not seek help directly in connection with suspicions (either their own or those of others) that they might be suffering from autism. Instead, they present with problems at work, relationship problems, burnout or depression, which can mislead the primary mental health carer involved. As a result, it may be a long time before the suspicion arises that an ASD might explain the reported or observed problems, and before action appropriate to a disorder of that nature is taken. Furthermore, the professionals who first detect such cases often do not know to whom they should refer someone suspected of suffering from an ASD.

When individuals approach the mental health care service, or are referred to it without a specific suspicion of ASD, experience shows that this service's knowledge of autism spectrum disorders is sometimes inadequate. In such cases, it often fails to identify ASD as the root cause of the behavioural problems in question. This lack of knowledge is mainly encountered in the area of adult psychiatry, although this situation is slowly but surely changing for the better.

When those suspected of suffering from an ASD are referred directly to the appropriate carer, they will be faced with waiting lists. For example, autism teams throughout the country have waiting lists of three to twelve months. When the referred individuals finally reach the top of the list, the preparatory work carried out by the professionals who first detect such cases is not always 'trusted'. The result is that the preliminary detection work (or parts of it) tends to be repeated.

Funding and an emphasis on production also pose difficulties. Making a diagnosis within the autistic spectrum is a labour-intensive affair. Ideally, the individuals passing through this system will all receive an action-oriented diagnosis, one which creates avenues for further assistance. In practice, however, those involved often restrict themselves to an ‘all-or-nothing’ or ‘black-and-white’ diagnosis. This involves establishing a DSM-IV classification without properly identifying the specific capabilities, limitations and care requirements of the individual in question.

There are four factors that tip the balance in favour of all-or-nothing diagnosis. These are costs, shortage of time due to the focus on production, the DTC (Diagnosis Treatment Combination) system, and the fact that applying for an indication for care under the terms of the Exceptional Medical Expenses Act (AWBZ), client-linked budgets (PGB) or special education/pupil-specific funding (LGF) requires only one classification, and not a more extensive diagnosis and treatment report. Simple classification is faster and cheaper than preparing a full, action-oriented diagnosis. The DTC (Diagnosis Treatment Combination) classification system too, which links a simple diagnosis to an associated course of treatment, is primarily classification oriented. While specialist DTCs capable of overcoming this problem are under development, it is not yet known when they will actually become available.

3.4 Comorbidity

Comorbidity is defined as the occurrence of two or more psychiatric and/or somatic disorders in the same individual. A significant proportion of ASD sufferers have comorbidity.

One problem associated with descriptions of psychopathological comorbidity is that there is uncertainty about whether certain symptoms should be seen as separate pathologies (i.e. ‘real’ comorbidity) or as symptom clusters within the autistic spectrum.[31] This section makes no comment on this issue. Comorbidity is described in accordance with the criteria adopted by the authors of the literature used.

3.4.1 Intellectual disabilities

The current international literature shows that between 40% and 60% of ASD sufferers also have an intellectual disability. Earlier studies cite a higher percentage for intellectual disability. Table 1 illustrates the results of a literature survey.

In children with an ASD, IQ partly determines the ratio of boys to girls. The lower the IQ, the lower the ratio of boys to girls. In the case of very severe intellectual disabilities, just as many girls as boys are affected. In highly intelligent children with an ASD, the ratio of boys to girls is 8:1. In this regard, no ethnic differences were found. In general, intellectual disability is the most common comorbid characteristic of ASD.

3.4.2 *Other comorbidity*

A recent article by Simonoff *et al.* (2008) reported 70% psychiatric comorbidity in a group of 112 children with an ASD. The most common diagnoses were: social anxiety disorder (29.2%), ADHD (28.2%), and oppositional defiant disorder (28.1%).[36] Eighty-four percent of ADHD sufferers also had a second comorbid disorder. Nicolas *et al.* (2008) argue that the DSM-IV-TR prohibits a diagnosis of ADHD if a diagnosis of ASD has already been made.[35] Nevertheless, they observed ADHD-like symptoms in more than 80% of children in South Carolina with an ASD. The new Guideline on Autism Spectrum Disorders from the Dutch Association for Psychiatry cites ADHD and anxiety disorders as the most common comorbid psychopathologies.[29]

Instances of somatic comorbidity have also been reported in the literature. For instance, epilepsy is more common in people with an ASD (4% to 42%) than

Table 1 Literature survey of intellectual disabilities among individuals with an ASD.

References	Study population	% intellectual disability	n =
Yeargin-Allsopp 2003[32] ASD prevalence study	Children aged 3-10 from five counties in Atlanta, Georgia, US, who participated in the Metropolitan Atlanta Developmental Disabilities Surveillance Program.	68	880 (from 987ASS)
Fombonne 2005[33] Survey article on the epidemiology of ASD	Children from different age groups/backgrounds	70	19 studies
Chakrabarti 2005[34] Prevalentiestudie ASS	Children born between 1-1-1996 and 31-12-1998, living at Stafford or Cannock, in the English midlands, on 1-4-2002	60 (total) 67 (childhood autism) 12 (PDD-NOS) 0 (Asperger)	57 21 25 11
Nicholas 2008[35] Prevalentiestudie ASS	Eight-year-old children in South Carolina, U.S. - CDC Autism and Developmental Disorders Monitoring Network.	62	182 (from 295 ASD)
Kraijer 2004[264] manual on ASD and intellectual disability	ASD sufferers	40-60	Literature survey
2001, 2004, 2008 surveys of NVA members[12,41,42]	Members of the NVA IQ<70	14 (2001) 13 (2004) 13 (2008)	2088 respondents 3035 respondents 2275 respondents

in the general population (0.7% to 1.7%).[37-40] Motor problems are also mentioned just as frequently. Motor skills in young children with an ASD, often appear to develop more slowly. Among 154 children with an ASD, Ming *et al.* (2007) reported hypotonia in 51% and motor apraxia (clumsiness) in 34%. These individuals tend to close this developmental gap in later life. In another study, Nicholas *et al.* (2008) confirmed the high frequency of motor problems, reporting this type of comorbidity in 62% of children with ASD.[35] In addition, they found that more than half of the cases presented with sleeping or eating problems. The 2002 and 2005 surveys of NVA members showed that, respectively, 34% and 44% of respondents received sensomotor therapy, psychomotor therapy or physiotherapy. In the respective surveys, forty and fifty percent of respondents were above the age of twelve.[41,42]

Gurney *et al.* (2006) showed that, compared to the parents of non-autistic children, the parents of autistic children indicated that their children had a much greater requirement for medical care.[43] This is reflected by more frequent visits to their GP and to hospital. This is primarily related to autism-related behavioural problems and to spoken language disorders, but also to anxiety disorders and motor problems. Highly intelligent adult ASD sufferers also have a higher than average risk of depression.[44]

3.5 Nature or nurture?

3.5.1 Aetiology

The cause of ASD is unknown. Kanner believed that a lack of parental love may be involved, as well as a high socioeconomic status (Kanner 1943). However, it is now clear that neither parental love nor social background determines whether individuals develop an ASD.[3,45] In the 1990s, the combination vaccine for measles, mumps and rubella (MMR vaccine) was briefly suspected of causing autism. It soon became clear, however, that there was no valid scientific basis for this suspicion. Some large-scale epidemiological studies have now totally invalidated the suggested link between vaccination and autism.[46-49] Recent studies have produced evidence that the age of the parents is a risk factor for autism. Compared with younger parents, fathers aged over 40 and mothers aged over 35 are at increased risk of having a child with an ASD.[50,51]

A small proportion (3-10%) of ASD sufferers also have a known genetic condition –such as fragile-X syndrome or tuberous sclerosis – with autism as one of the associated characteristics.[33,52-54] In 80% of cases, Rett Syndrome too can be traced to a specific gene defect.[55]

While in most cases of ASD it is not possible to indicate a clear strictly causal factor, it is now apparent that autism is genetically determined in 90% of cases.[54,56-59]

New technology for 'testing' large quantities of genetic material for possible associations with various disorders has highlighted a number of genes that may be implicated in the development of autism. In this connection, it should be noted that autism is not caused by a single gene. The cause must be sought in a combination of genes, together with as yet unknown environmental factors. To date, genes implicated in this disorder have been identified on chromosomes 2, 7, 11, 15, 16 and 17.[60-65] These are mainly genes coding for proteins that are involved in the transmission of impulses between nerve cells in the brain.[66,67]

Not so long ago, genetic research into psychiatric disorders in general was expected to produce major advances. However, these overblown expectations have been tempered by the limited progress made to date. The reason for this is that psychiatric disorders appear to be largely multifactorial in nature, i.e. caused by a combination of genetic and environmental factors. Researchers have now switched their efforts to the search for endophenotypes. These are biological or neuropsychological markers that (a) are related to the disease within the population; (b) are themselves heritable; (c) can also be shown to be present when the disease has not manifested itself; and (d) cosegregate (are inherited together) with the disease within families; and (e) occur more frequently in the relatives of patients than in the general population. Endophenotypes are better defined and more quantifiable than either behaviour or subjective experiences. As a result, it is anticipated that it will be easier to link them to gene activity. Moreover, they are probably influenced by fewer genes than the ultimate manifestation of the clinical picture. Finally endophenotypes are much better suited than behavioural measures to studies that employ animal models. Given all these factors, endophenotypes offer an attractive intermediate step in research into the genotypes of psychiatric diseases.[68] The next few years will show which endophenotypes are involved in ASD. It should also be noted that social context will continue to play an important part in the manifestation of ASD.[69,70]

3.5.2 *Course*

Autism is a developmental disorder. However, that is not to say that children, young people, adolescents and adults with an ASD are incapable of developing. They do develop, each in their own way, just like everyone else. This fact makes it difficult to predict the course that ASD will take in a given individual. Research shows that 5% to 17% of such individuals lead a satisfactory social life and that they perform reasonably well at school and at work.[44,71,72] Two thirds to three quarters of all ASD sufferers also have a more serious disability, and remain dependent on counselling, special needs education and customised work. The prognosis in a given case depends on the intellectual capacities of the individual in question. Children with a normal IQ and normal language development have the best prognosis, while those with a low IQ and impaired language development have the worst prognosis. In the case of children with a normal to high non-verbal IQ but with impaired language development, it is difficult to give a prognosis. The degree of social adjustment is also a predictor for the prognosis.[3,73,74] However, most of those who had a good prognosis as children continue to remain dependant on support and on special facilities in adulthood (see also chapter 5).

3.5.3 Gender

Autism is more common in boys and men than in girls and women. This raises the question of whether these disorders are an expression of male thought patterns and whether boys are naturally more prone to develop autism than girls.

From the moment of birth, girls focus more on people's faces than do boys. Boys tend to be more attracted to moving objects. Throughout the entire course of development and into adulthood, girls are more sensitive than boys in social and communicative terms. Boys' talents lie more in the non-verbal area: spatial and technical insight are better developed in boys and men than in girls and women. Accordingly, autism is sometimes interpreted as being the product of an extremely male brain.[75]

Roughly speaking, there are two theories which explain gender-based differences in the occurrence of autism. The first theory postulates a link with the sex chromosomes. Men have only one X chromosome (and one Y chromosome), while women have two X chromosomes. One theory postulates a variety of mechanisms by which the possession of just a single X chromosome might lower the threshold for the development of autistic characteristics. It is suggested that a second X-chromosome might shield individuals from such susceptibility.[76-78] The second theory suggests that exposure to testosterone in the womb is linked to the development of autistic characteristics.[79,80] Such exposure would predispose individuals to excessive systematising while reducing their capacity for empathy.[81]

One aspect that is common to both theories is that autistic sensitivity is not peculiar to ASD sufferers as a group, instead it can be said to be a general characteristic of gender-based differences.

Among high-functioning autists, girls exhibited a higher incidence of psychiatric comorbidity than boys.[82,83] The girls tended to have more social problems, as well as problems with concentration and thinking. The explanation put forward to account for their social difficulties was that girls are more deeply affected by the failure of social interactions than are boys.[84] After all, girls are more socially oriented than boys and they demand more from their relationships. Furthermore, the possibility cannot be ruled out that parents place greater demands on their daughters' social interactions than on those of their sons.

3.6 Increasing prevalence?

3.6.1 Prevalence in the literature

The prevalence of a disorder is defined as the number of cases in the population (per thousand or per ten thousand) at a specific time or during a defined period. Incidence indicates the number of new cases of a disease in a given period of time. Given that autism spectrum disorders are congenital and chronic in nature, occurrence is usually described in terms of prevalence.

Estimates of prevalence have changed over the course of time. In the 1970s the reported prevalence was 2 to 5 per 10,000. These were mainly cases of childhood autism, as the categories of PDD-NOS and Asperger's disorder were not added to the DSM (the classification system for psychiatric disorders) until the 1980s and 1990s, respectively.

The increased prevalence of autism spectrum disorders since then cannot be solely attributed to the addition of the PDD-NOS and Asperger's categories. The most recent studies cite a prevalence of 9 (Portugal, Oliveira *et al.*, 2007) to 116.1 per 10,000 (South Thames UK, Baird *et al.* 2006).[85,86] Survey reports by Fombonne *et al.* (2001,2005), Wing *et al.* (2002) and the EU (2005) cite an average overall prevalence of around 60 per 10,000.[33,46,87,88] The most recent study from the United Kingdom (2008) gives a prevalence of 51/10,000, for all types of ASD combined.[89] Of these, approximately one quarter represented childhood autism, more than half were PDD-NOS, approximately one eighth were Asperger's, and the rest were other disorders in the autistic spectrum (for a literature survey see Annex F). To date, no differences in prevalence between ethnic groups have been observed.[32,33,90]

In a 2006 systematic review, Williams *et al.* screened and analysed literature on prevalence that was published between 1966 and 2004. The analysis reveals an increase in overall prevalence from approximately 10/10,000 (up to the 1990s) to approximately 100/10,000 in 2004.[91] It should be noted that, until 1998, the criteria used for the diagnosis of ASD were more restricted than in the period thereafter. The emphasis shifted from an assessment of severe deficiencies to an assessment based on qualitative deficiencies. In effect, this represented a broadening of the definition of autistic disorder. Moreover, growing familiarity with the disorder meant that it was detected more frequently.[33] The Committee has supplemented the above-mentioned survey by Williams *et al.* with material that was published between 2004 and 2008 (Figure 1).

The most recent studies are based on a group of children of a specific age, usually of primary-school age. A check is made to determine whether these children have been diagnosed with an ASD (such information is generally obtained from medical records and/or school records). If they have, then a check is made to see whether this diagnosis is correct, i.e. by means of a validated diagnostic instrument. Once the number of children with a valid diagnosis of ASD has been determined, the prevalence is calculated.

The most recent studies (since 2000) to be carried out using this method generally give a value for total ASD prevalence of about 60/10,000.

In 2006, Baird *et al.* took a different approach. They first took a given age group and selected a group of children who were at increased risk of ASD. These were children who had already been diagnosed with ASD and those with a statement for special educational needs.[86] Each of these children was sent a Social Communication Questionnaire (SCQ), which is used to screen for ASD. A group of children (selected using statistical methods) whose parents had completed the questionnaires was further examined for autism spectrum disorders. Statistical models were then used to convert the results into a prevalence value for the entire population. In making their selections and calculations, Baird *et al.* corrected for factors such as the socio-economic status of the children, their gender, their scores on the SCQ, and the group from which they came (a local ASD diagnosis or a statement for special educational needs). Using this method, Baird *et al.* arrived at a prevalence of 116.1 per 10,000. Honda *et al.* (2005) and Tebruegge *et al.* (2004) also derived relatively high prevalence rates of 88 and 90 per 10,000.[92,93]

As yet, no data is available concerning prevalence in the Netherlands. In the autumn of 2008, Baron-Cohen’s group at the University of Cambridge (UK) launched a study into the prevalence of ASD in the Dutch regions of Eindhoven (the local authority areas of Eindhoven, Waalre and Veldhoven), Utrecht (the city only, not the province of the same name) and Haarlem (the local authority areas

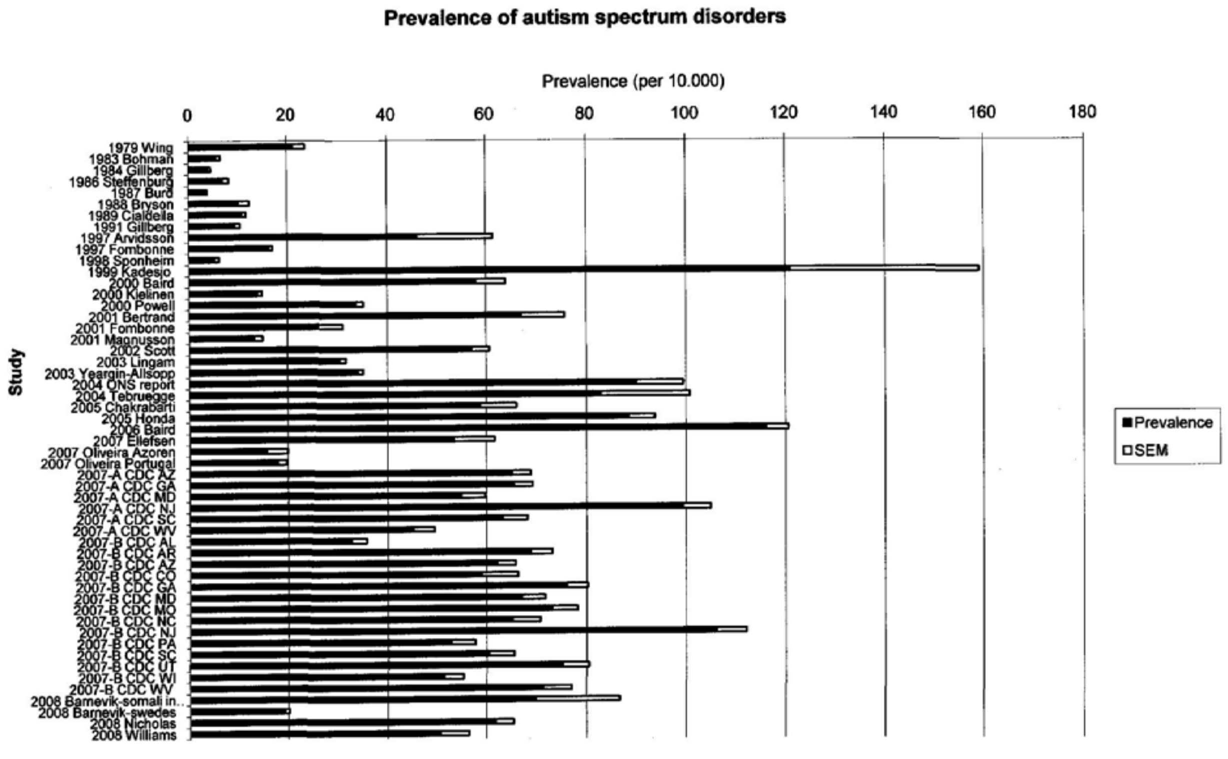

Figure 1 Bar chart of prevalence estimates + SEM (standard error of the mean) of studies of all autism spectrum disorders, Williams *et al.* 2006, supplemented with literature from 2004-2008.

of Haarlem and Haarlemmermeer). The researchers will be writing to all primary and secondary schools (both special needs and mainstream) in these regions. The researchers are interested in the prevalence of ASD in these regions, and in possible regional differences in prevalence. In the first phase of the study, enquiries focus solely on the number of children at school who are registered with an officially established diagnosis. Accordingly, any as yet undiagnosed children are not included in the study. Inasmuch as it does not use screening procedures to determine prevalence, the design of this particular study differs from that of most epidemiological prevalence studies. The first results are expected in the spring of 2010[*].

To date no ethnic or cultural differences have been observed in the prevalence of autism spectrum disorders. The obvious assumption, therefore, is that prevalence in the Netherlands will not be significantly different from that in other countries. The Committee has therefore assumed that prevalence in this country is between 60 and 100 per 10,000.

The European Autism Information System (EAIS) is a project funded by DG-SANCO (European Commission). Once it is up and running, this project is expected to contribute to efforts to determine the prevalence of ASD in Europe. As part of this project, instruments were developed between 2006 and 2009 that are intended for use throughout Europe to determine the prevalence of ASD and to enable its early detection. The Netherlands is not among the European countries that are collaborating on this project. The closing conference took place on 26 September 2008. The aim is to mobilise additional funding instruments in order to establish a Europe-wide surveillance system for ASD, and to enhance early detection in the individual states.[94]

3.6.2 Possible explanations for this increase in prevalence

In the national and international literature, a number of factors have been reported that might account for the observed increase in the prevalence of autism spectrum disorders. This topic will be examined in greater detail in this section.

The most frequently cited factor for the observed increase in prevalence is the increased focus on autism spectrum disorders, together with the addition of the Asperger’s disorder and PDD-NOS categories to the DSM.[33,87] Also, the DSM-

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[*] personal communication from Dr. R. Hoekstra and Prof. S. Baron-Cohen.

IV (TR) will incorporate a broader definition of the autistic disorder than previous versions. Descriptions such as ‘severe deficiencies’ have been amended to ‘qualitative deficiencies’. Moreover, psychiatrists’ views concerning the severity of these disorders have changed. They now recognise that disorders such as Asperger’s and PDD-NOS, which were previously seen as a lighter form of ASD, can often have serious implications in terms of the activities of daily life. In addition, various publications have suggested that a catch-up manoeuvre with regard to previous diagnostic practices may have contributed to the increased prevalence that has been measured. Those who had not previously been diagnosed, were now being diagnosed with a disorder in the autistic spectrum.[95]

The second factor cited in the literature to account for the increase in prevalence is diagnostic substitution. For instance, a recent study by Bishop *et al.* found that when current diagnostic instruments were used, two-thirds of adults who had been diagnosed with a language acquisition disorder as a child now appear to have an ASD.[96-98] In these cases, the language acquisition disorder was a symptom of these individuals’ autistic disorder, not a distinct disorder in its own right.

In Canada, diagnostic substitution was observed when the classification for special needs education was changed.[99,100] This means that the introduction of a different classification, adding new diagnoses or subdividing existing ones (to assess whether a child was eligible for special needs education) boosted the numbers of children falling into the ASD category (previously they had been classified into a spoken-language disorder group, for example).

A third factor may be the changes that society has undergone over the past thirty years. During that period, the Western world has developed from an industrial society to one based on service industries, in which social skills have become increasingly important and social systems ever more complex.[101] Today, workers often hold meetings on the shop floor, something that was virtually unheard of in the 1970s. Thirty years ago, traditional classroom teaching methods were still in use, with a teacher at the front of the class and each child working independently. Schools currently expect children to work in groups and to be able to plan their studies independently (the ‘study house’ system). These days schools organise a range of projects and activities (both ad hoc and scheduled), whereas order and regularity was the motto in the past. The systems in use thirty years ago tended to favour individuals with PDD-NOS or Asperger’s disorder, in the sense that they did not stand out so much, and that they were able to function reasonably well. These days, they are unable to meet the social demands placed on them.

A fourth explanation for the observed increase in the prevalence of autism spectrum disorders derives from the fact that they are multifactorial in nature. In other words, both genetic and environmental factors are implicated in the development of these disorders. It may be that, these days, the environmental factors which interact with a pre-existing susceptibility to ASD to produce the disorder were simply not present in the society of thirty years ago. This, in turn, gives rise to two possible explanations. The first is that the environment might augment latent disorders, causing them to be more clearly manifested.

The other possibility is that initially there is no disorder at all, just a predisposition (increased susceptibility to developing the disorder). The actual development of the disorder is triggered by environmental factors. There are indications that environmental factors can instigate genetic changes in the *function* of genes without involving any changes in the structure of the DNA itself. This field of research is known as epigenetics. There appears to be a form of regulation that can permanently switch genes on or off. These ‘on and off modes’ can then be passed on to a subsequent generation. If a predisposition to autism were to arise during the life of an individual, it could also be transferred to subsequent generations in this way. Environmental factors such as a ‘more dynamic’ and flexible society would then be a prerequisite for setting genetic changes in motion, subsequently leading to an increase in incidence.[102-105]

The fifth and final explanation – related to diagnostic substitution (the second factor cited) – concerns the so-called ‘perverse incentives’ inherent to the funding of care or disability.[106] If inflow rates for ‘cluster 4’ special needs education (the system within which most children with an ASD are educated) are used to calculate ‘prevalence’, the figure obtained is higher than those cited in the international scientific literature (145/10,000 versus 60 to 100/10,000). If prevalence in the Netherlands does indeed exceed 100/10,000, then Dutch mechanisms for the funding of care may well have something to do with this. Those with psychiatric problems require a DSM-IV classification to qualify for care covered by health insurance under the terms of the Exceptional Medical Expenses Act (AWBZ) or in the form of a client-linked budget (PGB). The same applies to the process of obtaining an indication for special needs education (and the associated pupil-specific funding). In short, labels are the key to funding. No label equals no support. This funding mechanism tends to increase the risk that schools or parents will, to some extent, tend to exaggerate the problems of the children in question. In addition, those involved might also be at risk of adopting a blinkered approach to this issue. This would result in an all-or-nothing diagnosis whose sole purpose is to produce a classification that makes no allowance for the specific potential and limitations of the individual in question. Furthermore, in the case of pupil-specific funding, the organisation setting the indication (the Needs Assessment Committee (CVI), which is usually located in a Regional Centre of Expertise) has an indirect vested interest in assigning an indication.

This fifth explanation should be interpreted with the appropriate degree of caution, as its statements are unsupported by any previous studies.

3.7 Conclusions

There is room for improvement in the use of case finding to detect autism spectrum disorders at various stages of life. Instruments for the detection of an ASD are not available for all of the stages of life at which such disorders can start to cause problems. In particular, there is a lack of reliable and valid instruments for detecting ASD in adults, and in children from two to four years of age. However, such instruments are available for children below the age of two, and for those of school-going age.

Generalists often have too little knowledge of ASD for them to be able to reliably indentify such disorders. Clarity about care and knowledge infrastructures varies from one region to another. Furthermore, they have long waiting lists, which jeopardises referral and coordinated (seamless) healthcare. Within the mental health care service too there is still insufficient knowledge about autism spectrum disorders. This applies to the area of adult psychiatry in particular, although there have recently been some changes in this regard. Little confidence is placed in any preparatory work that has not been carried out by mental health care diagnostic facilities.

The way in which mental health care and special needs education are funded may tend to favour the use of all-or-nothing diagnoses.

Alongside intellectual disabilities, the majority of comorbidities observed in autism spectrum disorders consist of ADHD-like symptoms, anxiety disorders, and motor problems.

On the basis of its study of the scientific literature, the Committee concludes that ASD prevalence in the Netherlands is at least 60/10,000, and possibly as high as 100/10,000. The observed increase in prevalence cannot be traced to a single cause. It was – and still is – multifactorial in nature.

3.8 Recommendations

The Committee recommends that a uniform method for the early detection of ASD prior to the second year of life be adopted throughout the country. This method consists of an extension of the Van Wiechen schedule, involving the use of ‘red flags’ for developmental disorders, thereby enabling most of the detection work to be carried out at post-natal clinics. This may require that the scope of youth healthcare be expanded. If they are to perform such detection work effectively, GPs and physicians at post-natal clinics will require further training.

The Committee recommends that a similarly uniform method be adopted for the detection of ASD in children of school-going age. Affected individuals would then be detected in schools, by the school doctor, or by their own GP. This would require special training for GPs and for those responsible for individual educational needs programmes.

All of those involved would have to make appropriate arrangements with regard to referring children for diagnosis.

The Committee recommends that expertise on autism spectrum disorders be improved throughout the health care chain. Enhanced expertise will produce corresponding improvements in detection. Detection instruments for the later stages of life have yet to be developed.

Professional development in the mental health care system will help professionals to consider autism when reviewing possible underlying causes of symptoms that are not specific to autism, such as those associated with burnout and depression.

The DTCs (Diagnosis Treatment Combinations) employed in the mental health care service should provide for a complete diagnostic path for ASD.

Chapter 4

Treatment and counselling

This chapter deals with the current level of knowledge with regard to treatment and counselling interventions used for ASD sufferers and/or their families. It also examines the current practice of treatment and counselling, and the needs assessment required to fund such measures. The final part of this chapter is devoted to conclusions and recommendations.

4.1 Current level of knowledge

4.1.1 Treatment of ASD

The term ‘treatment’ can be interpreted in two ways, either as a procedure aimed at curing the disorder or as a procedure aimed at combating the effects of the disorder (combating symptoms) or those of any comorbidity that may be present. Counselling refers to other interventions, focused more on helping to structure and organise everyday life and to provide support for daily activities.

Searches at the highest level* of evidence for treatments for autism yield extremely meagre results. Simply stated, there is no cure for ASD. Furthermore, searches for tried and tested ways of simply treating the symptoms also yield little or nothing. Just twenty systematic reviews have been found. Without exception, these conclude that the studies that have been carried out to date are too limited in scope and too diverse in design to enable valid conclusions to be drawn about effectiveness. These include reviews of studies into the effectiveness of various methods of treatment ranging from intensive behavioural interventions to music therapy and pharmacotherapy. Table 2 contains a summary of the above-mentioned systematic reviews, and their conclusions. These are mainly reviews of studies carried out in children. For further details of these reviews, see Annex G.

Early intensive behavioural interventions (EIBI) are, for the time being, the best option in terms of their effectiveness in improving cognitive, communicative and social skills, as well as reducing problem behaviour of children with an ASD (evidence level 2 to 3). Although there are various forms of EIBI, they all have certain essential elements in common, namely techniques developed within learning theory and behavioural science. In addition, it is vital that parents be involved in all aspects of the treatment.[125] In EIBI, a specially trained team, which includes both teachers and parents, visits children with an ASD (usually at home) and teaches them a number of skills. The training courses are given in a one-on-one setting. The content of these training courses are tailored to the child's specific capabilities and limitations. The therapy is intensive (twenty to thirty hours per week for one to two years on average and up to a maximum of forty hours per week for more than six years) and the children's average age at commencement is three-and-a-half.[125,128] The literature gives no indication of whether and if so, to what extent, this therapy is useful for older children (e.g. those who were not diagnosed until they were seven years of age).

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* *Evidence level 1:* Study conclusions based on a systematic review of at least two high-quality, double-blind randomised controlled trials or high quality, cohort or case control studies carried out independently of one another.
Evidence level 2: Study conclusions based on at least one high-quality, randomised, double-blind trial or high quality, cohort or two high quality, cohort or case control studies.
Evidence level 3: Study conclusions based on one comparative study or case control study.
Evidence level 4: Expert opinions See also Annex D.

Table 2 Summary of systematic reviews of therapeutic interventions for ASD.

Intervention	Cogency of evidence
There is no evidence that vitamin B6 supplements can improve the behaviour of ASD sufferers B [107]	Level 3
There is no evidence that gluten-free and casein-free diets improve the behaviour of ASD sufferers B, C [108,109]	Level 3
It is not possible to evaluate the safety and efficacy of omega-3 fatty acids in terms of improving the behaviour of ASD sufferers B [110]	Level 3
The intravenous administration of secretin is not an effective treatment for autism B [111]	Level 2
There is no evidence that music therapy in a clinical setting can improve expression and communication skills in children with an ASD C [112]	Level 3
There is no evidence that auditory integration training improves the behaviour of people with an ASD C [113]	Level 3
The use of augmentative and alternative communication intervention to improve the speech production of children with an ASD is of only very limited effectiveness. C [114]	Level 3
Pharmacotherapy (e.g., antipsychotic drugs such as risperidone) is of only limited effectiveness in alleviating the symptoms of internalising or externalising problem behaviour in ASD sufferers. B [115-118]	Level 3
There is no evidence to show that alternative medicines can either cure autism or alleviate its symptoms C [119]	Level 3
In some children with an ASD, early intensive behavioural interventions (EIBI) appear to be effective in improving communication and social skills and in ameliorating autism-related symptoms. B [120-126]	Level 2-3
There are questions surrounding the effectiveness of social skill training in young people with an ASD. C [127]	Level 3

As yet, the database of effective youth interventions that is maintained by the Netherlands Youth Institute contains just as few tried and tested interventions for children/young people with an ASD or their families.[129] Before the end of 2009, a few additional interventions may be submitted to the Youth Intervention Accreditation Committee (see also section 4.2).

Alternative therapies promise much, even complete cures, but none of these promises have yet been fulfilled. They would, therefore, seem to offer nothing more than false hope.[108,111,119,130] These treatments include homeopathic medicines, worm eggs, faith healing or spiritual healing. Moreover, promises are made concerning the effect of various food supplements and plant extracts. These ‘therapies’ are even potentially dangerous, as the ingestion of large doses of various vitamins and minerals can be toxic, especially in children. In addition, plant extracts are by no means always harmless.[131,132]

In the field of influencing behaviour, a wide range of therapies are on offer, many of which fail the test of scientific criticism. Some examples are magic therapy and music therapy, but there are also very intensive programmes such as the Son-Rise programme or Higashi school. Son Rise and Higashi (*daily life therapy*) are very intensive and place great demands upon the entire family, while their effectiveness is still in doubt.[133-135]

One problem with alternative treatments is that they are not subject to monitoring. Anyone operating outside the insured care sector in the Netherlands can open a practice for the treatment of any type of disorder, including autism. Part of the budgets used to enable individuals to purchase their own care (client-linked budgets) is spent on these alternative treatments.

At first glance, this picture would seem to be rather bleak as there are no effective treatments for autism spectrum disorders. This picture is confirmed by the evidence-based guideline ‘Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. A national clinical guideline’ from the Scottish Intercollegiate Guidelines Network (SIGN) (2007) and the ‘Autism in children and young people’ guideline from the Dutch Psychiatric Association (2008).[29,136] Accordingly, there is no cure for autism. For this reason, in the remainder of this advisory report, the term ‘treatment’ is used to refer to treatment of the effects of autism rather than treatment aimed at achieving a cure.

4.1.2 Research

There are several reasons for the lack of well-designed studies of sufficient scope. First, ASDs are relatively rare disorders, making it difficult for research groups to recruit sufficiently large experimental and control groups. Secondly, there is a spectrum of such disorders, making it difficult to create a sufficiently homogeneous experimental group. Thirdly, in the case of studies in children, there is the complicating factor of ethical considerations. The Advisory Council on Health Research advisory report entitled ‘Youth and Health’ – which will be published in the course of 2009 – explores this issue at greater depth. Furthermore, a scientific research culture does not necessarily extend into every social sphere in which people with an ASD are treated and given counselling. One example of this would be youth care services.

The development of practice-based evidence is a growing trend which is aimed at encouraging youth care services in the Netherlands to improve the quality of their interventions. This entails the collection of empirical evidence of effectiveness, which involves the monitoring of results and the use of performance indicators. To this end, the Netherlands Youth Institute, together with Praktikon and PI-Research, has taken the initiative by establishing the Netherlands Effective Youth Care Services Partnership (*Samenwerkingsverband Effectieve Jeugdzorg Nederland* or SEJN). Twenty-seven youth organisations have already joined the 'View of Effectiveness' project. Supported by the three above–mentioned organisations, these twenty seven youth organisations have launched impact monitoring operations. The SEJN is the result of their efforts (see: www. jeugdinterventies.nl). This is a bottom-up approach (to be implemented in practice alongside the top-down approach to evidence-based interventions). One advantage of the bottom-up approach is that front-line professionals can (continue to) see themselves as problem owners. This is because they are involved in the data-collection process and because the results are channelled directly back to them, thereby enabling them to improve their own practice.

The Netherlands Youth Institute maintains a publicly accessible database under the name of Dutch Studies in Youth and Education. It contains details of ongoing and completed studies on treatments/interventions.[137]

A final reason for the lack of well-designed studies of sufficient scope is that some interventions have become so established and accepted that any attempts to test their effectiveness in a randomised trial can be regarded as unethical. These include psycho-education, for example. In modern medicine, information and education concerning a patient's disorder are provided as a matter of course. The value of this approach is no longer in doubt.

The absence of evidence at the highest level by no means implies that no studies are being carried out, nor indeed that ASD sufferers should not be treated and counselled. Such treatment and counselling is primarily intended to promote and optimise development, as well as limiting the adverse effects of the disorder and treating sporadic or chronic comorbidity (both psychiatric and somatic).

A 2007 manual entitled 'Child and youth psychiatry: treatment and guidance' contains a good summary of current views on the treatment and counselling of the effects of an ASD, both for the affected individuals and their families. Similar summaries can be found in a recent theme issue of the journal *Wetenschappelijk Tijdschrift Autisme* (2008), in the Autism guideline by the Dutch Psychiatric Association, and in a report entitled '*NOK/PSY revalidatiecentra: doelgroepen, wetenschappelijke evidentie en zorgorganisatie*' ('NOK/PSY rehabilitation centres: target groups, scientific evidence and care organisation) produced by the Belgian Federal Health Care Knowledge Centre.[29,130,138,139] These summaries reveal a consensus on how ASD sufferers are treated and counselled in the Netherlands and Flanders. This national consensus is based on current knowledge and understanding, which – as pointed out – still has only limited scientific support.

The next section sets out the main thrust of the existing consensus in the Netherlands with regard to treatment and counselling.

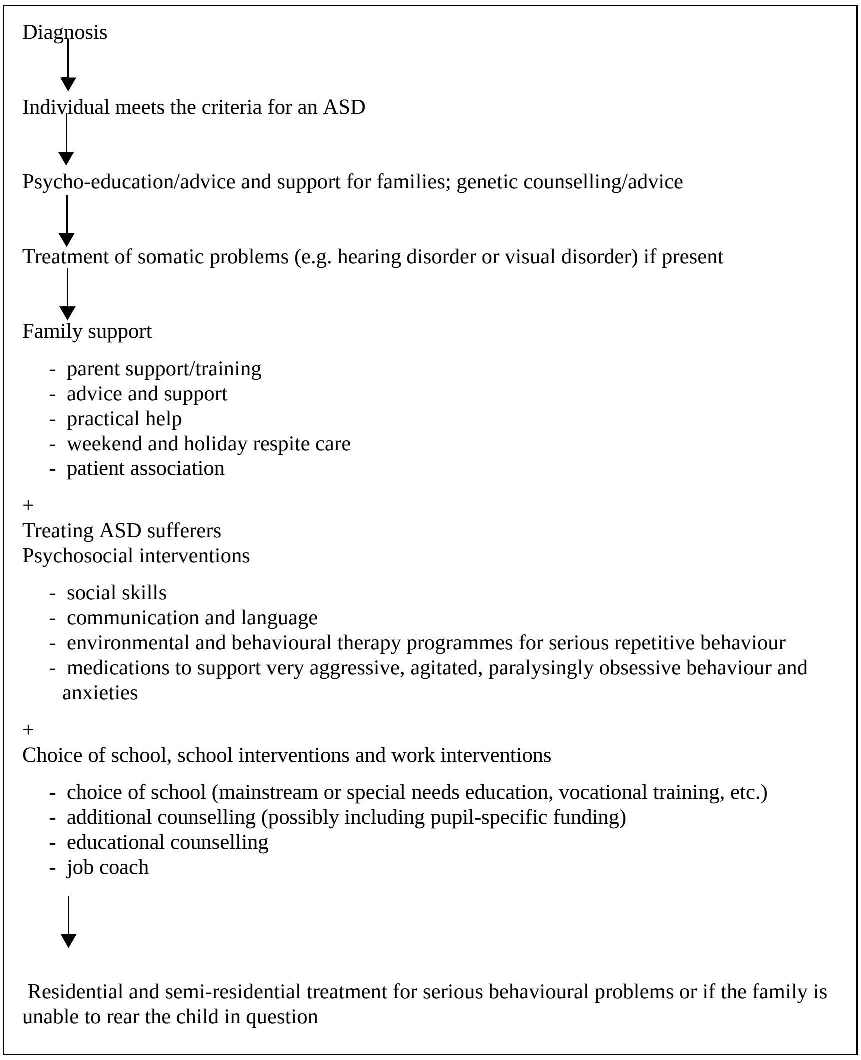
4.2 Consensus on treatment and counselling

The treatment and counselling offered to ASD sufferers are designed to optimise the activities of everyday life. The process involves taking into account every aspect of a person's ability to function, such as the severity of their limitations, their level of development, their ability to cope with social interactions, and their stage of life.

Flow diagram 1 shows which components of treatment and counselling are employed in cases involving an autism spectrum disorder. This chart is a slightly modified version of a figure from '*Kinder- en jeugdpsychiatrie. Behandeling en begeleiding*' (Child and Adolescent Psychiatry. Treatment and counselling). It is based on 'Practice parameters for the assessment and treatment of children, adolescents and adults with autism and other pervasive developmental disorders' (Volkmar *et al.* 1999) and on guidelines (both national and international) for the treatment and counselling of autism spectrum disorders.[29,130,136,140,141]

The basis of treatment and counselling is to organise a structured environment within which the ASD sufferer can feel safe, and where possible changes in behaviour can be established. Some important issues in this connection are structure, predictability, repetition and a focus on the generalisation of learned behaviour. Treatment and counselling serve as a prosthesis for the ASD sufferer, ensuring that they are able to function (or function more effectively) despite their disability. They will continue to require such adjustments throughout life, the intensity of their need will vary from time to time. On some occasions they will require more intensive treatment or counselling than at other times.

Various forms of treatment are required/possible in different settings, often several at the same time. The appropriate treatment will be selected on the basis of the diagnosed problems, the level of cognitive functioning, and the age of the ASD sufferer in question. The settings in which treatment takes place are: outpatient and clinical situations within child and adolescent psychiatric clinics (and outpatient clinics), and within youth care service institutions, within specialised



Diagnosis

Individual meets the criteria for an ASD

Psycho-education/advice and support for families; genetic counselling/advice

Treatment of somatic problems (e.g. hearing disorder or visual disorder) if present

Family support

- parent support/training
- advice and support
- practical help
- weekend and holiday respite care
- patient association

\+
Treating ASD sufferers
Psychosocial interventions

- social skills
- communication and language
- environmental and behavioural therapy programmes for serious repetitive behaviour
- medications to support very aggressive, agitated, paralysingly obsessive behaviour and anxieties

\+
Choice of school, school interventions and work interventions

- choice of school (mainstream or special needs education, vocational training, etc.)
- additional counselling (possibly including pupil-specific funding)
- educational counselling
- job coach

Residential and semi-residential treatment for serious behavioural problems or if the family is unable to rear the child in question

Flow Diagram 1: Treatment and counselling in ASD (adapted from: *Kinder- en jeugdpsychiatrie. Behandeling en begeleiding*. (Child and Adolescent Psychiatry. Treatment and Counselling) Verhulst Verheij Ferdinand ed. 2007).[130]

autism teams, in primary and secondary schools, within special needs education (including the ‘cluster’ system), in employment, and within the system of care for people with intellectual disabilities.

Ideally, therefore, the type of treatment used will be tailored to the situation in which the individual in question finds themselves at that particular moment in time. This involves achieving an effective balance of interests between the current state of affairs and what may be needed in future. It also entails the issue of who, or which agency, will provide the relevant component of the treatment or counselling in question. In practice, this balancing of interests is not always as effective as it should be. Something that has been missing in the care chain is a regular, multi-disciplinary review of the assistance and care requirement.

The following subsections explore the various components of treatment and counselling in greater depth.

4.2.1 *Psycho-education*

The aim of psycho-education is to provide knowledge, structure and security for ASD sufferers, as well as for their families and close friends. Psycho-education sessions involve an explanation of the nature of the disorder (including details of the diagnosis and classification in each specific case) and its implications for the ASD sufferer's ability to function in the context of their family, school, work, and leisure time. They also address the aetiology of ASD and may provide genetic counselling. The potential and limitations of treatment and counselling are discussed, as is prognosis.

While psycho-education is primarily for the benefit of the parents, it can also involve the ASD sufferer in question (age and development permitting), their brothers, sisters, other relatives, friends and others (such as teachers, colleagues at work and the job coach). Rather than being a one-off exercise, psycho-education is both repetitive and interactive, depending on the needs of the ASD sufferer and/or their immediate social circle. Several psycho-education protocols have been developed which can be given to parents and children, either individually or in groups.[142]

4.2.2 *Support measures both for the family and for childrearing*

The purpose of family support is to enable affected families to cope with the ASD of one or more family members as effectively as possible, thereby enabling them to function effectively and to create the best possible environment for the family member with ASD. Support with childrearing is often required as well, in addition to the treatment and counselling provided to the individual in question. Raising a child or young person with an ASD imposes a heavy burden on parents and other family members. It affects the way in which each and every member of the family relates to the others.

Family support provides all manner of support and advice. A good guide is '*Protocol autisme en aan autisme verwante contactstoornissen*' (Protocol for autism and related disorders) by Van der Gaag and Van Berckelaer-Onnes (2000).[143] It provides a framework for the definition of focal points that can be attuned to specific individuals in each stage of life. This makes it possible to tailor an action plan to the individual in question, one that incorporates all of the issues relating to the child and its family. The action protocol consists of a matrix with two axes. The first axis consists of a child-oriented line of treatment and another that is family-oriented. The second axis incorporates three distinct action strategies.[144] The first-degree action strategy involves the creation of a tailored, nurturing social environment by means of parent training, for example[*]. The second-degree strategy is about individual types of therapy which enable the child in question to develop as fully as possible, by means of play training, for example. The third-degree treatment strategy takes into account the specific personal characteristics of the individual child, see also Van Berckelaer-Onnes in the Scientific Journal of Autism (2008).[138]

Both family support and psycho-education fall under Kok's first-degree strategy. Without a beneficial and safe environment in which the child can grow and in which the parents feel that they are receiving support in the childrearing process, interventions focusing on individuals with ASD cannot 'take root' and so will have no effect, or not the desired effect.

4.2.3 *Psychosocial interventions*

The goal of psychosocial interventions is to teach the skills that enable ASD sufferers to cope more effectively with day-to-day life. Psychosocial interventions fall under Kok's second-degree strategy, as they focus on the individual.

A general effort is being made, based on the principles of behavioural therapy, to improve the three core symptoms of autism spectrum disorders: limitations in social skills, limitations in communication, and rigid, stereotypical behaviour patterns. Some examples of these interventions are social skills training, individual (cognitive) behavioural therapy and early intensive behavioural interventions (EIBI).

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[*] The NJI is attempting to determine whether a course for brothers and sisters and training for parents of children with an ASD might be eligible for inclusion in the Effective Youth Interventions database.

Dawson and Osterling indicate that in young children the main emphasis should be on imitation, communication and socialisation.[145] Noens and Van Berckelaer-Onnes believe that the main emphasis should be on communication.[146] Further research is needed to determine which specific interventions or components are responsible for the beneficial effects of behavioural therapy treatments.

The Netherlands Youth Institute (NJI) is currently assessing two types of training for inclusion in the Effective Youth Interventions database: Theory of Mind training, which teaches children with autism how to better recognise and assess emotions in others, and social skills training for children with ASD.

4.2.4 Pharmacotherapy

The goal of pharmacotherapy is to support non-pharmaceutical treatments. Few pharmacotherapeutic studies are conducted in children. In the field of ASD, studies are limited in number and experimental groups limited in scope.[115-118] The majority of systematic studies in larger groups have focused on the effects of classical and atypical neuroleptics on aggression and anxiety in children with ASD.[147-149] The pharmacotherapy of ASD is based on the application of existing medicinal products that were developed for other clinical pictures, such as psychosis, ADHD, anxiety disorders, etc. These medicinal products are only prescribed to treat associated symptoms such as hyperactivity, aggressive behavioural problems, and anxiety or sleep problems, rather than the ASD itself.

Child and youth psychiatrists in the Netherlands work in accordance with '*Medicatie van het Landelijk Kenniscentrum Kinder- en Jeugdpsychiatrie*' (Medication of the National Expertise Centre for Child and Adolescent Psychiatry, 2006) and the Dutch Psychiatric Association guideline (2008). These also include information on the off-label[*] prescription of medicinal products.[29,30]

Despite rapid advances in pharmacogenetics, behavioural genetics and molecular neurobiology, no ASD-specific medicinal products can be expected in the short term (<10 years).

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[*] Off-label prescribing means that a medicinal product is prescribed for a condition or patient group other than those for which the medicinal product is registered. Drug research in children poses various technical and ethical difficulties. Accordingly, many medicinal products are prescribed to children off label, i.e. they are registered for the disorder in question, but not specifically for use in children.

The following medicinal products are used in the Netherlands:

‘ADHD’ cluster (hyperactive, impulsive; lacking in concentration)	Anti-ADHD medicinal products: methylphenidate clonidine atomoxetine
‘Aggressive’ cluster (fits of anger and other aggressive behaviour; self injury; tics, cognitive disorganisation (chaotic/overstimulated), compulsive behaviour/stereotypes/impulsive acts	Antipsychotic drugs: risperidone pipamperone haloperidol
‘Anxious obsessive’ cluster (Obsessive thoughts and preoccupations; anxiety symptoms, symptoms of depression/resentment)	Antidepressants: fluoxetine citalopram fluvoxamine
‘Labile mood’ cluster (‘Emotional deregulation’)	Mood stabilisers: valproate carbamazepine

4.2.5 *Interventions at school and at work*

The purpose of interventions at school and at work is to enable the individual with ASD to function as effectively as possible in these environments, and to learn how to deal more easily with situations at school. These interventions fall under Kok’s first-degree strategy, as they focus on creating a pleasant, safe environment.

Children and young people with an ASD often exhibit learning and behavioural problems at school. The first intervention is to make an estimate of an appropriate match between child and school. The first question to answer is whether the child can cope with mainstream education unaided or with ambulatory support, or whether they require special needs education. Counselling provided for children in the classroom will always be a three-pronged process:

- instruction for teachers
- instruction to other pupils and their parents about the behaviour of the pupil with ASD (e.g. the ‘*Zo is er maar één*!’ (One of a kind) programme)
- specific measures/intervention aimed at adapting the environment to the pupil with ASD and vice versa. This requires consultation with the parents.

Various psychosocial interventions are suitable for use at school. It is important that the teacher in question has some knowledge of ASD and of behavioural therapy, and that they are capable of administering the requisite interventions.

The main interventions to reduce problem behaviour and to encourage cognitive and social behaviour are:

- TEACCH: *Treatment and Education of Autistic and related Communication-handicapped Children.* This behavioural therapy programme for children and young people with an ASD provides a highly structured learning environment within which they can develop individual skills. It involves the use of icons, work schedules, and containers of educational material.[150,151]
- Social skills training
- Structuring situations in which social problems most often occur.

See also chapter 6 Education.

4.2.6 Residential and semi-residential treatment and counselling

Recourse is only made to this form of treatment or counselling if the ambulatory approach is having (or is expected to have) insufficient effect. All of the above-mentioned elements of treatment and counselling are also applied in this case, albeit more intensively (either in full or in part). The Dr Leo Kanner House, which was founded in 1974, is the oldest and best-known institution for ASD sufferers who require residential and semi-residential treatment and counselling. With a view to sharing their knowledge and experience with other institutions, this organisation devised a franchise model that enables knowledge to be disseminated and quality to be monitored. Their initial experience of this model has left users with a favourable impression.

4.3 Life coaching

Given the chronic nature and the changing clinical picture of ASD throughout life, it has become clear that the treatment and counselling of ASD sufferers is an open-ended process. The following chapters emphasise the importance of providing ASD sufferers with the best possible help in dealing with life's transitions, to avoid aggravating existing problems or creating new ones. However, ASD sufferers also require a degree of counselling in order to cope with the demands of everyday life. In this way, treatment and counselling are transformed into life coaching.

In the study entitled '*Van disease management naar levensloopbegeleiding*' (From disease management to life coaching), the Leo Kanner House (LKH) defines life coaching as follows: no ad hoc treatment of symptoms, but continuous monitoring and counselling at every stage of life, without the disadvantages of hospitalisation and loss of control and responsibility both by the client and by their system (parents, partner, school, work, friends, family).[11] The monitoring requirement varies from one individual to another. There is no single approach that is suitable for all ASD sufferers.

Life coaching is based on the principles of disease management (DM), which involve total prevention, treatment and care focused on a patient with a specific chronic disorder. The essence of DM is the continuous proactive monitoring and treatment of chronic patients, according to evidence-based protocols. In this respect, the patient also plays an important part in promoting his or her own health. Self management is actively encouraged and supported. Various caregivers provide coordinated support for self management and treatment.

The importance of DM is that the chronic nature of the disorder is taken into account. In that sense, DM is also applicable to ASD. However, DM takes no account of non-medical fields, while ASD sufferers have a real need for counselling and support in education, daily activities and work, home life, leisure time, friendship and relationships. In the case of ASD sufferers, therefore, DM should be embedded in a broad social context. For this reason, the Leo Kanner House prefers the term ‘life coaching’ to ’disease management’.

The Committee feels that this approach is in keeping with current scientific knowledge concerning the treatment and counselling of ASD sufferers and with its own views on ASD.

The corollary of this vision is that a comprehensive approach is required for ASD sufferers. There are three aspects to this approach. Firstly, a comprehensive approach should be made to *individual ASD sufferers*. This involves dealing with them as an individual with their own character, talents, capabilities and limitations, and as a person suffering from this ASD, in its specific context (background, stage of life). Any problems should be assessed and resolved within the context of this comprehensive approach. Secondly, it is in the nature of this disorder that sufferers always require assistance in more than one domain. The fact is that *all areas of life (family, school, work, leisure, friendships)* are interrelated and interconnected. If problems occurs in one area, then an assessment should be made to determine the extent to which these will impinge on other areas and to identify ways in which these problems can be solved in cooperation with all concerned. Finally, problems will often need to be tackled using a *multi-disciplinary* approach. This is especially true in the case of children or young people with an ASD. Caregivers within the mental health care service will have to cooperate and coordinate with teachers and educational sector caregivers, for example, as well as parents, and any other support workers/carers involved (and vice versa).

Efforts must be made to ensure a smooth transfer to other areas of care (e.g. from care for children to care for adults).

Increasingly, professionals from many disciplines and numerous different organisations are already collaborating and coordinating with one another in practice. The Committee takes the view that the creation of a special role for a 'life coach' would be of enormous benefit to the continuity and comprehensiveness of care.

This 'life coach' would provide information, advice and support in all spheres of life, ranging from personal issues to work, and from housing to education. A life coach can also offer support to the parents of children with an ASD and advise on any legal measures that might be necessary to enable them to act for, or on behalf of, their child when it reaches adulthood. This life coach can also be of assistance in finding and arranging for the right care and support, and in proactively preparing people for impending transitions, such as moving house or the transition from primary to secondary education. The Committee feels that if sufficient use is made of life coaches, then problems and the concomitant expenses (including care costs) can be avoided.

MEE is already providing various aspects of life coaching. Prior to 2004, MEE operated under the name of the *sociaalpedagogische dienst* (socio-educational service). It is a nationwide organisation focusing on providing customer support to people with physical or intellectual disabilities, non-congenital brain damage, a chronic illness, or ASD.[152,153]In other words, such individuals can approach MEE with requests for advice or support. MEE assists them in making choices about how to organise and give substance to their lives. The focus of MEE's activities is to boost its clients' self-reliance and to maximise their participation in society. MEE itself does not provide long-term care. If necessary, a care indication is requested, and MEE helps to arrange the necessary care. Nevertheless, MEE's services are always available should people need help in arranging certain matters and/or making decisions. MEE can also operate proactively if one of its social workers identifies specific upcoming events that will affect their client, such as the transition from primary to secondary education. In this way, potential problems are prevented.

To date, its activities have been financed from Exceptional Medical Expenses Act (AWBZ) funds. Following the introduction of the WMO (Social Support Act) on 1 January 2007, client support has now passed from the AWBZ to the WMO. Once an initial evaluation of the WMO has been completed, a decision will be taken regarding the transfer of funding from MEE to the local authorities.[154]

In 2007, MEE organisations supported a total of approx. 100,000 clients. From 2004 (when ASD sufferers were specifically added to MEE's target groups) to 2008, the number of clients with an ASD increased from approx. 5,000 to approx. 20,000. As a result of this rapid increase, MEE has now reached the limits of its capacity.

In 2007, as part of the 'Opportunities for Children' project, the Ministry for Youth and Families established the Youth and Families Centres (CJG).[155,156] The aim is to have a nationwide network of CJGs by 2011. These centres will offer customised advice, support and assistance. One of the CJG's basic functions is to serve as an open house for questions from parents and young people about education and growing up. Others are providing accessible advice and support to enable families to be self-sufficient; identifying young people and at-risk families with problems; offering timely assistance to families to prevent new problems from arising or existing problems from getting out of hand; and coordinating the care provided to families according to the 'one family, one plan' principle. If several members of a family require assistance, then such care must be coordinated. In the event of more serious problems or more complex requests for assistance, the centres provide coordination services and will also contact youth healthcare or youth care services. Links to the educational system are also established by means of the Youth and Families Centres (CJG) in Care Advisory Teams.

The Youth and Families Centres are subject to the authority of the local councils. They have considerable freedom in setting up these centres. Each council does so on the basis of its own capabilities and needs. While they are by no means uniform in character, these centres all have the same basic tasks. Working on the basis of customised local procedures, the local authorities must determine which other bodies and features should be added to these Centres, or in what areas consensus is achieved. This would involve collaboration with elements of the primary healthcare service (such as the GP, maternity care, and obstetrics), pre-school and early school facilities, youth mental health care, youth contact point for work and income, social service and debt restructuring, police and justice, safe houses, and district facilities such as broad-based schools (offering cultural activities such as music, dance and arts), youth work, outreach, churches and mosques and so on.[155,156]

The Committee believes that the MEE organisations are eminently capable of fulfilling the role of life coach, provided that they are given a suitable mandate and that they are adequately resourced in terms of staff and funding.

When they have achieved nationwide coverage, the Youth and Families Centres will also be able to take on this role, at least until the ASD sufferer in question reaches the age of twenty three. However, this is subject to the condition that they have the necessary specific expertise in dealing with children, young people, and young adults with an ASD.

4.4 Infrastructure

4.4.1 Chain of care

The infrastructure for assisting ASD sufferers is highly complex. Exactly which professionals and institutions become involved depends on the age at which problems were identified and at which a possible disorder in the autistic spectrum was first suspected. Table 3 gives an impression of this situation, but is by no means fully comprehensive.

Ideally, there will be a smooth transition from one phase of care to the next, professionals will be familiar with ASD, there will be effective cooperation between the different domains, and ASD sufferers and their immediate social circle will receive effective assistance and counselling. Sadly, this is not the case in reality.

ASD is a disorder which is neither easy to detect nor to diagnose. Any peculiarities or problems that develop may initially be underestimated or attributed to something other than ASD. As indicated in chapter 3, if the professional groups involved are fully conversant with ASD, this will enhance detection and diagnosis, while at the same time eliminating the waiting lists of diagnosticians and autism teams. With regard to treatment and rehabilitation, there are waiting lists for mental health care, youth care services, and ambulatory support at school. MEE is no exception in this respect. These waiting lists are the result of staff shortages and/or financial constraints. If effective cooperation is to be achieved, one of the parties involved must take responsibility for managing all aspects of the care process.

Table 3 An impression of the professionals and organisations involved in the ASD care infrastructure.

Professional	Institution / organisation	Domain
Detection		
Physicians and nurses at post-natal clinics	Post-natal clinic (youth healthcare)	Youth healthcare (JGZ)
School physician	Municipal medical and health service (GGD)	Youth healthcare (JGZ)
GP		Care
Occupational health physicians and insurance physicians	Company/UWV (the organisation for reintegration into the job market and temporary income)	Work
Teacher	School	Education
Diagnosis		
Psychologist		Mental health care (GGZ)
Psychiatrist		Mental health care (GGZ)
Remedial educationalist		Mental health care (GGZ)
Treatment and counselling		
Psychiatrist	Mental health care institution / independently practicing	Mental health care (GGZ)
Psychologist	Mental health care institution / independently practicing	Mental health care (GGZ)
Remedial educationalist	Mental health care institution / independently practicing	Mental health care (GGZ)
Social worker	Social work, MEE, CJG	
Youth care worker	Youth care agency, Youth and Families Centres (CJG)	Youth care services
GP		Care
Teacher-internal supervisor	School	Education
Ambulatory supervisor	REC (Regional Centre of Expertise)	Education
School psychologist/social work	School supervisory service	Education
Specialist teacher	Autism support office	Education
Job coach	Offices, UWV (the organisation for reintegration into the job market and temporary income)	Work
Health insurer	Health insurer, health care office	Care
Fellow sufferers	Dutch Association for Autism (NVA), Balance [a]	
Drivers	School transport	WMO (Social Support Act)

Needs assessment

Indication for	Organisation	Domain
Special needs education/pupil-specific funding	Needs Assessment Committee (CVI)	Education
Exceptional Medical Expenses Act (AWBZ) care, client-linked budget (PGB)	CIZ (care indication centre)	Exceptional Medical Expenses Act (AWBZ)
Exceptional Medical Expenses Act (AWBZ) care	Youth care agency	Youth care services
Wajong (Invalidity Insurance (Young Disabled Persons) Act), Sheltered Employment Act (WSW)	The organisation for reintegration into the job market and temporary income (UWV)	Work

[a] National association for the parents of children with developmental disorders affecting education or behaviour.

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Another infrastructural nettle which must be grasped involves the various needs assessment and application routes for AWBZ care, special education and other facilities. Those wishing to make use of more than one facility find that there is a considerable degree of overlap in the information required by the various application procedures. It is not efficient to require people to enter the same information time after time. However, help is on hand in the shape of *Regelhulp* (a type of route planner for the chronically ill, disabled and elderly) and *Integraal Indiceren*. *Regelhulp* can be used to request coordinated facilities under the Exceptional Medical Expenses Act (AWBZ), Social Support Act (WMO) and social security, *Integraal Indiceren* focuses on youth care services, special needs education, and AWBZ care.[157,158]

4.4.2 Autism Covenant

Organisational and financial divisions between the domains and a lack of familiarity with each other's areas of expertise, often make cooperation difficult if not impossible. This was the finding of various investigations conducted more than a decade ago, including one carried out by the Dutch Association for Autism (NVA). In 1999, the Autism Covenant was drawn up, signed and put into effect. Its goal was to improve cooperation and to streamline the care provided to ASD sufferers. The covenant was, and still is, intended to establish a clear network of autism support agencies in each region. Its purpose is to integrate provision of the individual care that ASD sufferers require at each stage of their life. The partners in this national covenant are the Dutch Association for Autism (NVA), MEE Nederland (which was still known as SOMMA in 1999), GGZ Nederland (the Dutch mental health care association), Vereniging Gehandicaptenzorg Nederland (VGN; Netherlands Association for the Care of the Disabled) and Zorgverzekeraars Nederland (ZN; the organisation representing the providers of care insurance in the Netherlands). In 2005, the Centre for Consultation and Expertise (CCE) and the Social Entrepreneurs Group (MOgroep, representing youth care services) signed up to the covenant, followed by the National Autism Network (LNA) in 2007.[159]

In regions where the Autism Covenant has been adopted, steering groups are set up consisting of the directors of the partner organisations. The goal is to guarantee support for the covenant. In most regions, a core team is also set up, consisting of professionals from the various participating domains. The core team discusses difficult cases and tries to provide assistance. There is also a network of professionals.

Twenty six regions signed the covenant in 2007, but its efficacy varies greatly from one region to another. The reasons for poor performance are organisational, staff-related, or financial in nature.

Regions differ in the way that they allocate staff resources to the covenant network. In one region a separate coordinator's post is created, while in another a MEE employee, for example, will carry out this work in addition to their normal duties. Participation in network meetings or core teams is becoming increasingly difficult. This is because the time involved cannot be ascribed to client contacts within the participating organisations, which are increasingly focusing on production. Collaboration and consultation are not rewarded.

The funding of covenant-related activities varies by region, although it is always fixed-term, regardless of the location and activities in question. Also, the financial resources involved are derived from a variety of sources. This is not conducive to the maintenance of networks, knowledge and experience within the regions.

The success factors for the operation of the Autism Covenant are:

- One or two covenant partners who take on organisational matters.
- A separate, permanent Coordinator.
- Scope for the covenant partners' staff to participate in network meetings or core teams.
- Systemic core funding.

4.4.3 *Guideline development*

Guideline development is a way of ensuring that, at a regional or national level (depending on the scope of the guideline in question), people with a given disorder are treated in a structured and uniform manner. This applies to the areas of detection, diagnosis, treatment and support, and should be based on the latest scientific knowledge and best practices.

In 2008, the Dutch Association for Psychiatry (NVvP) published a guideline entitled ‘Guideline for the diagnosis and treatment of autism spectrum disorders in children and young people’. This guideline deals with the diagnosis and treatment of children and young people with an ASD, from the perspective of child and adolescent psychiatry.[29] In the near future, the Dutch Psychiatric Association plans to develop a guideline for ASD in adults.

The ‘Autism and autism-related disorders guideline for youth healthcare’, which is scheduled for development in 2009 in the context of the Netherlands Organisation for Health Research and Development’s (ZonMw) ’Youth Health Guidelines’ programme, may provide a boost to the detection (or early detection) of ASD.[265]

The year 2009 saw the launch of a project for the preparation of guidelines in youth care services. The project’s aims are: 1) to determine which guidelines are most needed by professionals in the youth care services, 2) to draw up a plan on how exactly guidelines should be developed, implemented and maintained. This project was designed by those professional groups who are active in the youth care services. It is being supported by the Netherlands Youth Institute (NJI), with a grant from the Ministry for Youth and Families.[160] These guidelines may also address ASD.

When all of the above-mentioned guidelines are ready, they will strengthen the knowledge and care infrastructure that supports ASD sufferers. It is vital that careful consideration be given to the aspects of cooperation and referral between the various guideline areas. The Committee feels that the Autism Covenant would contribute to the implementation of the guidelines.

4.4.4 *The funding of care*

The funding of care for ASD sufferers is governed by three pieces of legislation in particular. These are the Health Insurance Act (Z V W), the Exceptional Medical Expenses Act (AWBZ), and the Social Development Act (WMO).[161-163]

Medical care, diagnosis, medication and various forms of psycho-education fall within the scope of the Health Insurance Act, and are therefore covered by health insurance. If a clinical treatment (admission) exceeds a period of one year, then the first year is covered by the Health Insurance Act (ZVW) and the subsequent period by the Exceptional Medical Expenses Act (AWBZ).

As ASD is a chronic psychiatric disorder, recourse is often made to the AWBZ. The types of care covered by the AWBZ include: personal care, nursing, support, treatment and hospital stays. Eligibility for health care under the AWBZ is subject to an indication from the Care Indication Centre (CIZ) or the Youth Care Agency. If an indication is given then care can either be obtained under health insurance cover, or individuals can purchase the care themselves using a client-linked budget (PGB).

With regard to counselling, in recent years children with an ASD in particular are increasingly turning to client-linked budgets rather than conventional health cover.[12,42,164,165] The main reason given is that people cannot find what they need in mainstream care provision. They also cited waiting lists as a reason for wanting to organise their own care with the aid of a client-linked budget.[12,42,165]

Needs assessment for treatment under the terms of the Exceptional Medical Expenses Act (AWBZ), or for obtaining a client-linked budget, changed at the beginning at 2009. Until 1 January 2009, enabling and supportive counselling were two separate and discrete activities. These activities have now been combined into a single counselling role. Counselling indications are now only given to those suffering from moderate to severe limitations. Part of the former enabling counselling role has been switched to the Treatment role. In addition, the social participation objective has been removed from the Exceptional Medical Expenses Act (AWBZ). All that remains is self-reliance.

The reason is that the government believes that it is not appropriate for social participation to be included in the AWBZ. It takes the view that this aspect should be addressed in other domains, such as family and other relationships, the Social Development Act (WMO), education and personal responsibility.[166-168]

Those who lose their indication for Counselling in 2009 can make use of a transitional scheme provided by MEE. This scheme, which is valid for one year, only applies to people who belong to one of MEE’s target groups (one of which is ASD) and whose indication has been completely withdrawn. People whose indications have only been partially withdrawn are not entitled to make use of this scheme, although they can avail themselves of MEE’s services in order to find a solution.

Yet, in the area of participation, ASD sufferers are especially dependent on other people's help. This is partly due to the fact that they are not always able to make journeys without assistance. Another consideration is that counselling by someone other than a family member can help in the transition from home to school, work or leisure-time activities. It will not always be possible to make provision for this, even in cases where the indication designates the restriction in question as 'moderate'. The individual's personal network, which for children mainly consists of their own family, already has a heavy burden to bear (see chapter 5). Another option is to invoke the Social Development Act (WMO). This legislation has only been in force since 1 January 2007. It gives local authorities a free hand in deciding to whom, when and how counselling will be offered. Due to the lack of preparation time, it was not possible to resolve this aspect effectively. As yet, the authorities have no clear idea of the size of the target group in question, nor indeed of how this group will be impacted by these changes. It is not known whether local authority budgets for the Social Development Act will be sufficient to cover the counselling involved.[169]

The withdrawal of support for ASD sufferers may adversely affect their disorder, possibly aggravating their problems still further. Particularly in the case of individuals such as these, it would have been better if the supportive counselling role had been retained, or if the transition to a differently structured scheme had been better prepared.

The AWBZ Taskforce found that the frequent selection and award of client-linked budgets for counselling meant that health care providers had no incentive to develop adequate care provision for such schemes. It also stated that this is a suboptimal situation in terms of the quality of care. Little is known about the quality of care that can be purchased with a client-linked budget. Care provided by practitioners of alternative medicine carries the risk that the treatment offered will be ineffective and that the individual being treated may be damaged as a result. What is needed is a certification of care, with regard to the treatment that is purchased with a client-linked budget. Recent studies have shown that 'PGB offices' routinely manage the entire budget of the person in question, and that they do not always provide clear information on how it is spent. This may also pose an obstacle to any assessment of the quality of purchased care.[170]

4.5 Instruments for determining the care requirement

No two ASD sufferers are alike. Earlier in this chapter (and in chapter 3) the importance of properly identifying the care requirement of ASD sufferers was emphasised. This must be based on their capabilities and limitations, and on the opportunities inherent to their social context. Various instruments have been developed for this very purpose. They can be used to assist the individual in question, their carer or their teacher. This section contains a brief discussion of three such instruments. None of the instruments mentioned has yet been scientifically studied and validated. Nevertheless, they may prove useful in streamlining the delivery of care to ASD sufferers. The redefinition of counselling and treatment at regular intervals allows them to be adapted to the ASD sufferer's needs and abilities throughout life. Accordingly, this process can contribute to a periodic update of the care requirement.

4.5.1 ASSwijzer (ASD compass; caregivers)

The *ASSwijzer* is a paper-based model, a navigation system which helps carers to make responsible and practical choices concerning the treatment strategy to be adopted. This also takes into account suggestions and proposals put forward by ASD sufferers themselves and by those in their social circle.[171]

The model was created on the basis of years of experience with ASD sufferers. It emerged that while there were no standard answers to requests for assistance the search always involved the same steps – review information processing, planning, deployment, development. While it provides guidance, the instrument is not easy to fill in. It is very much a work in progress, and there are plans to investigate its effectiveness.

4.5.2 Inter-RAI-AS (education and care)

Based on the International Research in Assessment Instruments used within the health service and in social work, the interRAI-ID for intellectual disability provided a basis for the development of a comparable questionnaire for ASD: the interRAI-AS.[172] This variant can facilitate the assessment of the educational and care requirement of children with autism. Its purpose is to determine the best educational approach for this particular target group. The questionnaire is the basis for:

- developing a classification of the effort required to successfully follow the current or desired course of instruction
- developing indicators for the quality of education (and care) that the pupils receive.

4.5.3 *Taksatieschaal® (home life, work)*

The taksatieschaal is a privately developed software instrument that helps to create a realistic picture of the client’s requirement for assistance with a given disorder and/or limitation, be it physical, mental or psychological in nature.[173] Accordingly, this instrument could also be used to determine the specific care requirement of ASD sufferers.

The instrument is intended to determine the type of assistance needed, when it will be needed, and what costs will be involved. One major variable is the required level of safety and security. This ‘support structure’ can range from complete dependence to complete independence. There are two ‘scales’, one for home life and one for work. A personal plan is created on the basis of an extensive questionnaire, which is completed together with the client and/or their parents/supervisors. In a series of specific steps, this plan suggests which types of assistance and interventions are needed, and when. The aim is to make the *taksatieschaal* a web-based application by 2010.

4.6 Conclusions

There is currently no cure for ASD. Nevertheless, the effects of ASD and comorbidity are being tackled using a variety of approaches, theories and disciplines. There is limited scientific support (*evidence*) for effectiveness, mostly due to the limited scope of the studies in question. Furthermore, the design of these studies made it difficult to compare them to one another. Of all the available interventions, behavioural interventions (which fall into the category of psychosocial interventions) have proven to be the most effective to date. Pharmaceutical treatment is only employed to a moderate extent in connection with ASD, and is primarily focused on comorbidity. As mainstream treatments are of only limited effectiveness, numerous alternative treatments are available that promise much but fail to deliver.

There is consensus among professionals about the types of treatment and counselling that should be offered to ASD sufferers, and to their families and close friends. This involves the treatment of comorbidity, psycho-education, family support, psychosocial interventions and school-work interventions. The main thrust of all such treatments is to provide structure, predictability, repetition and a focus on the generalisation of learned behaviour. Furthermore, the treatment and counselling offered should take account of the specific capabilities and limitations of the individual in question. The Committee endorses this view.

Something that has been missing in the care chain is a regular, multi-disciplinary review of the assistance and care requirement, as well as effective coordination between caregivers. Ideally, these aspects should be managed by one of the parties involved.

Given the chronic nature of the disorder, ASD sufferers must be able to make use of counselling and support services throughout their lives.

The knowledge and care infrastructure that supports ASD sufferers is complex in nature.

4.7 Recommendations

There is a need for efficacy studies into current and novel forms of treatment and counselling for ASD sufferers. The Committee recommends that lists be drawn up of relevant studies currently being carried out in the Netherlands and of the researchers involved (University Medical Centres, care institutions, educational institutions, youth care services, etc.). The views of ASD sufferers and researchers on the need for research should also be obtained. In this connection, efforts should be made to determine the extent to which studies currently in progress are actually in keeping with the identified research requirements. This stock-taking exercise should incorporate relevant research programmes being conducted by the Netherlands Organisation for Health Research and Development (ZonMw), the Netherlands Brain Foundation, and other organisations.

A research agenda can then be drawn up, which will enable subsequent research efforts to be better structured, coordinated and implemented.

As part of the Health Council of the Netherlands, the Advisory Council on Health Research (RGO) can take on these assignments.

The Committee contends that life coaches should play a pivotal role in the counselling of ASD sufferers. If optimum use is made of these professionals, the development or exacerbation of problems can be prevented, thereby keeping the care requirement within reasonable limits (secondary prevention). The MEE Foundation can directly tackle the role of life coach (indeed it is already doing so to some extent), provided that it has the requisite staff composition and resources (including financial resources). In time, Youth and Families Centres could extend their remit to incorporate life coaching, subject to the provision that they have specific expertise in the area of autism spectrum disorders.

Cooperation and coordination between caregivers should be rewarded. The Autism Covenant can play a major part in the necessary clarification and streamlining of care infrastructure, provided that the participants receive appropriate support.

It is important that certification be granted to care that falls outside the scope of the Health Insurance Act and which is mainly funded by means of client-linked budgets.

Chapter

5

The family and the road to an independent life

Though families with a child with ASD are often under a great deal of stress, parents are the most constant factor in the lives of ASD sufferers. It is not only the parents who are affected, other family members also experience stress as a result of this situation. Relations within the family can also be put to the test, as can relationships in the family members' social circles.

In broad terms, this chapter addresses what is known about: 1) the impact of a child with an ASD on the daily activities and income of its parents, 2) the well-being of the parents and siblings of a child with an ASD, 3) the nature of the counselling given by parents, their contribution to their child's independence, and their own needs in terms of support, 4) what is known about the friendships, leisure-time activities and social activities of children and adults with an ASD, and 5) the requisite and feasible degree of independence for adult ASD sufferers. This chapter closes with conclusions and recommendations.

5.1 Parental care

While parents generally devote a great deal of time to their family, the demands of rearing a child with an ASD often mean that there simply is not enough time available. In these cases, the daily round includes numerous activities, such as: personal care of their child; arranging for various forms of support; dropping the child off at school and collecting it at the end of the school day; arranging for additional medical and psychological care; assistance with social contacts, accompanying their children when they attend various social activities; and maintaining contacts with official bodies. In practice, most of the care burden is borne by the mother.

In general, there is no decline in the degree of assistance and support provided by parents as the child grows older.[174,175] In practice, the time that different parents spend with their children varies considerably. Some parents claim to spend more than one hundred hours per week caring for their child, whereas others say that this takes up no additional time at all. Järbrink (2007) calculated that, on average, the extra time that parents spend in caring for a child with an ASD amounts to one thousand hours per year.[176] The number of hours involved is not always dependent on the severity of the child's disorder. The lack of a 'normal' life, lack of leisure time, lack of understanding by those in their social circle, the feeling that official bodies are not providing sufficient support, the numerous formalities with which they must comply, and the often difficult relationship with their child, can cause parents to feel that they are isolated from the rest of society.[175,177,178]

Caring for children can affect an individual's ability to work for a living. Montes *et al.* (2008 USA) explored this issue in a series of interviews with well over 16,000 parents (in the general population) with children of preschool age (5).[179] Eighty-two parents in this group had a child with an ASD. Almost 40% of them replied that caring for their child in the previous twelve months had had a significant impact on their ability to work for a living. The effects ranged from switching to part-time work, changing jobs, turning down a job, or giving up work completely. In comparison, fewer than 10% of parents with a healthy child had had problems in finding or keeping a job. With regard to the impact that caring for their child had on their employment options, families on the lowest incomes were twice as likely to be affected than families in higher income brackets. In Britain, Curran *et al.* (2001) reached similar conclusions.[174] Three quarters of women with a severely disabled child had no paid work. Not only did the mothers work less, the fathers too adapted their activities accordingly, and often their career ambitions as well.[180] Aside from the fact that they worked less, the parents of children with an ASD also exhibited increased sickness absenteeism. These and other studies indicate that average family incomes are between 13% and 20% lower than those of comparable families without a child with an ASD.[181]

5.2 The psychological well-being and concerns of parents and siblings

There have been several studies into the psychological state and quality of life of parents of children with an ASD. These show that such parents are generally more prone to stress and that their mental and physical health is poorer than that of comparable parents without a disabled child. The mothers of children with a developmental disorder are at increased risk of depression and anxiety.[182-192] In addition to being concerned about their child's inappropriate behaviour and limited social skills, the parents of younger children also worry about the frequent bullying that takes place.[193] The parents of adolescents and young adults are more concerned about their child's social exclusion and lack of independence.

As a group, these parents all tend to exhibit more health problems and a reduced quality of life. Nevertheless, at the individual level, there is an enormous variation in the extent of their problems. Accordingly, while they clearly have an increased risk of depression, well over 70% to 75% of mothers had experienced no such symptoms.[184,192,194]

The genetic load of family members is one factor that may bias the psychological well-being of parents and the family's ability to cope in psychosocial terms. There is a distinct possibility that affected families will not only include several children with autistic characteristics (or even an ASD) but also that one of the parents will also be affected (usually the father, as ASD is more common in men than in women). There are no known studies into the capacity of 'multiple-ASD families' to cope and the specific impact on the care provided to the members of such families.

Most parents are actually coping quite well. As these children grow older, the degree of stress involved often declines. This is attributed to improved and more predictable behaviour on the part of the children in question, to family life becoming more orderly, and to parents' increased ability to cope with their child's problems.

Some studies indicated that children with autism are more often associated with single-parent families, but other studies were unable to confirm this finding.[183,191,194] There is no evidence that childrearing poses greater problems for single mothers than for married mothers.[191,194]

Over time, parents tend to focus more on the emotional aspects of their relationship with their child and less on the problems.[175,195] Guaranteed access to various facilities and support services tends to make room for acceptance of the disorder and for satisfaction with the results achieved.[196] Some families respond with enormous resilience, claiming that raising a child with an ASD has made them stronger.[197] The parents' emotional bond with their child often becomes stronger as it passes through adolescence and into early adulthood. There is a link between this bond and the degree of social adaptation shown by the child. The better adapted the child, the stronger the bond. Nevertheless, allowance should be made for the fact that children with an ASD can also exhibit antagonistic adolescent behaviour, resulting in the inevitable conflicts. Boosting the emotional bond at this stage of life may have major implications for the future care burden borne by the parents. After all, most children with ASD are unable to lead independent lives as adults, require lifelong care, and almost always continue to live at home well into adulthood.[198]

Studies into the impact that an autistic sibling has on other children in the family have failed to produce clear results. Some studies found evidence that siblings exhibit more behavioural problems than those growing up in a family without a child with ASD. The younger siblings of a brother or sister with ASD, in particular, are at greater risk in this regard. There is a correlation between the severity of the disorder and the degree of behavioural impairment suffered by those children without the disorder. In general, however, despite the family's genetic load and the social stress to which they are exposed, the healthy children were able to cope relatively well.[199,200]

5.3 What do parents need?

The provision of both emotional and formal support has a beneficial effect on the parents' well-being. Parents require various forms of practical assistance, such as babysitting, special provision for the transport for their child, financial advice, help with household duties, and advice on how best to deal with their child.[184,188] However, the provision of formal support alone is insufficient to maintain their morale. Parents clearly also have a need for informal support, and for appreciation of what is involved in raising a child with ASD.[178,188,189,201,202] Rejection by family and friends, and a lack of support from that quarter, clearly have an adverse impact on parents' welfare.[203] It is the parents of older children in particular who often feel that there is a lack of informal support – possibly due to the disintegration of their social network with the passage of time.[188] Parents of adult children have the greatest need of *respite care*. They also need help in planning the future of their child and information about the services that are available to them.[175]

5.4 Friendship and leisure time

Friendship is an important experience for children. There is a link between a lack of friendship in childhood and adjustment problems later in life. For the purposes of this section, friendship is defined as a relationship with someone of a similar age, involving joint activities of a varied nature which take place outside the context of a formal group. Such a relationship should also be mutual and of equal importance to both parties. Friendship helps individuals to develop important social skills such as the ability to give and receive care, the ability to deal with feelings of empathy and intimacy, as well as the ability to share with others and to compromise. However, individuals require certain skills in order to be able to form such friendships in the first place. Given the nature of their disorder, children with an ASD often lack the necessary skills to forge and maintain friendships. However, there are some exceptions.[204] It should also be noted that some important and lasting relationships do not necessarily meet all of the above-mentioned 'qualities' of friendship.

Orsmond *et al.* (2004) examined the social activities of 235 adolescents and adults with autism, both with and without intellectual disabilities, who did not suffer from Asperger's disorder or PDD-NOS, and who still lived with their parents.[205] Less than 10% of these individuals maintained a friendship that met all of the criteria cited above. Twenty percent maintained friendly ties by engaging in joint activities that take place in an unstructured or informal setting. Approximately one quarter of these subjects only took part in joint activities in a structured setting (e.g. at school, or at work) or in some other form of organised social activity. Almost half (46%) had no friendly relationships whatsoever with their peers. No association was found between forging relationships with peers and participation in mainstream education. As the young people in this study grew older, their number of social contacts declined still further. This finding was confirmed by other studies.[44,206,207]

Studies carried out in children with autism but without intellectual disabilities, showed more favourable results with regard to the maintenance of relationships with peers.[204,208-210] In these children, however, forming and maintaining relationships was largely dependent on the continued support of their parents. The relationships were of shorter duration, the contacts less frequent, and the activities more structured and with less social interaction than in peers without autism. The relationships between pairs of children in which one had autism while the other did not more closely resembled true friendship than those between children who both had autism. Young people and adolescents with Asperger's disorder generally have more friends than the above group. About one quarter of the 21 participants in one study said that they had one or more friends.[211] While many of them said that they wanted greater participation in social activities, they did not know how to achieve this. Those who did participate in social activities nevertheless experienced frequent feelings of loneliness.

Orsmond *et al.* (2004) also carried out a study into social and recreational activities, however this work did not specifically explore the existence (or absence) of friendships. Half of the study population had no hobbies whatsoever. Those who did have a hobby indicated a preference for walking (75%) and solitary activities (40%). There was little participation in everyday general activities, such as family visits, contact with neighbours, school activities outside the traditional classroom setting, or visits to autism contact groups. Engaging in social activities together with other members of the family, and sleeping away from home, were also rare events.

Mothers played a pivotal role in their child's participation in social and recreational activities. Studying in the mainstream education system and the availability of special amenities also affected children's participation in social activities. As the fathers were not involved in this study, their role may have been given too little emphasis. This finding by the study of Orsmond *et al.* was supported by a similar study.[212]

The Committee takes the view that transportation from home and back may be an impediment to participation in social activities. On average, many children with an ASD will be older than their non-ASD peers before they start driving vehicles or travelling by public transport. Indeed, some may never be able to travel independently. This delay imposes a greater burden on their parents.

The Dutch Association for Autism's 2008 survey of its members included questions about leisure-time activities and social relationships. The majority (57%) of young and adult respondents indicated that they had little social contact outside their own family. Just over one quarter indicated that they had formed friendships. Most contacts took place via a hobby or in connection with school or work. Thirty percent expressed a strong wish for friendships. Their leisure time was largely spent at the computer, watching movies or TV, and sleeping or resting. Forty percent of the younger respondents indicated that they engaged in sporting activities. The equivalent figure for adults was 30%.[12] The figures on friendships were in keeping with those published in a recent report based on a similar study conducted by The National Autistic Society of Great Britain in 2008.[213]

In the Netherlands, numerous initiatives have been launched for ASD sufferers in the areas of leisure-time activities, opportunities to meet others, and escorted holidays. It is not clear whether these schemes meet the existing requirement, either in qualitative or quantitative terms. A project conducted by the Dr. Leo Kanner House attempted to determine whether special leisure-time courses could help ASD sufferers without an intellectual disability to plan their leisure time independently and effectively.[214] This small-scale pilot project involved an experimental group of seven subjects and a control group of just five subjects. More extensive research is needed in this area.

5.5 Move out or stay at home?

An ASD is a lifelong disorder. In the early years, more than 90% of children are cared for at home, by their parents. The transition from childhood to adulthood involves the need for decisions to be taken concerning the continuation of care. Here too, it is the parents who are chiefly involved. In essence, there are three options. One is that young adults who are not fully capable of leading an independent life can continue to live at home. Other individuals can look for sheltered accommodation. Finally, if they are capable of doing so, the people in question can live independently, with or without a partner and/or paid work. In practice, there is a fourth variant. Parents often provide their ‘independently’ living son or daughter with more than average care and support.

When a child leaves home and moves to sheltered accommodation, this is a major step not only for the individual concerned but also for their parents (especially the mothers).[215] In opting for accommodation of this type, the parents are primarily motivated by the beneficial effects that this may have for their child. These involve better opportunities for personal development, the cultivation of new skills, additional social contacts, and access to the support needed for a less dependent life. The positive impact on the families that they leave behind – in the form of a reduced burden of care – is considered by most parents to be of secondary importance. Even though their child is no longer living at home, many parents continue to maintain close contact.[216]

The majority of parents feel that the beneficial and adverse effects of the child continuing to live at home tend to balance out.[217] The main benefit is the peace of mind that comes with knowing that their child is being cared for. The worries are mainly associated with the burdens of daily care and concerns about the future.

5.6 ASD and autonomy in adulthood

While studies have been carried out into the effects of an ASD in adulthood, the results have not provided a clear picture of the degree of autonomy achieved or of the care needed by the group as a whole, or by individual categories. One reason is that the frequency of ASD diagnoses during the past few years has been greater than was the case twenty or thirty years ago. This applies less to youngsters with childhood autism than to those with other forms of ASD. The current categories of PDD-NOS and Asperger´s disorder were only incorporated into the DSM in the 1980s and 1990s.

Initially, small study populations were used to investigate the autonomous performance of everyday activities in adulthood. The focus on adults with childhood autism meant that most of the subjects had intellectual disabilities. From 1985 onwards, studies were also carried out in adults with IQs above 50 and those of normal intelligence.[44,207,218]

Billstedt *et al.* (2005) published the first follow-up study of a group of 120 adults representing all the various categories of the spectrum.[219] This study also included individuals born before 1980, which meant that the group was not considered to be representative of people with Asperger’s disorder and PDD-NOS. Similar problems are associated with more recent studies.[210,220]

Another problem affecting comparisons of results on psychosocial performance in adulthood is that the studies in question were carried out in different countries. There is reason to believe that differences in care policy lead to different results. It is only possible to draw broad and very cautious conclusions concerning social performance and independence in adulthood.

A consistent finding was that the prognosis for the autonomous performance of everyday activities in adulthood largely depended on the IQ of the individual in question. Very few of those with an IQ below 50 were able to perform effectively in adulthood. Patients with an IQ of 60 and above also had significant social problems. In general, well over 70% of them remained dependent on help from their parents and/or others in the performance of everyday activities. While well over half of those with Asperger's disorder lived an independent life, almost all of them required support from their parents or others. Those living independently without the aid of third parties were the exception rather than the rule.

In 2001, 2004 and in 2007-2008, the Dutch Association for Autism conducted a survey among its members[12,41,42]

The findings with regard to the housing situation were as follows:

Age	Living at home			Independent/partner			Institution/type of housing		
	2001	2004	2008	2001	2004	2008	2001	2004	2008
2-4 years of age	97%	91%	}	-	-	-	3%	9%	}
5-12 years of age	95%	95%	} 94%	-	-	-	5%	5%	}6%
13-18 years of age	84%	99%	}	-	<1%	-	16%	1%	}
> 18 years of age	30%	26%	30%	22%	24%	35%	49%	50%	35%

The survey did not distinguish between the diagnosis, the severity of the disorder, and the type of housing. Almost all of the young people below the age of 18 lived at home. Of the adults, about 30% were still living at home, 35% were living independently (or with a partner), and 35% were in another type of housing or an institution. The adults who were still living at home were generally below the age of 30 and suffering from an intellectual disability.

The parents were not always satisfied with their child’s living arrangements. Their discontent centred around the frequent switching of counsellors, inadequate care, a lack of expertise on autism among the counsellors, and co-habitation with other residents.

It was claimed that there was a greater short-term need for supervised independent living among both young people and adults. It was also stated that adults increasingly wanted to live a completely independent life in future. Individuals with Asperger syndrome or PDD-NOS appear to have the greatest need for supervised independent living arrangements.

In 2000, 2001 and 2008, the National Autistic Society (NAS) of Great Britain published a series of reports in response to three surveys.[213,221,222] The percentage of ASD sufferers that live independently does not exceed 15%, which is less than the corresponding figure obtained in the Dutch surveys. Less than 10% of parents had adult children capable of autonomously performing all household tasks, such as shopping, preparing a meal, doing the laundry, and paying bills. Half of the children with Asperger’s disorder lived with their parents and only 3% lived completely independently. The parents felt that in 40% of cases their child would be able to live independently with a few hours of assistance per week.

Dutch policy is geared towards achieving the best possible coordination of housing, welfare and care packages, and to bringing them in line with the needs of those who require care. While this policy is partly still under development, it theoretically has the potential to meet all of the present and future residential care requirements of ASD sufferers. Various initiatives have been launched, such as client–linked budget (PGB – which allows individuals to purchase their own care and counselling), introduction of the care-weighted defrayment of costs for those with an indication for residential care (with the option of capitalising on the definitive official indication in a variety of ways), and the '*Beter (t)huis in de buurt*' (Better housing and more at home in the neighbourhood) action plan.

5.7 Conclusions

Various studies have explored the burden borne by the parents of a child with an ASD. However, these were conducted in different countries and sometimes with different goals, so only limited comparisons are possible. The same goes for the extent to which adult ASD sufferers are capable of living independently and of autonomously performing everyday activities. Nevertheless, it is possible to draw a number of broad conclusions.

The parents of children with an ASD (particularly the mothers) develop more stress-related symptoms and are more likely to have a depressive disorder or symptoms of anxiety than those without a disabled child. Despite this, however, many of these parents are coping relatively well. Yet this should not disguise the fact that many parents with a child with an ASD are at increased risk of health impairment, social isolation, loss of income and additional financial burdens. Furthermore, caring for their child impinges on their privacy. Most parents manage to cope, however, albeit at full stretch. In many cases, there is no lessening of the burden when their child reaches adulthood. As they get older, the parents will be increasingly unable to deal with the burden of care. More elderly parents are also concerned about what will happen to their child when they are no longer able to care for it. Yet very few studies have been conducted into the effects on elderly parents of caring for a child with ASD.

In only 5 to 15% of cases are adults with an ASD capable of autonomously performing everyday activities. Some require only very modest assistance, while others' needs are much more comprehensive. In many cases, indeed, there is no information concerning the optimum level of support that will enable the individual in question to live their life as independently as possible. We have no clear idea how well ageing ASD sufferers are coping in practice. In addition, many adult ASD sufferers are ‘under the radar’ entirely, as they have never had a diagnosis in the autistic spectrum.

5.8 Recommendations

Longitudinal studies into the quality of life, in the broadest sense, experienced by ASD sufferers at different stages of life could provide insight into the type of care and counselling required, as well as their duration and intensity. Furthermore, using longitudinal studies, it is possible to investigate the effects of such care and counselling on the degree of autonomy achieved. For this reason, the Committee recommends that studies of this type be initiated.

Previous studies into how well families with one or more children/young people with ASD are able to function have tended to focus solely on the role of mothers, who generally give up their job in order to keep the family going. Given that individual roles within such families are subject to change, it would also be useful to examine the fathers’ role, and to assess the options for compensating parents for some or all of their lost income.

Chapter 6

Opportunities and limitations in education

This chapter shows how the education of children and young people with an ASD is currently structured. It goes on to identify the main problems encountered, including the transition into education, the transition from one part of the educational system to another, and the transition from education to work. The following section briefly outlines the educational needs of children, adolescents and young adults with ASD, and indicates what is currently known about ASD and education. The next topic addressed concerns the upcoming reforms in the context of *Passend Onderwijs* (Appropriate Education). It identifies issues that are of specific interest to ASD sufferers. A separate section is devoted to the transition from education to employment, and to job placement assistance. The final part of this chapter is devoted to conclusions and recommendations.

6.1 Starting school in 2009

6.1.1 Organisation

In the Netherlands, children start school in their fourth year. They are officially of school age when they reach their fifth year. After a period of primary education, they switch to secondary education at the age of twelve. This, in turn, is followed by vocational training or higher education.

Most children do not encounter significant problems during their school years. Those who experience learning difficulties at primary school have the option of special needs primary education[*]. This is organised in the context of mainstream education, in conjunction with primary schools, in the form of the *Weer Samen Naar School* (Back to School Together; WSNS) partnerships. In order to be eligible for special needs primary education, pupils require a needs assessment from an Individual Educational Needs Committee, which is appointed by each WSNS partnership.

In secondary education, those children who find it difficult to keep up can make use of Study Course Supporting Education (LWOO), and Practical Training (PrO). LWOO is a component of pre-vocational secondary education (VMBO) as it is intended for pupils requiring additional support in one course of study within the VMBO system. Practical Training (PrO) is designed for pupils between 12 and 18 years of age who require an approach involving remedial education and affirmative teaching. Such children would be unable to obtain a pre-vocational secondary education diploma by the usual route. Practical Training (PrO) involves – as the name suggests – the use of practical training, as a way of preparing pupils for participation in the labour market. Eligibility for Study Course Supporting Education (LWOO) and Practical Training (PrO) are subject to national indication criteria. The indication is made by the Regional Referral Committee.

Children with disabilities (physical, psychiatric or intellectual) have the option of special needs primary (or secondary) education or pupil-specific funding (LGF, also known as ‘backpack’) for ambulatory support. Such support is provided from within the special needs primary (or secondary) education system. In addition, there are other forms of support in the areas of mainstream education in which the child is involved.[**]

Within and between these forms of education there are various collaborative ventures for the care and education of special needs pupils. For further details about the educational system, see Annex H.

6.1.2 Numbers of children with an ASD in education

Recent years have seen a rise in the number of children enrolling at ‘cluster 4’ special needs schools. The 2005 report entitled ‘Kanttekeningen bij de groei van de deelname aan cluster 4’ (Observations on the growth of participation in cluster 4) by the *Landelijke Commissie Toezicht Indicatiestelling* (National Super-

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[*] Prior to 1998 these were schools for children with learning and rearing difficulties (LOM), for children with learning difficulties (MLK), and for preschool children with developmental difficulties (IOBK)

[**] Accordingly, the terms ‘special needs primary education’ and ‘special needs education’ are somewhat confusing.

visory Committee for Needs Assessment; LCTI) shows that 44% of the 13,197 pupils applying for needs assessment for special needs education or pupil-specific funding in 2003/2004 and 2004/2005 had a disorder in the autistic spectrum. In 2004, a total of 22,078 children were enrolled in ‘cluster 4’ schools (in both primary and secondary education).

Sixty percent of the children who ultimately remained in mainstream education with an ‘LGF’ (pupil-specific funding) had an ASD. The corresponding figure for those attending a special needs primary (or secondary) school was 36%. The LCTI examined 330 files in 2006/2007. Well over 40% of the children in question had an ASD, compared to 33% in the preceding year. The bulk of this increase was in the PDD-NOS group. Indicative figures produced in October 2007 show that some 27,670 children were enrolled in ‘cluster 4’ schools at that time. They also reveal that 17,820 children with a ‘cluster 4’ indication were receiving ambulatory support by means of pupil-specific funding. The Committee was unable to obtain figures relating the background and gender of pupils to the type of school that they attended.

The 2005 and 2008 surveys of Dutch Association for Autism (NVA) members showed that approx. 7% of the children and young people of school-going age and with an ASD were not attending school (5% to 6% had an exemption from compulsory education, while about 1.5% simply stayed at home). More than half were in mainstream education (30.3% in primary education (or special-needs primary education), the others in mainstream secondary education). Almost 40% received special needs education (30% in ‘cluster 1-4’ primary education, the rest in special-needs secondary education; VSO). In special needs education, most children with an ASD attend ‘cluster 4’ schools.[12,42]

The response to the 2008 NVA survey revealed that almost two thirds of primary school pupils attended a mainstream primary school. In 2005, the corresponding figure was nearly half of this age group. During that period there was also an increase in the use of pupil-specific funding. The trend in secondary education is quite the opposite. In 2008, 53% of the respondents of secondary school age were in special needs education, as against 33% in 2005.

6.1.3 Detection and the road to help

Most pupils do not encounter problems during their school years. Individual educational needs programmes involve monitoring pupils’ cognitive and social-emotional development, and assisting them if they need a helping hand.

The detection of a problem is the first step towards solving it. Consultation and collaboration with the parents is essential in this regard. As stated in chapter 3, various general detection instruments can be used to delineate the behaviour of students who are not performing well at school. Some examples of instruments of this kind are the TRF and the SEV.

In practice, an initial attempt is made to resolve the problems within the school by recourse to its internal system of care. If this is not successful, then a *Zorg Advies Team*[*] (Care Advisory Team; ZAT) or professionals within the school supervisory service can be consulted. At present, use of the ZATs is still mainly restricted to secondary education. The application of this form of cooperation to primary schools is still in the developmental phase.

Further diagnostic testing is sometimes needed. Indeed this is more often than not the case with regard to ASD. In some regions, going through the usual channels (Youth Care Agency – Youth Mental Health Care) can be a very protracted process, taking up to several months. Accordingly, some schools ask parents to have their child examined (via a referral from their family doctor) by an independent general psychologist in primary health care, a health care psychologist, a child and adolescent psychologist, a psychiatrist, or a remedial educationalist.

If autism is suspected, the Committee considers it essential that obtaining a classification should not be considered an end in itself. As discussed in chapter 3, a classification within the autism spectrum must be coupled to a broad, action-oriented diagnosis. A failure to do so means that the parents, school or, at a later date, the individual charged with needs assessment, all have inadequate understanding of the capabilities and limitations of the child in question. As a result, there is an inadequate understanding of the child’s needs, both in and out of school. This is also unfair to teachers and parents, as it restricts their ability to help the child.

The results of the study can be used to support further attempts to solve the problems within the school itself. If that fails, the decision can be taken to request an indication for special needs education (SO) or pupil-specific funding (LGF) (see Annex H for details of the procedures involved). On the basis of the chronic nature of their psychiatric disorder, the usual course of action in the case of pupils with an ASD is to request an indication for ‘cluster 4’ schooling. Alter-

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[*] The ZAT is a multi-disciplinary team in which professionals who provide care and support to youngsters and their parents also work with schools to solve the problems encountered by children and young people. The agencies and individuals involved include youth care services (child healthcare), social work, school attendance officers, the police and the educational care co-ordinator. [223,224]

natively, applications may be made for ‘cluster 2’ (severe speech or language problems) or ‘cluster 3’ schooling (intellectual disability). At this stage, there are fewer applications for a ‘cluster 1’ (visually impaired) schooling indication on behalf of pupils with an ASD. Autistic children with a visual impairment are channelled into ‘cluster 1’ schooling early on, mainly on the strength of their visual problems.

The officially prescribed period for processing an application and issuing a decision is eight weeks. This process may take even longer if the needs assessment committee decides that it requires additional information. In the 2006-2007 school year, the average waiting list for a ‘cluster 4’ indication was 9.6 weeks. Those who received such an indication then faced a waiting list of almost 7 weeks before being able to enrol in ‘cluster 4’ special needs education.[*]

Simply issuing an indication is not always of immediate use, either to the child or the school in question. Figures from the Ministry of Education and various annual Regional Centres of Expertise (RECs) show that part of the pupil-specific funding is retained rather than being used, due to a shortage of ambulatory counsellors. If children encounter placement problems then educational consultants can be called in. Various individuals were specifically appointed for this purpose in 2003, by the Ministry of Education.[226]

These factors can cause delays of months or even years before ASD pupils receive effective help with problems at school. The seriousness of this issue is underscored by studies showing that the provision of counselling and treatment at the earliest possible stage can prevent these problems from worsening and give the development of such children a push in the right direction.[13,227]

6.2 Most common problems

In this section, the Committee explores the most common problems encountered by children with an ASD in the educational system.

6.2.1 Basic learning difficulties

The limitations in communication and imagination that characterise an ASD mean that children affected by these disorders are unable to study in the same way as non-ASD children of average ability.[228]

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[*] Source: Education Inspectorate annual survey.[225]

Childhood autism often involves limited speech/language development. Individuals with PDD-NOS and Asperger's disorder tend to stand out, due to their unusual way of speaking, which is characterised by echolalia (the verbatim repetition of words or phrases, either immediately or with a slight delay) and by verbosity. ASD sufferers are also oblivious to various linguistic subtleties, nuances and double entendres.

Their limitations in terms of imagination mean that these individuals' perception of images differs from that of other people. Accordingly, for them, static pictures cannot convey a sense of movement, for example, an image of two figures throwing a ball to one another. Such children simply see two dolls and a ball somewhere between them, they do not appreciate that this is a depiction of a game. Meaning is acquired in an entirely different way. This has implications for the teaching methods and educational materials used.

One problem is that pupils with an ASD have difficulty anticipating and planning events or activities.

Their limited social and cognitive skills often mean that the traditional classroom setting is altogether too tumultuous and confusing for pupils with an ASD. They also find it difficult to work in groups.

The Dutch system of education is very linguistically oriented, imposing particular demands on verbal intelligence. The system also places great demands on pupils' imaginations, in the sense that they are expected to be able to comprehend images, to extract useful information from them, or to use them for specific applications. Finally, classroom teaching methods have evolved over the past 30 years. There is now less emphasis on teachers giving instruction from the front of the class and more on exchanges with the teacher and with fellow students. In view of this, ASD should not only be seen as a purely behavioural problem but as a learning problem as well. Schools should take this into account when opting for particular teaching methods and materials.

6.2.2 Getting help involves lengthy procedures

Currently, too much time is allowed to pass between the first feeling that something is not right, a diagnosis being made, and a possible needs assessment for special needs education.

In many separate institutions, a wide range of professionals with different educational backgrounds and varying degrees of expertise on autism spectrum disorders are required to contribute towards a diagnosis. They will also be called upon to identify the nature of the problems and limitations, and to determine whether children with an ASD are or are not eligible for special needs education/ LGF.

The institutions in question are faced with a shortage of staff and with a degree of uncertainty brought about by changing legislation.

The procedures followed by these bodies appear to be overly formal and relatively inflexible. In many cases, an excessive compartmentalisation of responsibility acts as a barrier to effective coordination. As a result, the children involved spend much of their time being shunted from pillar to post. Furthermore, in the present situation, there is a lack of clarity about who is best acquainted with the child's case and with its needs.

With regard to applications for needs assessment, it is generally the parents who are required to set events in motion. Although counselling is an option, in most cases the parents and/or counsellors have neither sufficient knowledge of autism spectrum disorders nor the requisite language skills to fully comprehend and successfully complete all of the procedures involved.

All pupils in special needs education and with an LGF are subject to periodic reviews. If they are found to be making good progress then their indication may not be renewed. This places the 'prosthesis' of ASD pupils in jeopardy. It is like giving someone with poor eyesight a pair of glasses, thereby causing them to see so well that they are no longer eligible for glasses and have to return them. The system therefore seems to have a built-in disincentive for children with an ASD.

The institutions charged with needs assessment for special needs education/ LGF have an indirect interest in awarding an indication. Furthermore, rejecting applications is more labour intensive than approving them. Taken together, these effects might artificially boost the number of official indications granted.

The current educational system requires teachers to deal with a very heterogeneous group of children, both in terms of behaviour and of cognition. This begs the question of where exactly the boundary lies of what may reasonably be expected of teachers.

6.2.3 Transitions

In the life of every human being, there are transitions that place great demands on an individual's flexibility and adaptability, such as moving house. Other dramatic changes in everyday life are when people change job or when children make the transition from primary to secondary school. In general, people are able to deal with transitions of this kind. While at the beginning they may feel a little out of place, they usually adapt to the new situation in a month or two.

For children, adolescents and adults with an ASD, any transition involves the risk that it may aggravate their symptoms. An existing equilibrium is disrupted by a transition, the environment changes and the job requirements are suddenly different and/or more demanding. The disturbance of this equilibrium by a transition prompts a degree of development, which then leads to the establishment of a new equilibrium. The exact course that this development takes is then determined by the interplay of various forces.[266] Equilibrium may indeed be restored, but when the individual reaches the limits of their capacity for development this new equilibrium may involve a worsening of the symptoms of their disorder.

Furthermore, the nature of the transition involved affects the individual's ability to adapt to the new situation. For young people with ASD, transitions within the educational system, the transition from home to school, and the transition from education to work are often very complicated matters.

Chapter 3 shows that only those children with childhood autism are – or can be – identified before they reach school-going age. Given the current prevalence figures, this represents more than 25% of all cases of ASD. Three quarters of children with an ASD perform more or less normally before they reach school-going age, at least to the extent that parents have no or little incentive to sound the alarm or to the extent that their demands for care fall on deaf ears.

For all children, starting school is both an exciting time and a major step that they generally take successfully. For some, it can be a step that causes them a great deal of trouble. It is their first major moment of transition. The environment changes, and in education in particular the demands placed on the individual suddenly switch into a higher gear.

The 2008 survey of NVA members revealed that, on average, children were seven years of age when first diagnosed with ASD. It also showed that the first suspicions of autism tend to occur when children are 5.3 years of age, on average.[12]

In many of these cases, it is the teacher who first calls attention to the fact that something is the matter with the child. This partly involves children with an ASD, but other potential problem areas are ADHD, behavioural disorders and sensory impairment. Given the current prevalence rates, teachers in mainstream education can expect to have a child with an ASD in their class[*] once every four or five years. It is not necessary that teachers be aware of all possible disorders and behavioural problems, but it is important that they can draw attention to such cases and that they know how to deal with them.

Many children with an ASD encounter problems when they enter primary education. For others, however, this happens at a later stage. They may struggle with group assignments and homework in the more senior classes. Some may even enter secondary education without any problems, only to encounter difficulty with the study house system, for example.[12] In the 2008 survey of its members, the Dutch Association for Autism (NVA) indicated that problems often occur in secondary and further education as the school situation in these elements of the educational system is more complex than in primary education. This is also linked to the socio-emotional development associated with puberty and adolescence. Puberty is a time when teenagers and parents are preoccupied with plans for the future, all the more so when this involves the career options for young people with autism. After all, this is the time when decisions have to be taken concerning a course of study in further education.

In secondary education, pupils are not taught by just one single teacher day in day out. Furthermore, pupils are expected to be more independent in planning and completing their homework, for example. In addition, key concepts of the ‘new learning’ – such as problem-based education, competence-based learning and collaborative learning – play a much greater part than in primary education. Greater demands are placed upon today’s secondary school pupils in terms of the integration of distributed information, planning, self-control, reflection, and social and communicative skills. The same applies in higher education, often to an even greater extent.

The demands made of an individual in the workplace are entirely different from those that they encountered at school. Workers are generally expected to be more independent and self-reliant than school pupils. The way in which they communicate with colleagues and managers bears no resemblance to their interactions with teachers and fellow pupils (see chapter 7).

In its report *Bouwstenen voor betrokken jeugdbeleid* (Building blocks for a committed youth policy) (2007), the Scientific Council for Government Policy (WRR) is generally critical of the educational concepts of competency-based

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* In schools, the average class size ranges from 25 to 30. Assuming a prevalence of 1 in 100 to 167, this would suggest that there is one child to every four to five classes.

education and dual learning.[6] Due to the nature of their handicap – limitations in social and communicative skills and a predilection for predictability and regularity – children/young people with an ASD experience greater difficulty than the average young person with these forms of education. The same applies to the transition to secondary education, the process of secondary education itself, and entering the job market. They may even face greater challenges than those with another type of physical or mental limitation, who do not have to deal with these specific problems in the area of social communication. Another possible factor (and this is particularly true of normal–ability pupils with ASD) is that the behaviour exhibited by ASD sufferers is often wrongly interpreted and/or considered to have room for improvement.

There is a significant risk that, in times of transition, the child or young person/ adult in question will not be under the specific supervision of a given individual or institution. Primary schools do not prepare children for the transition from primary to secondary education as they have no stake in these pupils' subsequent school career. The same applies to the transition from secondary education to work. When an ASD sufferer joins a new school/company, those institutions certainly have a stake in ensuring that the individual in question functions to the best of their ability. By that stage, however, the transition is already a fact, and little or nothing can be done in the area of prevention. In effect, children/young people with ASD and their parents are often left to their own devices when it comes to preparing for (and working through) transitions. However, their courses of action are limited by the fact that they do not know exactly what the new situation will involve.

In recent years, the notion that transitions involve problems has been steadily gaining ground both within the secondary education system (both mainstream and special needs) and in government circles. This is evidenced by numerous reports and initiatives on the improved coordination and continuity of care in the education (and secondary education) system, and on job placement assistance for school leavers. Consideration is also being given to providing courses on how to deal with transitions, and there are plans to amend the Invalidity Insurance (Young Disabled Persons) Act (see chapter 7).

The majority of studies have tended to focus on the transition from education to work (see section 6.6). However, the transition from primary to secondary education also poses considerable challenges for children with an ASD. Accordingly, plans to give the child the best possible preparation for secondary education should be prepared and implemented well in advance of the transition to secondary education. Furthermore, someone should accompany the pupil through every step of the process of transition. This is because, however thorough the preparations may be, the impact of the transition on the burden of disease caused by the child's disorder is impossible to assess in advance.

6.3 What is needed?

In its publication entitled 'A place to live' (members survey 2008), the Dutch Society for Autism stated that many children with autism require some form of additional guidance or support during their education, particularly with the planning and structuring of exercises and assignments.[12] The extent to which such counselling is required varies from one pupil to another, and from one school situation to another. The purpose of such support and counselling is to provide ASD sufferers with a 'prosthesis' that prevents their limitations from becoming an insuperable obstacle to effective performance (see also chapter 4). After all, the way in which the disorder manifests itself is the result of an interaction between susceptibility, environment and the 'requirements of the job'.

Adjustments should be made to the environment and to 'job requirements' affecting basic situations (including those related to teaching) at home and at school. As to education, children can be characterised in terms of the special educational needs arising from their disorder. Three dimensions are sufficient to define a support 'prosthesis'. These are providing structure, assigning responsibility, and encouraging self-confidence (fitting teaching practice model, Vos, 2008). Adjustments must also be made to the physical environment and to teachers' expertise, to enable them to follow the thinking of pupils with ASD. For example, such children tend to take instructions literally, they cannot integrate information effectively, they have problems with generalisation and with the acquisition of meaning, and find it difficult to switch from one situation to another. Children with an ASD generally benefit from a calm environment and an orderly lifestyle. The creation of structure can involve fixed routines, standard procedures, order and regularity. Visual aids can also be used to clarify concepts of time, space and situation. Information can be presented by means of icons, and checked from time to time.

The TEACCH programme has shown that visualisation is often an effective instrument for ASD sufferers.[150,151] The CED group developed the '*Wijzer-Onderwijs: Autisme*' (A Good Educational Compass: Autism) as a guide to primary and secondary education. With regard to the 'prosthesis', the chronic nature of autistic spectrum disorders and their ever–changing form and intensity mean that the individuals in question will need this resource for the rest of their lives.

6.4 Expertise within the educational system about ASD

The presence of a pupil with an ASD can affect the entire class. Teachers therefore need to know how best to deal with the pupil in question, and with the group around them. To this end, schools can approach a regional autism support office (64 of which had been established by June 2009) for support with the education of pupils with an ASD. These support offices are affiliated to the Regional Centres of Expertise (RECs). They offer schools support in the form of consultation, instruction, training and regional cooperation. They also give presentations about autism at teacher training colleges, for example. In practice, the guidance relating to pupils with autism (on planning, clarity and structure) can also be very useful for the other pupils in the class. The support offices are usually part of a 'cluster 4' REC. However, various regions (such as North-Holland and North Brabant) have autism support offices that cooperate with the RECs of all four clusters.

The regional autism support offices are coordinated by the National Autism Network (LNA).[151] This network was set up in 2001, at the instigation of the Ministry of Education, to assist schools with the education of children with an autistic spectrum disorder.

The LNA provides information and encourages collaboration between schools, or as the employees of the network itself put it: *'The LNA encourages modified teaching and effective support for pupils with autism in mainstream and special needs primary education, secondary education, and vocational training. This involves professional development for those involved, as well as sharing the knowledge and information gleaned from everyday practice.'*[151,229] (for further information see Annex H). One special LNA project, which is fully compliant with this stated objective, is the PASSER project. PASSER is a Dutch acronym which stands for *expertisePlatform ASS Eindonderwijs in de Regio* (ASD expertise platform for final phase education in the region). PASSER provides a cooperative framework for eleven schools in mainstream and special-needs secondary education. One thing that these schools have in common is that they successfully offer diploma-based final phase education to large numbers of students with autism. They are also willing to share their expertise with other schools. They offer other schools a 'look behind the scenes' and are prepared to help schools that also want to provide appropriate final phase education to pupils with autism.

These eleven schools are not the only ones to offer appropriate final phase education for pupils with an ASD. One of the Platform's tasks is to develop a nationwide network of schools in mainstream and special-needs secondary education that can offer appropriate final phase education to pupils with autism. In total, more than 150 participating schools are listed on the PASSER website.[151]

Another of PASSER‘s activities is the ‘*Ommekeer met PASSER*’ (U-turn with PASSER) project, in which a number of schools are collaborating on the development of a digital teaching programme for final phase education at VMBO-T (preparatory secondary vocational education - theoretical)/HAVO (senior general secondary education)/VWO (pre-university education) for pupils with autism. The cooperating schools will be using a virtual environment – a nationwide ‘web-school with webcam teachers’ – to provide lessons to places where it is otherwise impossible to provide appropriate education (see section 6.5.1). Teaching materials and guidelines for developing teaching materials for children with an ASD are just some of the resources available at www.passer-webschool.nl.[230] The web-school concept might even enable pupils who do not leave their homes to take part in education once again. The autism support offices have found that, in practice, it is difficult to get a child back into education once it has become used to being at home. E-learning can be a first step in this process, but the main aim is still to get pupils back into school and in contact with their fellow pupils.

The PASSER schools have identified four building blocks for diploma-based ASD final phase education. Firstly, pupils with an ASD require more time than average pupils to prepare for mainstream schoolwork and for their entry into society (in this context, a plan for the individual's future prospects must also be prepared in good time). Secondly, schools must be flexible about the 1000-hour standard, and about the form and timing of examinations. Thirdly, ICT applications can be useful as teaching instruments and for the formulation of appropriate educational packages. Finally, cooperation with the care sector is seen as a prerequisite for success, primarily in the interests of being able to provide this target group with a wide-ranging, customised educational/care package.

The Dr. Leo Kanner House engages in projects in the field of education. For instance, it initiated the ‘Knowledge Development on the Treatment of Autism and Integration in Regular Education’ (KAIRO) project, which ran from 2005-2007.[231] KAIRO was launched in response to the lack of specific figures on the number of pupils with an ASD that were involved in vocational training. At that time, it was clear that only a small proportion of young people with ASD were enrolled in secondary education. The aim of the project was to link education and

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care, to enable young people with an ASD to undertake vocational training. Each of these pupils were surrounded by a personal support network consisting of three parties. In this network, the personal counsellor had a pivotal role with regard to treatment. In addition to frequent and regular contacts with the young person in question, the counsellor maintained contacts with the school and the parents. Within the school the pupil was assigned a learning coach. These pupils were given access to a broad-based Education Treatment Programme which was, as far as possible, in keeping with the day-to-day requirements of the vocational training programme in question. Training was given to enable the young people to adjust as much as possible to the requirements of the programme, while the schools adapted their learning environment and their teaching methods to the limitations of these students.

The Dr. Leo Kanner House is committed to achieving a wider implementation of this approach throughout the country.

6.5 Educational improvement initiatives

6.5.1 Policy Initiatives

Appropriate Education

The issues relating to the road to help were largely identified in the Broad Review of Back to School Together (WSNS), pupil-specific funding (LGF) and the policy on eliminating educational disadvantages (OAB) in 2004. They are not all specifically intended for ASD sufferers. In 2005, with a view to finding a solution to these problems, the State Secretary for Education introduced the concept of ‘duty of care’. ‘*Every school board has the responsibility of providing an appropriate education/care package to any pupil applying to – or already enrolled at – a school under its governance. If a school is unable to provide a given package from its own resources, then it must ensure that the pupil in question obtains that package elsewhere. To this end it must coordinate with those boards that do offer the package in question, and it must provide a referral that is supported by reasoned arguments.’* [232,233]

This duty of care must be translated into ‘Appropriate Education’. This was agreed in 2006, following consultations with those working in the field and with the organisations involved. It should be noted that Appropriate Education (PO) does not mean inclusive education. While special needs education will continue to exist, Appropriate Education will be more closely engaged with mainstream education.

The aim is to complete the Appropriate Education legislation in 2011. This will be followed by the phased introduction of the related measures. As a final step, the budgetary changes will take effect. Details of the main changes that the State Secretary has in mind for Appropriate Education are set out in the box below.[232-238]

- The introduction of duty of care.
- Establishing regional support offices to assist parents with the assessment of the education/care package that is on offer. This organisation also includes the educational consultants who already arbitrate placement issues in special needs education.
- It is not a requirement that all students who need extra care must also have an official indication. Dealing with more minor problems – such as some forms of dyslexia – will be financed from a basic care budget.
- Those pupils who need more support can obtain an indication on the basis of an objective system. An indication classification system for all students will be introduced. This will be used to assign an individual ‘care weighting index’ to each pupil.
- Wherever possible, the supply-oriented forms of funding that characterise the current system will be scrapped. The level of funding no longer has any impact on the institution at which the pupil is receiving their education. The vertical monitoring carried out by the inspectorate will be tailored to the new situation. This means that the inspection will verify that all students have been offered an education/care package and that both the quality of education offered and the results obtained are satisfactory.

Being based on the above principles, Appropriate Education is well placed to provide opportunities for children and young people with an ASD, as well as those with other disorders or support needs. The focus will be more on the child’s ability and less on its limitations. There is greater scope for differentiation in the way in which these pupils are catered for in terms of their individual educational needs and their education. Given the number of pupils involved, it will become more convenient and rewarding to create special ‘auti-classes’, for example. The experience gained by PASSER within the National Autism Network may prove very useful in the creation of Appropriate Education for pupils with an ASD. Hopefully, Appropriate Education may include sufficient scope for education in a broader sense. This might involve social skills training, internships and other forms of job placement assistance, as well as other aspects of preparation for an adult life that is as independent as possible.

The Committee has various comments concerning the plans for Appropriate Education. One advantage of the regional duty of care is that schools can specialise in a particular disorder. One disadvantage is that, depending on the agreements reached between schools, there will be a tendency to create clusters of pupils with similar problems, and that they will be denied a chance to become

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integrated into mainstream education. This may mean that pupils will once again have to travel considerable distances to and from school.

Although this will dispense with the risk of over-indication that is inherent to planned budget funding, it does nothing to eliminate the disincentive of terminating the funding for support and guidance in education when the child performs well. Children with an ASD who perform well as a result of the additional counselling still risk losing their indication, which makes a relapse all the more likely.

Final attainment levels in special needs education

Efforts are being made to formulate final attainment levels for secondary special needs education. Secondary special needs education is not currently authorised to set examinations, so pupils leave the educational system without any form of qualification. The issue of how to formulate final attainment levels is currently being examined. This might involve awarding certificates for individual course components to pupils in secondary special needs education or enabling them to put together a portfolio so that they would have some form of qualification for the job market.

6.5.2 Initiatives in the area of education

The national network will remain active in designing new strategies for improving the education of pupils with an ASD (see also section 6.4). PASSER and the autism support offices are essential activities. In addition, the National Autism Network has issued various publications to assist pupils, parents and teachers, such as the ‘Protocol for the transition of autistic pupils into secondary education’. This protocol is intended for secondary schools (preparatory secondary vocational education (VMBO), higher general secondary education (HAVO) and pre-university education (VWO)). It provides information on how to counsel pupils in secondary education about their options in further education. Increasing numbers of pupils with autism are making the transition from the secondary education system to a programme of further education at secondary vocational education (MBO), higher vocational education (HBO) or university (WO) level. These transitions do not always go smoothly.

An important element in the protocol is a permanent confidential counsellor/ contact who counsels students with an ASD throughout the process (including regular private interviews) and who monitors their progress. It is important that such counselling not be fragmented by being shared among many different ‘officers’. Students with autism in secondary education should preferably be supported by a personal coach throughout their entire school career. This coach will also provide counselling during the transition to further education. Even after such students have entered further education (MBO, HBO or WO), it is important that they continue to receive counselling from a single personal coach. This coach should hold regular interviews with the students and should monitor their progress in their chosen course of study. The personal coach also mediates between students (and their parents) and their teachers. Within the institution or organisation in question, the personal coach will be supported, for example, by an ambulatory counsellor from the Regional Centre of Expertise (REC) using pupil-specific funding (LGF) for secondary vocational education (MBO).

There are also various projects which, while not specifically aimed at students with ASD, are nevertheless available to them. One example is ’*Herstart*’ (Restart) which helps drop-outs to find the right school and to get used to the rhythm of school life again. Another is, ‘Op de rails’ (On track), which can help with behavioural problems and imminent expulsion, although this project is not strictly intended for pupils with a classified disorder.[223]

6.6 Measures to facilitate entry to the labour market in the context of education and course of study.

6.6.1 *From learning and studying to working with an impairment*

It is not only pupils with an ASD who have trouble with the transition from secondary education to the labour market. This process also poses difficulties for any young people with developmental, learning and behavioural problems. For this reason, from the 1990s onwards, special needs schools have experienced an increasing need to address the yawning gulf between school and work. Meanwhile, educational institutions throughout the Netherlands, particularly those offering Practical Training (PrO) and special-needs secondary education (VSO), are actively guiding their pupils into the labour market. This process involves both work training and measures to facilitate entry to the labour market.[239-241]‘Werknemer in opleiding’ (Employee in training) is a project aimed at helping these educational institutions place their students in the job market, in positions with good prospects.[*] Subsidies from the European Social Fund (ESF) are a key driver behind these developments. They enable the Practical Training (PrO) and special-needs secondary schools (VSO) to implement projects to this end. Another source of funding were the grants from the Invalidity Insurance (Young Disabled Persons) Act subsidy scheme.[242]

While schools can of course learn from one another's practical experience in this area, they still lack a shared vision of how the transition from school to work can best be managed. As a result, many simply adopt a trial and error approach. However, some schools are more progressive and work closely with specialised reintegration agencies which assist pupils in finding a job.[240] These agencies use job coaches who coordinate with work placement teachers. In addition to ensuring that such transfers proceed gradually, the coaches provide aftercare. Other schools provide very little support to their pupils who are making the transition to work.

One problem commonly encountered in practice is a lack of long-term support for pupils who have finished school. This particularly affects school leavers who are unemployed or who only worked for a short time before losing their jobs. They have to deal with numerous official bodies and individuals, many of whom have no clear idea of these young people's capabilities. Similarly, the young people in question do not fully comprehend the problems and opportunities that present themselves. For this target group, the consequences of a break between school and work are all the more distressing, as the knowledge and skills that they have acquired erode quickly through lack of use.[240]

While schools undoubtedly play an important part in supporting their pupils through the transition to work, it is the organisation for reintegration into the job market and temporary income (UWV) – and particularly the employment expert – that deals with those young people who will go on to claim benefits under the Invalidity Insurance (Young Disabled Persons) Act. Using the 'network formula', employment experts are expected to coordinate the responsibilities of those parties that can assist with the transition from school to work.

The networks are often organised at regional level. In addition to schools and the UWV employment experts, they often include local authorities, sheltered employment companies and MEE organisations. Until recently, the Centre for

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* '*Werknemer in opleiding*' (Employee in training) is a project commissioned by the Ministry of Education, Culture and Science and implemented by *De Vereniging Landelijk werkverband praktijkonderwijs* (National Association of employment and practical training), the WEC Council and representatives of the KPC Group. The objective is to collaborate with all the parties involved to develop job placement assistance measures within the areas of Practical Training and secondary special needs education (see also www.werknemerinopleiding.nl and www.liesa.nl (*Landelijk Informatie en Steunpunt Arbeidstoeleiding* = National Information and Support Office for Job Placement Assistance))

Work and Income (CWI) often participated in these networks. It now operates under the name of UWV WERKbedrijf, which is part of the UWV.[243]

Measures to facilitate entry to the labour market are not restricted to pupils at special-needs secondary schools (VSO) and to those in Practical Training (PrO). They are also available to pupils with disabilities who are enrolled at secondary vocational education (MBO) institutions. This group became eligible for MBO pupil-specific funding with effect from 1 January 2006. This funding has been embedded in legislation since 1 August 2008.[244,245] The introduction of pupil-specific funding is intended to smooth the transition from secondary education (VO) to secondary vocational education (MBO). The ultimate goal is to support students with disabilities in the transition to work.

All higher education institutions have a responsibility to offer their students with disabilities the opportunity to obtain a professional qualification when they complete their studies. They may, for example, require student counsellors and study advisers to provide counselling and support. A few years ago, the majority of students were still unaware of the special facilities that were available to them. The target group were not being kept sufficiently well informed in this regard.[246] In an attempt to correct this situation, many institutions of higher education now have a policy of actively informing their students about such matters.[247] In general, however, it is up to the students themselves to take the initiative and request support.[*]

Various educational institutions offer courses and workshops in which teaching staff are trained to recognise and counsel students with a mental limitation. Various instruments are available to help prepare students for the labour market. These include a career test and interview training – both developed by the Dutch Expert Centre for Studying with Disabilities. There is also a work placement guide, which includes a training module for work placement supervisors in higher education. The Expert Centre has also written a reader for counsellors at universities of applied sciences and for autism teams.

6.6.2 Job placement assistance for pupils and students with autism

Pupils with an ASD who are enrolled at a school offering Practical Training (PrO) and special-needs secondary education (VSO) will also benefit from these

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[*] See, for example, the policy paper entitled ‘Studying with a disability’. www.fontys.nl, as well as other universities of applied sciences and universities.

developments, the purpose of which is to improve job placement assistance for school-leavers. Hopefully, the current measures will also help students in secondary vocational education (MBO) and higher education by boosting their chances of a place on the labour market. A critical question in this context is what more needs to be done to enable pupils or students with an ASD, in particular, to successfully enter the labour market.

The report entitled '*Kinderen met speciale rechten; Arbeidstoeleiding van kinderen met autisme (2003)*' (Children with special rights; Job placement assistance for children with autism (2003)) explored the measures used at that time by various secondary schools (VO) and special-needs secondary schools (VSO) to prepare and support their ASD pupils throughout the transition to work.[248] It emerged that, despite making heroic efforts in this area, many schools were still struggling to develop a clear vision and policy, nor were they being open enough with one another concerning their successes and failures. Nevertheless, many similarities and common experiences were reported. One of these was the feeling shared by all schools that the counselling provided to young people with an ASD should always be tailored to the individual in question. Other common experiences were that, while schools can undoubtedly provide skills training for sheltered and general employment, the work and the workplace itself should also be suitable, or made suitable. In addition, pupils who have completed their education should receive long-term counselling, involving as few people as possible.

REA training institutes merit special consideration.[249]The five REA training institutes offer customised training courses and job placement assistance for young disabled people who cannot be educated within mainstream education nor counselled in that context during the transition to work. Over the years, REA training institutes have gained considerable experience both in training pupils with an ASD and in supporting them during the transition from school to work. Details of the knowledge and experience that they have accumulated in the course of this work are accessible for use in other schools.[250]

The Committee was unable to find any studies or project descriptions specifically relating to a smooth transition from full-time education to work for students with an ASD in secondary vocational education (MBO) and higher education.

6.7 Conclusions

In the case of children with an ASD, whose performance is not adversely affected by their disorder until they are in full-time education, it takes too long before their true status is identified and diagnosed. Furthermore, the delivery of aid gets off to a slow start due to the excessive bureaucracy involved in needs assessment and to a shortage of ambulatory counsellors.

Children with ASD require an education that takes their capabilities into account and that is tailored to their specific limitations. This has implications for teaching methods, for the organisation of classroom teaching, and for individual educational needs programmes. On paper, ‘Appropriate Education’ offers more opportunities for customisation than are currently available.

In addition to possessing the requisite teaching and academic skills, teachers are required to be experts in specific areas such as various psychiatric disorders, language development, dyslexia, preventing pupils from falling behind with their studies, support measures for childrearing, and integration. They are expected to have advanced knowledge in various areas and to be capable of teaching a highly differentiated range of programmes. Such requirements place great – and possibly excessive – demands on teachers.

There are still too few formal measures available to smooth pupils’ transitions into and within full-time education.

On the other hand, the transition from school to work of pupils at special-needs secondary schools (VSO) and those in Practical Training (PrO) has been something of a hot topic in recent years, and considerable progress has been made. There is rather less provision for pupils and students with a disability or a disorder who are studying at secondary vocational education (MBO) institutions and in higher education, indeed the process has barely started. It is worth noting that they too run the risk that their knowledge and skills will be under-used or simply wasted.

The transition from education to work requires enormous commitment on the part of schools and employers.

6.8 Recommendations

The Committee calls for an efficient use of teachers’ expertise (as generalists this spans many fields). It also feels that they have an important part to play in the general detection of psychiatric disorders (including ASD) and in referring (also within the context of the educational system) such individuals for care.

In the case of pupils with ASD who (with ambulatory support) are capable of remaining in mainstream education, appropriately trained ambulatory counsellors should be available to them immediately after an official indication has been given.

In the educational system, the transition from primary to secondary education must be carefully planned and supervised, in consultation with the parents.

All institutions of secondary and higher education should provide counselling during the transition from education to work, as a standard service. All aspects of such counselling should preferably be carried out by a single individual. Job coaches specialising in (and certified for) counselling young people with an ASD would be a welcome addition, in terms of measures to facilitate these young people's entry to the labour market.

A detailed specification is needed of the proposed long-term counsellor's competency profile with regard to education and to measures to facilitate entry to the labour market.

Chapter

7

Opportunities and limitations at work

ASD sufferers want to participate in society, and many want to work and earn a living. For many young people this is not an option, they simply end up in the incapacity benefits system (Invalidity Insurance (Young Disabled Persons) Act).

This chapter contains a summary of the growth in the number of incapacity benefits awarded, in terms of ASD sufferers' entitlement to incapacity benefit under the Invalidity Insurance (Young Disabled Persons) Act *(Wajong)* and the way in which this relates to current prevalence rates. The employment rate of young people on benefits under the *Wajong* is compared to that of young adults with ASD abroad. The problems encountered by ASD sufferers in the workplace are also outlined. However, there are also opportunities for increased participation in paid work. The requisite conditions are discussed in the final part of this chapter. This chapter, like the others, closes with a conclusions section and another containing recommendations.

7.1 Changes in the influx of ASD sufferers into the Invalidity Insurance (Young Disabled Persons) Act benefit system (*Wajong*)

Since the mid 1990s, and particularly after 2002, the influx of new claimants into the *Wajong* has risen faster than was expected on the basis of changes in the at-risk population alone (table 4).* This increase was associated with a shifting of clinical pictures, and with their changing composition.[251] The organisation for reintegration into the job market and temporary income (UWV) launched an extensive investigation of claimants' files, in an attempt to understand the causes of this increase. From 2002 to 2006, one quarter of the medical records (1,308) of new claimants at three offices were selected (by random sampling) and analysed. One of the questions posed by this study was 'what clinical pictures can be identified and how did they evolve over the years in question'?

Table 4 Growth of the total influx into the *Wajong* from 2002 to 2007.

Year	2002	2003	2004	2005	2006	2007
Number	7,654	8,218	9,378	10,424	13,575	15,323

The growth in the influx is associated with two specific diagnostic codes: P697 (intellectual disability) and P699 (other psychiatric disorders).** In percentage terms, the joint contribution of these two diagnostic codes increased from 43% to 55% between 2002 and 2006. However, these codes convey no information about the underlying disorders. When the study commenced, ASD had not yet been assigned a specific CAS code (working conditions and social insurance classification code). To understand the relative contributions of each of the various disorders, a new main group (group O: Developmental Disorders) was introduced. Random sampling was then used to select well over 1,300 records from 2002 to 2006, which were then recoded by fifteen insurance physicians (tables 5 and 6).

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* Individuals may be eligible for a *Wajong* scheme if they suffer long-term work disability before their 17th birthday, or during their studies. Approximately 70% of those in the *Wajong* joined the scheme during their 18th or 19th year. For this reason, the population of 18-year olds can be considered an at-risk population. Over the next few years, the number of 18-year olds in the Netherlands will be between 195,000 and 205,000.

** Insurance physicians and company doctors use CAS codes (Classification of Occupational Health and Social Insurance). The basis of this classification is the ICD-10. The CAS-coding is less detailed than the ICD-10, but does provide the opportunity for occupational and work-related conditions to code.

Table 5 Influx to first diagnosis after recoding, as a percentage *(from Table 5.3 Knowledge Notebook 07-01).*

	2002	2004	2005	2006
O30/O60 intellectual disability	31.5	36	39.3	37.5
O61 autism spectrum disorder	9.1	7.5	10.2	10.6
O62 attention deficit disorder	1.7	1.9	3.9	2.9
O63 behavioural disorder	0.5	1.2	1.7	0.8
O64 learning disorder	0	0	0.5	0.2
O69 other developmental disorders	0.2	1.4	0.6	0.6

Table 6 Subdivision of code O61 (2006).

O61 autism spectrum disorder	10.6	100%
O610 autistic disorder	2.5	24%
O611 Asperger syndrome	2.5	24%
O612 PDD-NOS	3.8	36%
O619 Other ASD	1.8	17%

From these numbers, it can be deduced that approximately 700 cases of ASD were diagnosed in 2002 (9.1% of 7,654 clients) rising to 1,450 in 2006 (10.6% of 13,575 clients).*

The Committee works on the basis of a prevalence of at least 60/10,000 and possibly around 100/10,000 (chapter 3). As an ASD is a lifelong disorder, the prevalence rate can serve as a benchmark for incidence (the number of new cases in a given period). If we apply this figure to the at-risk population in the Netherlands (about 200,000 per year), then an incidence of around 1,200 individuals per year can be expected. The influx of ASD sufferers into the *Wajong* is in line with this expectation. The increase in the measured influx can be partly explained by the refinement of the diagnosis over the years and, perhaps, also by a transfer of adults with an ASD from social security to the *Wajong*. A comparison with figures in international publications shows that the UWV has a relatively high diagnosis rate for Asperger’s disorder (24% against 12.5%) and a relatively low rate for PDD-NOS (36% against more than 50%).

7.2 Employment rates for ASD clients and their participation in the *Wajong*

The UWV assessed the participation status of those entering the *Wajong* between 2002 and 2006, up until the end of 2006.[252] Their participation status was derived

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* The UWV uses the term ‘clients’ rather than ‘patients’.

from data in their personal file, supplemented where necessary by information from the UWV's registration system. A total of seven categories were used (Table 7).

Table 7 Participation Status, as a %, of ASD sufferers as against the total number of individuals in the *Wajong*.

	ASD	Total in *Wajong*
Regular employer	26%	22%
Process leading to regular employer	12%	9%
Sheltered employment	7%	6%
Waiting list /indication for sheltered employment	3%	3%
Daily activities in voluntary work	14%	11%
(Temporary) no participation opportunities	17%	29%
Status undetermined	22%	20%[a]
Total	100%	100%

[a] Of those in the *Wajong* whose status was classified as 'indeterminate', about 15% are still at school, or are still studying.

Based on these figures, it can be concluded that, of those individuals with an ASD who entered the *Wajong* in 2006, about one quarter is participating in regular employment, and that this could rise to 38%. About 10% are employed, or are capable of undertaking employment under highly adapted conditions – such as those pertaining in sheltered workplaces. When they first apply for the *Wajong*, a number of clients are still at school, others are either involved in a counselling process or are on a waiting list for sheltered work. Most applicants are around 18 years of age and are still developing, which means that their employment prospects may improve still further. The UWV has conducted a study into individuals' potential employment opportunities at the time of application (table 8).[252]

Table 8 Participation judgement for primary diagnosis (in % terms), 2002-2006 (table 2.5 Knowledge Notebook 08-01).[252]

	ASD	Intellectual disability	Other developmental disorders	Psychiatric diseases	Somatic diseases	Total in *Wajong*
Counselling concerning regular employer	40	31	48	16	47	31
Counselling for move to sheltered work	10	19	16	7	9	13
Counselling for daily activities/volunteer work	15	9	4	5	5	7
Occupational considerations preclude all employment	8	9	9	18	15	13
Temporarily not possible (medical reasons)	15	4	17	41	8	18
Not possible for an extended period (medical reasons)	11	27	7	14	16	19
Total	100	100	100	100	100	100
% of influx into the *Wajong*	10	37	5	33	16	100

When the potential employment options are compared to the numbers currently in actual employment (40% and 26%), it can be concluded that the former have been somewhat overestimated. The individuals with an ASD in the *Wajong* fall into several subcategories. In consultation with the UWV, TNO has examined the subcategories to see which offers the best opportunities and for what kind of work (table 9).[253]

Table 9 Assessment of participation opportunities for ASD in %, by TNO/UWV.

	Very slight intellectual disability combined with autism	Autism alone	Autism with another developmental disorder	Autism with another secondary diagnosis
Regular work	53%	43%	27%	52%
Sheltered	7%	10%	12%	4%
Temporary unemployment	9%	23%	17%	8%
Long-term unemployment	32%	24%	44%	37%
Number	17	72	15	26

The subcategories used are not consistent with the subdivision of code O61. For that reason, no numerical comparison can be made with Tables 5 and 6. Further research is required to determine the extent to which these numbers can be achieved, and for which categories.

7.3 Occupational integration of young disabled people, a comparison with the situation abroad

The large number of young people with an ASD who are eligible for *Wajong* benefits could be seen as a problem, but it can also be viewed in a positive light. For instance, when young people use a *Wajong* scheme, this makes them ‘visible’ for official purposes, which helps the authorities to determine the extent of the ‘problem’. These young people have access to numerous opportunities for counselling and support in the transition to work. A comparative study involving six other European countries showed the *Wajong* benefits system to be a unique scheme. It also revealed that much more information is available in the Netherlands concerning the diagnosis, employment rate, and occupational integration of young people than is the case in other countries.[254] In the countries examined, integration policy for young people is still in its infancy. It is less easy to establish such policies in these countries than is the case here in the Netherlands, because they have not yet properly organised their schemes for young disabled people. The report concludes that the Netherlands lacks no instruments or facilities that could be used for integration.* In all countries, including the Netherlands, there is still a substantial shortfall of information concerning the effectiveness and impact of integration measures.

7.4 Employment rate of adult ASD sufferers – a comparison with other countries

Section 7.2 examined the employment rate and potential options for young ASD sufferers. The 2008 survey of NVA members produced figures for participation in paid employment and work in the context of sheltered employment that were comparable to those obtained by UWV with respect to individuals making use of the *Wajong*.[12] Approximately 30% of the members surveyed had paid employment and almost 13% had sheltered employment. It is noteworthy that nearly one quarter of the members have either been able to work while retaining their benefit payments or are performing supervised work. Compared to the 2001 and 2004 surveys of members, the percentage of adults engaged in paid employment doubled, from 15% to 30%. In the Netherlands (aside from the UWV data and the figures produced by these surveys) no scientific studies have been conducted into the extent to which adult ASD sufferers participate in paid employment.[41,42] Research of this kind has been carried out elsewhere, however.

Howlin *et al.* (2004) concluded that all of the studies into the effects of autism in adulthood involved relatively small groups, and that the diagnostic and outcome criteria used were not always precisely formulated.[44] A consistent finding, however, was that a good prognosis for the autonomous performance of everyday activities in adulthood largely depended on the IQ of the individual in question. Very few of those with an IQ of less than 50 were able to perform effectively in adulthood. Patients with an IQ of 60 and above also had significant social problems. In general, well over 70% of them remained dependent on help from their parents and/or others in the performance of everyday activities. Around 30% were in work requiring little or no qualifications, and the majority of them worked in a sheltered environment or in special training programmes.

Studies that were subsequently published in various countries presented a similar picture.[210,219,220] The percentage of adults participating in regular work

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* The report cites the reintegration instruments in the current *Wajong*. Mention is also made of the reintegration provisions in other legislation, as well as the no-risk policy in the Sickness Benefits Act, the facilities for modifying the workplace (Work and Income (Capacity for Work) Act), the job coach scheme (Work and Income (Capacity for Work) Act) and thhe Sheltered Employment Act (WSW).

ranges from only a few percentage points to 12%, with an occasional peak of 40%. If the number of people working in a sheltered environment is added to this figure, the percentage generally rises to well in excess of 30%. These figures also agree with those produced by a 2001 survey of the members of The National Autistic Society in Great Britain. Only 12% of adults of higher intelligence had full-time paid work.

In the Netherlands, the figure of 26% (30% of NVVA members) of ASD sufferers that are in regular work compares favourably with the 4-12% that are in employment elsewhere. In percentage terms, however, fewer people are in sheltered work here than in other countries (UWV approx. 10%, NVVA approx. 13%, and 20% abroad). The numbers should be interpreted with caution. The UWV's figures for the Netherlands reflect the situation for young adults in recent years, while the figures from abroad are based on follow-up studies of adults. The UWV and TNO both estimate that there is potential for improvement in the employment rate for young people with an ASD. This is not something that will happen by itself, however.

7.5 What makes regular work so difficult?

Numerous articles and books, as well as reports written by fellow sufferers, have recorded the personal experiences at work of people with a disorder in the autism spectrum.[*] Müller *et al.* (2003) and Hurlbutt *et al.* (2004) conducted qualitative studies of adults with Asperger's disorder or another disorder in the autism spectrum. These studies focused on how the individuals in question obtained and retained work.[255,256] Nearly all of their subjects were not diagnosed until later in life. Most interviewees were highly to very highly educated and all had work experience, usually without having had any form of support. They were therefore a group of normally gifted ASD sufferers who were able to express themselves adequately and who clearly wished to take their place in society. Nevertheless, both studies showed that the participants experienced considerable difficulty in finding and keeping work.

In summary, the following obstacles were cited. The subjects experienced difficulty both in looking for work and in the associated application processes. In most cases, it was the job interview that proved to be an insuperable hurdle. This was because most of the participants in the study had no grasp of conventional etiquette. Most subjects were offered jobs for which they were over-qualified,

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[*] The books by Temple Grandin are widely acclaimed. (Emergence: labeled autistic. New York: Arena Press, 1986. Thinking in pictures: reports from my life with autism. New York: Doubleday, 1995).

and which failed to meet their specific (occasionally very broad) range of interests. In the work situation, they were given too little time to learn new tasks and to adapt to new working procedures. Most participants complained about a lack of tolerance of their inability to fit the conventional mould, and also cited interpersonal problems with supervisors and colleagues. The most frequently mentioned obstacle to a successful job was their inability to meet the social demands of their work. Most recognised that it was their social deficits that had cost them their job, regardless of how well they performed in other areas.

7.6 Occupational integration of ASD sufferers

Michon and Weeghel (2008) recently described eight projects on the occupational integration of individuals with a severe psychiatric disorder.[257] None of the projects specifically targeted ASD sufferers. In the view of Michon and Weeghel, there is growing expertise with (and evidence for the effectiveness of) the Individual Placement and Support (IPS) model, both at national and international level, as a methodology for the occupational integration of people with a severe psychiatric disorder. The essence of the IPS model is that it integrates employment counselling with care provision. To date, no projects have been evaluated using the criteria applied by Michon and Weghel in the course of their research. Nevertheless, there are examples of good practice, such as the KIRA-project and the ‘People with autism get to work’ project. However, there is still a lack of data concerning the long-term outcome.

The key elements of the counselling provided within the context of the KIRA project are carried out by expert job coaches, who:

- List the client’s capabilities and limitations, both before the commencement of work and during the placement process.
- Involve those closest to the client and the employer in the process.
- Endeavour to achieve the best possible rapport between the client and their work.
- Provide long-term (sometimes permanent) support for the client and those around them.

The KIRA project

Four mental health care (GGZ) institutions, together with the Dr. Leo Kanner House, have developed an action matrix for job coaches and process counsellors, as a guide to the occupational integration of ASD sufferers. The matrix is based on the accumulated knowledge and experience that they gained during 67 transition to work processes. The starting point is the specific situation of the individual who is receiving counselling. For this reason, there is close collaboration with the client's personal network and with the associated caregivers (including health care providers). There are two principle links between the client and their work. Firstly, there is a focus on the acquisition of skills by the client. Secondly, the work itself and the working conditions are modified in keeping with the client's capabilities. Following an intensive initial period, the level of counselling rapidly declines. If there are changes at work or changes in the client's personal situation, however, there is a major risk of relapse. For this reason, there is a continuing need for regular evaluation and support sessions, possibly throughout the client's entire working life. Courses are available on the methodology that has been developed to this end.

Details of the long-term results of an occupational integration project have been published in Great Britain.[258] The counselling methods used in that case were similar to those described above. After two years, well over 60% of a group of normal-ability, adult ASD sufferers were employed in regular work. In a control group without counselling, the corresponding figure was just 25%.

In the Netherlands, actual counselling for the move to work and the support provided during the work itself are often provided by occupational reintegration companies and job coaching organisations. It is estimated that there are less than one hundred organisations that specifically deal with job training and job-placement assistance for young people with disabilities.[253] Some of these organisations have gone on to specialise in providing counselling for young people with an ASD. The demands placed on the qualities of the job coaches in everyday situations are diverse and not easily discernible. There is broad support for specific measures aimed at enhancing the professionalism and visibility of job coaches. These measures include the categorical listing of key competencies,

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setting up a register, a structured external training programme, and a standardised approach to coaching.[106,259]

7.7 Future participation in work

In September 2007, the government put forward its position on the participation of young people with disabilities. On 19 November 2008, it sent a legislative proposal to parliament for an amendment to the Invalidity Insurance (Young Disabled Persons) Act.[260-262]

The main purpose of the proposed legislative amendment is to assist young people with a disability in finding and keeping a job with a regular employer. UWV draws up a participation plan together with the young person who is entitled to work support. The legislative proposal is based on an assumption that the participation plan will seamlessly intersect with the school's action plan for the preparation and transition to work. The latter was drawn up within the framework of the Appropriate Education programme for young people with a disability. The UWV obtains important information from its network consultations with the schools and other partners in the chain. The participation plan provides a framework for counselling young people making the transition to work and guarantees that they will keep their jobs.

The available reintegration instruments used to effect participation by individuals in the *Wajong* are retained, but with various improvements. This primarily applies to the job coach facility. The idea is to improve the professionalism and effectiveness of job coaches, and to implement measures that will improve the match between the nature of the work and the employee's limitations and capabilities. From 2009 onwards, experiments will be conducted involving the use of job coaches during work placements, so that the same coach will provide counselling during the transition from school (work placement) to work.

Steps are also being taken to boost the number of openings for appropriate work and to make it easier for employers to take on young disabled people. Colleagues in the workplace are also expected to create specific, unconventional working conditions for many young disabled people.

In the legislative proposal, income support for young disabled people is structured such that it pays them to work (or to take on additional work). If they take on more work or earn a higher salary, they may be able to earn more than the minimum wage and thus no longer require income support. However, young disabled people will continue to be entitled to work support for as long as they need support to remain in work, regardless of what they earn. This entitlement can end after one or five years' employment, if the individual in question has no formal arrangements for work support[*].

When the individual is no longer eligible for work support on the basis of the *Wajong*, they may then claim support under the terms of the Work and Income (Capacity for Work) Act (WIA).[263]

7.8 Conclusions

Based on currently available research data, it can be concluded that – in the Netherlands – more ASD sufferers are employed by normal employers than is the case abroad. The counselling methods developed in the Netherlands for use during the transition to work seem to be in keeping with methods developed elsewhere. They are also in line with the Individual Placement and Support (IPS) model. In all models, care and job placement assistance are integrated. Furthermore, counselling throughout the individual's entire career is an option. With the methods that have been developed, there is every reason to believe that we are on the right track. Their internal logic is consistent with the nature of the disorder, and with the knowledge that there is an entire spectrum of disorders within which the personalisation of options and opportunities is an important factor. These methods also take account of the fact that the disorder is permanent, and that work, care and private life should be seen as an integrated whole. To date, however, nothing is known about how often this should be done, by whom, and for which groups. Nor, indeed, are there any details concerning the efficacy of these methods. This is hardly surprising, given that this expertise, its application, and the empowerment of ASD sufferers, are all still relatively recent developments.[10]

The Committee feels that the proposed amendments to the Invalidity Insurance (Young Disabled Persons) Act offer good prospects for improving ASD sufferers' ability to obtain and retain work. The Committee attaches particular importance to early and intensive cooperation between all the relevant bodies (school, care institutions, local authorities, and the UWV) and to the potential for continuity of counselling.

In addition to intensive cooperation, the Committee feels that it is vital not to underestimate the importance of a job coach's quality in achieving successful

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[*] The explanatory memorandum on the amendment to the *Wajong* has this to say on the subject: If a young disabled person is in work, but without formal work support, then their entitlement will terminate if they have earned 100% of the legal minimum wage for a period of one year, or if – after five years' work – they earn more than 75% of their *maatmanloon* (wage earned by an able-bodied wage earner compared to the income received by an equivalent disabled person).

employment participation. The current lack of uniform and identifiable criteria makes it difficult to assess this quality.

7.9 Recommendations

Improvements are required in the quality of counselling and job coaching provided to young people and ageing adults at a later stage of their working lives. In addition, criteria for the assessment of quality need to be formulated. The provision of employment counselling to ASD sufferers requires specific knowledge and skills.

The Committee considers it important that employment counselling remain accessible to ASD sufferers (even if they have not made use of this facility for a long period of time) and without losing time through lengthy administrative procedures.

If the quality of counselling is to be improved, research will be needed into the long-term results and the critical success factors involved.

Chapter 8

Conclusions and recommendations

In this chapter, the questions contained in the request for advice are answered individually. Accordingly, the chapter contains the advisory report's final conclusions and recommendations.

8.1 The prevalence of the autism spectrum

What is known about the prevalence (incidence) of ASD in children, adolescents and young adults? This question was largely answered in chapter 3.

Prevalence

On the basis of a review of the scientific literature, the Committee concludes that the prevalence of ASD in the Netherlands is at least 60 per 10,000 people, and possibly around 100 per 10,000. Approximately one quarter of ASD cases involve childhood autism, about half are PDD-NOS, and the remaining quarter have Asperger's disorder. Assuming a population of 5.5 million people aged 27 or less, then this age group must contain at least 32,500 ASD sufferers. In 1984, the Autism Memorandum was still based on a figure of 6000 individuals, which related purely to childhood autism (PDD-NOS and Asperger's disorder were not distinguished from childhood autism until the publication of the DSM-IV in 1994; since then ASD has been used as a collective term).

Distribution

No large-scale prevalence studies have previously been conducted into ASD in the Netherlands. However, the Autism Research Centre in Cambridge (UK) is currently investigating the number of children at Dutch schools who have been diagnosed with ASD. Although the most recent prevalence studies have been carried out in young children, given the nature of the disorder and the causes of the observed increase in prevalence in recent years (see section 8.2), there is no reason to suppose that the prevalence of ASD in older children and young adults is any different.

The scientific literature contains no evidence of differences between ethnic groups or between groups with a different socio-economic status.

ASD is more common in boys/men than girls/women. On average, the ratio of male to female ASD sufferers is 4:1. The higher the subjects' IQ, the higher the male to female ratio. The lower their IQ, the more this ratio tends to even out.

Comorbidity

Approximately half of all ASD sufferers also have some form of intellectual disability. In the group with classic autism, that varies from 60% to 75%. People with Asperger's disorder, by definition, have a normal level of intellectual ability.

Other common comorbidities in ASD include ADHD, anxiety disorders and motor problems.

8.2 Possible reasons for observed increases in prevalence of ASD

What is causing the observed increase in the number of cases of ASD? This question too was answered in chapter 3.

The prevalence of ASD (as reported in the scientific literature) has increased over the past twenty years from approximately 15/10,000 in the 1980s to about 60-100/10,000 today. Several reasons can be given to account for this increase.

Broadening of the diagnosis, from childhood autism to an autism spectrum

An important explanation is that the concept of autism spectrum disorders was not introduced until the 1980s. Prior to that, the only formally recognised autistic disorder was childhood autism. However, it became clear that there are other forms of autism in which the classic introverted behaviour is less marked. These related forms share the same characteristics (i.e. limitations in social and communication skills, coupled with stereotyped interests and behaviours) but to a lesser extent. In the 1990s, PDD-NOS and Asperger's disorder were incorporated into the autistic spectrum by DSM-IV, and began to draw increasing attention. One result was an increased frequency of autism spectrum disorder diagnoses. Another was that individuals who had previously been incorrectly diagnosed as having a different disorder could now be justifiably classified into the autism spectrum (diagnostic substitution).

Society has changed and continues to do so

Another plausible factor is a society that has changed and continues to do so. In today’s service economy, much greater demands are placed on workers’ flexibility, as well as their social and communicative skills, than was the case thirty years ago. The school environment is no different in this respect. ASD sufferers experienced fewer difficulties thirty years ago, as life then was more orderly (with fewer stimuli) and more structured than it is today. In today’s society, this group has a significantly higher risk of dysfunction.

Research currently in progress is attempting to determine the extent to which the increased frequency of this disorder might be explained by the effect of environmental factors on genetic regulatory mechanisms.

Mechanisms in the care system

Although no figures are available for prevalence in the Netherlands, many in our country feel that, here too, ever greater numbers of people (children) are being diagnosed with an ASD. The above factors will undoubtedly do nothing to assuage their fears. The Committee, however, believes that there may be an alternative explanation for this phenomenon. It has, as yet, been unable to rule out the possibility that this may be an artefact of the way in which access to care is organised in this country. If individuals experience problems of a psychological nature which compel them to seek assistance in the form of care provided under the terms of the Exceptional Medical Expenses Act (AWBZ) or special needs education, then they will require a classification in a DSM-IV category in order to obtain an indication. Without this, they will be unable to obtain a budget to fund the care that they require. This condition may distort the true situation by emphasising the problems experienced by the individual in question, with scant regard for their specific capabilities and limitations. There is a distinct possibility that this effect may result in overclassification in the autism spectrum. Even if this is the case, however, there is still a clear need for care.

Over-indication?

The question of whether there is over-indication or under-indication will not be an easy one to resolve. Before this can be tackled, we must first be clear about the extent to which the indication requirement (in order to gain access to care or special needs education) results in over-indication. As yet, no relevant data is available.

There is a possibility that the individuals charged with assessing such cases may themselves have an indirect interest in awarding an indication. Furthermore, the rejection of an application for an indication involves extra work for the individual responsible for needs assessment (they are required to supply a list of reasons) as well as added emotional pressure. Accordingly, those with an especially heavy workload may be tempted to grant an indication in order to avoid the inevitable conflicts and extra work.

The key to the potential problem of over-classification lies in requiring and enabling those involved to make a sound and meticulous diagnosis. This approach would enable both the problems and capabilities of the individual in question to be better identified. It would also ensure that classifications of PDD-NOS would not be granted too readily.

Requisite care

Strictly speaking, the fact of the matter is that children, adolescents and young adults with ASD will always require some degree of care. In this sense, the term ’care’ is not restricted to medical care alone. It also alludes to various forms of counselling. ASD sufferers who can manage without care, regardless of the situation, are few and far between. Nevertheless, this is a heterogeneous group with varied care requirements. Given the sheer breadth of the spectrum, it could be said that there are as many types of care requirement as there are ASD sufferers. Some individuals might require a great deal of professional care, while nothing more than periodic supervision might be sufficient in other cases. The degree of dependency is also influenced by the stage of life that the person with ASD has reached, and by any major changes (transitions) that may be taking place in their life. In short, the care requirement should be determined on the basis of an action-oriented diagnosis that focuses on the capabilities and limitations of the individual in question at their current stage of life, and not on a rigid approach in which care is determined by a diagnostic classification alone.

No medicalisation

This does not mean that an active (or proactive) approach to ASD inevitably results in the immediate medicalisation of the problems. The term ‘medicalisation’ means that an everyday or physiological problem becomes labelled as an illness or an abnormal situation. Medicalisation is only involved where people can be expected to deal with their problems themselves, albeit with the aid of some temporary support or advice. This is clearly not the case with chronic conditions such as ASD.

The type of counselling required by children, adolescents and young adults with ASD must be determined on the basis of an adequate dimensional and action-oriented diagnosis, which should be subject to periodic re-evaluation. This would avoid the need for repeated classification on the basis of the DSM-IV. While this does not inevitably mean that more care is required, it is a prerequisite for appropriate care at the appropriate time. This is in line with the principle of stepped care, in which care is tailored to the magnitude of the problem as it unfolds.

8.3 Problems encountered

What problems do children, adolescents and young adults with an ASD encounter in their social circle (especially within the family), at schools or colleges, and at work? The answers to these questions can be found in chapters 5, 6 and 7 respectively.

The problems encountered are almost all related to the core symptoms of ASD - limited social and communicative skills, coupled with rigid and stereotypical behaviour patterns. These core symptoms mean that ASD sufferers have a craving for extreme regularity and structure in their lives. They are often unable to make friendships and to maintain intimate relationships, nor do they perform well in group settings. They find everyday communication complicated as they are often unable to understand linguistic nuances, double entendres and body language.

Family

Children with ASD demand a great deal of care, often to the point that the life of the family revolves around them. Raising such children can pose particularly complex challenges. Lessons that they learn in a given context are often not applied in similar situations. They need a great deal of help to generalise such experiences. Any sudden departures from a calm, routine existence can give rise to tension and commotion. Outside school hours, the parents often remain responsible for all aspects (initiation and counselling) of their child‘s social life, something that ‘normal’ children deal with independently.

ASD has a genetic basis. As a result, it is often the case that one parent (usually the father) and/or a brother or sister will also have some form of ASD. This can affect family ties, testing both professional carers and the family as a whole.

Even if they possess the intellectual capacity to do so, young adults with ASD are often unsuccessful in making the transition to a fully or partially independent life outside the family. Young adults with ASD often have a very limited social network. They also have a limited ability to care for themselves, and a poor understanding of the diversity and changing social demands of ordinary life.

This has implications both for the family and for the childrearing support measures (in terms of their nature and intensity) that are offered.

Education

Pupils with ASD will experience learning problems in teaching situations and difficulties with social interactions in groups. They perform poorly when required to cooperate in group activities, and are often unable to play with other children. The way in which education is offered may cause problems. Children with ASD require more structure and predictability in their lives than do other children, and they are generally less able to work independently.

Moreover, children with an ASD differ from children who are able to function ‘normally’ in the way that they process information. This has implications for the choice of teaching methods. When an intellectual disability is involved, the level of education is also a problem. Those young people who have the intellectual capacity to cope with secondary and higher education will continue to encounter problems associated with their social adjustment to such surroundings and with the type of education on offer there.

These considerations require a degree of customisation to be provided for individual pupils. Nevertheless, this does not detract from the fact that a group approach can work quite well for some pupils with ASD – up to a point.

Work

In practice, these individuals encounter major problems in the course of regular (or occasional) employment. When seeking paid employment, normal-ability ASD sufferers encounter problems straight away, during the application procedure. Young adults with ASD who are in paid employment often perform below their educational level and intellectual capacities. In addition, they have difficulty in keeping jobs for any length of time. A major cause of this is their inability to adapt to the social codes and etiquette of the workplace. Another obstacle to social acceptance is that others quickly tire of endlesssly discussing these individuals' narrow range of interests. They are also unable to conform to changing job requirements and have difficulty in independently planning their activities.

This means that counselling will almost inevitably be needed. Moreover, employers must make an effort to create the conditions that will enable adults (of all ages) with ASD to perform their work to everyone's satisfaction. The latter point will be examined in greater detail in the forthcoming Social and Economic Council (SER) advisory report on young people with developmental and behavioural disorders, and job performance.

Transitions

Within and between the domains of family, education and work, there are any number of transitions. Each of these transitions can pose a new set of problems. Anticipating such transitions, and providing counselling throughout these periods, can often help to limit the associated problems. Both the parents and the professional groups in the various domains have a part to play in this process. Transitions can place great demands on the development of the ASD sufferer in question. Indeed, they may push the individual's capabilities to their limit, thereby aggravating the disorder still further.

8.4 Effective detection, treatment and counselling

In terms of the early detection, treatment and care of children, adolescents and young adults with ASD, what tried and tested methods (both clinical and social) are available? The answer to this question is twofold. Detection & diagnosis are dealt with in chapter 3, while treatment & counselling are covered in chapter 4.

Generally, the detection of ASD always involves a series of steps. The first step is identification and the second is final diagnosis. The procedure for individuals at various stages of life is shown in the summary below.

Early detection: before the second year of life

Given the current level of knowledge, it is only possible to detect childhood autism at an early age, i.e. around the second year of life. At present two detection instruments are in use at post-natal clinics. The first is a series of ‘red flags’ – various developmental characteristics that may indicate a developmental disorder. The second is a Van Wiechen schedule (a schedule used by post-natal clinics to chart and monitor the development of babies and young children) that has been expanded to include a number of items which can be used to detect possible developmental disorders. These detection instruments are part of any post-natal clinic’s standard ‘toolkit’. They are used to ‘monitor’ all children of up to four years of age who visit a youth healthcare institution (post-natal clinic). Where this is felt to be appropriate, the post-natal clinic can refer children on to key experts, who can then make a diagnosis. This approach may also be useful in GPs’ surgeries, but as yet it has not been widely used in this context.

Two observations need to be made at this point. First, most cases of ASD encountered in this age group will involve childhood autism, often coupled with an intellectual disability. At this age, it is not possible to clearly identify the other conditions within the autism spectrum, such as PDD-NOS and Asperger’s disorder. This is because, in a one-on-one situation, individuals with these conditions are often not noticeably different from healthy children. Secondly, no general detection instruments are yet available for children aged between two and four. If there is already evidence of ASD, then a more specific instrument – the AUTI-R scale (for two to thirteen year olds) – can be used for this age group.

Detection in children of school-going age (4-18)

The first step in detecting ASD in children of primary school age involves general detection instruments for behavioural or developmental problems, such as the Teacher’s Report Form or the Socio-Emotional Questionnaire, which can be completed by teachers and parents. Unlike generic ‘screening’ of the 0-4 age group, these instruments are only used when there are clear indications of dysfunction. A range of more specific detection instruments are available for use if the evidence is indicative of a disorder in the autistic spectrum. These include VISK, AUTI-R scale, and SCQ. These tests are carried out by professionals, who can then refer subjects for further diagnosis by key experts. There are plenty of validated instruments that can be used to assist in the diagnosis of children of primary school age (see chapter 3).

Detection in young people and adults (aged 18 and above)

The detection of ASD in individuals who have left school is a more complex matter. As yet, there are no validated detection instruments for this age group that could be used by general practitioners, occupational physicians and other generalists. Diagnostic instruments are available for young people and adults, though they are still not fully developed.

Treatment and counselling

As for treatment and counselling, ASD are clearly incurable. However, there are interventions that can alleviate the worst effects of ASD. These can be classified as follows: psycho-education, family support, psychosocial interventions, school-work interventions and the treatment of comorbidity. There are not always clear lines of demarcation between the various interventions, indeed there may even be some degree of overlap. Of all the available interventions, behavioural interventions (which fall into the category of psychosocial interventions) have proven to be the most effective to date.

The goal of psychosocial interventions is to teach the skills that enable people with an ASD to cope more effectively with everyday life. This generally involves combating the symptoms by using behavioural therapy principles to improve the subject's communication and social skills and by teaching them how to deal with stereotypical behaviour patterns. The other interventions are needed to maintain an equilibrium between the individual in question and their social environment.

The treatment of comorbid symptoms, such as anxiety disorders and ADHD-like symptoms, involves the use of medication. However, pharmaceutical treatment has only a modest part to play in the treatment of ASD.

As yet, there is no way of achieving the primary prevention (preventing the disorder for developing in the first place) of ASD. Nevertheless, secondary and tertiary prevention (preventing the effects of the disorder from worsening) are possible, with early detection, accurate diagnosis, and timely treatment and counselling.

8.5 Comprehensive approach to facilitate early detection

What type of comprehensive approach could resolve the conflicting needs of identifying children and young people with ASD at the earliest possible opportunity while avoiding a tendency towards overdiagnosis? This question was largely answered in chapter 3.

As already indicated in the previous section, only childhood autism can be detected at a very early stage. To improve early detection, it is recommended that post-natal clinics and GPs' surgeries be furnished with reliable detection instruments, and that GPs and the staff of these clinics be given further training. Detection instruments for older children and young adults need to be further developed before they can be deployed in education, youth healthcare bureaus, and GPs' surgeries. There is also a need to develop detection instruments for adults, which could be used by GPs, occupational physicians, and insurance physicians. This is linked to professional development in this field.

A full diagnosis, focusing both on classification and on the dimensional aspects, is necessary in order to avoid overdiagnosis. The Committee believes that a diagnosis made for the sole purpose of obtaining a DSM-IV classification is not only inadequate in qualitative terms, but that it also exacerbates the risk of overdiagnosis. Accordingly, classifications that are divorced from all other considerations should be avoided.

8.6 Comprehensive approach for optimal performance

What type of comprehensive approach best equips children, adolescents and young adults with an ASD to function effectively within their social environment, at educational institutions, and at work? The answers to this question can be found in chapters 4 to 7.

Comprehensive

The Committee interprets the word 'comprehensive', as it appears in this question, in three ways.

As indicated in section 4.3, a comprehensive approach should take into account both the individual characteristics of the person in question, and the various life domains within which they move and have their being. A multidisciplinary approach should also be involved. Efforts must be made to ensure a smooth transfer to other areas of care (e.g. from youth care services to care for adults).

Increasingly, professionals from many disciplines and numerous different organisations are already collaborating and coordinating with one another in practice. The Committee takes the view that the creation of a special role for a ‘life coach’ would be of enormous benefit to the continuity and coherence of care.

Life Coach

When setting out the guiding principles of this advisory report (chapter 2), the Committee indicated that a major goal of the counselling provided at various stages of life is to achieve the greatest possible autonomy for the individual in question. One of the associated conditions is that there be vigilant and, where necessary, proactive counselling throughout the subject’s life, especially during transitional periods and other events that disrupt relatively balanced situations. The Committee calls for a permanent life coach to be appointed, someone who will maintain a relationship of trust with the ASD sufferer, their parents, and other family members over a protracted period of time. These professionals can provide timely advice, as well as encouraging a network of experts to achieve effective cooperation on those occasions when this is needed. This life coach is the very embodiment of the requisite lifelong counselling for ASD sufferers.

8.7 The role of the professions

In the context of a comprehensive approach (see previous section), what might be the role of professionals in education, the health service, the youth care services, and social security? The answer to this question can be derived from the contents of chapters 4 to 7.

There are three stages at which professionals can become involved in autism-related issues. These are the detection stage, the diagnostic stage, and during treatment and counselling.

Detection

Detection is primarily a job for generalists. Depending on the age group involved, this means post-natal clinic physicians, GPs, school doctors, teachers, youth care service professionals, occupational physicians, and insurance physicians.

They must primarily have an appropriate basic understanding of ASD. Secondly, they must have access to short lines of communication for consultation and referral (both to individuals from within their own ranks, and to outside experts). An appropriate basic understanding of ASD will enable these professionals to detect new cases more quickly, to better recognise the limits of their expertise, and to cooperate more effectively with specialists.

Diagnosis

A proper diagnosis can only be made by certain professionals (child and adolescent psychiatrists, health care psychologists, child and adolescent psychologists) who are registered under the Individual Health Care Professions Act or by REG (remedial educationalist-generalist) specialised educationalists. In this connection, use is made of the input of other professionals who are experts in their own field, such as child neurologists, and social workers.

A referral from the professional groups responsible for detection is the cue for the diagnostic professional groups to take action. The essence of their work is to conduct a categorical and dimensional diagnosis with all due care. In addition, they actively participate in an action-oriented diagnosis with a view to establishing a treatment programme. In conclusion, an important aspect of their role is providing feedback to the professional groups responsible for detection.

Treatment and counselling

Treatment and counselling involve psycho-education and family support, as well as treatment and counselling for ASD sufferers in terms of the disorder, as such, and of their performance at home, at school and in the workplace. Counselling and treatment cover such a wide range of options that it is impossible to draw up an exhaustive list of the professions involved in the treatment and counselling of ASD sufferers. The types of therapists and/or counsellors who are actively involved is also dependent on the age of the ASD sufferer in question, their social context, the nature and severity of their disorder, and any comorbidity.

The role of therapists and counsellors is to alleviate the effects of the disorder as much as possible or to keep them within manageable limits. A comprehensive approach requires that all of the professionals involved be familiar with, and make use of, shared guiding principles and a common conceptual framework pertaining to all forms of autism.

Coordination and cooperation are essential to the success of the care effort. The purpose of the 1999 Autism Covenant was to promote and improve these aspects. While it has already been put into use in several regions, the Covenant has yet to achieve nationwide coverage.

8.8 Conditions governing the success of the comprehensive approach

What substantive and organisational conditions must be met to enable the comprehensive approach for children, adolescents and young adults with ASD to succeed? The answer to this question can be derived from the contents of chapters 3 to 7.

The Committee recommends that the success of a comprehensive approach to autism spectrum disorders should be determined on the basis of the following conditions.

Detection

A uniform, nationwide method for the early detection of ASD prior to the second year of life is the preferred option.

- expansion of the Van Wiechen schedule to incorporate ‘red flags’ for developmental disorders, plus an extension of the youth healthcare system’s (post-natal clinic physicians) assigned responsibilities;
- further training for post-natal clinic physicians and GPs;
- communication and coordination between post-natal clinics and GPs concerning the referral of subjects (for diagnosis) to child and youth psychiatrists, health care psychologists, child and adolescent psychologists or REG remedial educationalists.

A similar uniform method is the preferred option for the detection of ASD in children and adolescents of school-going age (4-18):

- the general availability of detection instruments for behavioural or developmental problems (TRF, SEV) for generalists in the health and education systems, plus an extension of the child healthcare system’s (doctors in youth health clinics, and school doctors) assigned responsibilities;
- the training of doctors in child health clinics, school doctors, GPs, those responsible for individual educational needs programmes in schools, and professionals in youth care services;
- in the event of indications of a disorder in the autism spectrum, referral to doctors in child health clinics, school doctors, psychologists (including school psychologists), or a care advisory team to deploy a more specific detection instrument (VISK, AUTI-R, SCQ);
- if an ASD is suspected: referral for diagnosis

One issue is that those responsible for individual educational needs programmes (internal counsellor, care advisory team) must be able to make direct referrals, if the detection of developmental disorders is to be improved.

The lack of good quality detection instruments is currently preventing the establishment of a uniform method of this kind for the detection of ASD in adults (aged 18 and above).

Diagnosis

- The categorical diagnosis should always be complemented with a dimensional diagnosis and an action-oriented diagnosis. The funding system should facilitate this approach.
- Once a classification has been established, as part of a thorough diagnosis, it will never be changed. Accordingly, a classification need no longer be repeated in the event of a renewal of the indication for care, special needs education, or pupil-specific funding.
- The dimensional and action-oriented diagnoses should be periodically repeated, however, to assess and update information on the individual’s development, capabilities, and limitations.
- The method of diagnosis should involve a standardised procedure, to ensure that it is identifiable and transferable between the various care domains and professionals.

Treatment and counselling

- The quality of treatment and counselling of ASD sufferers should be evidence based, as much as possible.
- The quality of caregivers in the health and education systems, and at work, must be identifiable and verifiable. All professionals must be able to show that they have a basic understanding of ASD. Certification is one of the options for quality assurance.
- Regional partnerships aimed at improving the care and support for people with autism should be so structured that the time that professionals devote to these activities is valued independently of patient-related funding. The partnership itself should be defined as a product, thereby rewarding those who devote a great deal of time and energy to it. The various agencies involved can then make arrangements concerning the allocation of separate but complementary responsibilities.
- Finally, the Committee recommends that the post of life coach be made a permanent feature of the care provided to ASD sufferers.

Education

- Sufficient numbers of qualified ambulatory counsellors should be available so that those children with ASD who, given such support, are capable of remaining in mainstream education, can actually do so.
- In accordance with their job description, those responsible for individual educational needs programmes in primary education are required to prepare pupils for the transition from primary to secondary education, and to counsel them throughout the process.
- Job placement assistance should be an integral part of secondary special needs education, and Practical Training, as well as preparatory vocational education and senior secondary vocational education for pupils with ASD.
- There should be a greater focus on job placement assistance in the transition from higher education (higher vocational education).
- It is important that counselling at school take place in consultation and collaboration with the parents.

Work

- Job coaches should start their assignments while the pupils in question are still receiving counselling at school, to ensure that the transition is as smooth and gradual as possible.
- Counselling by job coaches should not stop immediately after young people with ASD have been placed with employers. Instead, it should remain available throughout their working lives. Such counselling is generally indispensable when changing jobs within the company or when moving to another employer.

Research agenda

- The Committee has identified the current level of knowledge, in terms of published research results. It recommends that a survey be made of current and planned studies into effective treatments and interventions in ASD. This survey will provide the basis for a research agenda. As part of the Health Council of the Netherlands, the Advisory Council on Health Research (RGO) is well placed to take on this assignment.
- There is a need for a survey of the knowledge infrastructure with regard to professional development (education and training pertaining to detection, diagnosis, treatment and counselling). The results can be used for the professional development of care providers and caregivers.
- In anticipation of a survey of the knowledge infrastructure, the Committee would also like to highlight gaps in our knowledge concerning:

- the impact of ASD on the individual in question and their immediate circle throughout the lifetime of an individual with ASD
- detection instruments for generalists, especially for detecting 2-4 year olds, adolescents and adults with ASD
- diagnostic instruments for adults
- the results of job placement assistance and long term job counselling
- the critical success factors for the quality of job placement assistance and job placement counselling.

Literature

1 Kanner L. Autistic disturbances of affective contact. Nervous Child. anoniem 1943; 2: 217-250.

2 Asperger H. Die Autistische Psychpathen im Kindesalter. Archiv für Psychiatrie und Nervenkankheiten 1944; 117: 76-136.

3 Engeland H van. Autisme. In: Verhulst F.C., Verheij F, Ferdinand RF, editors. Kinder- en Jeugdpsychiatrie - Psychopathologie. Assen: Van Gorcum; 2007: 57-72.

4 Schrameijer F, Kannerhuis L. Een wankele wereld: in het workhome, een woon-werkgemeenschap voor mensen met autism. 2007.

5 Beroemde mensen met autisme - Wikipedia. http://en.wikipedia.org/wiki/List_of_people_on_the_autistic_spectrum. Accessed: 1-6-2009.

6 Lieshout PAH van, Vander Meij MSS, De Pree JCI. Bouwstenen voor betrokken jeugdbeleid. Wetenschappelijke Raad voor het Regeringsbeleid; 2007: Verkenningen nr. 15.

7 Widdershoven G. Ethiek in de kliniek. Hedendaagse benaderingen in de gezondheidsethiek. Amsterdam: Boom; 2000.

8 Widdershoven G, Berghmans R, Craste J, Baduin D. Autonomie in de hulpverlening. In: Assen: Van Gorcum; 2000: 47-59.

9 Berlin I. Twee opvattingen van vrijheid. Amsterdam/Meppel: Boom; 1996.

10 Leo Kannerhuis. Springzaad, van kiemen tot verspreiden. Doorwerth: Centrum voor autisme; 2003.

11 Leo Kannerhuis. Van disease management naar levensloopbegeleiding - Visie op disease management voor mensen met een autismespectrumstoornis. Doorwerth: Dr. Leo Kannerhuis, centrum voor autisme i.s.m. Ernst & Young Advisory; 2008.

12 Venderbosch S, Wijnker-Holmes B, Stekelenburg F, Rem D. Een plek om te leven. Een onderzoek naar de leefsituatie van mensen met autisme. Bilthoven: Nederlandse Vereniging voor Autisme; 2008.

13 Filipek PA, Accardo PJ, Ashwal S, Baranek GT, Cook Jr. EH, Dawson G *et al.* Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. Neurology 2000; 55: 468-479.

14 Swinkels SH, Dietz C, van DE, Kerkhof IH, Van EH, Buitelaar JK. Screening for autistic spectrum in children aged 14 to 15 months. I: the development of the Early Screening of Autistic Traits Questionnaire (ESAT). J Autism Dev Disord 2006; 36(6): 723-732.

15 Dietz C, Swinkels S, van Daalen E, van Engeland H, Buitelaar J. Screening for autistic spectrum disorder in children aged 14-15 months. II: Population screening with the Early Screening of Autistic Traits Questionnaire (ESAT). Design and general findings. J Autism Dev Disord 2006; 36(6): 713-722.

16 Wetherby AM, Woods J, Allen L, Cleary J, Dickinson H, Lord C. Early indicators of autism spectrum disorders in the second year of life. J Autism Dev Disord 2004; 34(5): 473-493.

17 Dietz C. The early screening of autistic spectrum disorders [Proefschrift]. Utrecht: Universiteit Utrecht; 2007.

18 Buitelaar JK, Dalen van E, Dietz C, Engeland van H, Gaag van der RJ, Steijn van D *et al.* ESAT-Screening van ASS op jonge leeftijd. Houten: Bohn Stafleu van loghum; 2009.

19 Siegel B. PDDST-II-NL | Pervasive Developmental Disorders Screening Test-II-NL: Nederlandse bewerking door I.A. van Berckelaer-Onnes. Amsterdam: Harcourt Assessment; 2006.

20 Berument SK, Rutter M, Lord C, Pickles A, Bailey A. Autism screening questionnaire: diagnostic validity. Br J Psychiatry 1999; 175: 444-451.

21 Hartman CA, Luteijn E, Moorlag A, De Bildt A. Handleiding voor de VISK. Amsterdam Harcourt: 2007.

22 Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. J Autism Dev Disord 2001; 31(1): 5-17.

23 Hoekstra RA, Bartels M, Cath DC, Boomsma DI. Factor structure, reliability and criterion validity of the Autism-Spectrum Quotient (AQ): a study in Dutch population and patient groups. J Autism Dev Disord 2008; 38(8): 1555-1566.

24 Baron-Cohen S, Richler J, Bisarya D, Gurunathan N, Wheelwright S. The systemizing quotient: an investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. Philos Trans R Soc Lond B Biol Sci 2003; 358(1430): 361-374.

25 Baron-Cohen S, Wheelwright S. The empathy quotient: an investigation of adults with Asperger syndrome or high functioning autism, and normal sex differences. J Autism Dev Disord 2004; 34(2): 163-175.

26 Bosch RJ van den, Minderaa RB. VIS-V. Groningen: Vakgroep Psychiatrie, Rijksuniversiteit Groningen; 2002.

27 Wing L. The autistic spectrum. Lancet 1997; 350(9093): 1761-1766.

28 Buitelaar JK, van der Gaag RJ. Diagnostic rules for children with PDD-NOS and multiple complex developmental disorder. J Child Psychol Psychiatry 1998; 39(6): 911-919.

29 Schothorst PF, Van Engeland H, van der Gaag RJ, Minderaa RB, Stockmann APAM, Westermann GMA. Richtlijn diagnostiek en behandeling van Autisme Spectrum Stoornissen (ASS). Nederlandse Vereniging voor Psychiatrie . 2008. Utrecht.

30 Kenniscentrum Kinder- en Jeugdpsychiatrie. http://www.kenniscentrum-kjp.nl. Accessed: 1-6-2009.

31 Matson JL, Nebel-Schwalm MS. Comorbid psychopathology with autism spectrum disorder in children: an overview. Res Dev Disabil 2007; 28(4): 341-352.

32 Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. JAMA 2003; 289(1): 49-55.

33 Fombonne E. Epidemiology of autistic disorder and other pervasive developmental disorders. J Clin Psychiatry 2005; 66 Suppl 10: 3-8.

34 Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children: confirmation of high prevalence. Am J Psychiatry 2005; 162(6): 1133-1141.

35 Nicholas JS, Charles JM, Carpenter LA, King LB, Jenner W, Spratt EG. Prevalence and characteristics of children with autism-spectrum disorders. Ann Epidemiol 2008; 18(2): 130-136.

36 Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. J Am Acad Child Adolesc Psychiatry 2008; 47(8): 921-929.

37 Danielsson S, Gillberg IC, Billstedt E, Gillberg C, Olsson I. Epilepsy in young adults with autism: a prospective population-based follow-up study of 120 individuals diagnosed in childhood. Epilepsia 2005; 46(6): 918-923.

38 Parmeggiani A, Posar A, Antolini C, Scaduto MC, Santucci M, Giovanardi-Rossi P. Epilepsy in patients with pervasive developmental disorder not otherwise specified. J Child Neurol 2007; 22(10): 1198-1203.

39 Hara H. Autism and epilepsy: a retrospective follow-up study. Brain Dev 2007; 29(8): 486-490.

40 Kobau R, Zahran H, Thurman DJ, Zack MM, Henry TR, Schachter SC *et al.* Epilepsy surveillance among adults--19 States, Behavioral Risk Factor Surveillance System, 2005. MMWR Surveill Summ 2008; 57(6): 1-20.

41 Stekelenburg FC. Resultaten van de leden-enquête van de NVA. Bilthoven: Nederlandse Verenging voor Autisme; 2002.

42 Stekelenburg F, Prins E. Buiten De Boot. Een onderzoek onder (ouders en partners van) mensen met autisme. Bilthoven: Nederlandse Vereniging voor Autisme; 2005.

43 Gurney JG, McPheeters ML, Davis MM. Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. Arch Pediatr Adolesc Med 2006; 160(8): 825-830.

44 Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. J Child Psychol Psychiatry 2004; 45(2): 212-229.

45 Schopler E, Andrews CE, Strupp. Do autistic children come from upper-middle-class-parents? Journal of Autism and Developmental Disorders 1980; 10: 91-103.

46 Fombonne E, Chakrabarti S. No evidence for a new variant of measles-mumps-rubella-induced autism. Pediatrics 2001; 108(4): E58.

47 Taylor B, Miller E, Farrington CP, Petropoulos MC, Favot-Mayaud I, Li J *et al.* Autism and measles, mumps, and rubella vaccine: no epidemiological evidence for a causal association. Lancet 1999; 353(9169): 2026-2029.

48 Halsey NA, Hyman SL. Measles-mumps-rubella vaccine and autistic spectrum disorder: report from the New Challenges in Childhood Immunizations Conference convened in Oak Brook, Illinois, June 12-13, 2000. Pediatrics 2001; 107(5): E84.

49 Miller E. Measles-mumps-rubella vaccine and the development of autism. Semin Pediatr Infect Dis 2003; 14(3): 199-206.

50 Croen LA, Najjar DV, Fireman B, Grether JK. Maternal and paternal age and risk of autism spectrum disorders. Arch Pediatr Adolesc Med 2007; 161(4): 334-340.

51 Durkin MS, Maenner MJ, Newschaffer CJ, Lee LC, Cunniff CM, Daniels JL *et al.* Advanced parental age and the risk of autism spectrum disorder. Am J Epidemiol 2008; 168(11): 1268-1276.

52 Vorstman JA, Staal WG, van DE, Van EH, Hochstenbach PF, Franke L. Identification of novel autism candidate regions through analysis of reported cytogenetic abnormalities associated with autism. Mol Psychiatry 2006; 11(1): 1, 18-1, 28.

53 Persico AM, Bourgeron T. Searching for ways out of the autism maze: genetic, epigenetic and environmental clues. Trends Neurosci 2006; 29(7): 349-358.

54 Mulder EJ. Genetica van Autisme Spectrum Stoornissen. In: Horwitz EH, Ketelaars CEJ, Van Lammeren AMDN, editors. Autisme Spectrum Stoornissen bij normaal begaafde volwassenen. Assen: Van Gorcum; 2008: 40-49.

55 Amir RE, Van dV, I, Wan M, Tran CQ, Francke U, Zoghbi HY. Rett syndrome is caused by mutations in X-linked MECP2, encoding methyl-CpG-binding protein 2. Nat Genet 1999; 23(2): 185-188.

56 Bailey A, Le CA, Gottesman I, Bolton P, Simonoff E, Yuzda E *et al.* Autism as a strongly genetic disorder: evidence from a British twin study. Psychol Med 1995; 25(1): 63-77.

57 Rutter M. Genetic studies of autism: from the 1970s into the millennium. J Abnorm Child Psychol 2000; 28(1): 3-14.

58 Bishop DV, Maybery M, Maley A, Wong D, Hill W, Hallmayer J. Using self-report to identify the broad phenotype in parents of children with autistic spectrum disorders: a study using the Autism-Spectrum Quotient. J Child Psychol Psychiatry 2004; 45(8): 1431-1436.

59 Freitag CM. The genetics of autistic disorders and its clinical relevance: a review of the literature. Mol Psychiatry 2007; 12(1): 2-22.

60 Ramoz N, Cai G, Reichert JG, Silverman JM, Buxbaum JD. An analysis of candidate autism loci on chromosome 2q24-q33: evidence for association to the STK39 gene. Am J Med Genet B Neuropsychiatr Genet 2008; 147B(7): 1152-1158.

61 Bonora E, Lamb JA, Barnby G, Sykes N, Moberly T, Beyer KS *et al.* Mutation screening and association analysis of six candidate genes for autism on chromosome 7q. Eur J Hum Genet 2005; 13(2): 198-207.

62 Szatmari P, Paterson AD, Zwaigenbaum L, Roberts W, Brian J, Liu XQ *et al.* Mapping autism risk loci using genetic linkage and chromosomal rearrangements. Nat Genet 2007; 39(3): 319-328.

63 Liu XQ, Paterson AD, Szatmari P. Genome-wide linkage analyses of quantitative and categorical autism subphenotypes. Biol Psychiatry 2008; 64(7): 561-570.

64 Weiss LA, Shen Y, Korn JM, Arking DE, Miller DT, Fossdal R *et al.* Association between microdeletion and microduplication at 16p11.2 and autism. N Engl J Med 2008; 358(7): 667-675.

65 Kumar RA, Christian SL. Genetics of autism spectrum disorders. Curr Neurol Neurosci Rep 2009; 9(3): 188-197.

66 Costa e Silva JA. Autism, a brain developmental disorder: some new pathopysiologic and genetics findings. Metabolism 2008; 57 Suppl 2: S40-S43.

67 Südhof TC. Neuroligins and neurexins link synaptic function to cognitive disease. Nature 2008; 455(7215): 903-911.

68 Zitman FG. Endofenotypen in de psychiatrie: een tussenstand. Ned Tijdschr Geneeskd 2008; 152: 1911-1913.

69 Constantino JN, Todd RD. Autistic traits in the general population: a twin study. Arch Gen Psychiatry 2003; 60(5): 524-530.

70 Constantino JN, Todd RD. Intergenerational transmission of subthreshold autistic traits in the general population. Biol Psychiatry 2005; 57(6): 655-660.

71 Lotter V. Social adjustment and placement of autistic children in Middlesex: a follow-up study. J Autism Child Schizophr 1974; 4(1): 11-32.

72 Lotter V. Factors related to outcome in autistic children. J Autism Child Schizophr 1974; 4(3): 263-277.

73 Mulder EJ, Minderaa RB. Stoornis van Asperger. In: Verhulst F.C., Verheij F, Ferdinand RF, editors. Kinder- en Jeugdpsychiatrie - Psychopathologie. Assen: Van Gorcum; 2007: 77-83.

74 Minderaa RB, Mulder EJ. Pervasieve ontwikkelingsstoornissen niet anderszins omschreven. In: Verhulst F.C., Verheij F, Ferdinand RF, editors. Kinder- en Jeugdpsychiatrie - Psychopathologie. Assen: Van Gorcum; 2007: 84-92.

75 Baron-Cohen S. The extreme male brain theory of autism. Trends Cogn Sci 2002; 6(6): 248-254.

76 Skuse DH. Genetic factors in the etiology of child psychiatric disorders. Curr Opin Pediatr 1997; 9(4): 354-360.

77 Skuse DH. Imprinting, the X-chromosome, and the male brain: explaining sex differences in the liability to autism. Pediatr Res 2000; 47(1): 9-16.

78 Skuse DH. Rethinking the nature of genetic vulnerability to autistic spectrum disorders. Trends Genet 2007; 23(8): 387-395.

79 Auyeung B, Baron-Cohen S, Ashwin E, Knickmeyer R, Taylor K, Hackett G *et al.* Fetal testosterone predicts sexually differentiated childhood behavior in girls and in boys. Psychol Sci 2009; 20(2): 144-148.

80 Auyeung B, Baron-Cohen S, Ashwin E, Knickmeyer R, Taylor K, Hackett G. Fetal testosterone and autistic traits. Br J Psychol 2009; 100(Pt 1): 1-22.

81 Knickmeyer RC, Baron-Cohen S. Fetal testosterone and sex differences in typical social development and in autism. J Child Neurol 2006; 21(10): 825-845.

82 Holtmann M, Bolte S, Poustka F. Autism spectrum disorders: sex differences in autistic behaviour domains and coexisting psychopathology. Dev Med Child Neurol 2007; 49(5): 361-366.

83 Holtmann M, Bolte S, Poustka F. Attention deficit hyperactivity disorder symptoms in pervasive developmental disorders: association with autistic behavior domains and coexisting psychopathology. Psychopathology 2007; 40(3): 172-177.

84 McLennan JD, Lord C, Schopler E. Sex differences in higher functioning people with autism. J Autism Dev Disord 1993; 23(2): 217-227.

85 Oliveira G, Ataide A, Marques C, Miguel TS, Coutinho AM, Mota-Vieira L *et al.* Epidemiology of autism spectrum disorder in Portugal: prevalence, clinical characterization, and medical conditions. Dev Med Child Neurol 2007; 49(10): 726-733.

86 Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D *et al.* Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet 2006; 368(9531): 210-215.

87 Wing L, Potter D. The epidemiology of autistic spectrum disorders: is the prevalence rising? Ment Retard Dev Disabil Res Rev 2002; 8(3): 151-161.

88 European Commission. Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union. http://ec.europa.eu/health/index_nl.htm. Accessed: 3-6-2009.

89 Williams E, Thomas K, Sidebotham H, Emond A. Prevalence and characteristics of autistic spectrum disorders in the ALSPAC cohort. Dev Med Child Neurol 2008; 50(9): 672-677.

90 Autism and Developmental Disabilities Monitoring Network Surveillance Year 2000. Principal Investigators. Prevalence of autism disorderes - Autism and Developmental Disabilities Monitoring Network, six sites. United States. 2007: 56, No SS-1.

91 Williams JG, Higgins JP, Brayne CE. Systematic review of prevalence studies of autism spectrum disorders. Arch Dis Child 2006; 91(1): 8-15.

92 Honda H, Shimizu Y, Rutter M. No effect of MMR withdrawal on the incidence of autism: a total population study. J Child Psychol Psychiatry 2005; 46(6): 572-579.

93 Tebruegge M, Nandini V, Ritchie J. Does routine child health surveillance contribute to the early detection of children with pervasive developmental disorders? An epidemiological study in Kent, U.K. BMC Pediatr 2004; 4: 4.

94 European Autism Information Systems. http://www.eais.eu.

95 Fombonne E. Epidemiology of pervasive developmental disorders. Pediatr Res 2009; 65(6): 591-598.

96 Shattuck PT. Diagnostic substitution and changing autism prevalence. Pediatrics 2006; 117(4): 1438-1439.

97 Shattuck PT. The contribution of diagnostic substitution to the growing administrative prevalence of autism in US special education. Pediatrics 2006; 117(4): 1028-1037.

98 Bishop DV, Whitehouse AJ, Watt HJ, Line EA. Autism and diagnostic substitution: evidence from a study of adults with a history of developmental language disorder. Dev Med Child Neurol 2008; 50(5): 341-345.

99 Coo H, Ouellette-Kuntz H, Lloyd JE, Kasmara L, Holden JJ, Lewis ME. Trends in autism prevalence: diagnostic substitution revisited. J Autism Dev Disord 2008; 38(6): 1036-1046.

100 Ouellette-Kuntz H, Coo H, Lloyd JE, Kasmara L, Holden JJ, Lewis ME. Trends in special education code assignment for autism: implications for prevalence estimates. J Autism Dev Disord 2007; 37(10): 1941-1948.

101 Weehuizen R. Mentaal kapitaal - Een verkennende studie naar de psychologische dimensie van economische ontwikkeling. Den Haag: Commissie voor Overleg Sectorraden (COS); 2006. Internet: www.toekomstverkennen.nl.

102 Mehler MF, Purpura DP. Autism, fever, epigenetics and the locus coeruleus. Brain Res Rev 2009; 59(2): 388-392.

103 Jones JR, Skinner C, Friez MJ, Schwartz CE, Stevenson RE. Hypothesis: dysregulation of methylation of brain-expressed genes on the X chromosome and autism spectrum disorders. Am J Med Genet A 2008; 146A(17): 2213-2220.

104 Allan AM, Liang X, Luo Y, Pak C, Li X, Szulwach KE *et al.* The loss of methyl-CpG binding protein 1 leads to autism-like behavioral deficits. Hum Mol Genet 2008; 17(13): 2047-2057.

105 Goos LM, Ragsdale G. Genomic imprinting and human psychology: cognition, behavior and pathology. Adv Exp Med Biol 2008; 626: 71-88.

106 Commissie fundamentele herbezinning Wsw. Werken naar Vermogen. Den Haag: 2008.

107 Nye C, Brice A. Combined vitamin B6-magnesium treatment in autism spectrum disorder. Cochrane Database Syst Rev 2005;(4): CD003497.

108 Millward C, Ferriter M, Calver S, Connell-Jones G. Gluten- and casein-free diets for autistic spectrum disorder. Cochrane Database Syst Rev 2008;(2): CD003498.

109 Elder JH. The gluten-free, casein-free diet in autism: an overview with clinical implications. Nutr Clin Pract 2008; 23(6): 583-588.

110 Bent S, Bertoglio K, Hendren RL. Omega-3 Fatty Acids for Autistic Spectrum Disorder: A Systematic Review. J Autism Dev Disord 2009; Mar31.[Epub ahead of print]

111 Williams KW, Wray JJ, Wheeler DM. Intravenous secretin for autism spectrum disorder. Cochrane Database Syst Rev 2005;(3): CD003495.

112 Gold C, Wigram T, Elefant C. Music therapy for autistic spectrum disorder. Cochrane Database Syst Rev 2006;(2): CD004381.

113 Sinha Y, Silove N, Wheeler D, Williams K. Auditory integration training and other sound therapies for autism spectrum disorders: a systematic review. Arch Dis Child 2006; 91(12): 1018-1022.

114 Schlosser RW, Wendt O. Effects of augmentative and alternative communication intervention on speech production in children with autism: a systematic review. Am J Speech Lang Pathol 2008; 17(3): 212-230.

115 Broadstock M, Doughty C, Eggleston M. Systematic review of the effectiveness of pharmacological treatments for adolescents and adults with autism spectrum disorder. Autism 2007; 11(4): 335-348.

116 Jesner OS, ref-Adib M, Coren E. Risperidone for autism spectrum disorder. Cochrane Database Syst Rev 2007;(1): CD005040.

117 Jensen PS, Buitelaar J, Pandina GJ, Binder C, Haas M. Management of psychiatric disorders in children and adolescents with atypical antipsychotics: a systematic review of published clinical trials. Eur Child Adolesc Psychiatry 2007; 16(2): 104-120.

118 Stachnik JM, Nunn-Thompson C. Use of atypical antipsychotics in the treatment of autistic disorder. Ann Pharmacother 2007; 41(4): 626-634.

119 Levy SE, Hyman SL. Complementary and alternative medicine treatments for children with autism spectrum disorders. Child Adolesc Psychiatr Clin N Am 2008; 17(4): 803-20, ix.

120 Diggle T, McConachie HR, Randle VR. Parent-mediated early intervention for young children with autism spectrum disorder. Cochrane Database Syst Rev 2003;(1): CD003496.

121 McConachie H, Diggle T. Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. J Eval Clin Pract 2007; 13(1): 120-129.

122 Reichow B, Wolery M. Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. J Autism Dev Disord 2009; 39(1): 23-41.

123 Ospina MB, Krebs SJ, Clark B, Karkhaneh M, Hartling L, Tjosvold L *et al.* Behavioural and developmental interventions for autism spectrum disorder: a clinical systematic review. PLoS ONE 2008; 3(11): e3755.

124 Spreckley M, Boyd R. Efficacy of Applied Behavioral Intervention in Preschool Children with Autism for Improving Cognitive, Language, and Adaptive Behavior: A Systematic Review and Meta-analysis. J Pediatr 2008.

125 Howlin P, Magiati I, Charman T. Systematic review of early intensive behavioral interventions for children with autism. Am J Intellect Dev Disabil 2009; 114(1): 23-41.

126 Eldevik S, Hastings RP, Hughes JC, Jahr E, Eikeseth S, Cross S. Meta-analysis of Early Intensive Behavioral Intervention for children with autism. J Clin Child Adolesc Psychol 2009; 38(3): 439-450.

127 Bellini S, Peters JK. Social skills training for youth with autism spectrum disorders. Child Adolesc Psychiatr Clin N Am 2008; 17(4): 857-73, x.

128 Remington B, Hastings RP, Kovshoff H, degli EF, Jahr E, Brown T *et al.* Early intensive behavioral intervention: outcomes for children with autism and their parents after two years. Am J Ment Retard 2007; 112(6): 418-438.

129 Effectiviteit van Jeugdinterventies, NJI. http://www.jeugdinterventies.nl. Accessed: 1-6-2009.

130 Bildt AA de, Blijd-Hoogewijs EM, Dijkstra SP, Huizinga P, Ketelaars CEJ, Kraijer DW *et al.* Pervasieve ontwikkelingsstoornissen. In: Verhulst F.C., Verheij F, Ferdinand RF, editors. Kinder- en Jeugdpsychiatrie - Behandeling en Begeleiding. Assen: Van Gorcum; 2007: 31-81.

131 Research Autism. http://www.researchautism.net. Accessed: 1-6-2009.

132 Gezondheidsraad. Naar een voldoende inname van vitamines en mineralen. Den Haag: Gezondheidsraad; 2009: 2009/06.

133 Williams KR, Wishart JG. The Son-Rise Program intervention for autism: an investigation into family experiences. J Intellect Disabil Res 2003; 47(Pt 4-5): 291-299.

134 Williams KR. The Son-Rise Program intervention for autism: prerequisites for evaluation. Autism 2006; 10(1): 86-102.

135 Larkin AS, Gurry S. Brief report: progress reported in three children with autism using daily life therapy. J Autism Dev Disord 1998; 28(4): 339-342.

136 Scottish Intercollegiate Guidelines Network. Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders - a national clinical guideline. Edinburgh: NHS Quality Improvement Scotland; 2007: 98.

137 Nederlands Jeugdinstituut. http://www.nji.nl/smartsite.dws?id=108522. Accessed: 1-6-2009.

138 Berckelaer-Onnes I van. Autisme: van beeldvorming naar evidence-based (be)handelen: een proces in ontwikkeling. Wetenschappelijk Tijdschrift Autisme 2008; 2: 43-98.

139 Scheiris J, Pieters S, Block de K, Graeve de D, Eyssen M, Erdeghem Van S *et al.* NOK/PSY revalidatiecentra: doelgroepen, wetenschappelijke evidentie en zorgorganisatie. Federaal Kenniscentrum voor Gezondheidszorg; 2008.

140 Verhulst FC, Verheij F, Ferdinant RF. Kinder- en jeugdpsychiatrie. Behandeling en begeleiding. Assen: 2007.

141 Volkmar F, Cook E Jr, Pomeroy J, Realmuto G, Tanguay P. Summary of the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Autism and other Pervasive Developmental Disorders. American Academy of Child and Adolescent Psychiatry. J Am Acad Child Adolesc Psychiatry 1999; 38(12): 1611-1616.

142 Blijd-Hoogewijs EM, Ketelaars CEJ. Behandeling ASS: psycho-educatie, gedragstherapieën, bejegening en psychofarmaca. Autisme en stoornissen bij normaalbegaafde volwassenen. In: Assen: Van Gorcum; 2008: 50-61.

143 Gaag van der RJ, Berckelaer-Onnes IA. Protocollen in de jeugdzorg. Richtlijnen voor diagnostiek, indicatiestelling en interventie. Lisse: Swets & Zeitlingern; 2000.

144 Kok JFW. Specifiek opvoeden in gezin, school, dagcentrum en internaat. Gedragsproblemen in orthopedagogisch perspectief. Leuven/Amersfoort: Acco; 1984.

145 Dawson G, Osterling J. Early intervention in autism: Effectiveness and common elements of current approaches. 1997.

146 Noens I, Berckelaer-Onnes IA. Making sense in a fragmentary world: Communication in people with autism and learning disability. 2004.

147 Anderson LT, Campbell M, Grega DM, Perry R, Small AM, Green WH. Haloperidol in the treatment of infantile autism: effects on learning and behavioral symptoms. Am J Psychiatry 1984; 141(10): 1195-1202.

148 McDougle CJ, Scahill L, McCracken JT, Aman MG, Tierney E, Arnold LE *et al.* Research Units on Pediatric Psychopharmacology (RUPP) Autism Network. Background and rationale for an initial controlled study of risperidone. Child Adolesc Psychiatr Clin N Am 2000; 9(1): 201-224.

149 Gencer O, Emiroglu FN, Miral S, Baykara B, Baykara A, Dirik E. Comparison of long-term efficacy and safety of risperidone and haloperidol in children and adolescents with autistic disorder. An open label maintenance study. Eur Child Adolesc Psychiatry 2008; 17(4): 217-225.

150 Treatment and Education of Autistic and related Communication-handicapped Children. http://www.teacch.com. Accessed: 1-6-2009.

151 Landelijk Netwerk Autisme. http://www.landelijknetwerkautisme.nl. Accessed: 1-6-2009.

152 MEE. http://www.mee.nl. Accessed: 1-6-2009.

153 MEE Nederland. http://www.meenederland.nl. Accessed: 1-6-2009.

154 Tweede Kamer der Staten-Generaal. Zorg en maatschappelijke ondersteuning; Brief staatssecretaris met de eerste voortgangsrapportage over de in- en uitvoering van de Wet maatschappelijke ondersteuning (Wmo). Vergaderjaar 2006-2007, nr. 29538-38. Den Haag.

155 Ministerie voor Jeugd en Gezin. http://www.jeugdengezin.nl. Accessed: 1-6-2009.

156 Ministerie voor Jeugd en Gezin. Alle kansen voor alle kinderen: Programma voor Jeugd en Gezin 2007-2011. Den Haag: Ministerie voor Jeugd en Gezin; 2007.

157 Regelhulp. https://www.regelhulp.nl. Accessed: 1-6-2009.

158 Integraal Indiceren. http://www.integraalindiceren.info. Accessed: 1-6-2009.

159 Convenant Autisme. http://www.convenantautisme.nl. Accessed: 1-6-2009.

160 Berger MA. Voorbereiding Richtlijnontwikkeling Jeugdzorg: projectvoorstel voor het programmaministerie voor Jeugd en Gezin. Utrecht: Nederlands Jeugd Instituut; 2008.

161 ZVW - Zorgverzekeringswet. Staatsblad 2005, 358 Laatste wijziging: 12 jun 2008, Staatsblad 2008, 271.

162 AWBZ - Algemene Wet Bijzondere Ziektekosten. Staatsblad 1967, 617 Laatste wijziging: 5 feb 2009, Staatsblad 2009,108.

163 WMO - Wet Maatschappelijke Ondersteuning. Staatsblad 2006, 35 Laatste wijziging: 10 apr 2004, Staatsblad 2008,164.

164 Linschoten RLO, Goudswaard KP, Kamps JA. Verkeerd verbonden: naar houdbare voorzieningen voor jeugdigen. Taskforce invoering maatregelen AWBZ-zorg voor jeugd-LVG en jeugd-GGZ; 2008.

165 Ramakers C, Schellingerhout R, van den Wijngaart M, Miedema F. Persoonsgebonden budget nieuwe stijl 2007. Vervolgonderzoek. Nijmegen: ITS - Radboud Universiteit; 2008.

166 Tweede Kamer der Staten-Generaal. Beleidsregels indicatiestelling AWBZ 2009. Vergaderjaar 2008-2009, nr. 30597-43. Den Haag.

167 Tweede Kamer der Staten-Generaal. Beleidsregels indicatiestelling AWBZ 2009 - bijlage 1: Algemeen. Vergaderjaar 2008-2009, nr. 30597-43. Den Haag.

168 Tweede Kamer der Staten-Generaal. Beleidsregels indicatiestelling AWBZ 2009 - bijlage 6 Begeleiding. Vergaderjaar 2008-2009, nr. 30597-43. Den Haag.
169 Sijde A van der, Jongerius A, Gorter N, Hofman N. Veranderingen financiering zorg en gevolgen voor mensen met een autismespectrumstoornis. Hendrik-Ido-Ambacht: RIAN Zuid-Holland Zuid; 2009.
170 College voor Zorgverzekeringen. Onderzoek PGB-bemiddelingsbureaus. Diemen: CVZ; 2009: 09/02.
171 Steenman I, Liefhebber-Van der Veer T. De ASSwijzer als navigatiesysteem. Wetenschappelijk Tijdschrift Autisme 2005;(3)
172 Frijters D, Krame A, Stukstette B, Hasper S. Ontwikkeling van een instrument voor zorgzwaartebepaling van leerlingen met diagnose autisme. Eindrapportage. Utrecht: Prismant; 2007.
173 Taksatiezorg. http://www.taksatiezorg.nl. Accessed: 1-6-2009.
174 Curran AL, Sharples PM, White C, Knapp M. Time costs of caring for children with severe disabilities compared with caring for children without disabilities. Dev Med Child Neurol 2001; 43(8): 529-533.
175 Hare DJ, Pratt C, Burton M, Bromley J, Emerson E. The health and social care needs of family carers supporting adults with autistic spectrum disorders. Autism 2004; 8(4): 425-444.
176 Järbrink K. The economic consequences of autistic spectrum disorder among children in a Swedish municipality. Autism 2007; 11(5): 453-463.
177 Barnhill GP. Outcomes in adults with Asperger syndrome. Focus on autism and other developmental disabilities 2007; 22(2): 116-126.
178 Woodgate RL, Ateah C, Secco L. Living in a world of our own: the experience of parents who have a child with autism. Qual Health Res 2008; 18(8): 1075-1083.
179 Montes G, Halterman JS. Child care problems and employment among families with preschool-aged children with autism in the United States. Pediatrics 2008; 122(1): e202-e208.
180 Rosenzweig JM, Brennan EM, Ogilvie AM. Work-family fit: voices of parents of children with emotional and behavioral disorders. Soc Work 2002; 47(4): 415-424.
181 Montes G, Halterman JS. Association of childhood autism spectrum disorders and loss of family income. Pediatrics 2008; 121(4): e821-e826.
182 Wolf LC, Noh S, Fisman SN, Speechley M. Psychological effects of parenting stress on parents of autistic children. J Autism Dev Disord 1989; 19(1): 157-166.
183 Higgins DJ, Bailey SR, Pearce JC. Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. Autism 2005; 9(2): 125-137.
184 Benson PR, Karlof KL. Anger, stress proliferation, and depressed mood among parents of children with ASD: a longitudinal replication. J Autism Dev Disord 2009; 39(2): 350-362.
185 Hastings RP, Kovshoff H, Brown T, Ward NJ, Espinosa FD, Remington B. Coping strategies in mothers and fathers of preschool and school-age children with autism. Autism 2005; 9(4): 377-391.
186 Allik H, Larsson JO, Smedje H. Health-related quality of life in parents of school-age children with Asperger Syndrome or High-Functioning Autism. Health Qual Life Outcomes 2006; 4: 1.

187 Mugno D, Ruta L, D'Arrigo VG, Mazzone L. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Health Qual Life Outcomes 2007; 5: 22.

188 Sivberg B. Family system and coping behaviors: a comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. Autism 2002; 6(4): 397-409.

189 Bromley J, Hare DJ, Davison K, Emerson E. Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. Autism 2004; 8(4): 409-423.

190 Fombonne E, Simmons H, Ford T, Meltzer H, Goodman R. Prevalence of pervasive developmental disorders in the British nationwide survey of child mental health. J Am Acad Child Adolesc Psychiatry 2001; 40(7): 820-827.

191 Montes G, Halterman JS. Psychological functioning and coping among mothers of children with autism: a population-based study. Pediatrics 2007; 119(5): e1040-e1046.

192 Singer GH. Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. Am J Ment Retard 2006; 111(3): 155-169.

193 Lee LC, Harrington RA, Louie BB, Newschaffer CJ. Children with autism: quality of life and parental concerns. J Autism Dev Disord 2008; 38(6): 1147-1160.

194 Lounds J, Seltzer MM, Greenberg JS, Shattuck PT. Transition and change in adolescents and young adults with autism: longitudinal effects on maternal well-being. Am J Ment Retard 2007; 112(6): 401-417.

195 Smith LE, Seltzer MM, Tager-Flusberg H, Greenberg JS, Carter AS. A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. J Autism Dev Disord 2008; 38(5): 876-889.

196 Gray DE. Coping over time: the parents of children with autism. J Intellect Disabil Res 2006; 50(Pt 12): 970-976.

197 Bayat M. Evidence of resilience in families of children with autism. J Intellect Disabil Res 2007; 51(Pt 9): 702-714.

198 Orsmond GI, Seltzer MM, Greenberg JS, Krauss MW. Mother-child relationship quality among adolescents and adults with autism. Am J Ment Retard 2006; 111(2): 121-137.

199 Pilowsky T, Yirmiya N, Doppelt O, Gross-Tsur V, Shalev RS. Social and emotional adjustment of siblings of children with autism. J Child Psychol Psychiatry 2004; 45(4): 855-865.

200 Schuntermann P. The sibling experience: growing up with a child who has pervasive developmental disorder or mental retardation. Harv Rev Psychiatry 2007; 15(3): 93-108.

201 Dunn ME, Burbine T, Bowers CA, Tantleff-Dunn S. Moderators of stress in parents of children with autism. Community Ment Health J 2001; 37(1): 39-52.

202 Twoy R, Connolly PM, Novak JM. Coping strategies used by parents of children with autism. J Am Acad Nurse Pract 2007; 19(5): 251-260.

203 Pottie CG, Cohen J, Ingram KM. Parenting a child with autism: contextual factors associated with enhanced daily parental mood. J Pediatr Psychol 2009; 34(4): 419-429.

204 Bauminger N, Shulman C. The development and maintenance of friendship in high-functioning children with autism: maternal perceptions. Autism 2003; 7(1): 81-97.

205 Orsmond GI, Krauss MW, Seltzer MM. Peer relationships and social and recreational activities among adolescents and adults with autism. J Autism Dev Disord 2004; 34(3): 245-256.

206 Howlin P, Mawhood L, Rutter M. Autism and developmental receptive language disorder--a follow-up comparison in early adult life. II: Social, behavioural, and psychiatric outcomes. J Child Psychol Psychiatry 2000; 41(5): 561-578.

207 Engstrom I, Ekstrom L, Emilsson B. Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. Autism 2003; 7(1): 99-110.

208 Bauminger N, Shulman C, Agam G. Peer interaction and loneliness in high-functioning children with autism. J Autism Dev Disord 2003; 33(5): 489-507.

209 Bauminger N, Kasari C. Loneliness and friendship in high-functioning children with autism. Child Dev 2000; 71(2): 447-456.

210 Eaves LC, Ho HH. Young adult outcome of autism spectrum disorders. J Autism Dev Disord 2008; 38(4): 739-747.

211 Koning C, Magill-Evans J. Social and language skills in adolescent boys with Asperger syndrome. Autism 2001; 5(1): 23-36.

212 Hilton CL, Crouch MC, Israel H. Out-of-school participation patterns in children with high-functioning autism spectrum disorders. Am J Occup Ther 2008; 62(5): 554-563.

213 Barnard J, Prior A, Potter D. Inclusion and autism: Is it working? 1.000 examples of inclusion in education and adult life from the National Autistic Society’s members. National Autistic Society. London: 2000.

214 Leo Kannerhuis. http://www.leokannerhuis.nl. Poject ‘Lege tijd wordt vrije tijd’ Accessed: 1-6-2009.

215 Krauss MW, Seltzer MM, Jacobson HT. Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. J Intellect Disabil Res 2005; 49(Pt 2): 111-124.

216 van Berckelaer-Onnes IA, Hansen MAT. Een leven lang ouderen. In: Nijs de PFA, Verheij F, Vlutters JL, Gelderblom IL, editors. Ontwikkeling langs de levenslijnen. Apeldoorn: Garant-uitgevers; 2004:

217 Larson E. Reframing the meaning of disability to families: the embrace of paradox. Soc Sci Med 1998; 47(7): 865-875.

218 Howlin P. Outcome in adult life for more able individuals with autism of Asperger syndrome. Autism 2000: 4(1):63-83.

219 Billstedt E, Gillberg IC, Gillberg C. Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. J Autism Dev Disord 2005; 35(3): 351-360.

220 Cederlund M, Hagberg B, Billstedt E, Gillberg IC, Gillberg C. Asperger syndrome and autism: a comparative longitudinal follow-up study more than 5 years after original diagnosis. J Autism Dev Disord 2008; 38(1): 72-85.

221 Barnard J, Harvey V, Potter D, Prior A. Ignored or ineligible? The reality for adults wit autism spectrum disorders. National Autistic Society. Londen: 2001.

222 Rosenblatt M. I exist, the massage from adults with autism in England. National Autistic Society. Londen: 2008.

223 WEC-Raad. http://www.wecraad.nl, Accessed: 1-6-2009.

224 Tweede Kamer der Staten-Generaal. Programma voor Jeugd en Gezin; Brief minister en staatssecretarissen over de ontwikkeling van Zorg en Adviesteams (ZAT's). Vergaderjaar 2007-2008, nr. 31001-51. Den Haag.

225 Inspectie van het Onderwijs. http://www.onderwijsinspectie.nl, Accessed: 1-6-2009.

226 Onderwijsconsulenten. http://www.onderwijsconsulenten.nl, Accessed: 1-6-2009.

227 Lord C, Bristol-Power MCJM, Filipek PA, Gallagher JJ, Harris SL *et al.* Educating children wit autism. Report of the Commitee on Educational Interventions for Autistic Children. (Lord C, McGee JP eds) Washington DC: National Academy of Science; National Academics Press 2001.

228 Hermans-Franssen A. Lezen wat er (niet) staat [Proefschrift]. Leiden: Universiteit Leiden; 2005.

229 Ministerie van Onderwijs, Cultuur en Wetenschap. http://www.minocw.nl, Accessed: 1-6-2009.

230 PASSER Web-school. http://www.passer-webschool.nl, Accessed: 1-6-2009.

231 Project Kairo. http://www.projectkairo.org, Accessed: 1-6-2009.

232 Tweede Kamer der Staten-Generaal. Wijziging van de Wet op de expertisecentra, de Wet op het primair onderwijs en de Wet op het voortgezet onderwijs in verband met de invoering van een leerlinggebonden financiering en de vorming van regionale expertisecentra (regeling leerlinggebonden financiering); Brief minister bij notitie 'Vernieuwing van de zorgstructuren in het funderend onderwijs'. Vergaderjaar 2005-2006, nr. 27728-85. Den Haag.

233 Tweede Kamer der Staten-Generaal. Notitie vernieuwing van de zorgstructuren in het funderend onderwijs; bijlage bij Kamerstuk 27728, nr. 85. Vergaderjaar 2005-5006, nr. 27728-85. Den Haag.

234 Tweede Kamer der Staten-Generaal. Wijziging van de Wet op de expertisecentra, de Wet op het primair onderwijs en de Wet op het voortgezet onderwijs in verband met de invoering van een leerlinggebonden financiering en de vorming van regionale expertisecentra (regeling leerlinggebonden financiering); Brief staatssecretaris over haar beleidsvoornemens voor passend onderwijs. Vergaderjaar 2006-2007, nr. 27728-98. Den Haag.

235 Tweede Kamer der Staten-Generaal. Wijziging van de Wet op de expertisecentra, de Wet op het primair onderwijs en de Wet op het voortgezet onderwijs in verband met de invoering van een leerlinggebonden financiering en de vorming van regionale expertisecentra (regeling leerlinggebonden financiering); Brief staatssecretaris inzake overwegingen en keuzes bij uitwerking van passend onderwijs. Vergaderjaar 2007-2008, nr. 27728-101. Den Haag.

236 Tweede Kamer der Staten-Generaal. Tweede voortgangsrapportage Passend Onderwijs. 2008-2009, nr. 31497-12. Den Haag.

237 Tweede Kamer der Staten-Generaal. Tweede voortgangsrapportage Passend Onderwijs, Bijlage: rapportage november 2008. Vergaderjaar 2008-2009, nr. 31497-12. Den Haag.

238 Tweede Kamer der Staten-Generaal. Passend onderwijs; Brief staatssecretaris met eerste Voortgangsraopportage Passend Onderwijs. Vergaderjaar 2007-2008, nr. 31497-1. Den Haag.

239 Schel A, Voets M. Begeleid naar een toekomst: bouwen aan transitieonderwijs. ‘s-Hertogenbosch: KPC Groep; 2007.

240 Vink CR, Van Schilt-Mol TMML, Sontag L. De arbeidsmarkt op!: de aansluiting tussen onderwijs en arbeidsmarkt voor schoolverlaters uit het Praktijkonderwijs en Voortgezet Speciaal Onderwijs. Tilburg: IVA; 2008.

241 Werknemer in Opleiding. http://www.werknemerinopleiding.nl, Accessed: 1-6-2009.

242 Van wajong naar werk. http://www.vanwajongnaarwerk.nl, Accessed: 1-6-2009.

243 Wajong en Werk. Onderzoek naar de arbeidsparticipatie van jonggehandicapten. 2007.

244 Wet Educatie en Beroepsonderwijs. Staatsblad 1995, 501 Laatste wijziging: 12 mrt 2009, Staatsblad 2009,151.

245 Platform Gehandicapten MBO. htt://www.platformgehandicaptenmbo.kennisnet.nl

246 Broenink M, Gorter K. Studeren met een handicap: Belemmeringen die studenten met een lichamelijke beperking, psychische klachten endyslexie in het hoger onderwijs ondervinden. Utrecht: Verwey-Jonker; 2001.

247 Onderwijs en handicap. http://www.onderwijsenhandicap.nl, Accessed: 1-6-2009.

248 Clijsen A, Loman E. Kinderen met speciale rechten - Arbeidstoelieidng van kinderen met autisme. VSLPC (Vereniging de Samenwerkende Landelijke Pedagogische Centra); 2003: 111009.

249 Genabeek J van, Andriessen S, Ooms D, Fermin B, Klerkx M. Scholing en arbeidsintegratie van Wajongers met ernstige scholingsbelemmeringen: volumeontwikkeling en effectiviteit. Hoofddorp: TNO Kwaliteit van Leven; 2008.

250 Intakeprotocol voor de toeleiding van mensen met autisme naar opleiding of werk. Wijk aan Zee: Heliomare; 2008.

251 UWV. De groei van de Wajonginstroom: Een onderzoeksrapport in het kader van het dossieronderzoek Wajong 2007. Kenniscahier 07-01. http://www.uwv.nl. Accessed: 3-6-2009.

252 UWV. De participatiemogelijkheden van de Wajonginstroom: Een onderzoeksrapport in het kader van het dossieronderzoek Wajong 2007. Kenniscahier 08-01. http://www.uwv.nl. Accessed: 3-6-2009.

253 Besseling J, Andriessen S, De Vos E, Wevers C. Participatiemogelijkheden van Wajongers. Hoofddorp: TNO Kwaliteit van Leven; 2008.

254 Borghouts-Van de Pas IWCM, Pennings FJL. Arbeidsparticipatie van jonggehandicapten: Een onderzoek naar Europese systemen en praktijken. Tilburg: OSA; 2008.

255 Müller E, Schuler A, Burton B.A., Yates GB. Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. J Vocational Rehabilitation 2003; 18: 163-175.

256 Hurlbutt K, Chalmers L. Employment and adults with Asperger syndrome. Focus on autism and other developmental disabilities 2004; 19(4): 215-222.

257 Michon H, Weeghel van J. Rehabilitatie-onderzoek in Nederland. Overzicht van onderzoek van synthese van bevindingen in de periode 2000-2007. Utrecht: Trimbosinstituut en Kenniscentrum Rehabilitatie, Den Haag: ZonMw, 2008.

258 Howlin P, Alcock J, Burkin C. An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. Autism 2005; 9(5): 533-549.

259 Aarts L, Van Hout Ch, Thijs C, Visscher K. Evaluatie jobcoaching: eindrapport. http://www.ape.nl. Accessed: 3-6-2009.

260 Tweede Kamer der Staten-Generaal. Wijziging van de Wet arbeidsongeschiktheidsvoorziening jonggehandicapten in verband met het bevorderen van de participatie van jonggehandicapten door werk en arbeidsondersteuning; Koninklijke boodschap. Vergaderjaar 2008-2009, nr. 3178-1. Den Haag.

261 Tweede Kamer der Staten-Generaal. Wijziging van de Wet arbeidsongeschiktheidsvoorziening jonggehandicapten in verband met het bevorderen van de participatie van jonggehandicapten door werk en arbeidsondersteuning; Voorstel van wet. Vergaderjaar 2008-2009, nr. 31780-2. Den Haag.

262 Tweede Kamer der Staten-Generaal. Wijziging van de Wet arbeidsongeschiktheidsvoorziening jonggehandicapten in verband met het bevorderen van de participatie van jonggehandicapten door werk en arbeidsondersteuning; Memorie van toelichting. Vergaderjaar 2008-2009, nr. 31780-3. Den Haag.

263 WIA - Wet Werk en Inkomen naar Arbeidsvermogen. Staatsblad 2005, 572 Laatste wijziging: 5 feb 2009, Staatsblad 2009,108.

264 Kraijer DW. Handboek autismespectrumstoornissen en verstandelijke beperking. Lisse: Harcourt Book Publishers; 2004.

265 ZonMw. Richtlijnen Jeugdgezondheid, ronde 2009. http://www.zonmw.nl, Accessed 1-6-2009

266 Netelenbos JB. Oorzaak en gevolg bij een motorische stoornis. In: Bosch JD, Bosma HA, Vijt A, editors. Jaarboek ontwikkelingspsychologie, orthopedagogiek en kinderpsychiatrie. Houten: Bohn Stafleu Van Loghum; 2002.

267 Lauritsen MB, Pedersen CB, Mortensen PB. The incidence and prevalence of pervasive developmental disorders: a Danish population-based study. Psychol Med 2004; 34(7): 1339-1346.

268 Ellefsen A, Kampmann H, Billstedt E, Gillberg IC, Gillberg C. Autism in the Faroe Islands: an epidemiological study. J Autism Dev Disord 2007; 37(3): 437-444.

269 Bildt A de, Sytema S, Kraijer D, Minderaa R. Prevalence of pervasive developmental disorders in children and adolescents with mental retardation. J Child Psychol Psychiatry 2005; 46(3): 275-286.

270 Trimbos-instituut. Psychische stoornissen. Informatie voor professionals. Autismespectrumstoornissen. Literatuurverwijzingen: Fombonne, E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. J Autism Dev Disord 2003; 33(4): 365-382. http://www.trimbos.nl, Accessed 1-6-2009.

271 Chakrabarti S, Fombonne E. Pervasive developmental disorders in preschool children. JAMA. 2001; 285(24):3093-9.

272 Naarden Braun K van, Pettygrove S, Daniels J, Miller L, Nicholas J, Baio J, Schieve L, Kirby RS, Washington A, Brocksen S, Rahbar H, Rice C; Centers for Disease Control and Prevention. Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. MMWR Surveill Summ. 2007 Feb 9;56(1):29-40.

273 Keesenberg H. Praktijkserie Basisschoolmanagement nr 47: Passend onderwijs. Alphen aan den Rijn: Kluwer; 2008.

Annexes

Annex

A

The request for advice

Date of request: 12 July 2008

Letter reference: DJenG/SenS-284281

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?

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. Dijksma

Annex

B

The Committee

- Professor A.L.M. Lagro-Janssen, *chairperson*
  Professor of General Medicine and Women's Health Sciences, Radboud University Nijmegen Medical Centre
- Professor I.A. van Berckelaer-Onnes
  emeritus professor of Remedial Education, University of Leiden
- Dr. R.L.P. Berghmans
  ethicist, Maastricht University
- Professor S.E. Buitendijk
  Professor of Integrated Preventive Health Care for Children, Leiden University Medical Center
- Dr. G.A. Donker
  General practitioner, Nivel, Utrecht
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- Professor R.J. van der Gaag
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- Dr. M. de Graaf
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- Professor R.B. Minderaa
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- Dr. A.J.C. Struiksma
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- C.W.J. Wevers
  Occupational physician, senior researcher Employment Rate Department, TNO Quality of Life, Hoofddorp
- Dr. V.W.T. Ruiz van Haperen, *scientific secretary*
  Health Council, The Hague
- F. Westerbos, physician, *scientific secretary*
  Health Council, The Hague

Official advisers

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  Ministry for Youth and Families, Youth and Family Division, Management and Systems (Sturing en Stelsel) department, The Hague (representative in the Committee meetings)
- M.C.J. van Dal
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- R.J.C.M. Kolsteren
  Ministry of Social Affairs and Employment, Loss-Of-Income Insurance and Facilities Directorate (*directie Inkomensverzekeringen en -voorzieningen*), The Hague (from 1 January 2009)
- E. Gorter
  Ministry of Health, Welfare and Sport, Long-term Care Directorate (*directie Langdurige Zorg*), The Hague
- E. Wennink
  Ministry of Health, Welfare and Sport, Curative Care Directorate (*directie Curatieve Zorg*), The Hague
- L.J. Molenaar
  Ministry of Health, Welfare and Sport, Curative Care Directorate (*directie Curatieve Zorg*), The Hague
- M.E. Schouten
  Ministry of Education, Culture and Science, Directorate of Youth, Education and Care (*directie Jeugd, Onderwijs en Zorg*), The Hague

The Health Council and interests

Members of Health Council Committees – which also include the members of the Advisory Council on Health Research (RGO) since 1 February 2008 – are appointed in a personal capacity because of their special expertise in the matters to be addressed. Nonetheless, it is precisely because of this expertise that they may also have interests. This in itself does not necessarily present an obstacle for membership of a Health Council Committee. Transparency regarding possible conflicts of interest is nonetheless important, both for the President and members of a Committee and for the President of the Health Council. On being invited to join a Committee, members are asked to submit a form detailing the functions they hold and any other material and immaterial interests which could be relevant for the Committee's work. It is the responsibility of the President of the Health Council to assess whether the interests indicated constitute grounds for non-appointment. An advisorship will then sometimes make it possible to exploit the expertise of the specialist involved. During the establishment meeting the declarations issued are discussed, so that all members of the Committee are aware of each other's possible interests.

Annex

C

Experts consulted

- Professor S. Baron-Cohen, Autism Research Centre, Section of Developmental Psychiatry, University of Cambridge, Cambridge, UK
- C.A.A.M. Brekelmans, senior policy officer, Dutch mental health care association (*GGZ Nederland*), Amersfoort
- Professor T. Charman, Professor of Developmental Disorders, Behavioural & Brain Sciences Unit, UCL Institute of Child Health, London, UK
- Dr. I.M.F. de Coo, child neurologist, Children's hospital Erasmus MC Sophia, Rotterdam
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- Dr. C. Deckers, Deckers Adviesgroep, Amsterdam
- A.A. van Dijk, R&D Manager, Dr Leo Kanner House, Doorwerth
- Professor T. Doreleijers, forensic child and adolescent psychiatrist, *Bascule*, Academic Medical Centre, Amsterdam
- M.J. van den Dries, Youth Programme Manager, Province of North Brabant, Den Bosch
- F. Egberts, insurance physician, Invalidity Insurance (Young Disabled Persons) Act policy officer, UWV,
- Dr. R. Gongrijp, Appropriate Education Evaluation and Advisory Board, The Hague
- N. Gorter, Director Eddee, Zwijndrecht / RIAN
- Th. Haasdijk, policy officer, MEE Nederland, Utrecht

- S. Hasper-Sitton, WEC Council, National Autism Network, Utrecht
- Dr. R. Hoekstra, Autism Research Centre, Section of Developmental Psychiatry, University of Cambridge, Cambridge, UK
- N. Hofman, Coordinator of the RIAN (Regional Inter-sectoral Autism Network) autism network South – South Holland
- Dr. L. Hooft, Dutch Cochrane Centre, Amsterdam
- E. Hoogervorst, Circuit Manager Children and Young people, De Grote Rivieren, Dordrecht / RIAN
- Professor P. Howlin, Professor of Clinical Child Psychology, Institute of Psychiatry, King's College, London, UK
- A. Jongerius, Southern Region Manager, *Pameijer*, Rotterdam / RIAN
- A. Kapteijn, Coordinator Gelderland Regional Autism Partnership, MEE Gelderse Poort, Tiel
- M. van Lieren, regional staff insurance physician, Invalidity Insurance (Young Disabled Persons) Act portfolio, UWV,
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- L.A.J.M. Middelhoff, Chairman of the Board, MEE South East Brabant
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- S. Nijhuis, Project Manager, Heliomare, Wijk aan Zee
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- T. Post, Health Care Psychologist, Stichting Philadelphia Zorg (Philadelphia Care Foundation), Nunspeet
- A. Ranzijn, corporate secretary, Woonzorg Netherlands, Amstelveen
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- G. Smilde, *Taksatiezorg*, Annen

- M.E.C.P. Smits, psychiatrist, member Board of Directors, Dr Leo Kanner House, Doorwerth
- R. van der Steen, chairperson, Autism Covenant Implementation Committee, Bilthoven
- F. Steendam, policy advisor, WEC Council, Utrecht
- F. Stekelenburg, Director, Dutch Association for Autism, Bilthoven
- A. Tichelaar, Project Manager Invalidity Insurance (Young Disabled Persons) Act, UWV,
- S. Venderbosch, Autism Covenant Project Assistant, Dutch Association for Autism, Bilthoven
- H. Vermolen-van Gerwen, Vice President, Dutch Association for Autism, Bilthoven
- M. Weijmans, Core Team Coordinator, Southeast North-Brabant Regional Autism Partnership, Eindhoven
- M. Wijnen-van de Broek, behavioural scientist, East Brabant Youth Care Agency, Uden/Oss

Annex

D

Justification for approach adopted

Search period

The selection of grey literature was carried out intermittently from June 2008 to May 2009.

The systematic literature search for systematic reviews and large-scale studies covers all literature included in the cited databases up until December 2008. Either in full or in part, the literature is supplemented with articles from the period December 2008 to May 2009.

Databases

- PubMed/Medline
- Cochrane Database of Systematic Reviews
- PsychLit
- National Guideline Clearinghouse
- Guidelines Finder

Search strategy filters: Autism Spectrum Disorders and systematic review

Autism spectrum disorders:
Search string: ((autism) OR (pervasive developmental disorder))

Systematic review:
(Source: University of Rochester): Filter: (((((((((("Meta-Analysis "[MeSH Terms] OR meta-analysis [pt]) OR medline [tiab]) OR ((((meta analysis [tiab] OR meta analysis [tiab]) OR meta analytic [tiab]) OR metaanalytical [tiab]) OR metaanalytically [tiab])) OR "meta analysis" [All Fields]) OR (((((overview [tiab] OR overview / literature [tiab]) OR overviewed [tiab]) OR on viewer [tiab]) OR on viewing [tiab]) OR overviews [tiab])) OR clinical trial [pt]) OR multicenter study [pt]) OR evaluation studies [pt]) OR validation studies [pt]) OR review [pt]) OR (systematic review [All Fields] OR systematic reviews [All Fields]))

Degree of cogency of the evidence in the literature (Chapter 4 treatment and counselling)

Source: CBO: Levels of Evidence (http://www.cbo.nl/product/richtlijnen/handleiding_ebro/article20060207153532/view)

	For articles on: intervention (prevention or therapy) (types of evidence)
A1	Systematic review of at least two independently conducted studies of A2-level
A2	Randomised, double-blind, controlled clinical trial of good quality and sufficient scope
B	Controlled trial, but not including all of the features listed under A2 (such as cohort studies, case-control study)
C	Non-controlled trial
D	Opinion of experts, such as the Preconception Care Committee

Formulating conclusions from the literature

Conclusions were then formulated on the basis of the available evidence, together with an indication of the degree of cogency of the evidence, in accordance with the following categories:

Degree of cogency of the evidence supporting the conclusions

Level 1	Based on one A1-level systematic review or at least two independently conducted
Level 2	Based on one A2-level systematic review or at least two independently conducted B-level studies
Level 3	Based on one B-level or C-level study
Level 4	Based on the opinion of experts, e.g. the working group members

Note: A conclusion is as firm as the study with the most cogent evidence. Accordingly, a systematic review can only lead to a level-1 conclusion if it is based on at least two independently conducted, randomised, controlled clinical trials. If the best study discussed in a systematic review is level B or C, then any conclusions drawn on the basis of that systematic review can never be stronger than level 2 or 3. The latter applies to most systematic reviews in the area of interventions for autism spectrum disorders.

Digital references

Use was also made of information derived from websites. On 1 June 2009, all of the web references were verified by checking that they were still active in the designated form, and that they contained the information in question.

Annex

E

Classification criteria for Autism Spectrum Disorders from DSM-IV

DSM-IV criteria for Autistic Disorder

(taken from the ‘Autism Spectrum Disorders in children and young people’ guideline produced by the Dutch Psychiatric Association)

A. In order to make this diagnosis, the child must meet a minimum total of 6 items from (1), (2), and (3), with at least two criteria from (1), and one criterion from both (2) and (3).

(1) qualitative deficiencies in social interaction, as manifested by at least two of the following items:
  a. clear shortcomings in nonverbal behaviour that regulates social interaction: eye contact, facial expression, body postures and gestures
  b. an inability to build age-appropriate relationships with peers
  c. a clear inability to rejoice in other people’s happiness
  d. lack of social and emotional reciprocity

(2) qualitative deficiencies in communication, as manifested by at least one of the following items:
  a. a delay in the development of spoken language, or a total lack of spoken language (with no attempt to compensate for this deficiency by using alternative methods of communication such as gestures or facial expressions)
  b. in individuals with adequate speech development, a clear inability to start or maintain conversations with others
  c. stereotypical, repetitive use of language, or idiosyncratic use of language

    - d. a lack of varied spontaneous pretend play or social-imitative play appropriate to the age of the individual in question

(3) limited, repetitive and stereotypical behavioural patterns, interests and activities, as shown by at least one of the following items:

  - a. preoccupation with one or more stereotypical and restricted areas of interest, of an abnormal intensity or nature.
  - b. a compulsive adherence to specific, non-functional rituals or habits
  - c. stereotypical and repetitive motor peculiarities (flapping hands, spinning, or complex body movements)
  - d. a persistent preoccupation with certain parts of objects

B. Retardation, or abnormal performance in at least two of the following domains, starting at age three:

  - (1) social interaction
  - (2) communication-oriented use of language, or
  - (3) symbolic or imitative play

C. The disorder cannot be better classified as Rett syndrome or childhood disintegrative disorder.

DSM-IV-TR criteria for Asperger's disorder

A. Qualitative limitations in social interactions, as manifested by at least two of the following items:

  - (a) Marked impairment in the use of various forms of nonverbal behaviour, such as eye contact, facial expression, body postures, and gestures to determine social interaction
  - (b) Failure to develop relationships with peers that are in keeping with the developmental level of the affected individual
  - (c) Lack of spontaneous efforts to share pleasure, activities or performance with others (e.g. hiding/bringing/pointing out objects of importance)
  - (d) Absence of social or emotional reciprocity

B. Limited, repetitive and stereotypical behavioural patterns, interests and activities, as shown by at least one of the following items:

  - (a) Marked preoccupation with one or more stereotypical and restricted patterns of interest that are abnormal in terms either of intensity or nature.
  - (b) Clearly inflexible adherence to specific, non-functional routines or rituals
  - (c) Stereotypical and repetitive motor mannerisms (e.g. hand flapping, twisting the hand or fingers, or complex movements of the whole body)

(d) Persistent preoccupation with parts of objects

C. The disorder causes clinically significant limitations in social or occupational performance, or in performance in other important areas.

D. There is no significant general delay in language development (e.g. the use of single words at age two, communicative phrases by age three).

E. There is no significant delay in cognitive development or in the development of age-appropriate self-sufficiency skills. The same applies to the ability to adapt behaviour (other than in social interactions) and to curiosity about the environment.

F. Affected individuals do not meet the criteria for another specific pervasive developmental disorder, or for schizophrenia.

DSM-IV criteria for the classification PDD-NOS:

Severe and pervasive limitations in the development of reciprocal social interaction with deficiencies in either verbal or nonverbal communication skills, or due to the presence of stereotypical behaviour, interests and activities. Failure to comply with the criteria for a specific pervasive developmental disorder, schizophrenia, schizotypal personality, or avoidant personality disorder.

Annex F

Literature survey on prevalence

Table 10 Prevalence of Autism Spectrum Disorders.

Country	Year of observation	Age	Cohort (n)	Prevalence	Reference
General	1998-2002	0-20		60/10,000 total 13/10,000 childhood 44/10,000 PDD-NOS 3/10,000 Asperger's 0.2/10,000 CDD	Fombonne 2005[33]
Atlanta GA, USA	1996	3-10	289,456	34/10,000 total, no ethnic differences were found	Yeargin-Allsopp 2003[32]
British Columbia Canada	1996 and 2004	4-9	2,198 ASD	1996: 12,3/10.000 2004: 43,1/10.000 At least one third of the increase can be attributed to diagnostic substitution (change in the classification for special needs education). Also catch-up manoeuvre vis-à-vis previous diagnosis.	Coo *et al.* 2008[99] Ouelette 2007[100]
Denmark	1971-2000	<10	2,400,000	11.8/10,000 childhood 3.3/10,000 atypical 4.7/10,000 Asperger's 14.6/10,000 PDD-NOS	Lauritsen 2004[267]
EU	Studies 1967-1999		7117-549,255	3.3-16/10,000 childhood 30-63/10,000 total	EU 2005[88]

Faroer Islands	2002	8-17	7,689	53/10,000 total 16/10,000 childhood autism 26/10,000 Asperger’s* 12/10,000 atypical autism * The high prevalence of Asperger’s is due to the fact that the authors ‘added’ PDD-NOS and Asperger’s together	Ellefsen 2007[268]
Friesland	2004	4-18	1,436	16.7% of children with mental retardation (1% prevalence in general population) – 9.8% with mild mental retardation, 26.1% with moderate/ severe mental retardation	De Bildt 2005[269]
The Netherlands	Start of the 21st century	0-20		60/10,000 total Most PDD-NOS	Trimbos op basis van Fombonne 2003[270]
The Netherlands	1990s	0-20		10/10,000 childhood 15/10,000 PDD-NOS 3/10,000 Asperger's	Trimbos op basis van Fombonne 2003
Portugal	1999-2000	6-9	332,808 mainland 10,910 Azores	9.2/10,000 mainland 15.6/10,000 Azores 20% comorbidity with unexpectedly large number of mitochondrial respiratory chain disorders	Oliveira 2007[85]
South Carolina, USA	2000 and 2002	8	3,217	6,2/1000 3.1 boys : 1 girl 79% in special needs education, of which 36% admitted with indication of ASD IQ <70 72.2% of the girls 56.4% of the boys, IQ <34 equal numbers of boys and girls, no racial differences	Nicholas 2008[35]
South Thames UK	2000	9-10	56,946	38.9/10,000 autism 77.2/10.000 other PDD	Baird 2006[86]
Stafford	1998	4-6	15,500	61.9/10,000 total 16.8/10,000 childhood 36.1/10,000 PDD-NOS 8.4/10,000 Asperger's 0.6/10,000 CDD	Chakrabati & Fombonne, 2001[271]
Stafford	2002	4-6	10,903	58.7/10,000 total 22/10,000 childhood 24.8/10,000 PDD-NOS 11/10,000 Asperger's 0.9/10,000 CDD	Chakrabati & Fombonne 2005[34]
United Kingdom	2003	11	14,062	51.1/10,000 total 21.6/10,000 childhood 10.8/10,000 atypical 16.6/10,000 Asperger’s 13.0/10,000 unspecified	Williams 2008[89]
USA (14 sites)	2002	8	database analysis	3.3 – 10.6 per 1,000 total Most sites 5.2-7.6 per 1,000	CDC 2007[272]
USA (6 sites)	2000	8	21,532-45,322	4.5-9.9 per 1000 total	CDC 2007[90]

Annex **G**

Systematic reviews of therapeutic interventions for ASD

Table 11 Summary of systematic reviews of therapeutic interventions for ASD.

First author, year	Title review, therapy type
Nye, 2002[107]	Combined vitamin B6-magnesium treatment in autism spectrum disorder.
Treatment objective: Improving behaviour, as well as social and communicative skills	Conclusion: It was only possible to analyse the data from a single study. The results were inconclusive and the studies small-scale. The contention that vitamin B6 improves the behaviour of ASD sufferers cannot be confirmed.
Bent 2009[110]	Omega-3 fatty acids for autistic spectrum disorder: a systematic review.
Treatment objective: Improving behaviour and cognitive skills	Conclusion: The limited quality and scope of the studies that were found make it impossible to determine the safety or efficacy of the use of omega-3 fatty acids in the treatment of autism spectrum disorders.
Diggle 2003[120]	Parent-mediated early intervention for young children with autism spectrum disorder.
Treatment objective: Improving skills and reducing stress for children with ASD and their parents	Conclusion: The findings are based on two small studies. There is evidence that parents and children both benefit from parent training. Large-scale RCTs (Randomised Control Trials) are needed to investigate both the short-term and long-term effects, and to identify is the most efficient and effective type of training.
McConachie 2007[121]	Parent implemented early intervention for young children with autism spectrum disorder: a systematic review.
Treatment objective: Improving skills and reducing stress for children with ASD and their parents	Conclusion: Very few of the studies found were sufficiently well designed to enable conclusions to be drawn about effectiveness. The studies found seem to indicate that parent training leads to: improved communicative behaviour on the part of the child, increased maternal knowledge of autism, improved maternal communication style and parent-child interaction, and reduced depression in the mother.

Williams, 2005[111] Treatment objective: Cure for autism	Intravenous secretin for autism spectrum disorder. This review of thirteen randomised studies found no evidence for the efficacy of one or more intravenous infusions of secretin (a gastrointestinal hormone) in ASD. This treatment should therefore not be recommended or administered as a treatment for ASD.
Sinha, 2006[113] Treatment objective: improved behaviour by improving auditory processing defects and concentration by listening to electronically modified music/sounds	Auditory integration training (AIT) There is insufficient evidence for the use of AIT to be approved
Gold, 2006[112] Treatment objective: Improving expression and communicative skills	Music therapy Conclusion: There is insufficient evidence to support the use of music therapy in the clinical setting. The limited number of available studies seems to indicate that music therapy may help children to improve their communication skills. More research is needed into the long-term effects and into its use in a clinical setting.
Broadstock 2007[115] Treatment objective: Alleviating the symptoms of internalising or externalising problem behaviour.	Pharmacotherapy Conclusion: There are too few reliable studies to make it possible to advise physicians about the efficacy and safety of pharmacotherapy in young people or adults with an ASD. Randomised Control Trials with larger patient and control groups are needed in order to determine the potential contribution of pharmacotherapy for people with ASD
Jesner, 2007[116] Treatment objective: Alleviating the symptoms of internalising or externalising problem behaviour.	Risperidone Conclusion: While risperidone may be useful for some characteristics of autism (stereotypical behaviour, irritability), it does have some unpleasant side effects. The available studies are small in number and limited in scope. There is a need for research into long-term effects, and for a standardised measure of outcome – which would make it possible to compare studies.
Jensen, 2007[117] Treatment objective: Alleviating the symptoms of internalising or externalising problem behaviour.	Atypical antipsychotics Conclusion: Risperidone appears to reduce stereotypical behaviour in children with severe autism. However, it has no effect on their social and communicative limitations. The available studies were small in scale and limited to children with ASD who also had severe behavioural problems. This medicinal product has harmful side effects, such as weight gain and drowsiness. There is a need for the standardisation of research instruments, in order to properly monitor behavioural changes in children with ASD.
Stachnik 2007[118] Treatment objective: Alleviation of aggressiveness, hyperactivity and self-harming behaviour in ASD	Use of atypical antipsychotics in the treatment of autistic disorder Conclusion: the use of atypical antipsychotics is a treatment option for ASD. However, these medicinal products do not affect the core symptoms of ASD and do give rise to harmful side effects. There is also a lack of randomised trials to determine their actual effectiveness and long term safety in children.

Millward 2008[108]	Gluten-and casein-free diets for autistic spectrum disorder
Treatment objective: Improving behaviour, as well as cognitive and social performance	Conclusion: Special diets are widely used to treat children with ASD. These include gluten-free and casein-free diets. On the basis of evidence obtained to date it has not proved possible to demonstrate the effectiveness of these diets. Large, well-designed, randomised control trials are needed.
Elder 2008[109]	The gluten-free, casein-free diet in autism: an overview with clinical implications
Treatment objective: Improving behaviour, as well as cognitive and social performance	Conclusion: There is no evidence to support the efficacy of gluten-free and casein-free diets in the treatment of autism.
Bellini 2008[127]	Social skills training for young people with autism spectrum disorders.
Treatment objective: Improvement of social skills.	Conclusion: Studies exhibit varied results with regard to efficacy. Conditions for effectiveness: higher frequency, longer duration training than has been customary, provision of training in the child’s natural surroundings, attune training to type of social limitation, assure patient compliance.
Levy 2008[119]	Complementary and alternative medicine treatments for children with autism spectrum disorders.
Treatment objective: Dependent on the therapy: cure for autism or alleviation of symptoms	Conclusion: Most alternative therapies have not been adequately studied, which means that there is too little evidence to support their use. While secretin has proven ineffective, there is some evidence that melatonin might be effective.
Schlosser 2008[114]	Effects of augmentative and alternative communication intervention on speech production in children with autism: a systematic review.
Treatment objective: Improving speech production	Conclusion: Although these interventions do not appear to impede speech production and, indeed, might even boost it in some cases, the observed changes were limited.
Reichow, 2008[122]	Comprehensive synthesis of early intensive behavioural interventions for young children with autism based on the UCLA young autism project model.
Treatment objective: Improve cognitive, communicative and social skills while reducing autistic symptoms and other problem behaviour	Conclusion: The review produced mixed results. Although the results could be interpreted in terms of the effectiveness of this type of intervention, this review also identified several gaps in our knowledge of this field. It is not possible to say whether or not early intensive behavioural interventions (EIBI) are more effective than other therapeutic interventions. At best, EIBI are effective for some children with ASD.
Ospina, 2008[123]	Behavioural and developmental interventions for autism spectrum disorder: a clinical systematic review.
Treatment objective: Improve cognitive, communicative and social skills while reducing autistic symptoms and other problem behaviour	Conclusion: Although this review suggests that the Lovaas method might improve a number of core symptoms of ASD, these findings are based on the aggregation of a number of small, poorly conducted studies with few participants and a relatively short follow-up. Because no single behavioural or developmental intervention can improve all of the symptoms experienced by individuals with ASD, it is recommended that the treatment and care of ASD sufferers be based on individual needs and the availability of resources.

Spreckley, 2008[124]	Efficacy of applied behavioural intervention in preschool children with autism for improving cognitive, language and adaptive behaviour: a systematic review and meta-analysis.
Treatment objective: Improving cognitive and communicative skills, as well as speech development	Conclusion: As yet, there is insufficient evidence that applied behavioural intervention provides better outcomes than standard care for children with autism. Well-designed, sufficiently large-scale trials with broader outcome measures are needed.
Howlin, 2009[125]	Systematic review of early intensive behavioural interventions (EIBI) for children with autism.
Treatment objective: Improve cognitive, communicative and social skills while reducing autistic symptoms and other problem behaviour	Conclusion: There is evidence that EIBI is effective for some but not all children with ASD. This seems to depend on their initial IQ, rather than their age. There is also an enormous amount of individual variation in terms of the response to treatment. Furthermore, there are still too few good quality, randomised control trials to conclusively determine effectiveness.
Eldevik 2009[126]	Meta-analysis of early intensive behavioural intervention for children with autism.
Treatment objective: Improve cognitive skills and behaviour in autism	Conclusion: The results support the current medical assumption that (in the absence of other interventions of proven efficacy) early intensive behavioural interventions now represent an appropriate treatment for children with autism.

Annex

H

Organisation of the education

This annex contains a brief outline of the way in which education is organised. Sources: Keesenberg. Appropriate Education Primary School Management – Everyday Practice Series. Kluwer Alphen aan den Rijn, 2008[273], www.minocw.nl[229], www.wecraad.nl.[224]

Primary education

In primary education, a distinction is drawn between the mainstream system (consisting of primary schools and special needs primary education (SBO)) and special needs education, which consists of four clusters.

The schools offering primary and special needs primary education coordinate their efforts at regional level within the framework of the *Weer Samen Naar School* (Back to School Together) partnership (WSNS-SWV or SWV-Primary Education). The purpose of these partnerships is to frame and implement a coherent educational needs policy. Initially, most children will simply attend a mainstream primary school. These institutions employ one or more internal counsellors: these are normal teachers with special responsibility for coordinating individual educational needs programmes within the school, supporting the teachers of those children who need extra attention, and serving as a link between the school and the care provided beyond its walls (e.g. in terms of special needs education). In the event of problems, the Standing Committee for Individual Educational Needs (PCL) can issue an order, enabling the pupil in question to transfer to a special needs primary school with smaller class sizes and additional human resources. If that is not sufficient, or if the child's problems exceed even the capabilities of a school offering special needs primary education, then an indication for special needs education may be requested. The application is reviewed by a Committee for Needs Assessment on the basis of national criteria. Approval of the application results in an indication for special needs education in one of the four clusters or within the context of a pupil-specific budget.

Special needs education, which is intended for children with disabilities, is divided into four clusters: Cluster 1 schools for visually handicapped children with or without multiple disability. Cluster 2 schools for deaf and hearing-impaired children and for children with severe speech difficulties, possibly in combination with another handicap. Cluster 3 schools for pupils with intellectual and/or physical limitations and pupils with chronic illnesses. Cluster 4 schools for severely maladjusted children, chronically ill children without a physical disability and schools attached to paedological institutes.

Schools for special needs education coordinate their activities within a regional expert centre, which usually also houses the Needs Assessment Committee (CvI). The regional expert centre can help parents with their application for an indication or for pupil-specific funding. The registration and advisory office for needs assessment in pupil-specific funding (*meld- en adviespunt indicatiestelling LGF*) can also provide assistance to parents and can mediate between the parents and the Committee for Needs Assessment. Parents can lodge an appeal with the Objections and Advisory Committee if they dispute a decision made by the Needs Assessment Committee (CvI). If, after their child has been granted an indication or assigned pupil-specific funding, parents encounter problems in finding a school, then educational consultants can advise and counsel them (and the school) in order to find a solution.

Secondary education

In secondary education too, a distinction is made between mainstream and special needs education. The secondary education system has several levels of schools: pre-vocational secondary education (VMBO), higher general secondary education (HAVO) and pre-university education (VWO). These can be either single category schools (offering just one level of education) or multi-category schools (offering several different levels of education). For pupils with specific educational support requirements there is Study Course Supporting Education (LWOO), and Practical Training (PrO) for students who are unable to obtain a diploma by conventional means. These ‘special’ forms of sec ondary education are, to some extent, comparable to special needs primary education. Individual educational needs programmes in mainstream secondary education mainly take the form of tutoring and pupil counselling. Care coordinators are comparable to the internal supervisors in mainstream primary schools. They coordinate internal care arrangements and serve as links to those aspects of care that take place outside the school. Care advisory teams also play an active part in this context.

Admission to LWOO or PrO is dependent on an order (granted on the basis of national criteria) by a regional referral committee (RVC), to release additional funds to cover extra counselling for the pupil in question. VMBO, LWOO and PrO work together at regional level in the context of a secondary education partnership (SWV-VO). At MBO level, there is no mandatory partnership between institutions.

Special needs secondary education uses the same four clusters as special needs primary education. Schools offering special-needs secondary education (VSO) coordinate with those in special-needs primary education in the above-mentioned regional expert centres (RECs).

Needs assessment in the educational system

Take the case of children who have problems at school. They have no friends, for example, are unable to work well with other children, find it difficult to deal with changes in their daily routine, quickly become over-stimulated, require a great deal of attention from the teacher, and throw tantrums in the classroom. These children usually exhibit similar problems (to a lesser extent) at home. In the case of the PDD-NOS group, however, there are often no problems at home. However, their ‘disposition’ can cause problems when they start school. Initially, an attempt is made to resolve the situation in the mainstream setting:

- An investigation is launched into the cause of the problem. This might involve school social workers or the school supervisory service, the GP, a primary health care psychologist, or a youth care agency.
- The teacher receives support from the internal counsellor.
- The parents receive guidance from social workers (either school-based or external).
- The child receives remedial teaching, and counselling either via a youth care agency or within the youth mental health care service.

If these measures fail to achieve a satisfactory result, then an order for special needs primary education can be requested. The application and enclosed documents (an educational report, a psychological investigation, an action plan, and – if applicable – reports from youth care services, social workers, speech therapists, etc.) are dealt with by the Standing Committee on Individual Educational Needs within the *Weer Samen Naar School* (Back to School Together) partnership. There are no nationwide assessment criteria. Each Back to School Together partnership draws up its own set of criteria.

If special needs primary education is not appropriate, then the parents (possibly via or in cooperation with a special-needs school for special education or another support organisation) can apply for an indication for special-needs education and/or pupil-specific funding (LGF, also known as ‘backpack ’). The LGF may enable such children to remain in mainstream education, where they may receive ambulatory support/counselling from an educational institution providing special needs teaching.

The application is submitted to a Committee for Needs Assessment or to an REC office (Regional Expert Centre; the organisation of which varies from one region to another) by means of an application form. In addition to details of the subject’s name and address, the following must be supplied:

- Report of a psychodiagnostic and/or psychiatric examination by a qualified expert (in the case of ASD this involves a DSM-IV classification, written within the past one to two years, depending on the type of investigation involved)
- Where applicable, a speech therapy study (which should be as recent as possible; with a possible referral for cluster 2 in the case of speech/language difficulties)
- An educational report (issued no more than six months previously)
- A plan of action from the school,
- Details of any investigations carried out by social workers
- Data from youth care services and/or child psychiatry concerning the care effort
- Data from the healthcare sector.

The Needs Assessment Committee (CvI) focuses on three areas:

- The nature of the disorder/disability.
- The educational limitations resulting from the disorder.
- The limited scope of the care structure of mainstream schools.

These primary criteria have been tailored to each individual cluster.

The Needs Assessment Committee (CvI) includes various experts, such as an educationalist, a social worker, a youth care worker, and a psychologist. The chairperson is often someone who is an expert in special needs education (a former director of a school for special needs education, for example). Most dossiers are handled by the chairperson and by the secretary. With effect from 1 January 2008, responsibility for needs assessment was transferred from the National Supervisory Committee for Needs Assessment to the Education Inspectorate. Responsibility for managing the Needs Assessment Committee's database was transferred to the Central Funding of Institutions Agency (CFI).

In general, children with an ASD can have indications for any of the four clusters. It is their dominant limitation (or limitations) that determines the cluster in which they will ultimately pursue their education. Most children with an ASD attend cluster 4 schools. The indication is valid for three years, after which a renewal of the indication should be sought. In addition to pupil-specific funding (LGF), part of the client-linked budget (PBG) can also be used at school. However, that does involve a separate application procedure.

In secondary education, an order from the Regional Referral Committee (RVC) is required for admission to Study Course Supporting Education (LWOO) or Practical Training (PrO). The Regional Referral Committee (RVC) is usually associated with a regional school advisory service. It assesses applications on the basis of national criteria (see www.rvc-vo.nl, www.minocw.nl)

Children with an ASD (and their parents) will also encounter the Care Allowance for Handicapped Children Living at Home (TOG), the Social Development Act (WMO, e.g. for school transport), and – when the children reach the age of 18 – the Invalidity Insurance (Young Disabled Persons) Act (Wajong). Each of these schemes has its own procedures and needs assessments.

During the past two years, various initiatives have been launched with a view to harmonising (merging) the needs assessment for various schemes. One example is *Regelhulp* (one-stop shop for the client–linked budget (PGB)/Exceptional Medical Expenses Act (AWBZ), Invalidity Insurance (Young Disabled Persons) Act (Wajong), Social Development Act (WMO), etc.) and indicate the *Kader Integraal Indiceren* (one-stop shop for PGB/AWBZ and needs assessment for special needs education/pupil-specific funding (LGF)). In addition, numerous reports have been published on the tightening-up of indication criteria, applying austerity measures to the various schemes, etc. (including the Social and Economic Council (SER), Council for Public Health and Health Care (RvZ), TNO, National Supervisory Needs Assessment Committee (LCTI)).

National Autism Network

The National Autism Network (LNA) conducts the following activities:

- Taking stock of the numbers of pupils with autism in the education system.
- Investigating the characteristics and support needs of pupils with autism.
- Developing instruments to measure the support needs of pupils with autism.
- Organising one or more national conferences on autism.
- Developing and disseminating support material for schools in collaboration with external institutions.
- A demand-driven and interactive website containing detailed information, and a forum where teachers, ambulatory autism counsellors and autism support officers from the Regional Expert Centres (REC) can exchange information and views, as well as discussing practical issues and new developments.
- The 'Schools for Schools' knowledge bank, where schools share expertise in the field of education and autism and in which knowledge is classified and archived.

In organisational terms, the National Autism Network (LNA) is an activity of the Council for the Centres of Expertise Act, (WEC Raad), an association which in turn represents the interests of special needs education. Its members are national associations of the four clusters in special needs education. (www.wecraad.nl)**.**

Annex I

Abbreviations

ADHD	Attention deficit / hyperactivity disorder
ADOS	Autism diagnostic observation schedule
AQ	Autism quotient
ASD	Autism Spectrum Disorders
AWBZ	Exceptional Medical Expenses Act
BJZ	Youth care agency
CIZ	Committee for Needs Assessment in the Healthcare System (AWBZ care)
CJG	Youth and Families Centre
CVI	Committee for Needs Assessment (special needs education/ pupil-specific funding (LGF))
CWI	Centre for Work and Income
DBC	Diagnosis-treatment combination
DSM	Diagnostic and Statistical Manual of Mental Disorders
EIBI	Early Intensive Behavioural Interventions
EQ	Empathy quotient
ESAT	Early screening of autistic traits questionnaire
GGZ	Mental health care system
GR	Health Council of the Netherlands
ICD	International Statistical Classification of Diseases
Inter-RAI	International Research in Assessment Instruments

IQ	Intelligence Quotient
IVH	Integrated early childhood intervention
JGZ	Youth healthcare
LGF	Pupil-specific funding
LNA	National Autism Network
LWOO	Study Course Supporting Education
MBO	Senior secondary vocational education
NAS	National Autistic Society (UK)
NJI	Netherlands Youth Institute
NVA	Dutch Association for Autism
NVvP	Dutch Psychiatric Association
OCW	Ministry of Education, Culture and Science
PASSER	ASD expertise platform for final phase education in the region
PDD-NOS	Pervasive developmental disorder – not otherwise specified
PCL	Standing Committee on Individual Educational Needs
PGB	Client-linked budget
PRN	Practical Training
REC	Regional Centre of Expertise (special needs education)
RGO	Advisory Council on Health Research
SBO	Special needs primary education
SCQ	Social Communication Questionnaire
SEJN	Netherlands Effective Youth Care Services Partnership
SEV	Socio-emotional questionnaire
SIGN	Scottish Intercollegiate Guidelines Network
SO	Special needs education
SQ	Systemising quotient
SZW	Ministry of Social Affairs and Employment
TEACCH	Treatment and Education of Autistic and related Communication Handicapped Children
TI	Trimbos Institute
TRF	Teacher’s Report Form
UWV WERKbedrijf	Merger between CWI and UWV (as of 1 January 2009)
UWV	The organisation for reintegration into the job market and temporary income
VISK	Questionnaire for taking stock of social behaviour in children
VISV	Questionnaire for taking stock of social behaviour in adults

VMBO	Preparatory vocational education
VO	Secondary education
VSO	Secondary special needs education
VWS	Ministry of Health, Welfare and Sport
Wajong	Invalidity Insurance (Young Disabled Persons) Act
WEC	Centres of Expertise Act (special needs education)
WIA	Work and Income (Capacity for Work) Act
WMO	Social Development Act
WO	University education
WRR	Scientific Council for Government Policy.
WSNS	Back to School Together
ZAT	Care Advisory Team (Education)
ZVW	Health Insurance Act