



# Autism spectrum disorders

## Diagnosis and interventions, organization of care and patient involvement

SBU ASSESSMENTS | ASSESSMENT OF METHODS IN HEALTH CARE AND SOCIAL SERVICES

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THIS REPORT WAS PUBLISHED MORE THAN 2 YEARS AGO. THE NATURE OF THE EVIDENCE MAY HAVE CHANGED.

## Summary

### Conclusions

- ▶ **Autism spectrum disorders in many cases involve major disabilities, and the instruments for diagnostic assessment should be better researched.** There is scientific support for 2 of the 14 instruments evaluated. These instruments are Autism Diagnostic Interview-Revised (ADI-R) and Social Communication Questionnaire (SCQ) for autism spectrum disorders. For details of the diagnostic sensitivity and reliability of the two methods see the section "Evidence graded results". There is insufficient scientific evidence to draw any conclusions regarding other diagnostic instruments and assessment forms.
- ▶ As the instruments have not been adequately evaluated, the diagnostic process should remain within the sphere of specialised care. It is also important to follow up the use of diagnostic instruments and assessment forms.
- ▶ **Many different interventions and treatments, apart from drugs, are currently used but knowledge of their benefits, risks and costs must be improved.** We have identified 25 different interventions and treatment methods that are used with autism spectrum disorders. The scientific evidence for assessing the effectiveness of these is insufficient. Training which involves a combination of several methods is normal in Sweden, but its effectiveness has not been studied.
- ▶ **Drug treatment with risperidone reduces severe behavioural disturbances such as aggression and self-destructive behaviour in individuals with autism spectrum disorders.** In children with autistic disorder short term treatment (2 months) with risperidone produces a slightly better effect than placebo in cases of severe behavioural disturbances such as social withdrawal, hyperactivity and stereotypical behaviour. A common side effect is weight gain.
- ▶ Studies are needed into how care and community-based interventions should best be organised and coordinated for individuals with autism spectrum disorders.
- ▶ **The involvement of people with autism spectrum disorders and their families need to be improved. They should be asked more about their own ideas on care and schooling.** At present people with autism spectrum disorders and their families experience stigmatisation, social isolation, a lack of knowledge amongst healthcare and school personnel, a lack of resources and a sense of powerlessness. Early diagnosis can reduce stigmatisation. It is also important that a lack of involvement does not impede the efforts of the care system and schools to achieve good communication and contact. It is also important to pay particular attention to siblings, who might otherwise experience problems with social relationships and sometimes might even be exposed to intimidating and violent behaviour. The scientific knowledge concerning the importance of involvement in autism spectrum disorders can be improved substantially.

### Background

Autism spectrum disorders (ASD) is a collective name for conditions involving a restricted development of social interaction and communication as well as repetitive and stereotypical forms of behaviour and limited interests. There are also differences in how sensory impressions are experienced and processed. ASD include autistic disorder, Asperger's syndrome and atypical autism. Prevalence studies in Europe

and North America show that 0.6–1.0 percent of the population has ASD.

ASD produce symptoms early in life. It is common for people with ASD to also have other developmental abnormalities, such as mental retardation (developmental disorder), speech disorders, specific learning difficulties, Attention Deficit Hyperactivity Disorder (ADHD) and Tourette's syndrome. Many people with ASD also have comorbidity with depressive and anxiety disorders.

In this literature review we have examined the scientific evidence for diagnostic instruments and treatment interventions used for ASD in Sweden. The report is part of a government commission for evaluating the diagnosis and treatment of psychiatric conditions. The diagnostic instruments alone do not provide sufficient basis for diagnosis, but should always be considered in conjunction with other examination results in coming to a consensus diagnosis (this can also be termed LEAD; Longitudinal Observation by Experts using All Data). With regard to interventions and treatment, a large number of methods have been developed. The majority of the treatment models deal with pedagogic interventions, including behavioural therapy, which focus on basic skills in social interaction and communication, as well as adapting the environment by, for example, creating visual clarity. There is currently no drug treatment targeted at ASD. However, risperidone is sometimes used when there are severe behavioural disturbances, such as aggression and self-destructive behaviour, in individuals with ASD and we have carried out a systematic examination of the relevant literature. The review also includes sections which look at the current knowledge on how individuals with these disorders experience their participation and involvement in the assessment and treatment. We have also examined the literature on the organisational, ethical and health economic aspects of the diagnosis and treatment of individuals with ASD.

### The assignment

The aim of this literature review is to examine the scientific evidence for the diagnosis and treatment of autism spectrum disorders (ASD) with regard to:

- The diagnostic reliability of the instruments used in assessment
- Effectiveness of early intervention
- Effectiveness of psychopedagogic and psychotherapeutic methods
- Effectiveness of pedagogic interventions and adaptations in the social environment

### Fact box 1 Diagnosis in ASD.

Criteria for diagnosis in ASD have been established through international cooperation. They comprise a series of descriptions of symptoms, which should be included to some extent when making a diagnosis. A number of tools have been created to facilitate the interpretation of diagnostic criteria and to carry out the diagnosis in a more standardised manner. In part this involves questionnaires and interviews which, in a structured manner, collect information from the relatives of children or from an adult who is being assessed. The tools also include a basis for conducting behavioural observations in a systematic manner.

A comprehensive neuropsychiatric assessment normally includes an aptitude test, and often an additional assessment of language skills and of other areas in development. The diagnosis of ASD also involves deciding whether there is need for a medical examination, bearing in mind background factors and possible changes in comorbidities or disabilities.

There are no difficulties in diagnosing ASD in its most typical form, but atypical disorders can present an ambiguous picture and it may be difficult to arrive at the correct designation. Diagnosis can be particularly difficult in children and adults who also have other developmental abnormalities or psychiatric symptoms. It is not realistic to expect that, in 100 percent of all cases, the diagnostic instrument will give the same result as obtained from appraisals by a qualified assessment team, which has a larger amount of information to draw upon.

- Effectiveness of interventions that focus on diet
- Effectiveness of treatment with risperidone
- Side effects and undesirable effects of the various interventions
- Health economic aspects
- Ethical and social aspects
- The patient's involvement
- Organisation of health and social care.

### Method

The systematic review was carried out in accordance with SBU's process. SBU has a precise and systematic methodology whereby all relevant literature concerning the question being studied is searched in accessible databases. Each of the studies included was quality reviewed and tabulated in accordance with a special methodology. The strength of the scientific evidence was assessed using GRADE.

Studies with qualitative methodology were quality assessed in accordance with a special protocol. The results from the selected studies were weighed together in a secondary qualitative analysis. Through further analysis the data from the studies were consolidated into a number of themes which were recorded as synthesized results.

## Evidence graded results

### Instruments for examination of ASD

Diagnostic instruments and assessment forms, together with other assessment methods, are part of the process for identifying an ASD. There are no studies that have evaluated the entire diagnostic process. We have therefore evaluated the diagnostic instruments and assessment forms that are used as tools in the diagnostic process in Sweden to identify ASD.

Of the fourteen diagnostic instruments used only three were evaluated in more than one study. Social Communication Questionnaire (SCQ) misses 3 out of every 10 individuals with autism spectrum disorders and gives a false indication in 3 cases out of 10.

Autism Diagnostic Interview-Revised (ADI-R) appears to have acceptable capability of correctly identifying children diagnosed with autistic disorder but is not as capable in ruling out a diagnosis.

Autism Diagnostic Observation Schedule (ADOS) appears to be good at detecting individuals with autistic disorder. But the scientific evidence is not sufficient to assess the capability of not giving false diagnoses. As the capabilities of making the correct diagnoses and not giving false diagnoses are related, the overall conclusion is that the scientific evidence for ADOS is insufficient.

The scientific evidence for the other diagnostic instruments and assessment forms is insufficient.

### Social Communication Questionnaire (SCQ)

#### Identifying ASD

- There is moderately strong scientific evidence that SCQ has a sensitivity of 71 percent (95 % CI, 66 to 74; cut-off 15 points) for identifying ASD with DSM-IV or ADI-R and ADOS in combination as the reference standard in children and young people aged 2–16 years in specialized care for ASD (⊕⊕⊕○).

### Fact box 2 Diagnostic reliability.

The relationship between test results and disease status can be expressed by various measures. We express the strength of evidence for the diagnostic forms as sensitivity and specificity: Sensitivity gives the probability of those who are ill getting a positive test result. Specificity gives the probability of those who are healthy getting a negative test result.

- There is moderately strong scientific evidence that SCQ has a specificity of 74 percent (95% CI, 69 to 79; cut-off 15 points) to rule out ASD with DSM-IV or ADI-R and ADOS in combination as a reference standard in children and young people aged 2–16 years in specialized care for ASD (⊕⊕⊕○).

### Social Responsiveness Scale (SRS)

#### Identifying ASD

- There is insufficient scientific evidence (one study) to assess the reliability of identifying ASD with SRS (parental assessment) in children (⊕○○○).
- There is insufficient scientific evidence (one study) to assess the reliability of identifying ASD with SRS (parental and teacher assessment combined) in children (⊕○○○).

### Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R)

#### Identifying ASD

- There is insufficient scientific evidence (one study) to assess the reliability of identifying ASD with RAADS-R (self-assessment) in adults (⊕○○○).

### Autism Spectrum Screening Questionnaire (ASSQ)

#### Identifying ASD

- There is insufficient scientific evidence (one study) to assess the reliability of identifying ASD with SRS (parental assessment and teacher assessment) in children (⊕○○○).

## Autism Diagnostic Interview-Revised (ADI-R)

### Diagnosing autistic disorder

- There is limited scientific evidence that ADI-R has a sensitivity of 79 percent (95 % CI, 73 to 84) for diagnosing autistic disorder with DSM-IV as reference standard in individuals aged 1.5–22 years in specialised care for ASD (⊕⊕○○).
- There is limited scientific evidence that ADI-R has a specificity of 66 percent (95 % CI, 60 to 72) for ruling out a diagnosis of autistic disorder with DSM-IV as reference standard in individuals aged 1.5–22 years in specialised care for ASD (⊕⊕○○).

## Autism Diagnostic Observation Schedule (ADOS)

### Diagnosing autistic disorder

- There is limited scientific evidence that ADOS has a sensitivity of 88 percent (95 % CI, 88 to 92) for diagnosing autistic disorder with DSM-IV as reference standard in individuals aged 1.5–22 years in specialised care for ASD (⊕⊕○○).
- There is insufficient scientific evidence (heterogeneity) to assess the diagnostic reliability measured as specificity for ruling out the diagnosis of autistic disorder using ADOS in children and young people (⊕○○○).

## Childhood Autism Rating Scale (CARS)

### Diagnosing autistic disorder

- There is insufficient scientific evidence (one study) to assess the diagnostic reliability for diagnosing autistic disorder in children using CARS (⊕○○○).

## Other diagnostic instruments

- There is insufficient scientific evidence (no studies) for assessing the reliability of identifying ASD with the following instruments (⊕○○○):
  - Asperger Syndrome Diagnostic Interview (ASDI)
  - Autism Diagnostic Observation Schedule-Toddler Module (ADOS-TM)
  - Autism Spectrum Disorder Adult Screening Questionnaire (ASDASQ)
  - Autism spectrum Quotient (AQ)
  - Childhood Autism Spectrum Test (CASD)
  - Development and Well-Being Assessment (DAWBA)

- Diagnostic Interview for Social and Communication disorders (DISCO)
- Schedule for Affective Disorders and Schizophrenia for school-aged children (Kiddie-SADS)

## Interventions in ASD

Here we present all assessed treatment interventions except drug treatment.

### Effectiveness

#### Early intervention

The scientific evidence is insufficient for assessing the effectiveness of early (before 3.5 years of age) intensive training focusing on social interaction and communication because of the heterogeneity of the studies. There is a lack of studies that assess the effectiveness of Floortime and the Son-Rise Program in children with ASD.

- There is insufficient scientific evidence (six randomised controlled studies with inconsistency and flaws in study quality) to assess the effectiveness of early intensive training focusing on social interaction and communication in children with ASD (⊕○○○).
- There is insufficient scientific evidence (one randomised controlled study and nine cohort studies with inconsistency and flaws in study quality) to assess the effectiveness of early intensive training, with behavioural therapy-focused methodology in children with ASD (⊕○○○).
- There is insufficient scientific evidence (no studies) for assessing the effectiveness of Floortime in children with ASD (⊕○○○).
- There is insufficient scientific evidence (no studies) for assessing the effectiveness of Son-Rise in children with ASD (⊕○○○).

#### Side effects and undesirable effects

- There is insufficient scientific evidence (no studies) with regard to the side effects of early intensive training focused on social interaction and communication and of early intensive training with behavioural therapy-focused methodology (⊕○○○).
- There is insufficient scientific evidence (no studies) with regard to the side effects of Floortime and Son-Rise in children with ASD (⊕○○○).

## Psychological and psychotherapeutic interventions

The scientific evidence for various psychological and psychotherapeutic interventions in ASD is insufficient.

- There is insufficient scientific evidence (two studies with inconsistency and flaws in study quality) to determine whether cognitive behavioural therapy gives symptom alleviation with regard to core symptoms and/or associated problems in individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (one study) to determine whether cognitive behavioural therapy combined with risperidone produces better effects than risperidone alone, measured in terms of irritability, hyperactivity and stereotypical behaviour using Aberrant Behavior Checklist (ABC) (⊕○○○).

## Pedagogic interventions and environmental adaptation

The scientific evidence for various pedagogic interventions and social training in ASD is insufficient.

### Effects on core symptoms

- There is insufficient scientific evidence (no studies) to determine whether Treatment and Education of Autistic and Communication handicapped Children (TEACCH) gives symptom alleviation with regard to core symptoms in individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (one study) to determine whether Picture Exchange Communication System (PECS) gives symptom alleviation with regard to core symptoms in individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (one study) to determine whether the training of social skills gives symptom alleviation with regard to core symptoms in individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (no studies) to determine whether computer-based training gives symptom alleviation with regard to core symptoms in individuals with ASD (⊕○○○).

### Effects on associated problems

- There is insufficient scientific evidence (two cohort studies) to determine whether Treatment and Education of Autistic and Communication handicapped Children (TEACCH) gives improved adaptive skills in individuals with ASD (⊕○○○).

- There is insufficient scientific evidence (one cohort study) to determine whether Treatment and Education of Autistic and Communication handicapped Children (TEACCH) gives better cognition in individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (three studies with inconsistency and flaws in study quality) to determine whether computer-based training gives improved social skills in individuals with ASD (⊕○○○).

## Interventions focusing on diet

There is insufficient scientific evidence to assess the benefits and risks of diet in ASD.

- There is insufficient scientific evidence (one study) to determine whether a gluten- and casein-free diet produces a better effect than dietary advice in children with ASD (⊕○○○).
- There is insufficient scientific evidence (one study) to determine whether supplementing the diet with omega-3 produces a better effect than placebo in children with ASD (⊕○○○).
- There is insufficient scientific evidence (one study) to determine whether supplementing the diet with omega-3 produces a better effect than a healthy diet in children with autistic disorder (⊕○○○).
- There is insufficient scientific evidence (one study) to determine whether supplementing the diet with vitamin B12 produces a better effect than placebo in children with autistic disorder (⊕○○○).
- There is insufficient scientific evidence (no studies) for the treatment methods below for patients with ASD (⊕○○○):
  - Vitamin B6 and magnesium
  - Vitamin D
  - Probiotics.

## Other interventions

- There is insufficient scientific evidence (no studies) for the treatment methods below for individuals with ASD. (⊕○○○):
  - Social stories
  - Comic strip conversations
  - CAT-kit
  - Autism preschool programme
  - Early bird programme
  - Special education, structured teaching aside from being part of the TEACCH programme above.

- Sensory and motor interventions such as sensory integration therapy
- Music therapy
- Transcranial magnetic stimulation (TMS)
- Deep brain stimulation (DBS), vagus nerve stimulation (VNS)

### Drug treatment with risperidone in ASD

There are currently no drugs to treat ASD. But risperidone is used to treat severe behavioural disturbances such as aggression and self-destructive behaviour in individuals with ASD.

- In children with autistic disorder short term treatment (2 months) with risperidone produces a slightly better effect than placebo for severe behavioural disturbances such as social withdrawal, hyperactivity and stereotypical behaviour. The side effects are weight gain and reduced alertness. For adults there is insufficient scientific evidence. Risperidone treatment leads to weight gain and reduced alertness in children and young people. There is a lack of scientific evidence for side effects in adults with ASD. However, it has been shown that this type of drug produces side effects in other patient groups. There have been no long term follow ups.

### Effects

#### Children and young people

- There is moderately strong scientific evidence that short term treatment (2 months) with risperidone produces a slightly better effect than placebo in the form of improvements with respect to social withdrawal, hyperactivity and stereotypical behaviour, measured using Aberrant Behavior Checklist (ABC), in children and young people with severe behavioural disturbances and autistic disorder (⊕⊕⊕○).
- There is limited scientific evidence that short term treatment (2 months) with risperidone produces a slightly better effect than placebo in the form of improvements with respect to irritability and inappropriate language, measured using Aberrant Behavior Checklist (ABC), in children and young people with severe behavioural disturbances in autistic disorder (⊕⊕○○).

- There is limited scientific evidence that risperidone produces a better effect than placebo in the form of improvements with respect to clinical global impression (CGI) in children and young people with severe behavioural disturbances in autistic disorder (⊕⊕○○).

- There is insufficient scientific evidence (one study) to determine whether treatment with risperidone of children and young people with severe behavioural disturbances in autistic disorder produces a better effect than placebo with respect to core symptoms measured using Childhood Autism Rating Scale (CARS) (⊕○○○).

#### Adults

- There is insufficient scientific evidence (one study) to determine whether treatment with risperidone produces a better effect than placebo in the form of improvements with respect to clinical global impression (CGI) in adults with severe behavioural disturbances in autistic disorder (⊕○○○).

### Side effects

#### Children and young people

- There is moderately strong scientific evidence that risperidone, when compared with placebo, causes weight gain (circa 2 kg) in children and young people with severe behavioural disturbances in autistic disorder (⊕⊕⊕○).
- There is insufficient scientific evidence (one study) that risperidone, when compared with placebo, causes increased somnolence (reduced wakefulness) in children and young people with severe behavioural disturbances in autistic disorder<sup>1</sup> (⊕○○○).
- There is insufficient scientific evidence (one study) to determine whether risperidone, when compared with placebo, does not increase the risk of extrapyramidal side effects in children and young people with severe behavioural disturbances in autistic disorder (⊕○○○).

#### Adults

- There is insufficient scientific evidence (one study) to assess side effects in the treatment with risperidone of adults with severe behavioural disturbances in ASD<sup>1</sup> (⊕○○○).

<sup>1</sup> It is shown in other patient groups that this type of drug produces side effects.

## Organization in psychiatry with a focus on ASD

- There is insufficient scientific evidence (no studies) to determine whether primary care/first line care is comparable with care within the specialised psychiatry offered to people with ASD (⊕○○○).
- There is insufficient scientific evidence (no studies) to determine whether specialised rehabilitation/habilitation services are better than rehabilitation/habilitation within existing organisational structures for individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (no studies) to determine whether support interventions for individuals or structural aids for organisations improve the diagnosis and treatment of individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (no studies) to determine whether types of organisation which actively use communication with modern technology (computers, mobile telephones, etc.) are better for people with ASD than types of organisation which do not use such forms of communication (⊕○○○).

## Patient involvement in ASD

In the section on patient involvement almost all the studies used qualitative methodology. The strength of evidence was assessed in a different way (Fact box 3).

- There is scientific evidence that people with ASD experience uncertain identity and loneliness. Many individuals lack material and emotional support and resources, as well as a sense of belonging and of being accepted.
- The scientific evidence is insufficient to assess how people with ASD perceive their opportunities for participating in the assessment and treatment.
- There is scientific evidence that individuals with ASD and their parents think that there is insufficient knowledge amongst personnel in care and in schools and that resources and support are too limited. Parents and siblings are sometimes involved in a way that can lead to disagreements within the family.
- There is scientific evidence to indicate that individuals with ASD, their siblings and their parents experience problems with stigmatisation and that this is reduced by an early diagnosis.

- There is scientific evidence to indicate that families and professional carers for individuals with ASD experience a lack of resources, stress, distress and a sense of powerlessness, but also increased sympathy and a sense of responsibility.

**Fact box 3** Study quality, strength of the evidence and conclusions.

### Quantitative study design

**Study quality** concerns the scientific quality in an individual study and the ability of the study to answer a particular question in a reliable manner.

**The strength of evidence** is an assessment of the ability of the total scientific evidence to answer a particular question in a reliable manner. SBU uses the internationally designed evidence grading system GRADE. For each effect measure one proceeds from the design of the studies in the overall assessment. Thereafter the strength of evidence can be affected by the presence of weakening or reinforcing factors such as the quality of the study, relevance, agreement, transferability, effect size, precision of data, risk of publication bias and other factors, e.g., dose-response relationship.

The strength of evidence is graded into four levels:

**Strong scientific evidence (⊕⊕⊕⊕).** Based on studies with high or medium quality without weakening factors in an overall assessment.

**Moderately strong scientific evidence (⊕⊕⊕○).** Based on studies with high or medium quality in the presence of isolated weakening factors in an overall assessment.

**Limited scientific evidence (⊕⊕○○).** Based on studies with high or medium quality in the presence of weakening factors in an overall assessment.

**Insufficient scientific evidence (⊕○○○).** When scientific evidence is lacking, accessible studies are of low quality, or studies of similar quality show conflicting results, the scientific evidence is deemed to be insufficient.

The stronger the evidence, the less likely it is that the results recorded will be affected by new research findings in the foreseeable future.

*The fact box continues on the next page*

## Fact box continued

### Qualitative study design

The strength of evidence of the results is assessed according to the following:

**There is scientific evidence.** Conclusions can be drawn because the studies identified have sufficient quality and relevance.

**There is insufficient scientific evidence.** No conclusions can be drawn because the studies identified lack sufficient quality and relevance.

### Conclusions

SBU's conclusions include an overall assessment of benefits, risks and cost effectiveness.

## Health economics

- There is insufficient scientific evidence (no studies) to determine whether risperidone is cost effective in the treatment of individuals with ASD (⊕○○○).
- As there is insufficient scientific evidence for the effectiveness of non-pharmacological interventions, this also means that:
- There is insufficient scientific evidence (no studies) to determine whether non-pharmacological interventions are cost effective in the treatment of individuals with ASD (⊕○○○).
- There is insufficient scientific evidence (no studies) to determine the cost effectiveness of various organisational aspects in the treatment of individuals with ASD (⊕○○○).

## Knowledge gaps

Within the framework of this assessment, a large number of knowledge gaps have been identified. For a complete list see [www.sbu.se/sv/publikationer/kunskapsluckor/](http://www.sbu.se/sv/publikationer/kunskapsluckor/). Some of the most important knowledge gaps are:

- Many of the autism diagnostic forms currently used in Sweden have not been adequately studied.
- There is a lack of evidence for the effectiveness and side effects of interventions in ASD. It is therefore important that the knowledge gaps are filled for those types of interventions that are currently used the most, such as early intervention, social

training (e.g., social stories and comic strip conversations) and environmental modifications.

- There is a lack of knowledge about the effectiveness of risperidone treatment with regard to its effectiveness and side effects in adults.
- There is a lack of studies on cost effectiveness for all types of interventions in ASD.
- The organisation of interventions by the care system and the community on behalf of individuals with ASD is to a large degree an unresearched field.
- There is insufficient scientific evidence for how individuals with ASD experience assessment and treatment. This applies to children, adults and the elderly.
- There is insufficient scientific evidence for effects of participation in treatment and how the involvement of patients can be encouraged.
- There is insufficient scientific evidence concerning the desire of individuals with ASD to communicate. There is also insufficient scientific evidence on how to communicate so as to ensure that these individuals understand the information.
- To a large extent there is a lack of studies concerning gender considerations in individuals with ASD. The different experiences of men and women need to be elucidated. Swedish studies are also needed.

## Concluding discussion and consequence analysis

### Diagnosis

This systematic review indirectly supports the existing practice with regard to the diagnosis of ASD, namely that it is a specialist task which requires a specially trained physician (child psychiatrist, child neurologist or paediatrician with special expertise in this area) and a psychologist with specialised training in this area. Development is ongoing with regard to defining the disorder and setting diagnostic boundaries, and with regard to diagnostic technology.

There are risks of over- and under-diagnosis but these are not as great as for some other neuropsychiatric disorders, particularly ADHD. This risk is minimised if the diagnosis is conducted by a team of professionals.

Our assessment has shown that no one particular method of assessment in itself, whether this be questionnaires or various forms of observation schedules, can establish a diagnosis. What is required is a combination of information from parents, close relatives and other people in the individual's environment, such as preschool teachers and teachers, and from a clinical assessment. There is need for research which looks at a combined battery of research methods and at how well such a battery satisfies the requirement for reliability in diagnosis. There is also reason to establish national guidelines on how diagnosis should be carried out to achieve diagnoses with the greatest possible consensus throughout the entire country.

There is a broad spectrum of ASD disorders, from those involving major disabilities to those involving high-functioning individuals. Those individuals with ASD and low levels of development (severe developmental disorder) require considerable supervision and practical help. Nevertheless individuals with ASD and normal or high aptitude have a reduced ability to manage situations in everyday life (lack of adaptive skills). At all levels of aptitude it is normal to see abnormalities in behaviour which have a negative impact on both the individuals themselves and on their friends and family, for example, difficulty in finding constructive activities with those of a similar age, becoming locked into repetitive behaviour, resistance to change, etc.

As a whole this means that the diagnosis must be adjusted to pick out these individuals with major differences in levels of functioning in a variety of areas. This makes the diagnostic process complicated. However, with the most severe forms of ASD it is much simpler to make a diagnosis than with milder forms and when there is substantial comorbidity. The diagnosis can be made as early as infancy, and also at any time during the developmental period of children and young people. Detailed knowledge is therefore important during the various phases of development in children and young people. For example, it is useful to begin discussing personality disorders in children and young people before they have completed their entire development period up to adulthood. In the same way, psychiatric disorders such as depression and psychoses vary according to the development level of children and young people.

Diagnosis is best carried out in an environment where assessment, treatment and follow up are conducted in close collaboration. Those who carry out the assessment also learn from participating in the treatment work, just as personnel carrying out the

treatment learn from participating in the diagnostic process. The agency in charge should therefore consider whether it is wise that these activities should be carried out separately.

## **Interventions**

Nowadays the community offers interventions in the form of habilitation and health via local and national agencies. It has generally been established that these interventions are absolutely necessary and are often of great help. Interventions are partly of a practical nature to make the situation easier for the individual and for relatives, and partly as training or treatment focused on affecting symptoms. This report mainly deals with the latter type of focused interventions.

Our assessment has shown that there are many treatment methods that are used to a greater or lesser extent without adequate scientific evidence. There is thus a substantial need for research in the area of treatment. Existing research mainly concerns small children, whereas very little research is conducted into the treatment of teenagers and adults. In habilitation and health care in Sweden individuals with ASD are often offered so-called eclectic treatment. This frequently means the use of a mixture of various methods in a more or less systematic manner. There are no studies on the effectiveness of these combined interventions, other than proven experience. Studies generally compare various treatment alternatives with this type of intervention. For the most part very little is reported of possible side effects and problems with all the various treatment models that are being tested.

Early intervention with small children requires considerable resources and most often the task falls on the parents. It is normal for interventions in preschool to be combined with interventions in the home. This can be a very burdensome task for parents. At the same time they have to be responsible for siblings and have some time for themselves. This can become a great strain and can also have major financial consequences for the family. Studies of early intervention require major resources as they are dealing with resource-intensive interventions over a long period of time, possibly for the entire period of growing up, with repeated follow ups.

There are clear methodological problems with this type of study. For example, there is no simple, commonly used method, for measuring the effectiveness of interventions. For ethical reasons it is not currently possible to compare the effect of a programme with how things would have turned out without any intervention. The control group is often not clearly de-

scribed. Despite these weaknesses there is nevertheless a substantial body of seriously conducted research on interventions in ASD. This compares with many reports (in the media and via the internet) on various treatments which describe advances without there being any comparator group and without any critical examination of the methodology.

No drug has been developed to treat core symptoms<sup>2</sup> in ASD. As the causes of these disorders are not fully known fundamental research in this area should be encouraged. In our assessment we have not evaluated drugs other than risperidone as it is the only drug approved for the treatment of severe behavioural disturbances such as aggression and self-destructive behaviour in ASD. An assessment should be made of which other drugs have been tested in ASD without having an indication for these disorders.

There are few studies of the health economics for these disorders despite the fact that they involve a group with major needs and often a life-long requirement for support interventions from the community. Studies are needed on the cost effectiveness of various types of treatment interventions.

### **The organization of diagnosis and interventions in ASD**

There is a need for further clarification of who is responsible for both assessment and treatment amongst the various government agencies, county councils, the health care system and municipal authorities, with regard to preschools, schools and social services, as there is a major need for interventions within the various areas of responsibility. The role of the healthcare system is more restricted to the diagnostic process and certain treatment interventions whereas preschools and schools have a major responsibility for pedagogic interventions. It is therefore important that all these various players work in close collaboration with each other. Everyone has the right to an individual plan but in practice these are not always created.

The diagnosis, care and treatment of these disorders need to be carried out in close collaboration between the various organisations involved. This requires collaborative procedures and a common basic outlook with regard to children and young people, the nature of the disorder and the consequent needs. The privatisation of care can be expected to have consequences

for how diagnosis and treatment are conducted. Government agencies and regulatory authorities should monitor this.

### **Patient involvement in ASD**

Two groups of individuals with ASD can be discerned in the studies. The first group comprises children and young people whose disabilities are so extensive and/or require such major resources that they cannot be cared for at home. The other group comprises children and young people who can manage themselves at home and in school with various types of support. The second group also includes individuals with Asperger's syndrome who can have strong opinions about their identity and about how the community views them. All these groups have similar problems with social interaction and social rules, varying degrees of communication difficulties, limited interests and repetitive behaviour. Siblings and parents are significantly affected by the situation while at the same time they also have to act as spokespersons. When a child has ASD this is not just an isolated problem for the child, but a problem for the entire family, relations and friends, teachers and support workers.

The studies show that siblings of people with ASD can be adversely affected; they feel a lot of responsibility and sympathy, but also fear and uncertainty, and experience difficulties in their own social relationships. The entire family needs support. The studies also indicate that the parents of children with ASD consider that an early and clear diagnosis reduces stigmatisation.

In the studies, parents of children with ASD say that their task is arduous and their situation difficult from the economic and social perspectives, as well as in terms of day-to-day existence, with pronounced anxiety over both the present situation and the future. They realize that only they can look after their child's interests in the long term and therefore they have to start battling with the situation as early as preschool. They lack reliable support from the community, even though such support will reduce their anxiety. Special schools and increased access are needed. They feel that they need to take the lead, to discuss educational structures and even to serve as spokespersons for teachers. Moving from one place to another or from one school year to another, should be well prepared for and needs should be assessed.

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<sup>2</sup> Core symptom are those symptoms that are characteristic of a disease or condition.  
For ASD the core symptoms are a lack of social interaction and communication plus stereotypical behaviour.

## Ethical, social and gender-related considerations

The most important considerations that emerged from the studies were that persons with ASD form a vulnerable group, in many cases with limited autonomy, and that there are many knowledge gaps, in terms of both diagnostic instruments and interventions. This lack of knowledge can create a sense of powerlessness

within care, but proven experience can be of some value here. Several different government agencies are involved in helping people with ASD. These individuals could therefore "fall between two stools". This is where government agencies have a responsibility to improve collaboration. Adults with ASD may have difficulty entering the jobs market and this can lead to social marginalisation.

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