



National Autism Plan

- a summary

National Autism Plan – a summary

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Contents

5 Foreword

6 Summary

9 Autism Spectrum Disorders

10 Occurrence and derived conditions

10 Human rights and inclusion

12 Investigation

17 Course of life

19 Early intervention 0-6 years old

20 School age, 6-17 years old

25 Youth, 15-35 years old

26 Adult life, 20-65 years old

29 Old age, from 60 years old



All six pamphlets can be downloaded free of charge at www.autismeportalen.dk

Foreword

National Autism Plan (NAP) was first published in Danish in 2006 as a guide for the new municipalities. After the reform and merger of the municipalities in 2007, it is now their responsibility to establish and run services for people with Autism Spectrum Disorders (ASD). It was the hope of the publishers that the recommendations would initiate professional and political reflections throughout Denmark, and subsequent to its publication in 2006, some municipalities did chose to base their policy on NAP.

In a lot of services for people with autism staff and management offer a specialized pedagogical service characterised by professional knowledge and understanding of autism. These services are characterised by respect for the autonomy and integrity of their users. NAP makes it possible to share this knowledge, making it beneficial to others.

In other services it may be necessary to strengthen the individually based approach in order to make the values of the law on services regarding citizens' right to autonomy and personal integrity, as well as the professional knowledge in the field of autism, the guiding principle. Over the last years cases of unworthy and disrespectful treatment of people with disabilities have come up in the press. Some of these people have autism. These examples have highlighted the need to focus on the efforts we are making for the weakest members of our society. Based on these cases

politicians are talking about increased supervision, accreditation and supplementary training as part of the reform to improve the quality of public services in Denmark.

Since the publication of the original six NAP reports requests for a shorter version focusing on the knowledge in the field and on sharing our own experiences have been posed to the publishers. Requests have also been made for a translation of this shorter version into English, in order to allow us to share our knowledge and experiences with colleagues internationally. The publishers passed on this task to the editors of the NAP and this pamphlet is the result.

We hope that this pamphlet will highlight the professional and political aspects of the quality of the efforts made in the field of autism and thus improve the quality of life for people with autism.

Thanks are owed to psychologist Bo Hejlskov Jørgensen, director and psychologist Jannik Beyer, librarian and mother Birgitte Bjørn, headmaster Bent Vandborg Sørensen, journalist Eva Isager and project manager Charlotte Holmer Jørgensen for authoring and editing as well as for their journalistic leg-work.

April 2008

The publishers

Summary

Autism Spectrum Disorders (ASD) is a term used to denote the problems known as Pervasive Developmental Disorders and which include highly differentiated levels of reduced social, verbal and intellectual functional abilities. People with ASD may have other disorders or conditions. This is known as comorbidity and may require special treatment, e.g. medical.

The number of people with ASD is increasing and people with ASD now constitute almost 1% of the population. This increase may be due to increased attention to and knowledge of the area but it may also be caused by the fact that people with ASD are often unable to live up to society's increasing demands regarding social abilities and the ability to adapt.

The number of people with ASD has reached a point that requires that a set of actions similar to those in the fields of vision, hearing and speaking impairment are developed.

An increased need for autism specific efforts in the areas of school, youth, studies, work and day services is expected, and the need for housing adapted to people with ASD, specialised institutions and support schemes will increase.

Because all kinds of autism affects daily communication, the ability to identify with others and social interaction, this group has a particularly high risk of developing serious social and psychiatric problems later in life.

Regardless of the person's age it is therefore important that society initiates assessments and offers relevant and continuous support when the problems of ASD are discovered. Symptoms change with age and development but if individually adapted support is ensured, it is possible to reduce the severity of the problem. High functioning people with ASD have the possibility of gaining personal insight as well as developing strategies to cope with difficult situations.

It is the continuous assessment of development and special needs - not the diagnosis – which forms the basis of the pedagogical intervention. It is necessary, in this regard, to be particularly aware of the fact that a person with ASD, despite being seemingly high functioning, may experience difficulties when having to define his or her needs and ask for the necessary support.

The UN Convention on the Rights of Persons with Disabilities requires that the responsible authorities set up guidelines and action plans to ensure that people with functional disabilities such as ASD are not put in a position of disadvantage regarding their participation in society.

The responsibility for the treatment of and support for people with ASD lies with the municipality. The municipalities should ensure that the people and staff closest to families with children, i.e. health visitors, pedagogues, preschool teachers, teachers and general practitioners, have a basic knowledge of ASD, in order to deal with the concerns of parents, pedagogues, preschool teachers or teachers in a serious manner. The municipalities must maintain and develop an organisation that, in case it is suspected that a child has an ASD, ensures the primary examination, assessment of development and diagnostic considerations as well as referral to a specialist examination. The regions are responsible for specialised assessment of children and young people, as well as for psychiatric treatment, particularly treatment of the psychiatric complications that may occur due to ASD.


The waiting time for psychological examinations should be no more than three months and during that time provisional pedagogical treatment and guidance for parents should be initiated.

Autism specific counselling should be available for users, relatives and professionals.

Efforts for people with ASD should, regardless of functional abilities and age, be based on a fundamental respect for the individual and a high level of autonomy.

In the case of relatively high functioning people with ASD this will often translate into personalized support in relation to employment, education or courses. If the person has ASD and developmentally delay, personal care or assistance will be the main focus. It is important to be specifically aware of the quality of life of this group, as they are often incapable of expressing their needs.

Efforts in relation to people with ASD should, apart from attentiveness and respect, include a targeted organising of the physical environment and structuring of everyday life. Activities and routines should be clear and manageable, e.g. through the use of daily schedules, work systems and visualisation.



The wish for social relationships may cause people with ASD to end up in situations that do not benefit them.

Autism Spectrum Disorders

In this guide the term autism spectrum disorders (ASD) is used to denominate the problems which in psychiatric terms are known as pervasive developmental disorders. The term ASD is chosen to emphasize the fact that we are dealing with a spectrum of autism related conditions which include highly differentiated degrees of social, verbal and intellectual functional levels. Thus, ASD covers a number of disorders where a need for specifically designed support and guidance is recognised, mainly on the basis of a diagnosis. The term also accentuates the fact that people with ASD develop throughout life and might develop positively from a severe degree of autism, if the relevant support is ensured.

A diagnosis may, with reasonable certainty, predict how a person might develop from different kinds of treatment. A specific and effective treatment for a disorder or functional reduction requires a precise diagnosis.

ASD occurs among people of all ages and is most pronounced in the interaction with other people. In some children, the characteristics of ASD and lack of social contact are so striking that it is possible to diagnose the child very early on. Others have such a mild degree of the disorder that the symptoms are identified at school age or later, when the demand for social competence is increased, for example during adolescence.

People with ASD often act from a different starting point than people without ASD. This is partly due to a lack of social understanding and a lack of understanding of the consequences of their actions.

People with ASD may also commit a crime. They generally do not commit crimes more often than other people, but their crimes will be committed for different reasons.

Since autism is a developmental disorder, symptoms will change with age and development and as autism often occur combined with other developmental problems, the diagnosis should always be ensued by a continuous and interdisciplinary evaluation of the person's specific development and needs. It is the continuous evaluation – not the diagnosis – that should form the basis of the pedagogical effort.

Prevalence and comorbidity

Over a number of years an increasing number of people has received a diagnosis within the autism spectrum. It is believed that between 0.6 % and 0.9 % of the population today meet the diagnostic criteria.

Prevalence is now at a level that requires that a set of actions similar to that in the field of visual, hearing and speech impairment is developed.

People with ASD may have other disorders as well. This is known as comorbidity, or derived conditions. The comorbid diagnoses and disorders can be ADHD, developmental delay, anxiety disorder, epilepsy, depression, OCD, sleeping and eating disorders, Tourette Syndrome and Tuberous Sclerosis. Obvious signs of autism are also found in the case of some genetic syndromes.

It is important that these complicated conditions are thoroughly assessed, as they may require special treatment, e.g. medical. People with ASD should be referred to specialist doctors if multiple disorders are suspected.

Human Rights and inclusion

People with disabilities may have a disadvantage regarding full participation in society. On March 30th 2007 Denmark, along with 83 other countries, signed a UN convention on human rights for people with disabilities. The consideration of the convention is that people with disabilities should be ensured the right to participate fully as members of society, equal to the rest of the population.

This requires that the responsible authorities set up guidelines and action plans to ensure that people with disabilities are not disadvantaged in relation to participation in society.

An important issue is how to ensure the right to inclusion without losing the specialist knowledge and flexibility that is necessary to ensure a consistent service. Thus, the problem is double-edged. How may ordinary surroundings be arranged in order to generate successful inclusion? And what should special schools and institutions do to prepare children, young people and adults for a good life as autonomous, independent citizens in society?



Assessment

Assessment is an interdisciplinary process which includes a psychological/pedagogical description and the determination of a clinical diagnosis. A sound assessment should therefore include a thorough individual analysis that forms the basis of treatment and pedagogical efforts planned to meet future requirements, as well as an evaluation of the person's symptoms in relation to the diagnostic criteria (ICD-10).

Assessment is relevant when the person or his or her surroundings, often parents, pedagogues, preschool teachers, teachers or social workers find that the person is not coping in everyday life. Therefore, assessment only takes place when the demands from the surroundings become so large that the person's abilities to meet them are no longer adequate.

The task for the diagnostic team is to find out why the person is not coping in everyday life with ordinary support and understanding. The assessment must be nuanced enough to give concrete guidelines for action in the person's everyday life.

This usually entails that the person is examined by specialists in order for a multi-axial diagnosis based on ICD (International Classification of Diseases) to be made. I.e., the relevant clinical-psychiatric diagnoses including possible

comorbidity should be indicated (Axis I), specific (Axis II) and general (Axis III) cognitive disorders should be evaluated and physical diseases described (Axis IV).

As a supplement to this diagnostic profile a broader description must be made in which the person's ASD is considered in dynamic cooperation with the person's family, school, day-care etc. This broader description will naturally point to areas where intervention to help the person is needed.

Such an assessment must be repeated and revised in case new situations, which make the assessment inadequate, arise. In the case of adults the focus will be on the workplace and educational institution.

For preschoolers, referral is most often made by a health visitor, day-care institution or a psychologist in PPR (pedagogical-psychological counselling) when the child is not developing as expected. For children of school age the referring authority is often the municipality through e.g. PPR, although children may also be referred by their general practitioners. The cause of referral is most often that ordinary upbringing and pedagogical methods do not have the desired effect.

Young people are often referred by their general practitioner, PPR or another municipal body due to derived disorders such as depression or psychosis. The investigation may later on demonstrate that these disorders are partly caused by the ASD. Most investigations of children and young people are made by departments of child and adolescent psychiatry.

Adults are often referred through the social services department of the municipality in rehabilitation cases. Many adults also seek help on their own initiative, if they are experiencing problems in their work life or in social relations. In many cases the investigation is made by a practising psychiatrist or other practitioners, although a number of adults are given an ASD diagnosis in the psychiatric examination when a mental disorder is suspected.

After the assessment is made, responsibility for treatment is passed on to the municipality in the form of support both in everyday life and in relation to school/work. Information is often shared both verbally and in written reports and often in the format of a network-meeting in which the family, the municipality and the assessment authority are represented.

Because autism is a developmental disorder it should be ensured that an interdisciplinary team is continuously monitoring the person's development.

Most assessments are made as out-patient treatment. The good assessment is made by an interdisciplinary team that examines the person's intelligence, executive abilities, communication skills, abilities of mutual social interaction and the occurrence of autism specific disorders in interests, activities and other behaviour. In the case of young people and adults the personality function is also analysed.

This information is compared with information regarding the person's functional level throughout upbringing and development plus the genetic dispositions. Added complications such as depression, psychosis, physical diseases and functional reductions are also evaluated. It is important that an assessment includes a combination of standardised tests and observations and that information about the history and development of the person in question is included.



It should be a priority for the municipality that professionals most often in contact with families with children, i.e. health visitors, kindergarten teachers, general practitioners and teachers, have a basic knowledge of ASD so that concerns of parents, kindergarten teachers and teachers are always taken seriously.


The municipality must maintain and develop an organisation that, when ASD is suspected in children, can undertake primary investigation, evaluation of development, make diagnostic considerations and refer to specialists in case the suspicion is particularly strong. The best framework for these efforts is probably a specialised team within the PPR, or a corresponding municipal body. Waiting time should be no more than three months and during that time provisional pedagogical treatment for the child and counselling for parents should be initialised.

Easy access to telephonic support by specialists in departments on both child and adolescent psychiatry and adult psychiatry for the purpose of assessment and diagnostic questions should be ensured. Similarly, access to specialised pedagogical-psychological counselling by the municipality should be ensured.

A diagnosis should be made as early as possible in order to avoid psychological strain on the person in question and his or her surroundings; strain that can occur if the functional reduction is not acknowledged. This strain can lead to serious mental illness such as a behavioural disorder, depression or psychosis. An early diagnosis gives the family clarification and makes early pedagogical treatment and social training possible, which in turn may prevent behavioural problems, a feeling of defeat, exclusion and the aforementioned psychiatric complications.

The specialised assessment must take place in close cooperation with the parents or the young person/adult. The assessment must build on the information compiled by the municipality or the general practitioner.

The specialist's assessment must, apart from thorough anamnesis, also include a structured observation, including an autism specific examination, evaluation of developmental level and verbal function as well as an ordinary medical examination with the purpose of evaluating the need for somatic examinations and genetic counselling.

The background features a white space filled with various green scribbles of different densities and orientations. A large, solid blue triangle is positioned in the lower-left quadrant, partially overlapping the green scribbles. The text is centered within this blue triangle.

A diagnosis is a description of the current situation and should be evaluated continuously, as the person with ASD develops. Similarly, the pedagogical efforts should be continuously evaluated.

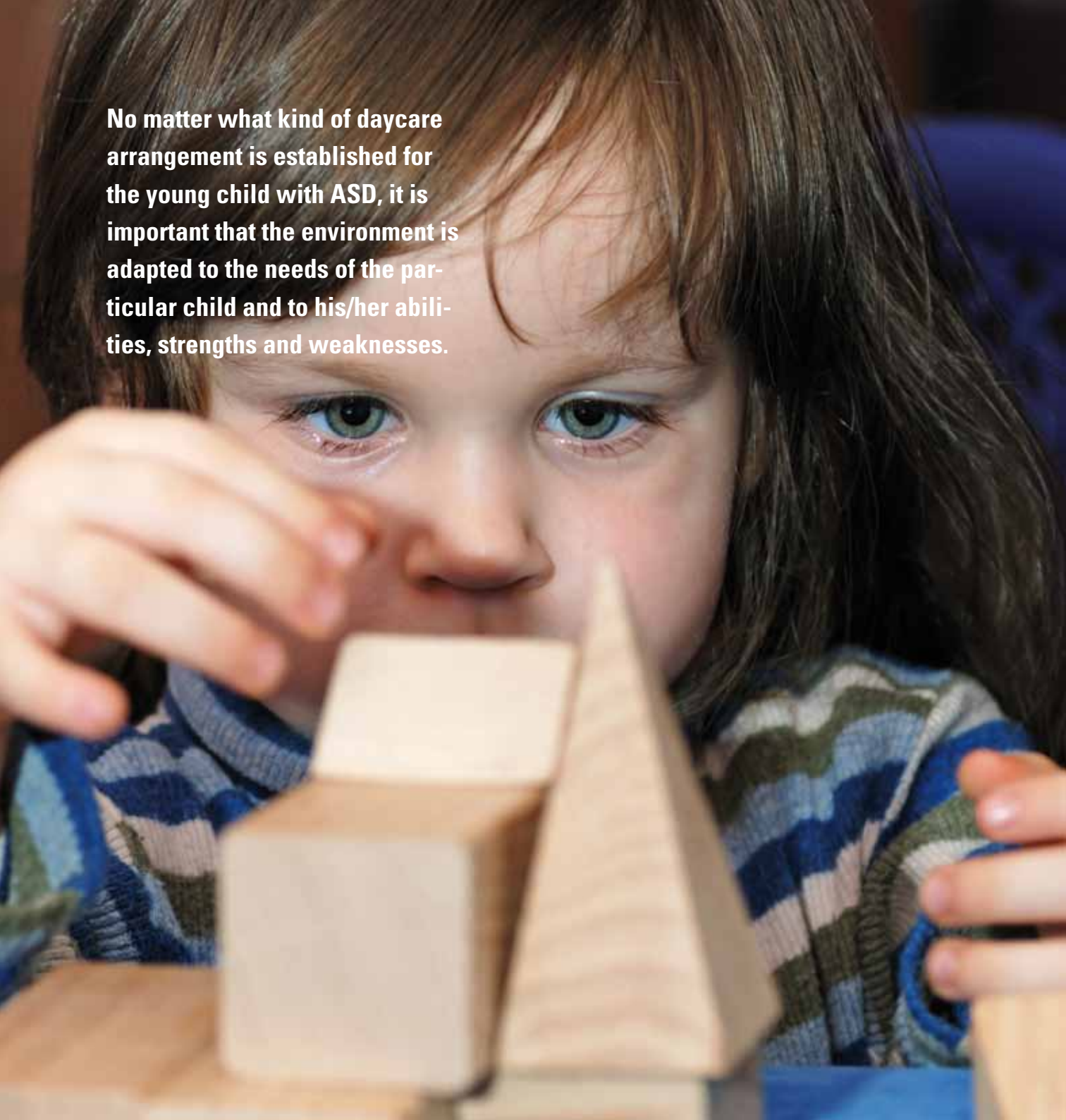
Course of life

Autism disorders express themselves very differently from person to person depending on age and developmental level, and people with ASD have very different needs in different phases of life. The criteria of diagnosis and the most common descriptions of people with ASD focus on the symptoms in and the behaviour of children with ASD. Assessing and relating to young people and adults with ASD can therefore be difficult. A diagnosis is a description of the current situation and should be continuously re-evaluated as the person with ASD develops. Similarly, the pedagogical efforts should also be continuously re-evaluated. It is therefore not uncommon that professionals have to re-evaluate an ASD diagnosis after some years.

A number of people with ASD have obvious and significant limitations in their functional ability from preschool age until old age. Other high-functioning people with ASD can periodically experience significant limitations in everyday life and at other times only experience difficulties in relation to unknown social situations and therefore do not have difficulties to any significant extent when it comes to work and family life. The scope of the limitations is thus large and entail different needs.

The efforts for people with ASD, regardless of functional abilities and age, should be based on a fundamental respect for the individual. For people with ASD and a relatively high functional level this means a high degree of autonomy, and the purpose of the potential support is to make sure that the individual can make a life for him/herself, as similar to those of people without ASD as possible. In the case of people with ASD and an early developmental level this respect will be expressed by a focus on the possibilities and quality of life of the individual. The expectations of the surroundings should therefore be of second priority.

No matter what kind of daycare arrangement is established for the young child with ASD, it is important that the environment is adapted to the needs of the particular child and to his/her abilities, strengths and weaknesses.



The preschool age, 0-6 years old

Children who are diagnosed with ASD before the age of 6 often have quite severe difficulties. Some have severe speech impairment, some are mentally retarded and a significant number are in need of substantial support. The pedagogical efforts are therefore based on specialised services, often in the form of specialised day-care institutions, special groups in the framework of the day-care or individual support in a normal day-care institution.

Regardless of what kind of day-care is established for a small child with ASD, it is crucial that the environment is adapted to the background of the individual child, and its abilities, strengths and weaknesses. In this regard, some of the key areas are a targeted organising of the physical environment and a structuring of the everyday life of the child, characterised by predictability and clarification of daily activities and routines. This is, of course, relevant in specialised day-care institutions, but in fact even more so in the case of inclusion in an ordinary day-care institution.

The principles behind the intervention should therefore include physical structure, daily schedules, work systems and visualisation and these should be incorporated both in the institution and at home.

Early intervention is of crucial importance for the child's developmental possibilities. The intervention should therefore be initiated as soon as possible after the disorder has been identified and should not wait for the final and formal diagnosis.

Significant variation is found in symptoms, age and characteristics of children with ASD. Regardless of diagnostic category and functional level, however, the children are all characterised by basic problems in social interaction, non-verbal and verbal communication and by stereotypical and limited patterns in behaviour and play. These problems should be central in the organising of the early intervention.

There is no documentation to date that indicates that one particular form of treatment or method is more effective than others. Professionals do generally agree, however, that a structured pedagogical, learning- and behaviour oriented approach is recommendable. It is also agreed that the intervention should be intensive and that an individually organised specialist-pedagogical effort on a daily basis should be made possible.

The family plays a crucial part in the intervention made for preschool children with ASD. A large part of the intervention must therefore be planned on the basis of the family's needs and the family must be included in the planning of

School age, 6-17 years old

all treatment. Counselling in the home and courses on ASD should be offered to the family and the family must be included as an important partner for the municipality. It is also recommended that the municipality offers the parents participation in courses on coping with ASD (empowerment) or something similar where the parents receive counselling and support and meet other parents in the same situation.

In the evaluation of the child's need for support the child's functional level should be taken into account. Children with severely limited functional abilities need massive support for many daily activities; children with moderate functional abilities need different types of support visually and verbally, whilst children with a normal level of intelligence need only limited support for practical and structuring purposes. They may also need support in social situations.

All intervention for preschool children with ASD should be specialised. Professionals with no specific knowledge of autism should not be consulted and methods developed for children without ASD cannot be expected to have the desired effect. It is therefore important that all personnel working with preschool children with ASD are given the opportunity to gain specialist knowledge through education, supplementary training and supervision.

Most children are not diagnosed until they reach school age. The number of children with ASD is therefore significantly higher in the later school years than during the early years of schooling. At the same time, the school age is the phase of life in which the need for support varies most from child to child. The scope runs from a child with ASD at an early developmental stage who wears a diaper, has no language and shows self-harming and in other ways problematic behaviour, to a child with Asperger syndrome who has difficulties making friends and coping with the school day, and is more interested in nuclear science than making friends, and receives high marks at school.

Many different types of services should therefore be made available for children with ASD, both in the framework of school, spare time, respite care and residential homes.

For people at one end of the autism spectrum services should be highly protected, highly individualised and specifically adapted. For children and young people on the autism spectrum, who are otherwise included in society at the same level as other children of the same age, services should include specialist counselling and guidance. Between these two poles specialised services that vary in both form and content are needed.



Children with ASD often find change difficult. It is important to inform the child of changes in schedules and the like. Pay particular attention to preparing the child for activities beyond the daily schedule at school.

Children and young people with ASD need a meaningful everyday life characterised by clarity, manageability, predictability and a mainly visually based well-structured pedagogical approach that provides the answers to the following questions:

- What am I going to do?
- How should I do it?
- Where should I do it? Or where are we going?
- With whom am I going to do it?
- Why should I do it?
- When will I finish?
- What am I going to do next?

This is similar for both school and spare time. The responsibility for this structure lies with different people in different situations, and should not lie with the child to begin with.

Professionals, and the surroundings in general, need autism specific knowledge, regardless of the service and the child's functional level. What characterises children with ASD, regardless of functional level, is that ordinary pedagogical methods do not have the desired effect – which is often the background for the referral to assessment in the school age. This is very often the case with methods of behavioural correction. It is therefore extremely important that all personnel dealing with the child in his or her everyday life have

the relevant education and supplementary training and is offered continuous autism specific guidance and supervision.

It is important to be aware of the fact that the child or young person with ASD usually finds the practice of transferring previous experiences to new situations (practical, learning and social) difficult – something we would otherwise expect children to be able to do.

Children with ASD often find changes difficult. It is important to inform the child of changes in schedules and the like. Pay particular attention to preparing the child for activities beyond the daily schedule at school (field trips, topic work, substitute teacher/changes in personnel etc.).

The social demands of group work can be difficult to cope with for children with ASD. Try to find just one partner for the child, or establish a particular role or a concrete assignment for the child. Be specific about expectations and avoid large academic and social demands at the same time.

Children with ASD often find participating in unstructured situations or creative classes difficult. Structuring of these situations with clear specification of e.g. time and place can be necessary as well as perhaps dividing the assignment into smaller assignments with frequent adult guidance.

Thinking differently about courses such as physical education or music may be necessary, as these classes involve motor skills and social demands that children with ASD often find overwhelming.

All pedagogical efforts for children with ASD should be based on a basic understanding of the cognitive nature of the functional disability. Competence and the will to use cognitive tools for the children, including structure, predictability and visualisation, is necessary. In particular, attention should be paid to the development of independence in all regards.



High functioning young people with a normal level of intelligence level need a lot of support to cope with the existential questions they face. For youngsters with a significantly limited functional ability practical support is often the most important thing.

Youth, 15-35 years old

Youth is a relative concept in case of ASD. We normally define youth as the phase of life during which a person develops and confirms his or her identity and gains independence. A high number of people with ASD and need for significant support never achieve this and in such cases, whether or not they experience such a youth can be debated. Some move away from home and educational initiatives into housing options and day-initiatives and thus move directly into adult life.

Others experience a form of delayed youth. They may find establishing their own clear identity more difficult than other people their age and they may, similarly, find defining themselves in social situations difficult. Also, they may find it difficult to establish the independence they desire.

Youth is characterised by changes and new challenges and this goes for young people with ASD as well. They are changing the way they live by moving away from home or by changing from residential homes to other housing options. They are also changing their daily activities from school to work or day-initiatives, possibly through education which may take place at all levels. They are moving from childhood to adulthood, either alone or in a new family. These changes are often more difficult for people with ASD than for people without ASD.

The individual's need for support should be evaluated on the basis of his or her functional level in order to ensure the right combination of psychological/pedagogical support. Young people with normal intelligence and a high functional level need substantial support to cope with the existential questions they face. For children with a significantly limited functional ability practical support is often the most important thing.

The necessary support should be made available for the young person. It can not be expected that young people with ASD, despite a high functional level, are able to complete an education or move out on their own in the same way as other young people. Similarly, it can not be expected that they are able to identify their own need for support. A mentor or a support/contact person can be a way of compensating for this, and it should be accepted that parents sometimes spontaneously take on this role.

Young people with ASD should have the possibility of a flexible course of education, regarding both duration and content. Many young people with ASD try out several educations before deciding on one.

Adult Life, 20-65 years old

Throughout the education it should be ensured that the educational institution is aware of the student's difficulties and that the necessary adjustments are made. The possibilities of support provided by the law should be made use of, and the young person with ASD – who is already facing difficulties – should not have to make a special effort to achieve this support.


The municipalities should make sure that different housing options are available for young people with ASD. Some young people need a home with 24 hour supervision, others need shared housing and others again need individual housing in supervised apartment complexes with support, or their own home with or without support.

Being able to identify and treat derived psychiatric disorders is important in order to ensure that the young person has the best possibilities for developing a differentiated understanding of his/her own self. Only through knowledge of his or her difficulties can the young person differentiate between functional disability, symptoms of a derived psychiatric conditions and personality, and thus be able to compensate for his or her functional disabilities.

A number of adults with ASD want a life with a partner, family and friends but have difficulties achieving this. The proper support and help from the surroundings may help to clarify dreams and expectations and gain a more realistic understanding of what the person can cope with. With the right support the person can achieve some of their desires and work with self-knowledge and development as well as gain a quality of life that makes him or her feel welcome and valuable in society, despite being different.

The number of adults diagnosed with ASD is expected to increase significantly in the years to come. This is due to a large increase in the number of children with ASD in comprehensive special education since 1992. The largest increase is found in the group of adults with a moderate or low need for support and is relatively small in the group of adults with a larger need for support.

The need for adapted housing options and support schemes regarding housing, family life, education and work is therefore also expected to increase.

A photograph showing a man with short brown hair, wearing a blue sweater, focused on a task in a kitchen. He is leaning over a large white bowl containing a yellow liquid. A woman with long brown hair, wearing a black and white striped shirt, stands behind him, smiling and looking at his work. The kitchen counter has a large black pot in the foreground and various items like a spoon and a green bag. In the background, there is a fire extinguisher on a shelf and a doorway.

If the adult with ASD wishes, his or her relatives should be included in the collaboration. It is recommended that professionals and family come to a clear agreement on what is included in this collaboration and how.

Society should offer several different kinds of housing options, ranging from housing with 24 hour support to supervised apartment complexes and home counselling. Meaningful daily activities, ranging from day centres with no requirement of productivity to actual jobs, should also be developed. Furthermore, mentor- and support schemes for people with ASD in regular jobs should be developed.

Adults with ASD should have the possibility of choosing occupation or daily activity based on their needs and abilities. Access to education and continuous learning should be ensured and the person should have the right to try out his or her possibilities on the regular labour market.

It is recommended that large firms employ or make use of job consultants with autism specific knowledge to guide and structure the work for people with ASD, including the ordinary working conditions and cooperation with colleagues. Firms and educational institutions can also use mentors to strengthen the introduction to a workplace or education. There is also the possibility of having a personal assistant assigned.

If the adult with ASD so desires, his or her relatives should be included in the collaboration. It is recommended that professionals and relatives come to a clear agreement on what is included in this collaboration and how.

People with ASD have different backgrounds for managing the role of being a parent. It is recommended that a coordinator with professional knowledge of autism is appointed and that a professional network is established around the family, if one of the parents has ASD.

A person with ASD and a high functional level cannot be expected to be able to define his or her own need for support and apply for it. However, offers should be made in a way that gives the person with ASD the possibility of relating to the actual circumstances.

Old age, from 60 years old

Old age is the term used to denote the period that ends our course of life. It is characterised by a reduction of our physical abilities, and generally also a reduction of our intellectual abilities. The reduced functional abilities can make everyday life more complicated. They may be caused by illness, walking-impairment, reduced eye-sight and hearing problems, problems with memory and increased social isolation. Elderly people with reduced functional abilities have a higher risk of being hospitalised and moving into a nursing home. They also have a higher mortality rate than elderly people with a higher level of functional abilities.

In the years to come, the number of elderly people with ASD is expected to increase. This is due to an increase in life expectancy in general and the fact that most elderly people with autism and relatively low functional abilities are not involved in autism specific initiatives. Many grew up in institutions for the mentally deficient and now live in housing options for the mentally handicapped.

The first people to get an autism diagnosis as children are in their fifties today. It will become increasingly necessary to form an understanding of how late adult life and early old age create new needs, or how old age demands a new way of looking at known needs.

Quality of life is a relevant focal point in the intervention for elderly people with ASD. It must be ensured that they lead a dignified life and have a meaningful, coherent and structured everyday life.

People with autism should, without prejudice to age, have the possibility of practical employment similar to light employment with pension. Occupation is necessary for this group of people in order to avoid passivity, stereotypical activities and depression. Work and leisure time are often not separated for people with ASD, regardless of age and functional skills.

It is also necessary to be aware of the fact that elderly people with ASD were not trained in structural environments as children. They therefore have a more individual need for structure and predictability than other age groups with ASD.

It is important to be aware that elderly people with ASD who previously managed on their own may have less of a network than other elderly people. It can also be difficult for them to recognise their own needs. This means that they may not seek out the help that they actually need.

In the care for older people with ASD it will be relevant to focus on the quality of life. It must be ensured that older people have a dignified life full of interesting, meaningful, coherent and structured days.



Elderly people with ASD will in all probability eventually experience physical disabilities and actual diseases that need treatment. It is important that nurses and doctors understand that the elderly person with autism needs special information in connection to treatment and possible hospitalisation. The information should be given in a clear and simple way in a calm setting, and a certain amount of time should be set aside for the person to process and understand the given information. The elderly person with autism should always be escorted by nursing staff and the personnel should ensure that the information is understood, e.g. by repeating it using visual aids, if necessary.

Nursing staff should supervise the intake of food and liquid, and be aware of the fact that people with ASD rarely inform their surroundings of unpleasant symptoms of disease.

Apart from medication necessitated by physical illnesses and age-related physical disabilities, elderly people with ASD often need psycho-pharmaceuticals. The risk of depression increases with age and an increased need for anti-depressants, e.g. SSRI-preparations, must therefore be expected. Furthermore, many elderly people with ASD have been medicated with Neuroleptica for many years and will therefore have side-effects entailing increased medical needs. It is therefore important that the doctors who treat

this group of elderly people have a specific knowledge of geronto-psychiatry.

The National Autism Plan is the product of a cooperation between approximately 50 Danish experts on autism, an expert committee and an editorial group.

The purpose of the National Autism Plan is to create a common basis for the work for people with autism in Denmark.

