



**AUTISM EUROPE**  
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## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

*Identification, Understanding, Intervention*

**An AE official document on autism elaborated by:**

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## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

### **FOREWORD OF AE EXECUTIVE COMMITTEE**

Autism-Europe is a European network of national, regional and local organisations of parents representing all persons with autism spectrum disorders (ASD) and notably those who are not able to represent themselves. The aim of **Autism Europe is to raise awareness across Europe of the fundamental rights and needs of individuals with ASD, and to do so by promoting positive actions and policies.**

**This document<sup>\*</sup> responds to one of the undertakings of Autism Europe to the European Commission, i.e., to publish evidence based data derived from European and international research which may lead to a positive impact on the everyday lives of individuals with ASD.**

Scientific evidence now confirms that ASD are pervasive and life long disorders, which affect the developing brain and which are apparent from infancy onwards. ASD is characterised by a triad of symptoms: impairments in social interactions; impairments in communication; and restricted interests and repetitive behaviour. The manifestations of ASD cover a wide spectrum, and the condition can affect individuals who are severely intellectually impaired as well as those who are of average or above average IQ. ASD has a strong inherited basis, although the genetics are complex and are far from being fully understood. It is becoming evident that ASD may result from multigene interactions or from spontaneous mutations in genes with major effects but the interaction between genetic and environmental factors is an area requiring much more intensive research.

In 2008, scientific evidence indicates that there are very many different possible genetic, medical and neurological causes of ASD. Although some reports of possible causes are controversial, the aim of Autism Europe is to provide high quality information that truly advances the understanding of ASD. For instance, there is no scientific evidence showing a causal association between autism and vaccination; rates of early gastrointestinal disorders prior to diagnosis are not higher in children with ASD than in the general population; there are no differences in the urinary profiles of children with ASD and a recent group control study does not justify the use of casein and gluten exclusion diets.

**Autism Europe wishes to express its sincere gratitude to the authors of this document. The work generously achieved by these internationally renowned professionals will permit a better understanding of ASD and the needs of those affected by this condition. This document is destined not only for parents but also for all professionals who are involved in interventions for persons with ASD, and for European and national authorities responsible for the care of individuals with disabilities.**

<sup>\*</sup> This document is an update of the Description of Autism published by Autism-Europe in 2000. The authors have not received any honoraries for this commissioned work. Autism Europe has not influenced the content of this document.

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### **Disclosures of potential conflicts:**

Prof. Barthélémy has no financial relationships to disclose.

Dr. Fuentes serves as a consultant / member of the speaker's bureau, and receives research support from Eli Lilly and Janssen-Cilag. He has received support for conference attendance and educational events organization from Eli Lilly, Janssen-Cilag and Juste Laboratory.

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## **PERSONS WITH AUTISM SPECTRUM DISORDERS**



**At present, Autism Spectrum Disorders (ASD) are diagnosed with international diagnostic and classification systems. These systems are a checklist of behaviours. They are updated with new research data and are used by doctors for reference and individual diagnosis.**

**The current *Document on Autism* complements these classifications. It considers other important issues for anyone with an interest in ASD.**

**Genetic factors are a major cause of autism. The interaction of many other factors is also involved. Key features vary greatly from one person to another. They also vary with age, abilities and experience.**

**Clinical diagnosis should be the basis for personalised support plans. The range of existing proven therapies can be considered in developing a support plan that best reflects individual abilities and needs.**

## **INTRODUCTION**

Until specific biological markers are identified, ASD continues to be defined in terms of the behavioural symptoms displayed. These features are listed in the international diagnostic and classification systems: DSM IV, (American Psychiatric Association), and ICD 10, (World Health Organisation). These classifications are periodically reviewed in order to incorporate new research data, and are essential for individual clinical diagnosis and for the advancement of our field.

The aim of this document on autism is not to act as a substitute for these classifications, but rather to complement them; going beyond diagnosis and considering those issues of relevance for anyone involved with or affected by this challenging condition. This document is written within the confines of our present knowledge, and future research findings may require its modification.

Although genetic factors play a major causative role, other multifactorial mechanisms are also involved in aetiology. The interaction of all these factors may result in considerable diversity in the manifestation of the core clinical features. Given that autism is essentially a developmental disorder, presentation will also vary with age, cognitive and learning abilities and experience.

Clinical diagnosis should be a signpost towards effective interventions and support, rather than a negative label, and should lead to recognition of the particular abilities and needs of each individual. Although there are certain key elements that are found in most successful programmes, there exists an extensive range of possible therapies, many of which may be helpful

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**Personalised support plans must be reviewed and monitored constantly as the person develops and his/her circumstances change.**

**Families and the community also need support in order to create the best possible environment for persons with ASD to live well and develop their potential.**

for particular problems, or for certain individuals. These possibilities should be considered when personalised support plans are developed.

These plans must be subject to constant review and monitoring with regard to their efficacy and also their appropriateness to the development and circumstances of the individual. It is also important to recognise that each individual is a member of a family and of society at large. All parties need to be encouraged and supported in the effort to develop an environment that allows and encourages individuals with ASD to fulfil their potential, enhance their happiness and the quality of their lives.

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The diagnostic term ASD is now substituting “Autism” and “Pervasive Development Disorder” in order to stress: 1) *specific* disorders of social development, and 2) the great variety in individual symptoms.

The latest DSM IV TR classification manual describes disorders found within the range of ASD.

Future revisions of classification systems will modify the present classification and diagnostic criteria for all psychiatric conditions on the basis of new research data from diverse sources.

The WHO is also reviewing its classification system (ICD). This should be finalized in 2014.

Using current diagnostic criteria, there is evidence

## IDENTIFICATION

Although not universally accepted, the diagnostic labels of “Autism” and “Pervasive Developmental Disorders” are being progressively substituted by the term “Autism Spectrum Disorders” (ASD) to stress two points: one, that we refer to *specific* disorders of social development, and, two, that there is a marked heterogeneity in the presentation of ASD, ranging from the full clinical picture to partial expression or individual traits that are related to ASD but do not merit clinical diagnosis.

In considering the latest DSM IV TR classification manual, the ASD concept does not include Rett’s Disorder, but includes Autistic Disorder, Asperger’s Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (Atypical Autism).

It is likely that future revisions of classification systems (e.g. DSM V, expected in 2012 from the American Psychiatric Association) will modify the present classification and diagnostic criteria for all psychiatric conditions. This will probably involve the consideration of both dimensional and categorical approaches to diagnosis, greater focus on developmental aspects and information derived from neurobiological and genetic sources, together with more detailed assessment of comorbid conditions. The World Health Organisation has also begun an ambitious review of its current classification system (ICD), aiming to submit the final version for approval by the World Health Assembly in 2014.

Despite the uncertainty of the future diagnostic criteria, which will have a key role in establishing the frequency of these disorders, there

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**that many more children are being diagnosed with ASD (1 in 150). Figures for adults with ASD are not yet available. It is confirmed that ASD is present in more boys than girls (4 to 1), and that it occurs in all social classes and different cultures.**

is now converging evidence that, using current diagnostic criteria, many more individuals, in many different countries are being diagnosed with ASD. Rigorous surveys from North America found that about 1 in 150 8-year-old children in multiple areas of the United States had an ASD. Epidemiological studies from Europe point to a similar figure among children (0,9 per 150, or 60 per 10.000). There are no empirical data on the frequency of ASD among adult populations, although there are on-going studies to clarify this important question. The over-representation of males (four to one) is confirmed, as well as the presence of ASD in all social classes and different cultures.

### **Clinical presentation**

**Within the autism spectrum, features of behaviour vary greatly from individual to individual and also within the same individual over time.**

The clinical expression of autism varies greatly, not only between different individuals but also within the same individual over time. Some symptoms may be more prominent and intense at one age and may fluctuate in nature and severity at another, leading to very different clinical profiles, yet all are expressions of the same spectrum.

**There is also individual diversity in Intellectual ability - from superior intelligence to profound retardation. However, many individuals are in the normal range.**

In addition to variation in behavioural expression, there is also wide diversity in cognitive ability, which can range from average or even superior intelligence to profound retardation. Although it was previously thought that the majority of individuals with autism were severely intellectually impaired, recent research indicates that many individuals have intellectual abilities in the normal range.

**All cases present symptoms in three diagnostic areas:**

Despite this individual diversity, all cases present with clinical features in three domains:

#### **Disturbances in the Developmental of Reciprocal Social Interaction**

**Persons with autism can be quite indifferent or generally passive in social**

In some individuals there is significant social aloofness; others are passive in social interactions, with only very limited or fleeting interest in others.



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**interactions. Attempts by some to actively relate to others can be odd, one-sided and intrusive. Understanding of the reactions and emotions of others is limited but most can show affection in their own way.**

**The development of speech in ASD also varies from individual to individual. Some never speak, some begin to speak but regress. Others speak well but have difficulties in expressing and understanding abstract concepts.**

**Language and emotional reactions to others' speech and body language tend to be unusual with abnormal features.**

**In summary, social understanding is difficult for them. Persons with ASD have problems in understanding and sharing the emotions of others and also in self-expression and self-regulation of emotions.**

Some individuals may be very active in their attempts to engage in social interactions but do so in an odd, one-sided, intrusive manner, without full consideration of others' reactions. All have in common a limited capacity for empathy – although, again the extent of deficit is very variable- but most are able to show affection in their own terms.

### **Impairment of Verbal and Non-Verbal Communication**

The development of language in ASD is extremely variable. Some individuals never acquire speech. Others begin to speak, but then, (often around the age of 18 months to 2 years) there may be a period of regression. Other individuals appear to have superficially good language but have difficulties with understanding - especially of more abstract concepts. In those who do learn to use language, both receptive and expressive difficulties are common. All individuals with autism show some degree of difficulty in reciprocal, to-and-fro interactions with others. In both form and content, language tends to be unusual, and abnormal features include echolalia, pronoun reversal and making up of words. Emotional reactions to verbal and non verbal approaches by others are also impaired, and are often characterised by gaze avoidance, inability to understand facial expressions or the messages conveyed by others' body postures or gestures.

In summary, there are deficits in all the behaviours required to engage in and regulate reciprocal social interaction. There are often marked difficulties in identifying, understanding and sharing others' emotions; the individual's own repertoire of expression and regulation of emotions is also affected.

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### **Restricted Repertoire of Interest and Behaviours**

**Imaginative skills in children with autism are often limited. Their capacity for pretend play and social play does not develop well. As a result, they have difficulties in understanding or adapting to the intentions and emotions of others, managing past events or anticipating the future.**

Imaginative skills are almost always impaired to some degree. As children, most individuals fail to develop normal pretend play and this, in turn, limits their capacity to understand and represent intentions and emotions in others. In some cases imaginative activity may be present, indeed even excessive, but this does not lead to improved functional adaptation or participation in social play with peers. The failure to develop an inner representation of others' minds also affects the capacity both for anticipating what may happen in the future and for coping with past events.

**Behaviour is often stereotypical, repetitive and ritualised.**

Behavioural patterns are often repetitive and ritualised. These may include attachments to unusual and bizarre objects. Stereotyped, repetitive movements are also common.

**Most children with autism demonstrate strong resistance to change and insistence on routine. Their interests are often specific or unusual.**

There is often a strong resistance to change and insistence on sameness. Even minor changes in the environment can cause profound distress. Many children with autism, particularly those with higher intellectual ability, develop specific interests or preoccupations with unusual topics.

### **Other important aspects to be taken into consideration**

**Many persons with autism over- or under-react to tactile, auditory and visual stimuli. They may also have unusual responses to heat, cold and/or pain.**

Many individuals show hyper- or hypo-sensitivities to tactile, auditory, and visual stimuli; there may also be unusual responses to heat and cold and/or pain.

**Persons with autism may also have other problems such as: anxiety, sleep problems, abnormal feeding patterns, severe tantrums and self-injurious behaviour.**

Other commonly associated, non-specific features include high levels of anxiety, sleep problems, abnormal feeding patterns, sometimes resulting in gastrointestinal disturbances (although these appear to be associated more with developmental delay than to autism per se), severe tantrums and self-injurious behaviour.

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**Many persons with autism also have other behavioural and psychiatric problems or associated disorders. These are called “Co-morbidities”.**

**“Co-morbidities” must be given proper consideration. Assessment may indicate that the environment or treatment plan is unsuitable and should be changed. In other cases, the associated disorder itself needs treatment.**

**ASD is normally present from birth but the age at which symptoms become evident varies greatly.**

**In classical cases of autism signs are evident within the first two years of life.**

**ASD in children with no intellectual problems or significant language delays may only be recognised when children begin school and have difficulties coping with the social demands of school and their peer group.**

**Persons with higher intellectual ability and special skills in certain areas**

Many individuals with ASD are affected by other behavioural and psychiatric problems. These are referred to as “Co-morbidities” and include psychiatric disorders such as anxiety disorders (in up to 60%), depression and other affective disorders, attention deficit hyperactivity disorder, obsessive-compulsive disorder, tics, catatonia and also, although more rarely, substance abuse and psychotic breakdown.

A thorough assessment of these features is essential. Many such problems (for example, depression or anxiety) may reflect the fact that the environment is inappropriate, or the treatment plan inadequate for someone with ASD. In these cases “comorbidities” should be considered as “complications”, requiring careful reappraisal of the intervention programme. In other cases, the associated disorders will need treatment in their own right.

### **Age of onset and impairment**

Although in most individuals ASD is present from birth, the age at which symptoms become clinically evident varies greatly. In classic cases of ASD, such as described by Kanner, and especially when associated with developmental delay, the first signs will be evident within the first two years of life. However, very young children who do not have cognitive impairments, and particularly those who show no significant language delays (for example those with Asperger syndrome), may be able to function relatively well in one-to-one relationships at home, with sensitive, understanding adults. Recognition of their impairments may be delayed until the social demands of school and the need to interact with their peer group become too difficult for them to cope with.

The problems associated with ASD may also be compensated for, at least partially, by higher intellectual ability, especially if this is accompanied by special skills in certain areas. Many individuals

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may simply be considered eccentrics for most of their lives.

In these cases, ASD may only be recognised if the person has a child with ASD or symptoms become more evident if the person is unable to cope with marital problems.

with Asperger syndrome, for example, succeed well in technical fields such as engineering or computer technology, and may simply be considered as somewhat eccentric for much of their lives. In such cases the diagnosis may only be recognised if the individual later has a child with ASD and that assessment reveals similar problems in the parent as well. Alternatively, symptoms may become more apparent when marital problems arise, due to the inability of the person with Asperger syndrome to cope with the “normal” demands for intimacy and companionship.

### **Clinical variants**

Currently, different clinical forms of ASD are described:

In the current literature and classification systems, different clinical variants of ASD are described:

- Autistic Disorder (see Kanner) - little or no speech or social relations; resistance to change; stereotypical behaviour, physical dexterity and obsession with parts of objects; occasionally impressive isolated skills.
  - Asperger syndrome - normal IQ and speech development; reduced communication skills; problems with social relations, obsessions and ritualistic behaviours.
  - Atypical autism and/or Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) - These diagnoses are given when the full criteria for ASD are not met. The
- Autistic Disorder is most closely related to Kanner's descriptions of individuals with severe impairments in social reciprocity, who are mute or significantly verbally impaired, and who show marked resistance to change. These individuals also tend to show motor stereotypies, and often motor dexterity, together with preoccupations with parts of objects, and in some cases impressive isolated skills.
  - Asperger syndrome is characterized by normal IQ and the acquisition of language at the normal age. However, pragmatic language skills are typically impaired, and problems of social reciprocity and the presence of preoccupations and ritualistic behaviours are similar to those found in autism more generally. .
  - Atypical autism and/or Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) are diagnoses that tend to be given when the full criteria for ASD are not met (for example, when age of onset is later than 3 years, or when symptoms are apparent in only two of the 3 principal diagnostic domains). However, it is

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**symptoms are not mild but these persons often receive little support or understanding and may also be greatly aware of their incapacity to relate well to others. Associated anxieties and episodes of aggression can be problematic for the persons themselves, their families and others. Some have problems controlling their imagination.**

important to recognise that the clinical impairment in such cases is by no means mild. These individuals may suffer greatly from their subtle symptoms, partly because they often receive little support or understanding, and also because they may be acutely aware of their incapacity to relate adequately to others. Their co-morbid anxieties and, sometimes, associated bouts of aggression may pose severe problems to themselves, to their family and to others. Some also have problems with controlling their imagination and tend to be carried away by their vivid thoughts. These cases have been well studied under the concept of Multiple Complex developmental disorders to help and specify some of the features of the "Not Otherwise Specified" areas of ASD.

### **ASD and Strengths**

**Many persons with ASD have made significant contributions to the field of science in particular. They excel in areas that require highly logical thinking, such as computer technology.**

Although ASD is frequently a clinically impairing disorder, there is no doubt that many individuals with this condition have made significant contributions to the field of science in particular. It is likely that many technical developments such as computer technology could not have taken place without the input of individuals with a highly logical and focussed style of conceptualisation and thought, and who are not distracted by the need for social interaction.



### UNDERSTANDING

Research findings consistently demonstrate that neurodevelopmental abnormalities underlie many of the core behavioural impairments of ASD.

#### The underlying mechanisms

**Research demonstrates that ASD is a group of developmental disorders affecting brain functioning and in particular the processing of social information. This affects how a person sees and understands the world around them and the thoughts, intentions and emotions of others. Persons with ASD are also limited in their organisational and planning abilities. Problems with sensory processes are also frequent.**

**Restricted and repetitive activities may be a way of coping with what is an incomprehensible social environment.**

**During diagnosis it is very important to include a profile of the person's strengths and weaknesses in problem areas in order to create an individual support plan that includes general treatment for ASD but is also adapted to the individual's needs.**

ASD are now viewed as a group of neurocognitive disorders that have in common deficits in processing socially related stimuli. Deficits in social-information processing affect individuals' perception and understanding of the world around them and limit the capacity for understanding others' thoughts, intentions and emotions (often referred to as an inability to understand minds). Other common areas of deficit include executive dysfunction, which affects organisational and planning abilities. Problems with the modulation of sensory processes (for example, vision, hearing, touch, pain) are also frequently described although the physiological basis for these phenomena remains unclear.

The presence of these severe and pervasive neurocognitive problems may explain why individuals engage in restricted and repetitive activities in order to cope with an incomprehensible social environment. Thus, as part of the diagnostic process, an assessment that provides insight in the strengths and weaknesses of an individual with ASD is of paramount importance. Such an assessment should include a profile of the individual's capacities on core psychological functions such as general intelligence, and strengths and weaknesses in areas associated with central coherence (global versus detail oriented perception) and executive functioning (planning, organizing behaviour and activities). Such information will help to tailor a personalised management plan that should include general treatment strategies for ASD, but adapted to individual needs.



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**Intense research is ongoing into the neurological causes of the problems relating to social relationships, linguistic abilities and adaptation to change.**

**It would appear that autistic dysfunction is not located in any one area of the brain.**

**Findings from neuroimaging and neurochemistry suggest an early brain “network” dysfunction.**

**Genetics are an important factor in the origins of ASD.**

**The clinical diversity of ASD reflects the complex involvement of several genes and gene-environment interactions.**

**A specific cause is only identified in 10% of ASD cases.**

**Genome (DNA) research techniques have identified small deletions and duplications, a large number of important loci (place a gene occupies on a chromosome) and new genetic mutations as**

The underlying neurological causes of problems related to social relationships, linguistic abilities and adaptation to change are under intense investigation. Different approaches combining clinical assessment and biological studies suggest abnormalities in brain growth, neural patterning and connectivity. Various possible candidate regions for autistic dysfunction have been located in the cerebellum, the temporal lobe, fusiform gyrus, amygdale, the frontal lobes and the white matter tracts of the corpus callosum. However, no one area has been consistently implicated, and findings from neuroimaging studies have often failed to be replicated. Research on neurotransmitters has focused mainly on serotonin and dopamine and more recently on the glutamatergic synapses. Findings from both neuroimaging and neurochemistry are suggestive of early brain “network” dysfunction rather than of primary and localized abnormalities.

### **What is known of the causes?**

Genetics strongly contribute to the pathogenesis of ASD. However the clinical heterogeneity of ASD likely reflects the complexity of its genetic underpinnings, involving several genes and gene-environment interactions. In only approximately 10% of all ASD cases can an associated cause be identified. These include genetic disorders (Fragile X syndrome, neurofibromatosis, tuberous sclerosis, Angelman syndrome, Cornelia de Lange, Down Syndrome, untreated phenylketonuria), chromosomal rearrangements (detectable by karyotyping) or rare environmental events (prenatal CNS infection by rubella or cytomegalovirus, prenatal exposure to valproic acid or thalidomide). The recent advent of genome-wide techniques has allowed the identification of small deletions and duplications, well below the threshold of detection by standard procedures, and has already identified a large number of potentially important novel candidate loci. These techniques also suggest that in many

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**causative factors.**

**Both large patient group research and single case studies are necessary to better understand how genetic factors cause ASD**

**Parents' associations should encourage participation in scientifically sound and bioethically approved projects.**

**In summary, the mass of evidence confirms that autism is caused by a biological, organic mechanism. It also confirms that parental attitudes and actions do not cause the development of ASD.**

cases *new* genetic mutations may be a causative factor, and that not all cases result from inherited factors.

Multiple parallel approaches are necessary to advance our understanding of the genetic factors underlying ASD. Both large well-characterized patient cohorts and single cases where a major gene effect can be identified have to be recruited.

Research in this field is necessary and parents' associations should encourage participation in scientifically sound projects on the condition that appropriate bioethical committees have approved them.

In summary, the evidence for a biological, organic causative mechanism for autism is now overwhelming, confirming that there is no causative link between parental attitudes and actions and the development of autism spectrum disorders.





### **IDENTIFICATION AND DIAGNOSTIC ASSESSMENT**

The principal features of autism are described in the clinical presentation section. In the first year of life there may be no obvious signs of abnormality, but by 18 months to two years deficits in the following areas should prompt referral for a general developmental assessment:

**Communication: failure to respond to name, difficulties in understanding, verbal/non-verbal language, gaze, gesture**

Communication: e.g. failure to respond to name; impaired understanding; delayed or unusual use of language; impaired response to/use of non-verbal communication, lack of appropriate gaze, lack of response to contextual clues, lack of showing or pointing.

**Social: lack of interest in others, imitation, interaction, play, emotions, sharing**

Social: e.g. lack of response to/interest in others; failure to imitate; impairments in social interaction and lack of social awareness; limited pretence and imaginative play; failure to understand/respond to emotions in others, failure to express emotional warmth or pleasure, lack of sharing interest or enjoyment.

**Repetitive and stereotyped interests: unusual sensory responses, mannerisms, resistance to change, repetition**

Repetitive and stereotyped interests: e.g. unusual sensory responses; motor mannerisms or posturing of body; resistance to change; repetitive movements with objects, repetitive play.

### ***Early warning signs***

**“Red flags” for parents and doctors include: poor eye contact; reduced responsive smiling; diminished babbling; reduced social responsiveness, difficulties with language, play and starting or maintaining social interaction.**

Recent studies have suggested that the “red flags” of which parents and physicians should be aware include: poor eye contact; reduced responsive smiling; diminished babbling; reduced social responsiveness, and difficulties with language development, play and initiating or sustaining social interaction.

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**The following signs indicate that a general developmental assessment is absolutely necessary:**

- **No babble, pointing or other use of gesture by 12 months**
- **No single words by 18 months**
- **No spontaneous 2-word phrases by 24 months**
- **Any loss of language or social skills at any age**

**No one single symptom is characteristic of ASD. The absence of any the above does not rule out a possible diagnosis.**

**If ASD is suspected, the child has the right to a thorough assessment. This is important for accurate diagnosis, to identify individual needs and ensure prompt intervention.**

**The general developmental assessment should include:**

- **a detailed history of all aspects worrying parents**
- **a developmental history**
- **physical / developmental examination**
- **assessment of family circumstances and social needs**

Experts also recommend that any of the following signs are absolute indicators of the need for a general developmental assessment

- No babble, pointing or other use of gesture by 12 months
- No single words by 18 months
- No spontaneous 2-word phrases by 24 months
- Any loss of language or social skills at any age

However, it is important to recognise there are no single pathognomonic symptoms that are indicative of ASD (i.e. there are no sine-qua-non symptoms) and that the absence of any of the above features does not rule out a possible diagnosis. In other words, there is great clinical diversity, but all those affected with ASD will share the constellation of core socio-communication and behavioural symptoms.

Each individual in whom a disorder within the autistic spectrum is suspected is entitled to a thorough clinical and medical assessment. The assessment is of great importance in order to make an accurate diagnosis, to identify individual needs, and to ensure that intervention is put into place to meet these needs.

The general developmental assessment should include:

- a detailed history of all the signs that cause concern to parents
- a developmental history (including ante- and pre-natal history and any relevant family history)
- physical and developmental examination (i.e. assessment of physical, cognitive and language development; exploration of other possible genetic disorders such as fragile X, tuberous sclerosis)
- assessment of family circumstances and social needs.

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**If this assessment indicates the need for an ASD specific assessment, further specific screening must be carried out. Frequently used assessment instruments include the SCQ, M-Chat, CAST and ESAT.**

If the general developmental assessment indicates the need for an ASD specific assessment further screening instruments may be employed. There is no firm evidence on which to recommend any one specific instrument, but the Social Communication Questionnaire correlates well with more detailed autism assessments. Other frequently used instruments include the M-Chat, the CAST and the ESAT.

### ***Assessment process***

**ASD assessment is multi-disciplinary. All members of the multi-disciplinary team should have ASD training. At least one member should have specific training in ASD assessment and diagnosis using standardised instruments. The team should have access to input from other professionals.**

Once the presence of an ASD is suspected the child should be referred for a multi-disciplinary assessment, in which all members of the team should have some ASD training and at least one member should be trained in the assessment and diagnosis of ASD using standardised assessments. The multi-disciplinary team should have access to input from psychologists, educationalists, language therapists, paediatricians and/or child psychiatrists, occupational and physio-therapists and social services support.

**Ideally, the child should be observed in a number of different structured and unstructured settings.**

For the purposes of assessment the individual should ideally be observed in a number of different settings, both structured and unstructured (e.g. in clinic, home setting, nursery/schools, day care centre etc.) Videos may be used if direct observations on site are not possible.

**The assessment itself should include:**

The assessment itself should include:

#### **1) Standardised autism specific assessment**

#### **1) Standardised autism specific assessment.**

**There are a number of specialised assessment instruments.**

Among the best validated of such assessments are the Autism Diagnostic Observation Schedule; the Autism Diagnostic Interview- revised; the Diagnostic Interview for Social and Communication Disorder; and the Developmental, Dimensional and Diagnostic

## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

**It is important to ensure that diagnostic assessment covers the main areas related to ASD. Interviews must be as systematic and structured as possible.**

**Despite possible problems of access, cost and time, it is important that services have at least one member of staff trained in the use of ASD specific instruments.**

### **2) Cognitive assessment**

**A variety of standardised tests is available depending on the child's age and ability level.**

**If direct testing is not possible, the Vineland Adaptive Behaviour Scales can provide information.**

### **3) Language assessment**

**A variety of different tests is available, depending on age and ability.**

**Full language assessment must include *functional* communication skills. Assessments of play ability may also provide important information.**

Interview (3di). Other assessments include the Behavioural Summarized Evaluation and the Childhood Autism Rating Scale.

It is recognized that not all services will have access to these specialized instruments. The cost and time involved in completing such assessments may also be impractical for some hard-pressed services. However, having at least one staff member trained in the use of such instruments is important in ensuring that the diagnostic assessment covers the principal areas related to ASD (communication, social and repetitive/stereotyped behaviours) and that interviews are conducted in as systematic and structured way as possible

### **2) Cognitive assessment**

A variety of different tests is available depending on the child's age and ability level. The best standardised assessments include the Wechsler tests (WPPSI, WISC, WAIS, and WASI) which span the age ranges of 3 to 60+). For younger children the Mullen Scales of Early Learning or the Bayley scales may prove useful. When direct testing is not possible for any reason the Vineland Adaptive Behaviour Scales can provide detailed information, based on parental report, on the individual's communication, social and adaptive behaviour skills.

### **3) Language assessment**

Again a variety of different tests is available, and the choice will depend on age and ability of the person with autism. However, many language tests assess a relatively circumscribed area of language and it is important to include assessments of comprehension, expression and pragmatic use of language in order to obtain a full assessment of the individual's *functional* communication skills. Assessments of play ability may also provide valuable information on the child's "internal

## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

### **4) Physical and medical assessment**

**Each child should undergo a thorough medical examination.**

**A routine neurological examination should be carried out.**

**Complementary neurological tests are not routine and should only be carried out if there is specific evidence to support further investigation.**

**For the same reasons, routine testing of the gastro-intestinal tract, vitamin levels, or other metabolic functions is not advised for autism.**

### **5) Behaviour and mental health assessment**

**This should cover behavioural and psychiatric symptoms especially in school age children. Functional analysis of behaviours can help understand the situations in which difficulties occur and indicate approaches to help persons with ASD cope with their environment.**

language” or imaginative ability.

### **4) Physical and medical assessment**

Each child should undergo a thorough medical examination. This should include assessment of visual and auditory acuity; height, weight and head circumference. Information about eating sleeping, bowel and bladder control, and possible epilepsy should also be obtained. A full neurological examination should be conducted if there is evidence of regression, fits, skin lesions, or significant hearing, visual or learning difficulties. A detailed neurological assessment is not recommended as a routine part of the diagnostic assessment, but if evidence of a neurological disorder is apparent additional tests might include genetic testing (for Fragile X, Rett syndrome, etc); lead screening (in cases of pica), or EEG for suspected epilepsy. Some investigations are warranted only if there are specific indicators. Thus, neuroimaging techniques (Magnetic resonance imaging, computerised tomography, etc) are unnecessary unless there are specific neurological indications, such as a possible diagnosis of tuberous sclerosis. Routine testing of the gastro-intestinal tract, vitamin levels, or other metabolic functions is not advised unless there are specific indications of abnormalities in these areas.

### **5) Behaviour and mental health assessment**

The assessment should cover behavioural and psychiatric symptoms (e.g. anxiety, mood disturbance, ADHD, impulsivity, conduct disorder, OCD, tics, etc.) especially in school age children. Conducting a functional analysis of the underlying causes of behavioural problems may also prove valuable in helping to establish why, when and where difficulties occur, and in suggesting alternative approaches that will help individuals with ASD to cope with the challenging environments in which they find themselves.

## ***PERSONS WITH AUTISM SPECTRUM DISORDERS***

### **6) Family functioning**

**Assessment of the needs and strengths of family members is essential for the development of the best possible intervention strategies.**

**In summary, diagnosis of ASD requires thorough clinical assessment by trained ASD professionals with different skills.**

**Diagnosis and assessment must lead to all-inclusive intervention and educational programmes appropriate for the individual needs of the child and those of his/her family.**

### **6) Family functioning**

Assessment of the needs and strengths of family members is an important part of the assessment process, and is essential for the development of appropriate and successful intervention strategies.

In summary, the diagnosis of ASD should only be made on the basis of a thorough clinical assessment, conducted by professionals with training in the field of autism and with a range of skills (medical, psychological, educational, and social)

The purpose of the assessment is not only to establish, with as much certainty as possible whether or not an individual meets criteria for ASD, but to ensure that this process leads to intervention and educational programmes that are appropriate for the needs of the child and those of his or her family.



## INTERVENTION

There is, as yet, no cure for ASD. Fortunately, however, there is strong evidence that appropriate, lifelong educational approaches, support for families and professionals, and provision of high quality community services can dramatically improve the lives of persons with ASD and their families.

Since the first Autism Europe Description of Autism published in 2000, the situation has greatly changed.

**There is no cure for ASD but we can dramatically improve quality of life. Updated good-practice expert guidelines are now available in Europe.**

**They correspond to similar guidelines from other parts of the world.**

**This means there is a worldwide, shared vision on treatment for persons with ASD.**

**Individuals or organisations must assume moral and legal responsibility if they propose approaches outside the established guidelines. They may be accused of discriminating against citizens with ASD and preventing their access to basic human rights of health and education**

**We now know which practices are supported by current scientific knowledge and which programmes are best for persons with ASD.**

We now have updated good-practice guidelines produced by expert committees in Europe. These include the National Institute of Health of Spain and the Scottish Intercollegiate Guidelines Network, which have reviewed all available evidence for the great variety of treatments advocated for ASD. The UK Departments for Education and Skills and for Health have also produced good-practice guidance for the education of students with ASD.

These position statements coincide well with similar guidelines arising from other parts of the world, such as the U.S.A., Canada and Australia. It can be said, without ambiguity, that we now have a shared vision on treatment for persons with ASD. In consequence, those individuals and organizations that propose radically contrary approaches must assume the moral and legal responsibility that results from practicing outside the main framework now accepted by the most prestigious and responsible professional bodies of the world. Those who ignore these well established guidelines run the risk of being accused of discriminating against citizens with ASD, and of preventing them from accessing their basic human rights to health and education.

We have learned much over the past few years about those practices that are supported by current scientific knowledge and those that are not, and about which programmes make a real difference to the lives of individuals with ASD.



## ***PERSONS WITH AUTISM SPECTRUM DISORDERS***

**This knowledge has not yet become general practice in Europe and there are still few opportunities for European citizens with ASD to receive the support they are entitled to.**

**Few treatment programmes meet the methodological criteria necessary to assess their scientific value.**

**Evidence-based research is increasing and is becoming more rigorous but it still focuses on very short-term goals and a limited number of outcome measures.**

**Different research strategies are necessary to study whether treatment maximises long-term potential and improves quality of life. They must include the views of persons with ASD.**

**Evidence-based psychological practices should integrate research evidence, the clinical judgement of experienced professionals and the culture and individual preferences of the person with ASD.**

Unfortunately, this knowledge has not yet been incorporated into general practice across Europe. Thus, there remains an unethical gap between knowledge and opportunities, and it is still evident that very few European citizens with ASD receive the state-of-the-science support to which they could and should be entitled.

Recent reviews of the evidence base for interventions for persons with ASD conclude that relatively few treatment programmes meet the methodological criteria that are necessary when assessing the value of medically based interventions (such as drugs, etc). Nevertheless, the evidence base for a range of different interventions is improving, with growing numbers of well conducted comparison studies. Randomised control trials, considered as the “gold standard” in medical research, are also increasing in number. However, even when outcome is found to be positive, most research still focuses on very short term goals and on a limited number of outcome measures. There is little attempt to address questions such as whether treatment succeeds in maximising the long-term potential of the individuals involved, or if it truly improves the quality of life. Such issues may require very different evaluation strategies such as external audits and reviews, systematic analysis of problems, and measures of personal satisfaction. It is also crucial to collect the views of individuals with ASD themselves on whether treatment has helped to enhance self-esteem, self-determination and their perceptions of social inclusion.

The American Psychological Association has proposed that evidence based psychological practices should be those that integrate the evidence generated by research together with the clinical judgment of experienced professionals, and within the framework of the characteristics of the individual with ASD, his or her culture and individual preferences.



## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

**The strongest, evidence-based programmes to date focus on behaviour, parent - child relations and communication skills.**

**There are many other elements essential for better, longer-term outcome:**

- 1. Education - an early start, attention to all areas of development, least restrictive environment, staff familiar with ASD and the child;**
- 2. Accessible community support - well-informed multi-agency services where a person with ASD can realise their potential and goals;**
- 3. Access to all generally available psychological and medical treatments**

**To be examples of good practice, Interventions must include four fundamental principles:**

- 1. Individualisation: to reflect diversity in the spectrum and individual differences.**
- 2. Structure: adapting the environment and monitoring methods to maximise participation.**

To date, programmes involving behaviourally based approaches to intervention, those designed to improve parent - child interaction, and those with an emphasis on developing social and communication skills appear to have the strongest evidence base (at least in the short term).

However, there are many other elements that are essential to improve longer term outcome.

1. Education – as early as possible, with special attention to social, communication, academic and behavioural development, provided in the least restrictive environment by staff who have knowledge and understanding both of autism and the individual student;
2. Accessible community support in terms of appropriate, well-informed multi-agency services that will help each individual to realise his or her own potential and life-time goals (either chosen by the individuals themselves, or those who know, love and legally represent them);
3. Access to the full range of psychological and medical treatments (adapted as necessary to meet the needs of individuals with ASD) that are available to the general population.

Those interventions that are best supported by the evidence as being examples of good practice include four fundamental principles:

1. Individualization: There is not, nor could there ever be, a single treatment that is equally effective for all persons with ASD. Diversity in the spectrum as well as individual skills, interests, life vision and circumstances mandate personalisation.
2. Structure: This requires adapting the environment to maximize each individual's participation by offering varying degrees of

## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

**3. Intensity and generalisation: long-term, systematic, daily interventions in different settings and involving all those in contact with the person with ASD ensures that skills learnt can be transferred to real life situations. Support and guidance from professionals in ASD for those responsible for interventions.**

**4. Family participation: parents are key elements in any professional intervention programme and must receive information, training and support that respects family values and culture. Other practical support is necessary to avoid discrimination and ensure the same quality of life as other European citizens.**

**You can read about the European good practice guidelines, specific interventions and treatments on Internet. See the *Sources of Information* section.**

predictability and stability, more effective means of communication, establishing clear short and long-term goals, defining the ways in which these goals can be met and monitoring the outcome of the methods chosen to meet these goals.

3. Intensity and generalisation: The interventions used should not be sporadic or short term, but applied in a systematic manner on a daily basis, across different settings, and by all those living and working with the person with autism. This will ensure that the skills acquired in more structured settings can be maintained in real life situations as well. Those responsible for carrying out the intervention should also have access to appropriate support and guidance from professionals with expertise in ASD.

4. Family participation: throughout childhood, and beyond, parents must be recognised and valued as the key elements of any intervention programme. Information, training and support, always within the context of family values and culture, should be the common denominator of any professional intervention. Other important sources of support, such as babysitting, respite care, short breaks, or tax benefits should be available to avoid the discrimination that many of these families still face across Europe. Adequate support for social, medical and educational services is necessary to ensure that they are able to enjoy the same quality of life as other citizens.

People interested in finding out more about the European good practice guidelines mentioned above or obtaining information about specific interventions or treatments, can access this for free from the Internet address listed in the section Sources of Information. There are different guidelines in English, Spanish and French.



## **THE SUPPORT PLAN SHOULD EVOLVE AS THE INDIVIDUAL PROGRESSES THROUGH THE LIFE CYCLE**

### **Early Childhood**

**Intervention and goals refer to the normal developmental process.**

**Full functional assessment and the implementation of a treatment plan must follow diagnosis. Early intervention can be beneficial. Parents need continuous information and support. Self-help organisations can contribute in this.**

**Home-based programs for challenging situations are needed.**

**Families and good nurseries play a crucial role in stimulating pretend and social play, communication and social skills.**

**Personalised plans should also focus on the activities of daily life.**

### **Early Childhood**

In this period the principal framework for intervention is the normal developmental process and the goal will be to parallel this as much as possible.

As soon as the diagnosis is made, a thorough functional assessment should be completed and a treatment plan implemented. A number of studies now demonstrate the benefits of early intervention, although there is great variation in outcome. Parents need continuous information and personal support after the diagnosis has been made. The contributory value of self-help organisations such as parents' associations is evident.

There is also a real need for home-based programs for challenging situations, something rarely available in the majority of European countries.

Families and good nursery provision can, and should play a crucial role in counteracting social isolation and withdrawal by encouraging imitation and shared attention, promoting communication and fostering the development of social skills. There are also many other aspects to be considered in the personalised plan of young children with ASD. In particular, special attention should be given to crucial aspects of daily life at this age, such as feeding, eating, toilet training, sleep, play and behaviour.

## ***PERSONS WITH AUTISM SPECTRUM DISORDERS***

### **School-age Children**

**Intervention is based on an appropriate, individualised, educational curriculum.**

**Students with ASD need a wide choice of educational possibilities.**

**The European Union favours integration and mainstream schooling.**

**The 2006 Autism Europe Position Paper on Education is a fundamental framework of reference.**

**Professionals should be trained in ASD and students with ASD helped to benefit from input from peers.**

**The implementation of recent educational technology and the application of proven educational approaches can make school a productive environment.**

**During the school years the student with ASD must learn the social and practical skills he/she will need in later life.**

### **School-age Children**

At this age the establishment of an appropriate, individually tailored, educational curriculum, will constitute main focus of intervention.

The diversity of students with ASD makes it necessary to have access to a wide spectrum of educational possibilities. Although the European Union favours integration and mainstream school, this must not mean that students are left unsupported with untrained personnel. A balance should be sought for each individual depending on the local conditions and available possibilities, but the 2006 Autism Europe Position Paper on Education constitutes a fundamental framework detailing the way to go ahead.

Clearly, emphasis should be placed on training professionals to understand ASD and helping the child with autism to benefit from the input of other students. There have been significant advances in educational technology over recent years and these deserve to be widely implemented. The application of visually supported learning, making use of information technology, functional curriculum, structuring of time and domestic environment, and peer tutoring can all help to make the school years optimally productive for the child with ASD and for his or her peers.

It is crucial that during the school years the student with autism acquires the skills that will be important in later life. To achieve this it is essential to involve the family, to adapt study materials to suit individual needs, to foster participation between the individual with autism and his or her peers in many different environments and to help establish social networks.

## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

### **Adolescence / Adulthood**

**The treatment plan should focus on the functions needed for the adult with ASD to be independent and participate in the social community.**

**For persons with co-morbid intellectual disability, the personalised plan must reflect chronological age and not only mental age.**

**A variety of services must be available for adults with ASD and reflect the diversity within this group.**

**The personalised 'adult' treatment plan must focus on:**

- **Access to housing/living facilities with a range of support networks**
- **Occupational activities and employment**
- **Ongoing, permanent education**
- **Support in making personal decisions and acting and speaking for one's self; access to legal protection and benefits.**

### **Adolescence and Adulthood**

At this stage the treatment plan should be ecologically-based, leading to the achievement of those functional aspects required for an independent life and for participation in the social community as an adult.

For those individuals with co-morbid intellectual disability it is important that, while considering the limitations posed by mental age, the personalised plan should also be appropriate to chronological age as far as possible.

Adulthood is the longest period of life. It is of paramount importance to ensure that an array of services (based upon an up-to-date knowledge of autism) is accessible to individuals with autism and that these services reflect the flexibility required by the diversity of adults with ASD.

The 'adult' treatment plan must focus on:

- Access to living/housing facilities with a support network ranging from residential care, through sheltered housing options, to intermittent support for independent living.
- Occupational possibilities must also encompass a wide range, including structured day-care centres, sheltered and specialist employment, to fully integrated employment with any necessary additional support.
- The need for on-going, permanent education and access to support to enable participation and inclusion within community life.
- Empowerment for self-advocacy and representation, and, if required, access to the legal protection and benefits established by European laws for citizens with disabilities.

## ***PERSONS WITH AUTISM SPECTRUM DISORDERS***

**Older and retired persons with ASD still need specialist support and an age appropriate plan.**

**At all ages, the focal point should be Quality of Life.**

It is also crucial to recognise that as individuals with ASD grow older and enter retirement, the needs for specialist support will not disappear and an age appropriate plan will have to be developed and maintained.

Emphasis, throughout the whole cycle, should focus on quality of life. The dimensions considered in this concept for individuals with intellectual and developmental disabilities, such as ASD include: emotional welfare, personal development, interpersonal relations, physical welfare, material welfare, self-determination, inclusion and human rights.

## **PERSONS WITH AUTISM SPECTRUM DISORDERS**



**In Europe scientific advances in ASD go hand in hand with the development of the European Union (EU) founded on the principles of the 1997 Amsterdam Treaty that adopts a positive approach to persons in general, and persons with disabilities.**

**Article 26 of the equality section of the 2007 Treaty of Lisbon reviews the integration of persons with disabilities and recognises their right to benefit from measures to ensure their independence, integration and participation in all activities of the community.**

**The Council of Europe resolution ResAP on the education and social inclusion of children and young persons with ASD defines 18 specific recommendations on equality of opportunity and education.**

**Autism Europe has a major role in the European Disability Forum (EDF) and**

### **IMPLICATIONS FOR PRACTICE**

The advancement of science in ASD in Europe proceeds in parallel to the development of the European Union, a multinational structure that according to the 1997 Amsterdam Treaty was founded on the principles of liberty, democracy, respect for human rights and fundamental freedoms, and the rule of law. This approach constitutes a unique venture in the history of the world and fosters a positive consideration of persons in general, and persons with disabilities.

Thus, the Treaty of Lisbon, approved in 2007 and pending ratification by Ireland and the Czech Republic, refers to the Charter of Human Rights, describing six of them: dignity, freedoms, equality, solidarity, citizen's rights and justice. Article 26 of the equality section reviews the integration of persons with disabilities, stating that the Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

The resolution ResAP of the Council of Europe on the education and social inclusion of children and young persons with ASD mandates the member states to adopt legislation and policies to mitigate the effects of the disorder and to facilitate social integration, improve living conditions and promote the development of independence of individuals with this disorder, by providing equality of opportunity and appropriate educational interventions. Eighteen excellent specific recommendations are defined.

Autism Europe adopts the view that persons with disabilities are citizens with equal rights and plays a major role in the European Disability Forum



## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

**believes that persons with disabilities are citizens with equal rights. Equality of opportunity is the objective of the EU disability strategy.**

**Member states have the responsibility to apply the principles defined by the EU.**

**If an individual or organisation believes their rights are not respected, they can submit a complaint to the European Committee of Social Rights.**

**Today the EU is involved in social policy and human rights.**

**Social activism for ASD In the 27 EU countries is needed in the following 3 areas:**

- 1. Multi-agency involvement in lifelong planning. Providers' organisational boundaries need to be removed in order to coordinate all-inclusive services. This is of particular importance at pre-school age and at transition to adult services.**
- 2. Quality in the management of the organisations and systems that provide**

(EDF). Equality of opportunity is the objective of the European Union strategy on disability and several instruments have been established such as the EU Disability Plan to mainstream disability issues into relevant Community policies and to develop concrete actions in crucial areas to enhance the integration of persons with disabilities.

Although the member states have the responsibility to apply, as part of their national policies, the principles defined by the Union, both individuals and organisations can submit a complaint to the European Committee of Social Rights if they consider that their rights are not fully respected.

This framework, established by the Union, constitutes an excellent background in which new advanced State policies can develop. Persons with ASD and their representatives need to remember that today the EU is not only concerned with economic matters, but also with social policy and human rights.

Some degree of social activism for ASD is required in the 27 countries, and there are three particular areas where action is needed.

1. The needs of persons with autism require multi-agency involvement in life long planning. Interagency working is crucial and is particularly important at the pre-school age and at the transition to adult services. In order to provide a comprehensive service statutory, voluntary and independent providers need to link and liaise across organisational boundaries, but in practice, there remain tremendous challenges in most European countries when inter-agency coordination is required.
2. The second aspect relates to pursuing quality in the management of the organizations and systems that provide support. However, the *intention* to improve quality is not enough, and



## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

**support. This must be structured and monitored. A specific European model, the EFQM, defines the fundamental principles of total quality and is suitable in the field of ASD.**

- 3. A person-centred approach: deciding life goals personally (or by an entrusted person), flexible support networks, own budgets. This is the cornerstone for ethically based practice that ensures a person rights and best quality of life.**

**To conclude - persons with ASD are full EU citizens. Support is not charity.**

**Appropriate, high quality support is a right and is also an added value for the community.**

must be linked to the necessary structures and facilities to achieve this. In our field we can profit from a specific European model, the EFQM, that defines the fundamental principles of total quality: leadership and consistency of objectives; client-oriented and result-oriented, development; learning, innovation and continuous improvement; development of alliances; management by processes and facts, and social responsibility.

3. The third aspect refers to the person-centred approach, empowering the person to decide on his or her life goals (or empowering, in the case of associated intellectual disability, his or her friends and legally authorized representatives to do so with justice and respect), with flexible support networks and a personalized budget. This is viewed as the cornerstone for a practice that will ensure each person rights and optimal quality of life, always guided by fundamental ethical guarantees.

To conclude - the time to consider support for persons with ASD as an optional charity is gone. By fostering transnational research and community based universal services, that are affordable, accessible and of high quality, we are not only providing individuals with ASD with the support to which they are entitled as full citizens, but we are also adding economic and societal wealth to the European Union as well as value to our own lives.

## **PERSONS WITH AUTISM SPECTRUM DISORDERS**

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