



PEOPLE WITH AUTISM SPECTRUM DISORDER

IDENTIFICATION, UNDERSTANDING, INTERVENTION

An Autism-Europe
official document

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FOREWORD

OF AUTISM-EUROPE EXECUTIVE COMMITTEE

Autism-Europe (AE) is an international network of around 90 national, regional and local autism organisations from 38 countries representing people on the autism spectrum and their families. AE main objective is to advance their rights to help them improve their quality of life and promote inclusion. Based in Brussels, it ensures effective liaison between its members, European as well as international institutions and other like-minded associations.

This document offers guidance on various key aspects from diagnosis to life-long support in view of promoting an evidence-based and rights-based approach to autism in line with the social model of disability and the UN Convention on the Rights of People with Disabilities. It aims at making evidence-based data derived from European and international research available to the wider public, so as to promote a better understanding of autism and in turn, have a positive impact on the lives of people on the autism spectrum.

Since the first publication of this reference document in 2000, the understanding of autism has greatly evolved but disparities persist in Europe regarding access to evidence-based knowledge. In addition, many research areas remain to be explored more in depth to offer people on the autism spectrum the best possible care and support as well as equal access to opportunities.

The manifestations of autism cover a wide spectrum, with some people requiring an intense level of support. Some people may also have learning disabilities or co-occurring conditions. For a diagnosis to be made, a person will usually be assessed as having had persistent difficulties with social communication and social interaction and restricted and repetitive patterns of behaviours, activities or interests since early childhood, to the extent that these “limit and impair everyday functioning”.

Enabling people on the autism spectrum to live long and fulfilling lives as autonomously and independently as possible, requires a change of mind-set in society to support their active participation and inclusion. It also entails to create and maintain the necessary support services and to foster accessibility for autism across all sectors. In particular, it is essential to consider their health needs beyond their autism diagnosis, as it has been evidenced that they are at increased risk of dying younger from virtually every cause of death. Many factors interfere with adequate access to healthcare. It includes social exclusion, lack of accessibility to health services and lack of awareness of the healthcare professionals, for example about the manifestation of pain and other health problems in people on the autism spectrum. Developing training, making health systems more aware and autism-friendly and designing careful diagnostic procedures for

people on the autism spectrum in all aspects of primary health care, is therefore required.

Each person on the autism spectrum is different, and they may display a range of strengths and abilities that can be directly related to their diagnosis. It is therefore of paramount importance to follow an individualised approach and build on these strengths to support people to develop to the best of their potential. Individual plans should take into account the whole life-span (from infancy to old-age) and special attention should be paid to support people during transition periods. Support should be tailored to maximise the quality of life and outcomes should be measured against the aspirations of each person.

The perspectives of people on the autism spectrum on their current circumstances or future, as well as their personally valued outcomes, should be central to elaborating these plans. They should therefore have choice and control over major life decisions, and their preferences should be respected. To this end, they should receive adequate support for decision-making. It is essential to involve family members, friends, supporters and people who are important to the person whenever needed. The role of families in supporting their relatives on the autism

spectrum should be valued and they should benefit from the necessary assistance to enable them to contribute towards the full and equal enjoyment of their rights.

The words used to describe autism vary across Europe and evolve over time. It is important to use terms that are respectful, positive and acceptable to the autism community. Some people like the term “autistic person”, some prefer “person with autism” or “on the autism (or autistic) spectrum”. Autism-Europe respects this diversity as explained in its acceptable language guidelines. In this publication, the authors have decided to use “autism” throughout the document, instead of “autism spectrum disorder”.

Autism-Europe wishes to express its sincere gratitude to the authors and reviewers of this document. The work generously achieved by these internationally renowned professionals will continue to foster a better understanding of autism. This document is destined not only for people on the autism spectrum and their families but also for all professionals who are working with people on the autism spectrum and for European and national authorities responsible to implement the necessary measures so that they can fully enjoy their rights and participate in society.

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DISCLOSURES OF POTENTIAL CONFLICTS

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This document was kindly reviewed by the following experts, who will prepare its renewed edition for 2024-2025: **Prof. Frédérique Bonnet-Brilhaut** (France), **Dr. James Cusack** (UK), **Prof. Wouter Staal** (The Netherlands), and **Marcos Zamora-Herranz, BS, MS** (Spain).

ABOUT THE TERMINOLOGY AND LANGUAGE USED IN THIS DOCUMENT

This document includes current terminology used in diagnostic manuals. As such, it might not always necessarily reflect the preferences of everyone in the autism community regarding the language to be used to describe autism.

For more information, please refer to:

<https://www.autismeurope.org/about-autism/acceptable-language/>.

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INTRODUCTION

To date no specific biological markers for Autism Spectrum Disorders (from now on referred to as autism) have been identified. So autism continues to be defined in terms of behavioural symptoms. These features are listed in the international diagnostic and classification systems: DSM-5, (American Psychiatric Association), and ICD-11 (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.

This section begins with the diagnostic criteria for autism followed by 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 results 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. Autism is lifelong and, as such, needs will change dynamically and in respect of environmental circumstances.

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 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 autism to fulfil their potential, enhance their happiness and the quality of their lives.

IDENTIFICATION

Clinical presentation

The number of individuals diagnosed with autism has increased significantly over past decades. Although estimates vary it is now generally recognised that prevalence is at least 1%-1.5%. Establishing exact prevalence figures is difficult because of modifications to diagnostic criteria over time and because of the heterogeneity of autism. Thus, severity of autism varies greatly, not only between individuals but also within the same individual over time. Some symptoms may be more prominent and intense at one age but can then fluctuate in nature and severity, leading to very different clinical profiles at different times.

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

Current understanding accepts that there is a significant gender bias in diagnosis. Males outnumber females by around 3-4 to 1 in childhood. However, there is also growing awareness that diagnosis in girls is often delayed and that current diagnostic systems may fail to identify more subtle difficulties in females. Thus, their special interests or preoccupations (e.g. with makeup, fashion or pop and film stars) are more likely to be more socially conventional than those of males; their social aloofness is often attributed to shyness and their capacity for “camouflaging” or imitating socially correct behaviour can also lead to missed or incorrect diagnosis.

Despite this individual diversity, diagnosis, in both ICD-11 and DSM-5, is based on the presence of clinically significant symptoms in two core domains: impairments in reciprocal social communication and the presence of restricted interests and repetitive behaviours. Although there were some differences between these two classification systems in the past, they are now very similar in terms of core features. However, in contrast to DSM-5, ICD-11 criteria do not include hyper- or hypo-reactivity to sensory input, or unusual interests in sensory aspects of the environment. For the convenience of the reader, the DSM 5 and ICD 11 criteria can be found in the appendix of this document.

Other important aspects to be taken into consideration

Individuals with autism are affected by a range of other, co-occurring difficulties. Neurological problems, such as epilepsy are common, especially in individuals with intellectual disability. Recent systematic reviews also highlight the association between autism and mental health problems. These include attention deficit hyperactivity disorder, eating disorders, tics, obsessive-compulsive disorder and a range of affective disorders. Individuals with autism are at particular risk of developing anxiety and depression, which can have a very negative impact on functioning in adulthood. Reported rates of psychotic disorders, such as schizophrenia, are relatively low. A range of other co-occurring conditions has been described including catatonia, substance abuse and addictive disorders (tranquillizers, alcohol, gambling, internet gaming, etc.).

However, estimated rates of such disorders vary widely and it is clear that much more research on their association with autism is needed. More research is also needed into the causes and treatment of chronic and acute physical health disorders, as those are much more frequent in autism than in the general population.

Other commonly associated disorders include, abnormal sleep patterns, feeding and elimination difficulties (sometimes resulting in gastrointestinal disturbances), motor difficulties and behavioural disturbance, including severe tantrums and self-injurious behaviour. Indeed, these non-specific features are often the cause of greatest stress to parents and children/adolescents with autism. As such they should always be given serious consideration.

A thorough assessment of these features and of the sensory-motor integration and capacities is essential. Many such problems, especially those related to poor mental health, may reflect the fact that the environment is inappropriate, or the treatment plan inadequate for someone with autism. In these cases adaptations to the environment and/or careful reappraisal of the intervention programme will be required. In other cases, the associated disorders will need treatment in their own right. The types of problems (anxieties, sleep, tantrum, mood...) may vary according to different developmental stages and are subject to change. Therefore, ongoing monitoring and support around self-management and caregiver management is essential.

Age of onset and impairment

Although, in most individuals, autism is present from birth, the age at which symptoms become clinically evident varies greatly. In severe cases of autism, 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 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.

Finally, it should be noted that autism is not only about impairment and disabilities. Although autism is frequently a clinically impairing disorder, there is no doubt that many individuals with this condition have made significant contributions to the art and sciences. Their better than average performance on cognitive tasks and perseverance may make the difference. For example, it is likely that many scientific and technical developments 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.

Prognosis in autism

Outcome in autism is highly variable. Longitudinal studies indicate that most individuals with autism and severe cognitive and language impairments require specialist educational provision as children and will continue to need support throughout adulthood. Nevertheless, even among individuals of average IQ or above (IQ 70+), outcome is generally poor, and research indicates that fewer than a third of adults achieve a “good” social outcome, in terms of employment, relationships and independent living.

For individuals of higher intellectual ability, the future frequently depends on the levels of support provided to enable them to be fully included in society. Follow-up studies into adulthood suggest that the severity of core autism symptoms decreases over time, and many individuals show marked improvements in social and communication skills as they grow older. Among the strongest predictors of a positive outcome are the development of language and having a non-verbal IQ in or around the average range. Within this more cognitively able group there is a small number of adolescents or young adults who no longer meet diagnostic criteria and show no clear remaining symptoms of autism. However, recent research suggests that they continue to show subtle difficulties in social understanding, pragmatic communication, attention, self-control, emotional maturity and psychiatric morbidity.

UNDERSTANDING

THE MECHANISMS AND CAUSES OF AUTISM

Research findings consistently suggest that neurodevelopmental abnormalities underlie most of the core behavioural, cognitive and socio-emotional characteristics of autism.

The underlying mechanisms

Autism is a developmental disorder characterised by difficulties and/or deficits in processing socially related stimuli. These difficulties affect individuals' perception and understanding of others' thoughts, intentions and emotions (often referred to as an inability to understand minds). Other common areas of difficulty include executive function, which affects planning abilities, flexibility and organisation skills. The DSM-5 diagnostic criteria for autism also highlight sensory processing as a key area of difficulty, affecting visual, auditory, tactile perception and multisensory integration.

Clinical studies focusing on the earliest manifestations of autism in babies indicate evidence of abnormalities in social, visual, vocal, and motor engagement long before diagnosis is confirmed. Neurophysiological and imaging studies have also highlighted abnormalities in the perception and/or processing of faces, voices and movement and in the detection and prediction of change. Current research is exploring how these early

difficulties in primary sensory processes might relate to later deficits in social, cognitive and adaptive behaviour.

Genetic and environmental studies suggest that, in most cases, autism originates prenatally, with the condition resulting from a deviant development of neural circuitry and connectivity in the brain network systems. Findings from both neuroimaging and neurochemistry are suggestive of early brain "network" dysfunction rather than of primary and localized abnormalities.

Possible candidate regions within this neural network have been located and include the cerebellum, the temporal lobe, fusiform gyrus, amygdale, the frontal lobes and the white matter tracts of the corpus callosum. However, using neuroimaging, systematic reviews regularly fail to show any consistent patterns in terms of functional activity.

Research on neurotransmitters has focused mainly on serotonin and dopamine and more recently on the glutamatergic synapses. Oxytocinergic gabaergic neuromodulating systems are also candidates. These observations raise interest in the development of animal models and pharmacological research.

What is known of the causes?

Genetic factors are strongly implicated in the development of autism. However, the clinical heterogeneity of the condition reflects the complexity of underlying causes, involving genes, the environment and gene-environment interactions. Cases of autism can be associated with specific genetic disorders (Fragile X syndrome, neurofibromatosis, tuberous sclerosis, Angelman syndrome, Cornelia de Lange, Down Syndrome, untreated phenylketonuria), chromosomal rearrangements (detectable by standard genetic examinations) or rare environmental events (prenatal CNS infection by rubella or cytomegalovirus, prenatal exposure to valproic acid or thalidomide).

Genome-wide assessment techniques have allowed the identification of very small deletions and duplications, and have identified a large number, several hundreds, of potentially important candidate loci. These techniques also suggest that in many cases *new* genetic mutations may be a causative factor, and that not all cases result from inherited factors.

The genetic research does not exclude the role of environmental risk factors - neuroinflammation, viruses, toxins, etc. - during pregnancy. However, the exact nature of the factors leading to a greater susceptibility to autism is currently unknown. Premature birth is recognised as an important risk factor, as are certain drugs given to the mother during pregnancy, such as sodium valproate. Parental age may also be important.

New research strategies are now being developed to better identify neurodevelopmental trajectories and pathophysiological processes in autism, as well as possible compensatory mechanisms. In particular these are focusing on several developmental windows and pivotal periods including the pre-and perinatal period, childhood, adolescence, adulthood.

Multiple approaches are necessary to advance our understanding of the genetic/environmental and epigenetic factors underlying autism. Recruitment of large, well-characterised patient cohorts as well as single cases, where a major gene effect can be identified, is needed to progress knowledge of the behavioural, cognitive and socio-emotional mechanisms involved in autism.

Continuing research in this field is crucial and parents' associations currently encourage participation in scientifically sound and ethically acceptable projects. On the condition that appropriate bioethical committees, in which they are involved, 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.

EARLY DETECTION AND DIAGNOSTIC ASSESSMENT

The principal Characteristics of autism are described in the attached appendix. In the first months of life there may be no obvious signs of abnormality, but very early limitations in some of the following areas should prompt referral for a general developmental assessment. These symptoms must be present in early childhood, but may not become fully manifest until social demands exceed capacities.

It is very important to recognise there is not a single symptom that indicates individually autism (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 autism will share the constellation of core socio-communication and behavioural symptoms.

Communication: e.g. impaired understanding; failure to respond to name; 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; ritualised or stereotyped patterns of verbal or nonverbal behavior.

Social: e.g. limited 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 appropriately to emotions in others; failure to express emotional warmth or pleasure; lack of sharing interest or enjoyment.

Repetitive and stereotyped interests: e.g. motor mannerisms or body posturing; resistance to change; repetitive use of objects; repetitive play; excessive adherence to routines; highly restricted interests that are abnormal in intensity or focus.

Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment.

Early signs

Studies have found that these are some of the early signs of autism, although, individually, they are not reliable indications in their own right.

- **Does not respond to their name by 12 months of age**
- **Does not point at objects to show interest (point at an airplane flying over) by 14 months**
- **Does not play “pretend” games (pretend to “feed” a doll) by 18 months**
- **Lack of eye contact and prefers to be alone**
- **Has trouble understanding other people’s feelings or talking about his or her own feelings**
- **Has delayed speech and language skills**
- **Repeats words or phrases over and over (echolalia)**
- **Gives unrelated answers to questions**
- **Gets upset by minor changes**
- **Has intense and focused interests**
- **Flaps their hands, rocks their body, or spins in circles**
- **Has unusual reactions to the way things sound, smell, taste, look, or feel**

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 immediate intervention is put into place to meet these needs.

The general assessment should include:

- **a detailed history of all the signs that cause concern to parents or relatives.**
- **a developmental history (including ante- and pre-natal history and any relevant family history). In the case of adults (late diagnosis), this information may not be available and may need to be substituted by self-report or information from other sources, and by assessment of current functioning.**
- **medical, psychological and psychiatric examination.**
- **assessment of family/ personal circumstances and needs.**

If the general developmental survey indicates the need for an autism specific assessment, further screening instruments may be employed. These vary in terms of age range, length and source of data (i.e. direct observation or responses from parents or professionals); many are brief, taking less than 20 minutes to complete, and most are inexpensive or free. Some are available in different languages and while the majority focus on children, a few are also appropriate for adults.

The purpose of these screening instruments is to alert relevant professionals to the possibility of autism; they are not designed to confirm diagnosis. Moreover, not all individuals with autism do score positively on these instruments, and failure to meet cut-off criteria does not **necessarily** mean that an autism diagnosis should be excluded. If other sources of information indicate developmental delay or disturbance, a full diagnostic assessment is still warranted.

The best validated screening tools in young children are the MCHAT R/F (Modified Checklist for Autism in Toddlers, Revised, with Follow-Up), CHAT (Checklist for Autism in Toddlers), STAT (Screening Tool for Autism in Toddlers & Young Children), and CSBS (Communication and Symbolic Behavior Scales Developmental Profile). In older children and adults, the better-known instruments are SCQ (Social Communication Questionnaire), CAST (Childhood Autism Spectrum Test), SRS (Social Responsiveness Scale), AQ (Autism Spectrum Quotient), and RAADS-R (Ritvo Autism Asperger Scale, Revised).

Assessment process in children

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

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

The assessment itself should include:

1) Standardised autism specific assessment.

Among the best validated of such assessments are the ADOS-2 (Autism Diagnostic Observation Schedule); the ADI-R (Autism Diagnostic Interview, Revised); the DISCO (Diagnostic Interview for Social and Communication Disorder); and the Developmental, Dimensional and Diagnostic Interview (3di). Other assessments include the BSE (Behavioural Summarized Evaluation) and the CARS (Childhood Autism Rating Scale).

It is recognized that not all services will have access to these specialised instruments. The cost and time involved in completing such assessments may also be impractical for some hard-pressed/ more economically disadvantaged 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 autism (communication, social and repetitive/stereotyped behaviours) and that interviews are conducted in as systematic and structured way as possible. Nevertheless, it is important to recognise that no single instrument should be used, in isolation, to make a diagnosis. A valid diagnosis depends on expert clinical judgement based on information gathered from all relevant sources.

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 package of tests, which span the age ranges from 3 to 60+. For younger children, the Mullen Scales of Early Learning, the Merrill-Palmer Revised Scales, or the Bayley Scales may prove useful.

3) Adaptative assessment

Many times functional abilities do not match with cognitive abilities in people with autism. In spite of high cognitive abilities, many people with autism show daily living adaptative difficulties. In order to diagnose a co-occurring intellectual disability, it is important to assess adaptative behavior, besides a cognitive assessment, as it is established on the diagnostic criteria for Intellectual disability. Standard test culturally adapted should be used, such as Vineland Adaptative Behavior Scales or ABAS II.

4) Communication 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. Language assessment is necessary to consider if there is a co-occurring language impairment. In non-verbal individuals, the possibility of using augmentative/alternative communication strategies (such as using pictograms) to assess comprehension and expressive language should be explored. Assessments of play ability may also provide valuable information on the child's "internal language" or imaginative ability.

5) 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.

Problems related to sensory processing are now recognised as a core difficulty in autism. These vary widely across individuals and across sensory modalities, and include both hypo- and hyper-sensitivities to sensory stimuli. Such difficulties can be very disruptive of daily life and are often associated with emotional and behavioural problems. At present, the validity and reliability of standardised instruments to detect abnormalities in sensory processing is limited but careful, systematic questioning should help to identify difficulties.

It has been estimated that up to 50% of individuals with autism show difficulties in both gross and fine motor skills, including motor delays, motor coordination and planning, imitation of body movements, perceptual-motor problems, and postural control. There are few comprehensive and/or well validated assessments of motor difficulties in autism, although the Vineland includes some assessment of motor skills in younger children. Otherwise, again, careful observation and systematic questioning are needed to help identify the presence of problems in these domains.

A clinical neurological examination should be conducted in all children, with additional tests, such as diverse methods of neuroimaging, or EEG (electroencephalogram), if these are warranted. More sophisticated (and now relatively inexpensive) genetic tests, such as CGH arrays (molecular systems to identify genetic variations), are becoming more common in most European countries.

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.

6) Behaviour and mental health assessment

The assessment should cover behavioural and psychiatric symptoms (e.g. Anxiety, Mood disturbance, Attention Deficit Hyperactivity Disorder, Impulsivity, Conduct Disorder, Obsessive-Compulsive Disorder, Tics, etc.) especially in school age children. A functional analysis of the underlying causes of behavioural problems can establish why, when and where difficulties occur, and in suggesting alternative approaches, and environmental modifications that will help individuals with autism to cope more effectively with the challenges they experience.

7) 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.

Assessment process in adults

The same basic assessment procedures as recommended for use in children should be adopted when establishing a diagnosis of autism in adults. The challenge lies in that almost all diagnostic instruments were initially developed for children not adults. Moreover, in adulthood, autism symptoms may be less evident than in childhood, especially in individuals of higher intellectual ability who have learned ways of circumventing or disguising some of their difficulties. Additional problems, such as challenging or traumatic life events, depression or anxiety can further

complicate the clinical picture. Information on past contact with child services, indications of earlier neurodevelopmental problems, and assessment of current functioning (especially when functional ability is out of synchrony with cognitive level) can also help to clarify diagnosis.

We know that it is essential to identify co-occurring disorders, both physical and psychiatric, in adults since they typically access health care less than the general population and also have a higher risk of premature death.

In summary, the diagnosis of autism 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 the individual meets criteria for autism, but to ensure that this process leads to support and interventions that are appropriate for the age, needs and wishes of the person, and those closest to him or her, in order to optimise quality of life.

INTERVENTION AND SUPPORT

There are no miracle treatments for autism. However, appropriate, lifelong educational approaches, support for families and professionals, and provision of high quality community services can improve the lives of all individuals with autism and their families.

Since the first Autism-Europe description of autism, published in 2000, we now have access to good-practice guidelines, produced by international expert committees, that have systematically reviewed evidence for the multiplicity of treatments advocated for autism. In Europe, these include the National Institute of Health of Spain, UK National Institute for Clinical Health and Excellence (NICE) and the Scottish Intercollegiate Guidelines Network. Similar guidelines have been published in the U.S.A., Canada, France, Australia and New Zealand. The UK Department for Education and Skills has also produced guidance for the education of students with autism.

On the basis of this evidence we have now established a shared vision of how people with autism should be supported and what interventions should be available. Consequently, individuals and organisations that propose radically contrary approaches must assume the moral and legal responsibility that results from practicing outside the frameworks endorsed by prestigious international and representative professional bodies. Failure to attend to evidence based guidelines can result in discrimination against citizens with autism, and may prevent them

from accessing their basic human rights to health and education.

We have learned much over recent years about interventions that are supported by scientific knowledge and those that are not, and about which programmes can make a real difference to the lives of individuals with autism. Unfortunately, this knowledge has not yet been incorporated into general practice across Europe. Thus, there remains an unacceptable and unethical gap between knowledge and opportunities, and it is still evident that very few European citizens with autism receive the state-of-the-science support to which they are entitled.

Recent reviews of interventions for autism conclude that relatively few meet the methodological standards required for assessing medical or pharmacological treatments. Nevertheless, evidence for a range of psycho-social interventions is improving, with growing numbers of well-conducted comparison studies. Randomised control trials, considered the “gold standard” in medical research, are also increasing. However, most research still focuses on 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. More research is needed, too, on the characteristics of individuals for whom treatment does, or does not work, and on types of intervention that are most

effective for families and children from socially disadvantaged or minority racial/ethnic groups. 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 autism themselves on whether treatment has helped to enhance self-esteem, self-determination and social inclusion.

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

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

However, there are many other elements that have the potential to enhance effectiveness and improve longer term outcome.

- Education – this should be available as early as possible and focus on social, communication, academic and behavioural development, and the acquisition of daily living skills. Education should be provided in the least restrictive environment by staff who have knowledge and understanding both of autism and the individual student.

- Accessible community support should be available from appropriate, well-informed multi-agency services, that will help all individuals to realise their potential and life-time goals (either chosen by the individuals themselves, or those who know, love and legally represent them).
- There should be access to the full range of psychological and medical treatments available to the general population. Autism is associated with a wide range of physical and mental health conditions that can result in premature mortality. Improvements in all health services, including the provision of regular monitoring and preventative care, are needed if people with autism are to maintain good health and reduce the risk of early death due to conditions such as epilepsy or suicide.

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

1. **Individualisation:** There is no single treatment that is equally effective for all people with autism. Diversity in the spectrum, and in individual skills, interests, life vision and circumstances, mandate a personalised approach to intervention and support.
2. **Structure:** This requires adapting the environment to maximise each individual's potential by offering 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:

Therapeutic interventions should not be sporadic or short term, nor based on a pre-determined number of hours or sessions of treatment. Instead intervention strategies should be 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 maximises the likelihood that skills acquired in structured treatment settings can be maintained in real life. Those responsible for carrying out the intervention should also have access to appropriate support and guidance from professionals with expertise in autism.

4. **Family participation:** throughout childhood and beyond, parents must be recognised and valued as the key elements of any intervention. Information, training and support should always be provided within the context of family values and culture. Other important supports, including child care, respite facilities and short breaks, and tax and other financial benefits, should be available to avoid the discrimination that many families still face across Europe. Adequate support from social, medical and educational services is necessary to ensure that they are able to enjoy the same quality of life as other citizens.

For those interested in the above mentioned European guidelines, and information about specific interventions, these can be downloaded for free via the internet (see reference section on Sources of Information). There are now different guidelines available in English, Spanish, French, Hungarian, and German.

THE SUPPORT PLAN SHOULD EVOLVE AS THE INDIVIDUAL PROGRESSES THROUGH 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 closely as possible.

As soon as diagnosis is made, a thorough functional assessment should be completed and a treatment plan implemented. Several studies now demonstrate the potential benefits of early intervention, although there is great variation in outcome. Parents need continuous information and personal support post-diagnosis, and organisations such as local or national parents' associations can also provide valuable social and practical support.

Help and guidance for families, and good pre-school provision, can play a significant role in reducing early social difficulties by encouraging imitation, shared attention and play, promoting communication and fostering the development of social skills. There are many other aspects to be considered in the personalised plan of young children with autism. In particular, attention should be given to crucial aspects of daily life at this age, such as feeding, eating, toilet training, sleep, and behaviour.

There is also a real need and increasing evidence for home-based intervention, something rarely available in the majority of European countries.

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 autism requires the provision of a wide spectrum of educational possibilities. There is no clear evidence for the superiority of any single model of schooling, and placement in mainstream school without appropriate support can be highly damaging. Thus, although the European Union favours integration and mainstream schools as the basis for an inclusive society, this must not mean that students are left unsupported with untrained personnel. A balance should be sought for each individual depending on locally available provision and the 2006 Autism-Europe Position Paper on Education provides an essential framework for the way forward.

Emphasis should be placed on training professionals to understand autism and helping the child with autism to benefit from the input of other students. Strategies that can help to make the school years optimally productive include the provision of a structured curriculum with a focus on social communication and the acquisition of functional and practical skills; the application of visually supported learning, and peer tutoring. Advances in educational technology (computers, tablets, mobile phones, robots etc.) also have potential for enhancing learning. However, over-reliance on computerised teaching methods can reduce teacher-child interaction and may impair progress.

There is little evidence for the effectiveness of sensory integration therapy, but environmental modifications to the

classroom (to sound, lighting, equipment etc.) can significantly reduce problems related to sensory reactivity.

It is crucial that during the school years' students with autism acquire the skills needed 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 pupils with autism and their peers in many different environments, and to help establish social networks.

Adolescence and adulthood

At this stage, the treatment plan should be ecologically-based, leading to the acquisition of the functional skills needed to enhance adult independence and participation in the social community. This is also the time to maximise opportunities for developing special strengths and interests and to ensure that social and academic provision is focussed on individual attainments that will enhance future quality of life.

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

For individuals who develop behaviours that challenge, the focus should be on exploring environmental factors that are causing or maintaining the behaviour. Appropriate modifications to the environment, and the teaching of skills that can help facilitate behavioural change can significantly reduce such problems.

Mental health difficulties, particularly anxiety and depression, are a major risk for adolescents and adults with autism. Intervention may involve cognitive behavioural strategies, social skills programmes, and combinations of educational, psychological and medical treatments. Because the effectiveness of mental health interventions is highly variable there is need for a more personalised approach to treatment according to individual and environmental factors.

Medication may be considered if psychosocial or other interventions, based on a detailed functional analysis of problems, prove ineffective. However, if medication is necessary this should be prescribed by a specialist, reviewed regularly, and discontinued if there is no indication of a clinically significant response within the time specified for a particular medication. Particular care should be taken around the use of psychotropic medication, given their side effect profile and the need to reduce their usage when possible.

Medication should NOT be used to treat the core symptoms of autism. Many other “alternative treatments”, including neuro-feedback; facilitated communication, auditory integration training, omega3 fatty acids; secretin; chelation; hyperbaric oxygen therapy; transcranial magnetic stimulation; intranasal oxytocin; probiotics, and/or exclusion diets have no place in the treatment of core autism features.

Adulthood is the longest period of life. Thus, it is of paramount importance to ensure that an array of autism-appropriate services is accessible and that these reflect the flexibility required by the diversity of adults with autism.

The ‘adult’ treatment plan must focus on:

- Access to living/housing facilities with a support network ranging from residential care, through sheltered housing options, intermittent support for independent living or fully independent community housing.
- Occupational possibilities must also encompass a wide range, from structured day-care centres, sheltered and specialist employment schemes, integrated employment with any necessary additional support, to a fully independent career.
- The need for on-going, permanent education and access to support to enable participation and inclusion within community life.
- Empowerment for self-determination and representation, and, if required, access to the legal protection and benefits established by European laws for citizens with disabilities. Individuals with autism should be included as fully as possible in the executive committees of autism societies and relevant education, health and social care providers, and should play an active role in organisations responsible for setting service and research priorities and in designing, funding and monitoring research.
- Finally, it is crucial to recognise that as individuals with autism grow older and enter retirement, the need for friends and peers, the good self-management, and the specialist support will continue, and an age appropriate plan must be developed and maintained.

Emphasis, throughout the whole cycle, should be laid on quality of life. This encompasses many different dimensions including emotional, physical and material welfare, personal development, interpersonal relations, self-determination, inclusion and human rights. However, it is important to recognise that concepts of a “good” quality of life for someone with autism may differ from those of the “typical” population.

The essential need is to ensure that each individual is helped, at all stages of life, to choose goals that are appropriate for his or her well-being and is provided with the means of successfully attaining those goals.

IMPLICATIONS FOR PRACTICE

In Europe, the scientific advances in the field of autism proceeds in parallel to the development of the European Union, a multinational structure that according to the 1997 Amsterdam Treaty were founded on the principles of liberty, democracy, respect for human rights and fundamental freedoms, and the rule of law.

In line with this spirit, the European Union ratified the UN Convention on the Rights of People with Disabilities (UNCRPD) in December 2010, becoming party to an international human rights treaty for the first time in history. The UNCRPD is the first international legally binding instrument setting minimum standards for the rights of people with disabilities. Every EU country has signed and ratified the UNCRPD, with 22 EU countries having also signed and ratified its Optional Protocol. This means that the EU itself and its Member States are committed to upholding and protecting the rights of persons with disabilities. At the EU-level, the European Disability Strategy is the main vehicle to deliver on the objectives of the UNCRPD.

At the European level, Autism-Europe advocates for people with autism by liaising

with EU institutions to ensure they are adequately considered when implementing the UNCRPD. It also cooperates closely with the European Disability Forum (EDF), and other human rights organisations to achieve this goal.

The Council of Europe (CoE) has also taken specific measures to support the rights of people with autism, such as the adoption of the resolution ResAP (2007) on the education and social inclusion of children and young people with autism.

It mandates that CoE member states adopt legislation and policies to facilitate social integration, improve living conditions, and promote the development of independence of individuals on the autism spectrum, by providing equality of opportunity and appropriate educational interventions, through eighteen recommendations.

People with autism and their representatives need to remember that today the EU is actively supporting the rights of people with disabilities. Therefore, social activism for autism is required across Europe and there are three particular areas to be considered.

1. The needs of people with autism require multiagency involvement and lifelong planning. Inter-agency cooperation is crucial and is important throughout the lifetime of autistic people, highlighted at various stages: the pre-school stage, the school stage, the transition to adulthood, and adult support services (including for the elderly). In order to provide comprehensive services, statutory, voluntary, and independent providers need to liaise across organisational boundaries. In practice, there remain tremendous challenges in most European countries where inter-agency coordination is required.
2. The second area relates to pursuing quality in relation to the management of the organisations and systems that provide support. However, having the *intention* to improve quality is not enough on its own, and must rely on structures and facilities to achieve this. In our field, we can profit from a specific European model, the European Foundation for Quality Management (EFQM) defines the fundamental principles of total quality. In practice this means, 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 area refers to the person-centred approach. To empower the individual to decide on their life goals (or being empowered – in the case of people with associated intellectual disability – through the support of their friends and legally authorized representatives), with flexible support networks and a personalised budget. This is viewed as the cornerstone for this practice that will allow all people to fully enjoy their rights and optimal quality of life guided by fundamental ethical guarantees.

To conclude, the time to consider support for people with autism as something ‘optional’ or seen as an just an occasional charitable side issue is gone. By fostering transnational research and community-based universal services, that are affordable, accessible and are of high quality, we are not only providing individuals on the autism spectrum with the support to which they are entitled to as full citizens, but we are also adding economic and societal wealth to the European Union as well as value to our own lives.

APPENDIX -

DIAGNOSTIC CRITERIA

DSM-5

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders published in 2013 notes that autism spectrum disorder is characterised by:

"A. **Persistent deficits in social communication and social interaction across multiple contexts**, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

"B. **Restricted, repetitive patterns of behavior, interests, or activities**, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

"C. **Symptoms must be present in the early developmental period** (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

"D. **Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.**

"E. **These disturbances are not better explained by intellectual disability** (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level."

ICD-11

The 11th edition of the International Classification of Diseases and Related Health Problems, 2019, notes that:

"Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests".

The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities.

Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities."

ICD-11 also notes that there are several sub-types of autism spectrum disorder, depending on levels of intellectual and language development. This encompasses the whole range of ability, from individuals with high IQ and good language to those with intellectual disability and no functional language,

Disorder of intellectual development Impairment of functional language

6A02.0	<i>Disorder not present</i>	<i>Not present or Mild impairment</i>
6A02.1	Disorder present	<i>Not present or Mild impairment</i>
6A02.2	<i>Disorder not present</i>	Impairment present
6A02.3	Disorder present	Impairment present
6A02.4	<i>Disorder not present</i>	Absence of functional language
6A02.5	Disorder present	Absence of functional language

- "6A02.0 Autism spectrum disorder All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behaviour are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is only mild or no impairment in the individual's capacity to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
- "6A02.1 Autism spectrum disorder with disorder of intellectual development and with mild or no impairment of functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is only mild or no impairment in the individual's capacity to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
- "6A02.2 Autism spectrum disorder without disorder of intellectual development and with impaired functional language. All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behaviour are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is marked impairment in functional language (spoken or signed) relative to the individual's age, with the individual not able to use more than single words or simple phrases for instrumental purposes, such as to express personal needs and desires.
- "6A02.3 Autism spectrum disorder with disorder of intellectual development and with impaired functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is marked impairment in functional language (spoken or signed) relative to the individual's age, with the individual not able to use more than single words or simple phrases for instrumental purposes, such as to express personal needs and desires.
- "6A02.4 Autism spectrum disorder without disorder of intellectual development and with absence of functional language. All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behaviour are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is complete, or almost complete, absence of ability relative to the individual's age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
- "6A02.5 Autism spectrum disorder with disorder of intellectual development and with absence of functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is complete, or almost complete, absence of ability relative to the individual's age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.

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THE SUPPORT PLAN SHOULD EVOLVE AS THE PERSON GOES THROUGH THE LIFE CYCLE

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IMPLICATION FOR PRACTICE

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EASY

TO READ



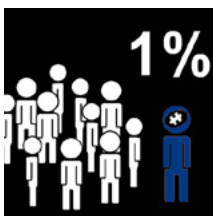
This book is about what autism is.



It is about what people with autism need to have a good life.



Autism is a disability.



1 person in 100 people has autism.



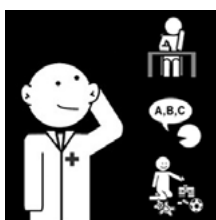
Every person with autism is different.



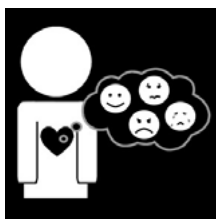
The doctor needs to look at many things to make a diagnosis.



Diagnosis is when the doctor finds out what is happening to someone.



The doctor looks at how somebody learns, speaks and does things.



People with autism find it hard to understand how other people think or feel.



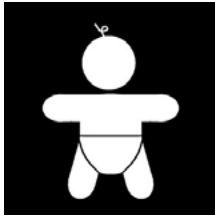
People with autism can find it hard to plan their day.



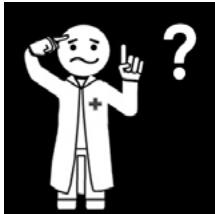
People with autism can find it hard to be flexible when there is change.



People with autism can have problems with the way they see, hear, or touch the world around them.



Autism starts when you are baby.



But it is not always possible to find out if a baby has autism.



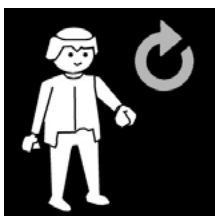
Babies with autism do not react to their names.



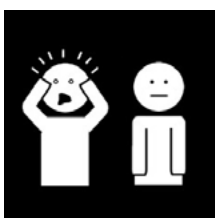
They do not play with other children.



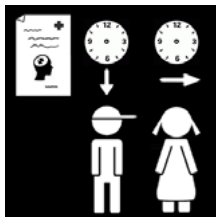
They do not show emotions in the same way as other babies.



They can play with the same object over and over.



Babies with autism can react too much or react too little to things around them.



Girls with autism are often diagnosed later than boys with autism.



People with autism have special interests.



Special interests means someone likes something very much.



People with autism repeat the same thing too much.



People with autism often have more health problems.



People with autism often have problems sleeping, stomach problems, and problems with their movement.



People with autism can get very angry or hurt themselves on purpose.



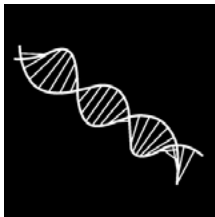
To avoid these problems,
it is important that people with autism
get the right type of care.



Some people with autism can do
amazing things in their lives.



Scientists want to know
why people have autism.



Our bodies have “genes” that
we get from our parents.



Our genes are what makes us look and
behave in our own way.



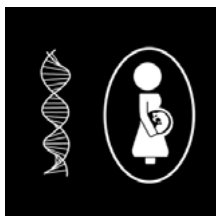
That is why genes play a role
in having autism.



The study of genes is called genetics.



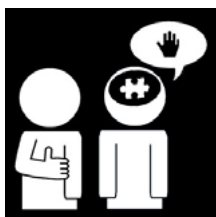
The study of genetics is really important to understand autism.



Scientists look at genes and the world around the mother when expecting the baby.



Research must be ethical.



Research is ethical when it respects the rights of the person.



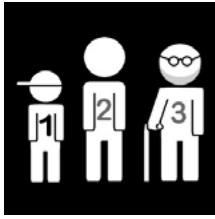
Rights are legal things you can or cannot do.



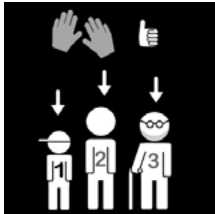
Autism is not caused by the way the parents treat their child.



It is important that people with autism and their families get support to live their best life.



Support for people with autism is different at each age of their lives.



It is very important to give the right type of support at the right time.



It is important to follow some rules to help people with autism in the right way.



Every person with autism needs to choose what they want in life and what support they need.



Today, more people know about autism in Europe.



The European Union is a group of 28 countries from Europe.



The European Union makes laws to defend people with disabilities.



Laws are rules all people and countries must follow.



Autism-Europe tells the European Union about autism in Europe.



Autism-Europe is a European organisation.



Autism-Europe asks the European Union to respect people with autism and their families.



Autism-Europe helps find common solutions to common problems.

Disclaimer:

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