



AUTISM EUROPE  
aisbl

# The Right to Healthcare and Habilitation for Persons with ASD

A toolkit for parents, self-advocates  
and advocacy organisations



For Diversity



Against Discrimination

The information contained in this publication does not necessarily reflect the position or opinion of the European Commission

Cover pictures from Autismo Burgos



## TABLE OF CONTENTS

---

<b>AUTISM-EUROPE AISBL</b> .....	5
<b>ACKNOWLEDGEMENTS</b> .....	6
<b>USING THE TOOLKIT</b> .....	7
<b>CHAPTER 1 - ABOUT AUTISM SPECTRUM DISORDERS</b> .....	8
<b>CHAPTER 2 - KEY ISSUES IN THE FIELD OF HEALTHCARE IN ASD</b> .....	9
A. General healthcare needs .....	9
B. Specific healthcare needs .....	10
C. Habilitation needs .....	11
D. Role of families .....	12
E. Role of healthcare providers .....	12
Conclusions .....	13
<b>CHAPTER 3 - WHY ACTION IS NEEDED TO PROMOTE THE RIGHT TO HEALTHCARE FOR PEOPLE WITH ASD</b> .....	14
A. General healthcare. ....	14
B. Diagnosis .....	15
C. Habilitation .....	16
<b>CHAPTER 4 - INTERNATIONAL LEGAL FRAMEWORK IN THE FIELD OF HEALTHCARE</b> .....	18
A. The Rights-Based Approach to Disability. ....	18
B. European instruments .....	19
a) The European Convention on Human Rights .....	19
b) The Revised Social Charter .....	19
c) The EU Charter of Fundamental Rights .....	19
C. UN Instruments.....	20

a) UN Declaration on the Rights of Mentally Retarded Persons .....	20
b) UN Declaration on the Rights the Rights of Disabled Persons .....	20
c) UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities .....	20
d) UN Convention on the Rights of Persons with Disabilities .....	23
The Right to Health and (re)Habilitation in the UN Convention .....	24
• Right to Health .....	24
• Right to (Re)Habilitation .....	24
<b>CHAPTER 5 - HEALTHCARE AS A POLICY ISSUE .....</b>	<b>25</b>
<b>CHAPTER 6 - THE EVIDENCE-BASED APPROACH IN THE FIELD OF ASD .....</b>	<b>28</b>
<b>ANNEXES .....</b>	<b>32</b>
Annex 1 : Case studies – Examples of Best Practices in the Field of Services .....	33
Annex 2 : Quality Indicators of Services for Persons with ASD .....	46
Annex 3 : Hungarian National Autism Strategy published in 2008 .....	59
1. Introduction.....	61
Executive Summary.....	61
2. Medium-term Action Plan .....	64
3. The Provisional Operation of the Autism Professional Workshop (Responsibility: Ministry of Social Affairs and Labour; Deadline: 31st May,2009 .....	68
4. Ensuring Professional Screening and Diagnosis of ASD (Responsible: Ministry of Health; Deadline: 31st December, 2010 .....	70
5. Improving Autism-specific Development and Educational Services (Responsible: Ministry of Education and Culture; Deadline: 30th September, 2013 .....	74
6. Operating an Adult Training Model Program (Responsible: Ministry of Social Affairs and Labour; Deadline: 30th November, 2008.....	80
7. Supplying Autism-specific Professionals (Responsible: Ministry of Social Affairs and Labour, Ministry of Education and Culture; Deadline: 31st December 2013 .....	82
8. Ensuring Autism-specific Employment (Responsible: Ministry of Social Affairs and Labour; Deadline: 31st December 2009 .....	86
9. Family Support (Responsible: Ministry of Social Affairs and Labour; Deadline: 31st August, 2009 .....	89

## Autism-Europe AISBL

---

**Autism-Europe aisbl** is an international association whose main objective is to advance the rights of persons with autism and their families and to help them improve their quality of life.

Autism-Europe ensures effective liaison among more than 80 member associations of parents of persons with autism in 30 European countries, including 20 Member States of the European Union, governments and European and international institutions.

Autism-Europe plays a key role in raising public awareness, and in influencing the European decision-makers on all issues relating to autism, including the promotion of the rights of people with autism and other disabilities involving complex dependency needs.

In order to implement its objectives and maximised its impact on EU policies, Autism-Europe has built strategic alliances with European social partners. Autism-Europe holds the vice-Presidency of the European Disability Forum (EDF). Autism-Europe is also a member of the European Coalition for Community Living (ECCL) and the Platform of European Social NGOs.

Autism-Europe has established a structured dialogue with the European Institutions and is also active towards the World Health Organisation (WHO).

## Acknowledgements

---

*This Toolkit is supported under the European Community Programme for Employment and Social Solidarity - PROGRESS (2007-2013).*

*This programme is managed by the Directorate-General for Employment, social affairs and equal opportunities of the European Commission. It was established to financially support the implementation of the objectives of the European Union in the employment and social affairs area, as set out in the Social Agenda, and thereby contribute to the achievement of the Lisbon Strategy goals in these fields.*

*The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies, across the EU-27, EFTA-EEA and EU candidate and pre-candidate countries.*

*PROGRESS mission is to strengthen the EU contribution in support of Member States' commitment. PROGRESS will be instrumental in:*

- *providing analysis and policy advice on PROGRESS policy areas;*
- *monitoring and reporting on the implementation of EU legislation and policies in PROGRESS policy areas;*
- *promoting policy transfer, learning and support among Member States on EU objectives and priorities; and*
- *relaying the views of the stakeholders and society at large*

For more information see:

<http://ec.europa.eu/progress>

## Using the Toolkit

---

This toolkit develops the previous documents of Autism–Europe on health issues, including the Position Papers “Autism and Health (2003) and “ A Rights-based, Evidence-based Approach to Autism Spectrum Disorders”, adopted by Autism-Europe, the European Society for Child and Adolescent Psychiatry – ESCAP - and the International Association of Child and Adolescent Psychiatry and Allied Professions – IACAPAP - at the VIII International Congress of Autism-Europe, Oslo, 2007, in the light of the new perspective to healthcare and rehabilitation enshrined in the UN Convention on the Rights of Persons with Disabilities (2007).

The present document is not intended to advise on how quality health and habilitation services for persons with ASD can be developed. It can, however, provide some ideas that can be useful to anyone wishing to advocate for the right to healthcare and habilitation of persons with Autism Spectrum Disorders, as well as to provide parents with some information that can help them to get the best possible care for their children with ASD.

Chapters 1 to 3 recall the main features of ASD, their consequences in the field of healthcare and habilitation and why the promotion of the rights to healthcare and habilitation are key issues for persons with ASD.

Chapter 4 takes you through the main legal instruments dealing with the right to healthcare at European and International level. Chapter 4 then goes on to the right to healthcare and habilitation as stated in the UN Convention on the Rights of Persons with disabilities.

Chapter 5 analyses why and how healthcare should be considered a policy issue and discusses the role and the responsibilities of families and advocacy organisations in developing policy actions in the field of best healthcare and habilitation.

Chapter 6 explains why the evidence-based approach is a key element of the right to health and habilitation of persons with ASD, and provides some suggestions aimed to help them and their parents in their choice of reliable intervention.

The toolkit has three annexes. The first reports case studies ensuing from the concrete experiences of the members of Autism-Europe in the field of healthcare provision and services. The second lists quality indicators of services for persons with ASD that were drafted by the members of the Council of Administration of Autism-Europe in 2007. The third is the strategy drafted by the Hungarian Association for People with Autism (AOSZ). The 5-years Strategy for Autism was commissioned by the Ministry of Social Affairs and Labour and drafted by experts as a recommendation under the supervision of the Hungarian Autistic Society. The strategy aims at improving care for persons with ASD notably by developing specific services for persons with ASD and improving diagnosis, as well as access to education (including training for adults). One of the objectives is also to train staff to care for persons with ASD and to provide support for families. Another target is to develop employment opportunities for persons with ASD.



ASDs are serious brain development disorders. 1 person in about 150 has some type of ASD. The condition can be seen in very young children everywhere in the world and lasts through the life span.

ASDs create difficulties in speaking, understanding and thinking, as well as in relationships with others.

Children with ASD also exhibit strange behaviours and interests. Most of them have learning difficulties.

Early detection is very important and educational intervention should begin as soon as possible to help children with ASD develop their language, social and adaptive skills and reduce their strange behaviours.

Intervention must be Intensive, long-term, and specialised. It must be adapted to the individual and involve the family.

Adolescents and adults also need quality interventions to develop the functional skills and behaviours necessary to live as independent a life as possible in their communities.

Medications can also help reduce strange behaviours and improve quality of life. They cannot cure ASD.

## Chapter 1 - About Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) or Pervasive Developmental Disorders (PDD) are early-onset neurobiological conditions that share fundamental impairments in social reciprocity, pragmatic and semantic communication, reactions to environmental stimuli, and the nature of preferred interests and activities. Although there is a broad range of cognitive, linguistic, and adaptive functioning across the autism spectrum, impairments in social understanding and communication are universally present and impact severely the learning and adaptive capacities of the affected persons.

ASDs result from abnormal brain development beginning early in gestation, and, although some of the manifestations of autism may improve over time, the condition persists throughout life. Recent reviews indicate that as many as 6/1000 individuals may have some type of autism spectrum disorder.

Manifestations of impairments associated with the autism spectrum depend on the individuals' level of intellectual and adaptive functioning as well as the timing, quality and duration of interventions. There is a growing body of evidence that early detection of ASD, when followed by intensive behavioural and educational intervention, can make a significant positive impact on long term outcomes for persons with autism. These include improved language, social and adaptive functioning, as well as reduction in inappropriate behaviours. It is therefore important to identify and refer children with ASD as early as possible to Early Intervention Programmes.

Broad treatment goals are to improve the overall functional status of the person with ASD by promoting the development of communication, social, adaptive, behavioural, academic and vocational skills, and lessening maladaptive and repetitive behaviours. A recent review of programmes serving children with ASD demonstrated that the best programmes are those that initiate intervention as early as possible, individualize services for children and families, use systematic and structured teaching, have a specialized curriculum, are intensive and involve families.

The impediments to effective social, communicative and cognitive functioning that exist in childhood continue into adolescence and adulthood. When individuals with autism become teenagers and adults, they continue to require adequate intervention to prepare them for vocational programmes, possibility for employment with or without support, and ultimately for as independent a life as possible in their communities. Therefore, there is an ongoing need for habilitation programmes aimed at developing social skills, speech and language, independence and self-determination.

There is no pharmacologic cure for ASD. However, medications can be helpful in conjunction with developmental and behavioural intervention, with the aim of facilitating access and maximizing the beneficial effects of non-medical interventions, preventing aggression or self-injurious behaviours, and improving the quality of life of the child and his or her family.



## Chapter 2 - Key issues in the field of healthcare in ASD

### A. General healthcare needs

Children with ASD have the same healthcare needs as children without disabilities and benefit from the same health promotion and disease prevention activities. In addition, children with ASD may have unique healthcare needs that relate to etiologic conditions (e.g., Angelman syndrome, fragile X syndrome, tuberous sclerosis) or other conditions (e.g., epilepsy) associated with ASD.

Ensuring careful follow-up of their general health condition is crucial for persons with ASD, as some medical problems can worsen their behaviour, mainly of those who are not able to communicate pain or other feelings. Detecting warning signs and treating health problems in these persons can be difficult, because of the social and communication impairments of ASD, the frequently associated sensory abnormalities, the adaptive difficulties and challenging behaviours. Nevertheless, it is essential in order to avoid more suffering, deterioration of health conditions, as well as unsuitable (and pointless) intervention. For example, unrecognised ear infections can cause tantrums, which are likely to be treated with behavioural intervention or medication, sometimes leading to pharmacological abuse. Recurrent ear infections can lead to hearing loss and further contribute to difficulties in communication.

Although for parents of children with ASD the rewards concerning their children's health are as great as for any other parent, their task can be more challenging because they have to take into account the child's difficulties and troubles in undergoing medical examination or treatment in all decisions about their healthcare. Physical assessment, diagnostic imaging and a variety of other interventions – both invasive and non-invasive – may induce fear and anxiety in people with autism. Their behavioural responses to such experiences often interfere with the care needed and increase the risk of physical and/or psychological trauma.



Children with ASD have general healthcare needs as well as special healthcare needs related to their condition.

It is essential to follow up the general health condition of persons with ASD.

Persons with ASD are not always able to communicate pain or other feelings.

Sensory abnormalities, difficulty to adapt and strange behaviours also make it difficult to understand their health problems and treat them correctly.

Parents must consider their children's behavioural responses to medical examination and treatment to avoid unnecessary suffering and inappropriate treatment



Diagnosis of ASD is the first step to ensuring proper intervention.

Detection, diagnosis and treatment of ASD are the responsibility of health systems.

Diagnosis should be made by specialists with expertise in the use of approved diagnostic instruments.

Reduced communicative ability is a main factor in ASD.

Specialist evaluation of speech, language and communication is vital for planning specific treatment in the area of language.

Assessment of adaptive skills is also necessary to understand individual strengths and problem areas in order to facilitate the day-to-day living of persons with ASD.

Diagnosis must be supported by a complete medical history and meticulous physical and neurological evaluation carried out by an expert practitioner.

## **B. Specific healthcare needs**

A diagnosis is a label that serves as shorthand for health professionals to communicate with each other. The diagnosis of ASD is much more. It is the first step needed to ensure proper intervention for the persons affected. Health systems are responsible for the specific actions necessary for detecting, diagnosing and treating ASD.

The diagnosis of Autism Spectrum Disorders should therefore be performed according to the diagnostic criteria listed in the international classifications ICD (International Classification of Diseases and Disorders - WHO) 10 and DSM (Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association) IV Revised, by means of reliable instruments. First of all, the diagnosis of ASD therefore demands particular expertise in the use of diagnostic instruments.

Speech-language-communication assessment is a core component of the diagnostic process, as delay and deviance in the area of communicative ability is universal in autism and is one of the most central areas for intervention.

The evaluation of autistic persons by speech pathologists will provide not only detailed information as to the nature of the language deficits incurred by the autistic individual, but will also be the first step in formulating a specific treatment plan with respect to language.

Assessment of adaptive skills has also important implications for treatment. Occupational assessment may be particularly helpful in determining the day-to-day strengths and vulnerabilities of the individual with autism (for example, sensitivity to clothing and food texture) and assist those who care for the person in promoting his or her strengths and in compensating for their challenges.

A careful medical evaluation is also needed to support the diagnosis and to detect other conditions associated with autism spectrum disorder. This evaluation begins with a thorough medical history. Physical examination should then be performed by a practitioner not only familiar with autism but with other disorders that may appear similar to or mimic the symptoms of autism. Neurological examination should be performed, as subtle findings may lead the examiner down a particular diagnostic path. If the neurological findings suggest a structural brain lesion, then a neuro-imaging study, preferably an MRI, should be performed.

## C. Habilitation needs

The principles of social inclusion should be the basis for any medical action aimed at people with ASD. This broader philosophy results from a long and difficult process of raising awareness by persons with disabilities not only about their needs and aspirations, but also about the importance of their participating in the rehabilitation process rather than merely being the recipients of services.

The shift from a medical model towards a social model of disability does not mean that health systems are exempted from ensuring adapted habilitation provision and services to persons with ASD. According to the social model of disability, rehabilitation and habilitation should not be understood in the purely medical or narrow sense of rehabilitation. Although not denying the need for health services, habilitation and rehabilitation should be understood broadly as in the words of Article 26 of the UN Convention, “appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”

Improving the lives of people with disabilities and ensuring that they are able to achieve a higher level of independence and self-determination should be the ultimate goals of healthcare and habilitation. Although the core impairments of ASD in the field of social communication cannot be overcome, they can significantly improve by means of intensive, ongoing habilitation programmes.

Moreover, as the social impairment is biologically determined, social habilitation of persons with ASD requires specific strategies and programmes, as well as skilled support. (National Institute of Mental Health – NIMH: Autism Spectrum Disorders, 2004).



All medical action should be based on the principles of social inclusion. All persons with disabilities have needs and aspirations and must participate actively in the (re) habilitation process.

The social model of disability means that health systems must ensure habilitation provision and services to persons with ASD that aim to maximize their independence, abilities, inclusion and full participation in society.

Problems in social communication cannot be resolved completely but persons with ASD can improve significantly in this area with continuous intensive programmes.

Persons with ASD also need continuous skilled support, specific strategies and programmes for social habilitation in general.



Parents must participate actively in the diagnosis process. They have vital everyday knowledge of their child and have a key role in the practical outcomes of healthcare and habilitation plans.

Family-centred practice provides service plans that recognise and value the needs of the person with ASD and those of the family as a whole.

Healthcare providers have an important role in improving lives of persons with ASD and their families. They can:

- listen to and act on parents' worries,
- monitor development and behaviour,
- refer for global evaluation,
- implement appropriate intervention strategies,
- manage medical issues
- coordinate care across service delivery systems.

## ***D. Role of families***

The involvement of parents in the diagnostic process is critical in order to provide crucial information on the child's strengths and adaptive behaviour in everyday living as well as in translating the assessment results into practical implications for intervention.

Children and adults with ASD are typically dependent on their caregivers and family, thus healthcare and (re)habilitation plans must consider the situation of the family as a whole, including the family's attitudes and knowledge about ASD and their willingness and ability to participate in therapy.

The belief that families know and are able to make decisions with the person with ASD is central to this approach. Family centred practice 'begins with the child's and family's strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. Parent training programmes lead to improved adaptive behaviour of children with autism'.

## ***E. Role of healthcare providers***

Healthcare providers can play a significant role in fostering the best development of individual potential and improving the quality of life of persons with ASD and their families by acting immediately on parental concerns, monitoring behaviour and development, referring promptly for a comprehensive evaluation, searching for etiologic and co-morbid conditions, expediting enrolment and implementation of appropriate intervention strategies, managing medical issues, and coordinating care among various service delivery systems. In so doing, the disabling aspects of ASD can be minimized to such a degree that, although not cured, more children with ASD will indeed be able to live independently as adults.

## Conclusions

Concrete measures are urgently needed in order to implement the right to health for persons with ASD, including:

1. Reasonable accommodations of general healthcare facilities, such as:
  - accessibility of the healthcare environments, avoiding waiting time, avoiding noisy and confusing settings...
  - ongoing personal support during all the phases of healthcare in public or private services, including hospitalisation or day care, by parents, personal assistants, or other skilled professionals provided by the health services
2. Available, suitable and reliable specific health services for :
  - identification and early diagnosis
  - prevention, diagnosis and treatment of general health problems in PWCDND
3. Skilled health professionals, by means of:
  - available and reliable training programmes for specialised health professionals in the field of proper and early diagnosis and appropriate treatments of ASD
4. Available, suitable and reliable (re)habilitation services, providing adequate (re)habilitation programmes:
  - aimed at achieving the maximum of the individual potentials, dignity and autonomy of persons with ASD
  - respecting the individual wishes and priorities
  - involving parents and/or other family members as active partners of the (re)habilitation process, in due respect of their willingness
5. Skilled professionals in the fields of (re)habilitation strategies and ethical issues related to ASD by means of:
  - Available, reliable and suitable training programmes in the field of proper (re)habilitation strategies for ASD
  - compulsory training on human rights, dignity and autonomy of persons with disabilities in the curricula of all (re)habilitation professionals



The concrete measures urgently needed to guarantee the right to health for persons with ASD include:

1. Reasonable accommodations of general healthcare facilities including accessibility and personal support.
2. Available, suitable and reliable specific health services identification and early diagnosis of ASD, as well as for general health problems.
3. Skilled health professionals trained in ASD.
4. Available, suitable and reliable (re)habilitation services and adequate programmes to maximise individual potentials, independence and dignity, which involve families actively and are respectful of diversity.
5. Skilled professionals, trained in approved (re)habilitation strategies for ASD and in human rights and ethical issues relating to persons with disabilities.



Many people with complex needs, including people with ASD, do not have the opportunity to access the general healthcare and support services they need to live like other people.

Many children risk death or are less likely to receive the right treatment. People with intellectual disability live 20 years less than the average.

This unfair discrimination takes place because:

- 1) The 'medical model' of disability cultivates the idea that people with severe disabilities cannot lead lives worth living.
- 2) Health systems use lack of funds to deny the ASD-friendly environment and skilled support needed to cope with the difficulties of persons with ASD.

## Chapter 3 - Why action is needed to promote the Right to Healthcare for people with ASD

### A. General healthcare

People most vulnerable to poor access and poor quality of support services remain people with complex needs, including persons with ASD. Many people with ASD have no opportunities to access affordable, quality care, leaving many gaps in their support needs in order to live in their communities as respected and equal citizens.

A recent report by the WHO recognises that many children with developmental disabilities in low and middle income countries are at a risk of death resulting from a lack of appropriate treatment or in any event lower health status resulting from being less likely to receive health interventions to aid their development.

People with intellectual disability also experience high levels of unrecognised, and when recognised, poorly managed secondary medical conditions. As a result, the life expectancy of people with severe intellectual disability is 20 years less than the rest of the population (WHO, 2008).

The first reason for this unjustified discrimination relies upon the "medical model" of disability that fosters in the health systems, services and staff the idea that persons with severe disabilities are not worthy of being cured, since for them a "pitiful death" would represent a relief and freedom from a poor life.

Secondly, health systems are likely to plead budget restrictions to deny the support needed to cope with the particular difficulties of persons with ASD including, in terms of reasonable adjustments of the healthcare environment, individual support during hospitalisation or day care and skilled health providers who are able to manage the major communication impairments and challenging behaviours seen in persons with ASD and identify unusual manifestations of pain or illness in these people.



## B. Diagnosis

Although a growing body of evidence has emphasized the importance of early detection and intervention for improving long-term outcome (Natl. Res. Council. 2001), and early signs of autism are apparent in many cases before age 12 months, delays in diagnosis of ASD are still very common.

According to De Giacomo & Fombonne, (1998), 90% of parents report that they recognised some abnormality about their child's development or noticed a gradual or rapid loss of language and/or social skills by 24 months. Two studies from the United Kingdom have demonstrated that most parents of children later diagnosed with ASD first became concerned about their child's development around 18 months old. However, the mean interval between the onset of concerns and seeking of professional help was approximately 6 months. On presentation of these concerns to a physician, almost 50% of parents were reassured and told not to worry. The usual interval between the parents' first awareness of a concern and a definitive diagnosis of autism was almost 4 years. The authors of these studies concluded that early parental concerns should be taken more seriously. Indeed, any concern should be valued and should lead to additional investigation.

The diagnosis of children with ASD therefore requires more diffuse information of the ASD condition and early signs among physicians and paediatricians, more attention to the parents' concerns and their involvement in the diagnostic process, and the availability of a range of experienced clinicians.

Late diagnosis of ASD is still common despite the documented importance of early detection and intervention.

Most parents suspect that there is something wrong with their child before it is 24 months old.

The child can be 6 years old before a definite diagnosis of autism is made.

Primary healthcare professionals should be well informed about ASD and its early signs. They should take parents' worries seriously and involve them in the diagnostic process.

A range of ASD specialists should be available for additional investigation.



Many persons with ASD still do not have access to the (re)habilitation programmes and facilities they need because of the severity of their disability and the high costs of provision in relation to outcomes.

This generates much suffering and additional disabilities.

Inadequate treatments affect wellbeing and physical health. Inadequately trained staff can lead to improper use of medications and disregard for informed consent

In a social model of disability, health systems should put in place positive measures, including (re)habilitation services, to enable persons with disabilities to enjoy independence, social inclusion and participate in all aspects of life.

The aim of (re)habilitation is not 'normality'. It should help each individual with a disability to reach their fullest potential by reducing the difficulties they face.

There is much evidence to support highly structured, intensive educational and behavioural interventions in ASD. There is a range of effective programmes for treating children with autism.

For persons with ASD, social habilitation is not an option.

## C. Habilitation

Nowadays, many persons with ASD do not have access to (re)habilitation programmes and facilities on the grounds of the severity of their impairments and of the high cost of these provisions compared to their impossibility to be cured. This failure generates much suffering and additional disabilities, preventing persons with ASD from achieving the maximum of their unique potential, independence, dignity and capacity for informed choice and self-advocacy.

Inadequate treatments can lead to serious problems in their wellbeing or physical health. A lack of trained staff can lead to improper or inappropriate use of medical drugs and to pharmacological abuse, often without the informed consent of parents or persons with ASD themselves, or against their will.

According to a social approach to disability (see Chapter 2), persons with disabilities need positive measures to achieve independence, social inclusion and participation. For many persons with disabilities, these positive measures include rehabilitation or habilitation. Services aimed at fostering independence, inclusion and participation should therefore be delivered by the health systems according to the individual needs of each person.

Indeed, the paradigmatic shift from a medical model towards a social model of disability does not mean that the health system is exempt from ensuring the right to habilitation or rehabilitation for persons with disabilities. On the contrary, this means that rehabilitation for persons with disabilities should not aim at erasing diversity in order to achieve "normality". This means that habilitation and rehabilitation should help persons with disabilities to achieve their fullest individual potential by alleviating difficulties with which they are confronted, either stemming from society or from their condition.

A large body of available evidence strongly supports the importance of intensive educational and behavioural interventions in ASD. The recent US National Research Council (2001) report has summarized the range of intervention programmes with demonstrated efficacy in the treatment of children with autism. Although there are some differences in these programmes, there is general agreement on the use of highly structured approaches to teaching, intensive involvement with the child, and a general focus on "learning to learn" challenges, i.e., basic abilities to participate in and benefit from instruction (Natl. Res. Council. 2001).

For persons with ASD, social habilitation is not an option. Denying persons with ASD appropriate, comprehensive, habilitation or rehabilitation programmes can result in many people becoming unnecessarily dependent. On the contrary, ensuring the availability, accessibility and affordability of proper habilitation and rehabilitation services to persons with ASD is a condition for them to enjoy equal opportunities in developing their fullest individual potential and in contributing to the social and economic development of their countries, as well as a means to securing democracy and social cohesion.





Coordinated multidisciplinary rehabilitation programmes are therefore essential for persons with ASD as they have been shown to be effective in helping them to overcome their major difficulties, to achieve independence, self determination and social inclusion in their communities, including the capacity to assert their own preferences and choices in order to live their every day lives in dignity and equality.

The outcomes of rehabilitation of persons with ASD should match the goals specified by the ten guiding principles of the Convention (see Chapter 4): facilitation and empowerment to secure autonomy and independence for the inherent dignity of the individual, to challenge discrimination and improve accessibility for equality of opportunity and full and effective participation and inclusion in society. Moreover, these goals are to be achieved with respect for human difference while accepting that persons with disabilities are part of human diversity and humanity.

With available, accessible, affordable quality (re) habilitation services, persons with ASD can enjoy equal opportunities and participate as citizens in all aspects of life in the community.

It is therefore essential for persons with ASD to have coordinated multidisciplinary habilitation programmes.

The outcomes of (re)habilitation of persons with ASD should be achieved with due respect for human difference and based on the guiding principles of the UN Convention.



The rights-based approach to disability recognises that factors influencing disablement are the person, the environment and the resources available.

In the 'medical' model of disability, the disability is more important than the person.

A rights-based approach adopts the social model of disability. Persons with disabilities are active subjects with rights, including the right to healthcare and (re)habilitation.

Healthcare systems cannot deny or restrict these rights. Lack of funds does not justify any restrictions.

Access to (re)habilitation is a priority and must be provided to persons with disabilities of all ages, whatever the nature or severity of the disability.

Norms, policies and provisions must secure human rights and individual needs. No specific disability law exists at EU level but disability issues are included in several legal human rights instruments.

## Chapter 4 - International legal framework in the field of healthcare

### A. The Rights-Based Approach to Disability

The new conception of disability recognizes that both the social and physical environments are factors in the disablement process (World Health Organization, 2001; Brandt & Pope, 1997) and that the impairment may have different impacts depending on the person, the environment and the resources available.

This new conception demands a paradigmatic shift from the so-called "medical" model towards a "social" model of disability. The "medical" model is an approach to disability that puts the impairment in the foreground whilst the person fades into the background. On the contrary, the rights-based approach to disability promotes a shift in values away from this model towards a social model that sees persons with disabilities as active subjects with rights and not passive objects of assistance.

According to a rights-based approach and in relation to the available European and international legal framework, access to fundamental rights, such as healthcare and (re)habilitation, cannot be denied to any person on the grounds of disability or other condition, including age. From this perspective, healthcare systems cannot, in any event, restrict or violate any individual right recognised by international and national normative sources.

Access for all persons in need of (re)habilitation programmes should be recognised as a priority and ensured, regardless of the nature or severity of the disability. Moreover, eventual financial claims invoked by national or local Authorities cannot, in any event, justify a restriction to fundamental rights. According to existing ordinances issued by presiding judges on these matters, the justification adopted by Public Authorities concerning the insufficiency of available financial resources is irrelevant in the face of inviolable subjective rights.

According to the rights-based approach to disability, rules and regulations, policies and provisions are established in order to secure human and fundamental rights and to meet individual needs.

## B. European Instruments

### a) The European Convention on Human Rights

European Institutions have never drafted a legal instrument that is specific for disability. Nevertheless, Disability issues are taken into account in several legal instruments on human rights

Article 14 of the European Convention on Human Rights states that the principle of equality means treating equals equally and providing different adapted measures for people in a different situation. In particular,

“the right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different.”

In other words, human difference in a democratic society should be viewed positively and should be responded to with discernment in order to ensure real and effective equality.

By underlying the need to treat differently persons whose situations are different, the principle of equality states the conditions to ensure equal opportunities to all. All services to people with disabilities should be characterised by an individual perspective. This means that they should tackle the needs of each individual with an aim to improve the quality of life and equality of opportunities of the person concerned. Recognising and meeting special needs is the key to inclusion for persons with ASD.

### b) The Revised Social Charter

Article 15 of the Revised Social Charter states the right to independence, social integration and participation in the life of the community. To this end, States which have signed up to and ratified the Charter have an obligation to promote the full social integration of persons with disabilities and their participation in the life of the community.

It should be noted that Article 15 applies to all persons with disabilities regardless of the nature and origin of their disability and irrespective of their age. It thus clearly covers both children and adults with ASD.

### c) The EU Charter of Fundamental Rights

The EU Charter of Fundamental Rights - notably article 26 - recognises as a fundamental right : “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”.

As the entitlement to the enjoyment of rights admits no hierarchy, the nature or severity of impairments cannot justify the denial of the right to habilitation or rehabilitation.



#### Article 14

The Principle of Equality covers the conditions necessary to ensure equal opportunities for all.

People whose situations are significantly different must be treated differently.

Services must recognise and meet the individual special needs of people with disabilities in order to improve their opportunities and the quality of their lives.

This is the key to inclusion for persons with ASD.

#### Article 15

The right of all persons with disabilities to full social inclusion in the community, regardless of the nature and origin of their disability or the age of the person.

This includes children and adults with ASD

#### Article 26

The right to measures, such as habilitation, to enable persons with disabilities to live, study work and participate in the life of the community, whatever the nature or severity of the disability.



The right of persons with intellectual disability to proper medical care, physical therapies, rehabilitation and such support necessary for the person to develop their ability and maximum potential.

This includes the right of all disabled persons to psychological treatment and the necessary services to develop their abilities and maximum potential for their social integration.

This is the first international instrument to introduce the concept of equal opportunities with a national system for monitoring respect for human rights.

In the Standard Rules, “rehabilitation” is a process of general and specific measures, including a wide range of activities that enables persons with disabilities to reach and maintain their best levels of independence and all aspects of functioning. Rehabilitation does not include initial medical care.

## C. **UN Instruments**

### a) **UN Declaration on the Rights of Mentally Retarded Persons (1971)**

At international level, the United Nations has focused on the rights of persons with disabilities since 1971. The UN Declaration on the Rights of Mentally Retarded Persons, proclaimed by General Assembly resolution 2856 (XXVI) of 20 December 1971, states that “The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential”.

### b) **UN Declaration on the Rights of Disabled Persons (1975)**

Then, the UN Declaration on the Rights of Disabled Persons, proclaimed by General Assembly resolution 3447 of 9 December 1975, stated that “Disabled persons have the right to medical, psychological and functional treatment, ... to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration”.

### c) **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)**

The process of recognizing the rights of people with disabilities culminated in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly of the UN on 20 December 1993 with Resolution 48/96. The Standard Rules were the first international instrument (non-binding for the countries that adopt them) to introduce the concept of equal opportunity for people with disabilities and, by nominating a Special Rapporteur, to create a national system for monitoring respect for human rights based on these same Standard Rules.

According to the Standard Rules, “the term “rehabilitation” refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation”.

Moreover, Standard Rules 2 and 3 focus on medical care and the rehabilitation of people with disabilities as follows:



## Rule 2 - Medical care

States should ensure the provision of effective medical care to persons with disabilities.

1. States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level.
2. Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.
3. States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.
4. States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.
5. States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.
6. States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.

Effective medical care for persons with disabilities means States ensure:

1. Programmes for early detection, assessment and treatment run by multidisciplinary teams, with the full participation of persons with disabilities, their families and organisations.
2. Local community workers trained in areas of the programme.
3. The same level of medical care within the same system as other people.
4. Adequate training and tools for doctors and paramedics. Access for persons with disabilities to treatment and technology.
5. Continuous training for doctors, paramedics and related staff to enable them to give appropriate guidance to parents
6. Regular treatment and medicines to maintain or improve levels of functioning.



Rehabilitation services that enable persons with disabilities to reach and maintain their best levels of independence and functioning means that States ensure:

1. Rehabilitation programmes for all disabilities based on the individual needs of the person, full participation and equality.
2. Programmes include a wide range of activities and occasional services.
3. Access to rehabilitation for all persons with disabilities, including those with severe or multiple disabilities.
4. The participation of persons with disabilities and families in planning and organising their rehabilitation services.
5. The availability of all services in the person's local community.
6. The active involvement of persons with disabilities and their families in the rehabilitation process.
7. Use of the expertise of disability organisations in planning and assessing rehabilitation programmes.

## **Rule 3 - Rehabilitation**

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

1. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality.
2. Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.
3. All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.
4. Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves.
5. All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form.
6. Persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counsellors.
7. States should draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programmes.

## d) **UN Convention on the Rights of Persons with Disabilities (2006)**

Despite the existing international and European legal instruments and undertakings stating human rights for all and proclaiming that everyone is entitled to all rights and freedoms without distinction of any kind, it has been recognized that “persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world”.

Therefore, a long process, launched by the disability community, began in order to foster the full enjoyment of human rights by all persons with disabilities through a legal instrument appropriate for all their different needs, as well as for the different cultures and political situations in the world. This process started in 2001 and led to the conception, drafting and adoption of the UN Convention on the Promotion and Protection of Rights of Persons with Disabilities on August 25th 2006. This new Convention does not establish new rights for persons with disabilities. It is based on existing human rights Treaties and their application to people with disabilities.

ASDs are not explicitly mentioned in the articles of the UN Convention. Nevertheless, the Preamble recognizes “the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support”.

Legal instruments cannot allow exceptions of any kind. The special needs of persons with ASD must be taken into account in order to guarantee these persons their full enjoyment of the rights stated in the UN Convention without discrimination. The strongly rights-oriented perspective of disability introduced by this Convention represents a unique opportunity to radically change mentalities and policies towards persons with ASD, who are still the excluded among the excluded in the enjoyment of human rights.



Barriers still prevent persons with disabilities from participating in society on an equal basis to others and their human rights are still violated.

In 2001, the disability community launched a long process to obtain a specific legal instrument on the human rights of persons with disabilities and respectful of their individual, cultural and political diversity.

In 2006, the UN adopted a specific Convention based on existing human rights, but applied to persons with disabilities.

The Preamble recognises that some persons with disabilities need more intensive support. This includes persons with ASDs. Their special needs must be taken into account for them to enjoy full inclusion in society.

The strong rights-based perspective of the UN Convention is an opportunity to change mentalities and policies towards persons with ASD



The UN Convention requires member states to take steps so that persons with disabilities have access to the same range and quality of healthcare as other people.

Article 25 prohibits all forms of discrimination.

Lack of funds cannot be used to deny the support necessary for persons with ASD to access healthcare services. Their individual needs must be taken into account.

Article 26 of the UN Convention recognises the right of persons with disabilities to the (re) habilitation services and programmes they need to reach, maintain and support maximum independence and abilities, full inclusion and participation in all aspects of life.

Services and programmes should be based on individual multidisciplinary assessment and include all assistive devices and technologies necessary.

## The Right to Health and (re)Habilitation in the UN Convention

### • Right to Health

The United Nations Convention on the Promotion and Protection of the Rights of People with Disabilities urges member states to take steps to ensure that the healthcare provided to persons with disabilities is of the same quality as that which is provided to others

Article 25 of the UN Convention prohibits all forms of discrimination, reaffirming that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”, and that “States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services...”

Under this perspective, there is no budget justification for denying persons with ASD any form of support needed to access “the same range, quality and standard of free or affordable healthcare and programmes as provided other persons”, or for neglecting their individual needs in this field.

### • Right to (Re)Habilitation

The new model of disability enshrined in the UN Convention shifts the focus of rehabilitation more toward the social and physical environment as an enabling force. The right of persons with disabilities to comprehensive, individually-tailored rehabilitation services and programmes, including the availability of assistive devices and technologies, with the aim to support their inclusion and participation in society, is fully recognised in the UN Convention for the Promotion and Protection of the Rights of Persons with Disabilities (Art.26).

Article 26 on Habilitation and rehabilitation establishes the principle that “Habilitation and rehabilitation services and programmes ... are based on the multidisciplinary assessment of individual needs and strengths”, “support participation and inclusion in the community and all aspects of society”, and are aimed at supporting persons with disabilities in attaining and maintaining their “maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”.



## Chapter 5 - Healthcare as a Policy Issue



Equality of opportunity is the objective of the European Union strategy on disability, which aims to enable disabled people to enjoy their right to dignity, equal treatment, independent living and participation in society. Although the policy instruments of the European Institutions are not binding on member States, European policies can impact the situation of people with disabilities at national level because they are taken into account by the Member States as guide-lines in developing national disability policies.

The Communication from the European Commission on the situation of disabled people in the enlarged European Union COM (2005) 604 final 28.11.2005) recognises that Healthcare Services are crucial for the wellbeing of disabled people. The European Disability Action Plan 2006-2007 has established as a priority at the core of EU mainstreaming actions to promote access to quality care services. Consequently, Health and Disability strategies need to be coordinated, both at the EU and at Member States level. There is indeed a need for coordination among these types of services in order to deliver integrated and comprehensive solutions to people with disabilities.

The Committee of Ministers' Recommendation No. R (92) 6 of the Council of Europe on a Coherent Policy for People with Disabilities recognises that rehabilitation of people with disabilities, by virtue of the economic and social integration it achieves, is a duty of the community, that it guarantees human dignity .... and that it should be included among the priority objectives of any society. A coherent policy for the rehabilitation of people with disabilities should therefore be consequent to the aim of enabling persons with disabilities to achieve a higher degree of individual ability, independence and participation in society, by preventing the deterioration of disability and alleviating its consequences.

Particular attention should be paid to mainstreaming the needs of persons with ASD in health and related policies as this population is still largely denied access to support and services fostering their inclusion and participation. Though the evidence in the positive long-term outcomes of social habilitation for persons with ASD is strong, new approaches to service provision are slow in disseminating. In many European countries, the rights of people with disabilities are a very low priority for policy makers. Where government policies that support social inclusion of people with disabilities exist, what is written on paper and what happens in practice are often two very different things. Moreover, organisations of people with disabilities are rarely consulted about decisions that concern them. This makes it very difficult to provide input for policy development and implementation.

Lack of resources is indicated as the main barrier in meeting the needs of people with disabilities and the main reason for a treatment gap (Chapter 3, Why Action is needed to promote the Right to Healthcare for persons with ASD). Nevertheless, barriers also exist in countries where health system budgets are consistent and budgetary reasons cannot be invoked to justify

Equality of Opportunity is the objective of the European Union Strategy on Disability.

The European Commission recognises that Healthcare Services are crucial for the wellbeing of disabled people. Mainstreaming actions to promote access to quality care services are a priority.

Health and disability strategies need to be coordinated at EU and national levels.

The Council of Europe recognises that the rehabilitation of people with disabilities should be a priority objective of any society.

Coherent rehabilitation policy is necessary for inclusion and participation.

It is particularly important to include the needs of persons with ASD in health and social policies. Many persons with ASD still do not have access to inclusive support and services.

In many EU countries, the rights of persons with disabilities have low priority or their needs are recognised but not met in practice. Disability organisations are rarely consulted or have no say in policy development and execution.

A lack of resources is often used to justify treatment gaps for persons with ASD, even in wealthier countries.

# The Right to Healthcare and Habilitation for Persons with ASD



However, there is some evidence that the cause may be found in strategic priorities in allocating health funds rather than in actual budgets.

a treatment gap in the field of ASD. There is some evidence that, rather than budgetary constraints, it is the choice of priorities in allocating health funds that leads to significant treatment gaps in the field of disability.

*According to a survey conducted by the Tuscany Region (Italy) across the public health services in 2006, the number of persons with Autism Spectrum Disorders charged to the public services of the region (6/10.000) is far lower than the expected prevalence (6/1000). As most persons with ASD have complex dependency needs, it can be argued that the majority live at home with their families without any support from the health system or, especially adults, disappear in the still-existing institutions, without any specific habilitation programme. It should be noted that, in a region where the income is higher than the national and European average (Eurostat, GDP per capita and employment rate in Europe's regions 2003), financial constraints cannot be invoked among the several reasons that can concur in determining the shortage of habilitation and care for persons with ASD.*

*Moreover, in the same region, the health system funds non evidence-based, non-essential interventions, such as homeopathy, phyto-therapy and acupuncture, for the whole population, while failing to ensure rehabilitation, habilitation and community-based support to most persons with ASD. This demonstrates the importance of ensuring that good science serves the interests of politics. Science, independent of political action and policy development, is empty; but policy development without good science is useless and may be counterproductive.*

*The combination of good science about disability and a sound political normative framework provides the platform upon which the right to healthcare for all can be built.*

The growing number of people with disabilities and complex support needs is a challenge for social and (re)habilitation policies.

People with ASD need new service models with adapted, lifelong, individualised support to enable them to enjoy inclusion in all areas of life and to participate on an equal basis to others.

A small but growing number of people with disabilities is in need of a high level of support. This group represents a challenge for both social and rehabilitation policies. A shortage of appropriate social and habilitation / rehabilitation services and a lack of coordination across relevant authorities, agencies and providers can affect the dependency of these people much more than the nature or severity of their impairments.

People with ASD need adapted, life-long support and services to enable them to enjoy full Inclusion and participation in all areas of life on an equal basis with others. Their needs for support depend on their individual circumstances and change over time, according to age and environmental demands. New service models are therefore needed which allow for more flexibility, individualized support and person-centred planning.

# The Right to Healthcare and Habilitation for Persons with ASD



Structured training programmes should be provided for health professionals, policy decision-makers and public administrators in order to improve their understanding of the rights-based approach to disability, to deal with prejudices and misunderstandings and to change mentalities towards persons with ASD.

The rights and responsibilities of the representatives of persons with ASD who are unable to represent themselves in supporting or, if necessary, in taking decisions should be fully recognised in the field of health, therapies and rehabilitation. Families are most often the major sources of support for people with ASD yet often get very little support from services, or adequate recognition in policies. In families providing support for their relatives with ASD one or more components can be forced to leave or reduce their work time and the family is likely to be at greater risk of poverty. Studies are needed in order to analyse the costs embedded in the full-time care of persons with ASD living at home by parents.

Moreover, in the perspective of a rights-based approach to disability, evaluation should be carried out as to whether the permanence at home of the disabled person in adulthood corresponds to his/her free choice, if family members are in the condition to support the personal development, inclusion and participation of an adult with ASD and to what extent living at home with parents can prevent or foster institutionalisation after their parents' death.

The representative organisations in the field of ASD should be systematically involved at all levels of the decision-making process in the field of rehabilitation and habilitation, from designing rehabilitation policy plans to evaluating the outcomes and quality of the programmes, services and instruments. Evaluation systems of the Quality of the services for persons with ASD should therefore focus on individual and social outcomes in terms of enjoyment of human rights, equal opportunities and quality of life of the person more than on the structural characteristics of the service (as currently happens).

Awareness raising actions by advocacy organisations are therefore needed to foster a radical change in health policy for persons with ASD. Although these actions are not likely to provide immediate solutions, they are the only way to achieve durable results. The UN Convention on the Rights of Persons with Disabilities ("the Convention") is an example of what can be achieved through awareness raising. Thanks to the efforts of the disability community over many years, the rights to healthcare and habilitation – stated in Articles 25 and 26 – are now protected by this Convention which is a legally binding treaty.

Health workers, policy makers and public administrators should be trained in the rights-based approach to disability and in how to deal with prejudices towards people with ASD.

The rights and duties of the representatives of persons with ASD should be fully recognised.

The situation of families providing care for their relatives with ASD should be reflected in policies. Families need support from services. Studies are needed into the costs of full-time informal care of persons with ASD.

Within a rights-based approach to disability, evaluation is necessary to determine whether living at home is the best environment for adults with ASD.

ASD organisations should always be involved in the entire (re)habilitation decision-making process. Quality in ASD services should focus more on individual and social outcomes rather than only on structural factors.

Awareness raising is needed to encourage radical change in health policy for persons with ASD.

The UN Convention legally protects the right of persons with disabilities to healthcare and habilitation. It is a fine example of what the disability community has achieved through its awareness raising efforts.



ASD is a lifelong condition. At present, there is no cure for ASD. Yet theories and treatments exist which claim to cure ASD.

These treatments are strongly promoted but they are not supported by scientific theories and research.

Autism is a particular target of controversial treatments because:

- ASD affects most aspects of functioning. Parents are vulnerable to any treatment promising to help their small child.
- The normal appearance of children with ASD makes it easy for caregivers and others to think that their condition is only temporary.

Autism is a spectrum of disorders. It is difficult to identify potentially effective treatments because:

- Each individual responds differently to the same treatment.
- Individuals can improve in an area of functioning for no apparent reason. Improvement can wrongly be attributed to an ongoing treatment that in fact has no effect.

However, not all traditional therapies for children with

## Chapter 6 - The evidence-based approach in the field of ASD

Because ASD is a chronic condition for which presently there is no cure, it has become the focus of several unconventional treatments. There may be many reasons for a family's pursuit of controversial therapies for their child, including: the basic and understandable parental desire to pursue anything that might possibly help their child, a simplification of behaviourally or educationally based therapies that might otherwise be very time consuming, claims of improvements made by other families, and rising scepticism people may have about scientifically based treatments.

According to Herbert, Sharp and Gaudiano, several factors render autism especially vulnerable to etiological ideas and intervention approaches that make bold claims, yet are inconsistent with established scientific theories and unsupported by research (Herbert & Sharp, 2001). Despite their absence of grounding in science, such theories and techniques are often passionately promoted by their advocates.

The diagnosis of autism is typically made during the preschool years and, quite understandably, is often devastating news for parents and families. Unlike most other physical or mental disabilities that affect a limited sphere of functioning while leaving other areas intact, the effects of autism are pervasive, generally affecting most domains of functioning. Parents are typically highly motivated to attempt any promising treatment, rendering them vulnerable to promising "cures."

The unremarkable physical appearance of autistic children may contribute to the proliferation of pseudoscientific treatments and theories of aetiology. Autistic children typically appear entirely normal; in fact, many of these children are strikingly attractive. This is in stark contrast to most conditions associated with mental retardation (e.g., Down's syndrome), which are typically accompanied by facially dysmorphic features or other superficially evident abnormalities. The normal appearance of autistic children may lead parents, carers, and teachers to become convinced that there must be a completely "normal" or "intact" child lurking inside the normal exterior.

In addition, autism comprises a heterogeneous spectrum of disorders, and the course can vary considerably among individuals. This fact makes it difficult to identify potentially effective treatments for two reasons. First, there is a great deal of variability in response to treatments. A given medication, for example, may improve certain symptoms in one individual, while exacerbating those same symptoms in another. Second, persons with ASD sometimes show apparently spontaneous developmental gains or symptom improvement in a particular area for unidentified reasons. If any intervention has been implemented, such improvement can be erroneously attributed to the treatment, even when the treatment is actually ineffective.



Standard or traditional therapy for children with developmental disabilities is one that should have a sound scientific basis supported by research. However, because some traditional therapies for children with developmental disabilities have not undergone rigorous scientific review, it is difficult to use the absence of scientific validation as the defining feature that distinguishes a therapy as nontraditional. The following characteristics of therapies constitute an operational definition of a controversial treatment for children with developmental disabilities:

- Treatments based on overly simplified scientific theories (e.g., the importance of crawling as a stage of motor development)
- Therapies claiming to be effective for more than 1 condition (e.g., megavitamins used for attention-deficit/hyperactivity disorder, learning disabilities, ASD, and developmental delay)
- Claims that children will respond dramatically and some will be cured, particularly if treated early
- Use of case reports or anecdotal data rather than carefully designed studies to support claims for treatments
- Failure to identify specific treatment objectives or target behaviours
- Treatments are stated to have unremarkable or no adverse effects; thus, proponents deny the need to conduct controlled studies

Non-traditional therapies will continue to gain local and national attention and questions about their efficacy and use will be brought to the attention of their primary healthcare provider. Because parents of children with ASD look to health professionals for advice about their children's health, practitioners can greatly assist families by:

- Ensuring they have access to standard services and are actively involved in all treatment decisions
- Discussing controversial therapies initially and whenever asked
- Becoming knowledgeable about traditional and controversial treatments or referring families for appropriate consultation
- Allowing adequate time for discussion and ensuring that comments are not unintentionally viewed as an endorsement of a treatment
- Discussing the placebo effect and the importance of controlled research studies
- Being willing to support a trial of therapy in select situations, and in such situations, requiring clear treatment objectives and pre-testing and post-testing
- Remaining actively involved, even if in disagreement with the family's decision

developmental disabilities are based on scientific review and scientific validation cannot always be used to define a therapy as good or bad.

Controversial, non-traditional therapies have the following characteristics:

- they are based on over-simplified scientific theories
- they claim to be effective for more than 1 condition
- they claim to greatly improve or cure the condition
- they are based on cases and anecdote
- they do not identify objectives or target behaviours
- they have no negative effects and so do not need scientific review.

Primary healthcare providers must be informed about non-traditional therapies since their role is to properly advise families about the health of their children with ASD.

Primary healthcare providers should:

- ensure access to services and involve families in decisions
- discuss controversial therapies
- be well-informed of all treatments or make referrals to specialists who do
- take time to discuss treatments without bias
- inform of the placebo effect and importance of controlled research
- support treatment trials carried out in ethical conditions



- be actively involved with the family at all times and respect their decisions

There are gaps in even the best ASD treatments. Parents and specialists must have as much information as possible to choose from the range of treatment options.

Parents and specialists must be especially cautious because:

1. Pseudoscientific treatments are not always exposed. The burden is thus on families to be informed. They can be misled or given false hope.

2. All treatments have costs in terms of funding, time and resources. Critical time and resources, particularly in early intervention, can be wasted on unproven treatments. In the absence of control conditions, additional resources may continue to be spent on unproven treatments. Families can thus become increasingly distrustful, even about successful treatments.

3. Above all, families and specialists must be aware of the potential for harm in pharmacologic treatment and invalidated interventions.

In a rights-based approach to

Even the most promising treatments for autism are typically far from ideally effective, leaving the autistic individual with substantial impairments. It is therefore natural for parents, educators, and even mental health professionals to ask what the harm is in trying an unproven treatment. This is a difficult question for which there is no easy answer. On the one hand, we are not suggesting that parents and professionals not be allowed to explore a range of treatment options. What we are suggesting is that they do so with as much information as possible, and armed with an attitude of healthy scepticism. For several reasons, such scepticism is particularly important in considering treatments for autism.

First, proponents of many treatments, both novel and established, often make impressive claims that are simply not supported by controlled research. Moreover, many health professionals are reluctant to speak out against pseudoscientific theories and practices. This silence places the burden directly on consumers to become educated about the empirical status of various treatment options. Unless they make efforts to become informed about the research literature themselves, consumers can be easily misled and given false hope.

Second, no treatment is without cost. Aside from the obvious financial burden, there are always other costs to consider when contemplating a new treatment. In particular, time and resources spent on an unproven therapy are time and resources that could have been spent on an intervention with a greater likelihood of success (what economists term “opportunity cost”). This point is especially critical with respect to early-intervention programmes, as a growing literature suggests the importance of early intervention with specialized behavioural and educational programmes (Fenske, Zalenski, Krantz, & McClannahan, 1985).

The issue of cost is complicated by the tendency, in the absence of appropriate control conditions, to misattribute any positive changes that may be observed to an intervention and then expend even more resources on that intervention when the improvement may not be due to the treatment. Alternatively, repeated experience with treatments that are promoted with much fanfare but turn out to be ineffective might cause family members of autistic individuals to become unnecessarily cynical about even legitimate interventions.

Finally and perhaps most importantly, one must always be aware of the potential for harm. There are numerous examples in the history of pharmacotherapy of substances that were initially believed to be therapeutically useful and devoid of harmful side effects that turned out to be quite harmful (e.g., combined fenfluramine and dexfenfluramine, thalidomide). The effects of long-term use of substances like secretin and DMG have not been investigated and are therefore unknown. The risk of harm is not limited to pharmacologic interventions, however. Consider, for example, the case of Facilitated Communication. The cases of family members being convicted



of abuse and sent to prison based on alleged communications provides a sobering example of the harm that can arise from non-validated interventions. (Gorman, 1999).

Parents and professionals should be careful when considering novel treatments for autism. The scientific reliability of treatment approaches and strategies is not a secondary issue in a rights-based approach to ASD. Inadequate treatments can have negative impact and irreparable consequences on the development of the full potential of the person with ASD. Health systems should therefore consider carefully their choices in terms of state-of-art in the field of accredited approaches when planning the rehabilitation and habilitation provisions and services for persons with ASD, including counselling for informed choice in designing individualized support programmes.

Intervention approaches providing evidence of effectiveness, in terms of achievement of “maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”, should be strongly recommended in order to maximise the resources of health systems. To this aim, effectiveness and cost-benefit analyses of rehabilitation and habilitation approaches and programmes should be regularly performed. Up-to-date information on the state-of-the-art of reliable rehabilitation and habilitation approaches for ASD and on the available facilities and services should be systematically disseminated.

ASD, the scientific reliability of treatment approaches and strategies is central to avoid negative impact and severe consequences for persons with ASD.

Health systems and parents should be cautious in the face of novel treatments.

Attentive choices should be made from among the accredited approaches available for (re)habilitation, services, individualised support and counselling for persons with ASD.

Intervention approaches should provide evidence of effective results, in terms of maximising independence, developing abilities and providing full inclusion and participation in society.

Effective intervention maximise a health system’s resources. Therefore, intervention outcomes and cost-benefit analyses should be routine. Information should be circulated regularly on state-of-the-art (re)habilitation approaches for ASD and on available facilities and services.

## **ANNEXES**

### **Annex 1 :**

Case studies – Examples of best practices in the field of services

- Gautena
- Autism-Initiatives - Outreach Support Service for Mainstream Education

### **Annex 2 :**

Quality indicators of services for persons with ASD

### **Annex 3 :**

Hungarian national autism strategy published in 2008



## Annex 1 : Case studies – Examples of best practices in the field of services



### HISTORY

The name GAUTENA is an acronym for the Gipuzkoan Association for Autism (in the Basque language).

The organisation was set up in 1978 as a non profit-making entity made up of families of those suffering from autistic spectrum disorders (ASD).

The Association is characterised by its close ties with the key institutions of the society in which it operates, as well as by its professional management in relation to the services it provides.

In this way, GAUTENA has agreements with various departments of the Basque Government, such as the Health and Education Department, as well as with departments of the Gipuzkoa Provincial Government, such as the Department for Social Policy and the Department for Youth and Sport.

Its work has been recognized also by the San Sebastián Local Council which, in the year 2003, awarded it the Medal for Citizen Merit.

# The Right to Healthcare and Habilitation for Persons with ASD



## MISSION

GAUTENA is a non profit-making Social Initiative Entity whose mission is to improve the quality of life of those suffering from autistic spectrum disorders and other intellectual disabilities with similar support requirements, and their families. To this end, it develops and provides specialist services, offering a comprehensive and individual response to patients' needs. It also seeks to inform society and raise the general awareness of the need for social inclusion.

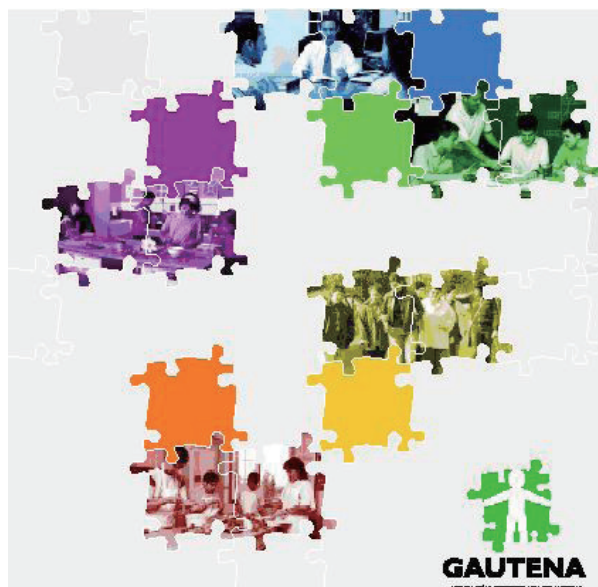
Our services include:

- » Diagnosis and Treatment
- » Day Care
- » Family Support
- » Education
- » Housing
- » Leisure and Free Time



## WHAT WE ARE AIMING TO ACHIEVE

- We aim to provide a comprehensive and, where necessary, life-long service to people with ASD in Gipuzkoa, attending their clinical, educational, leisure, occupational and community housing needs.
- Our objective is to ensure a good quality of life for both these people and their families, offering the latter diverse family support programmes, short breaks and home services.
- We aim to ensure the satisfaction of those receiving our services, the public institutions that pay for them and, in general, the Gipuzkoan community of which we form part. Our ultimate goal is to help build a better society, in which all those suffering from disabilities, including ASD, are both welcomed and supported.



## OBJECTIVES

GAUTENA has three types of external clients: its users (people suffering from autism and other intellectual disabilities with similar support needs and their families), the Administration and society.

The following objectives have been established with regard to these external clients:

- To provide a local, comprehensive response to the needs of those with autistic spectrum disorders in Gipuzkoa.
- To improve the quality of life of these people, offering an increasingly personalised service specially adapted to their individual needs.
- To increase public awareness of autism. All this in accordance with the overall aims of ensuring financial balance and boosting staff motivation.

## STRATEGIC AREAS

In order to achieve these objectives, the association focuses on three specific strategic areas:

- To promote innovation, focusing on the following fields:
  - Development and application of ethical principles. Innovations related to the way in which we carry out our work.
  - Adaptation to the Knowledge Society. Innovations which aim to improve communications with the users of our services and GAUTENA professionals, using all the possibilities offered by information and communications technologies.
  - Carrying out R&D projects. Innovations related to the prevention, diagnosis and treatment of autism.
- To improve the quality of life of those suffering from autistic spectrum disorders, through the improvement and development of new infrastructures, programmes and support services.
- To ensure a dynamic Association, increasing family participation and strengthening ties with voluntary workers.

## AN ASSOCIATION OF FAMILIES

GAUTENA is an Association of Families governed ultimately by an Assembly. There is also a Board of Directors that represents all the families and is elected by the Assembly.

With the aim of guaranteeing the maximum participation of all families and ensuring that their contributions are effective, there are a number of Service Monitoring Commissions made up by both representatives of the families and those responsible for the services. There are currently five such commissions:



- SCHOOL COUNCIL: responsible for monitoring the education service.
- DAY SERVICE COMMISSION: responsible for monitoring the housing service.
- DCC COMMISSION: responsible for monitoring the day care centres.
- LEISURE COMMISSION: responsible for monitoring the leisure and free time programme.
- QUALITY IMPROVEMENT COMMITTEE: responsible for monitoring the quality improvement norms.

## A STRONG COMMITMENT TO QUALITY

GAUTENA is an organisation which, right from its earliest days, has been fully committed to providing a High-Quality Service, making a concerted effort to constantly improve both its technical and management models.

This drive towards Quality has also resulted in the maintenance of close contact with some of the most acclaimed programmes for autistic persons in the world, and among other initiatives of interest, the adoption on 1 January 1997 of the ISO 9001 Standard, with the Association gaining the official AENOR (Spanish Accreditation and Standardisation Agency) certificate in February 1998.

In February 2000, GAUTENA was recognised by the British National Autistic Society (National Autistic Society [www.nas.org.uk](http://www.nas.org.uk)) which applied its Service Quality Accreditation system in GAUTENA. In 2002 it received a Special Mention for Quality as a finalist in the 1st Gizartekintza Awards for Quality, established by the Gipuzkoa Provincial Government. which applied its Service Quality Accreditation system in GAUTENA. In 2002 it received a Special Mention for Quality as a finalist in the 1st Gizartekintza Awards for Quality, established by the Gipuzkoa Provincial Government.

GAUTENA has adopted the EFQM Model for Total Quality as its management benchmark, and has carried out two self-assessments in accordance with this model, one in 1999 and one in 2003. It continues to work in this field.

GAUTENA is constantly on the lookout for support from other Entities in order to make headway in the field of quality, both

# The Right to Healthcare and Habilitation for Persons with ASD

within the Basque Autonomous Region [www.euskalit.es](http://www.euskalit.es), Spain [www.feaps.org](http://www.feaps.org), and at an international level [www.thecouncil.org](http://www.thecouncil.org)



**For more information about our activities, please consult:**

<http://www.gautena.org>

## **Contact details:**

C/ Francisco Lopez Alen, nº 4

20009 Donostia

GIPUZKOA

Tlf: 943 215344

Fax: 943 215239

Email: [info@gautena.org](mailto:info@gautena.org)

## **Autism Initiatives UK Outreach Support Service for Mainstream Education**



Autism Initiatives UK was founded some 35 years ago by a parent who had found that the needs of her autistic son were not being met by existing services. With the help of a small group of friends, she established Peterhouse - an autism specific school. Peterhouse School now has 55 pupils and will soon be complemented with a College supporting twelve students aged 19 to 25. Many of the young people attending these services are supported in residential accommodation.

The range of services provided by Autism Initiatives UK has also grown considerably, particularly in the last decade. Extensive adult services have developed providing residential, day, respite, social and employment opportunities and, (nearly) 10 years ago, the OSSME was introduced.

Autism Initiatives UK has its Head Office in Liverpool, England and there are National Offices in Edinburgh, Belfast and in Ireland.

### **OSSME**

OSSME is the Outreach Support Service for Mainstream Education operated by Autism Initiatives UK.

OSSME provides direct assistance for young people in mainstream education as well as support for parents, carers, health professionals, educationalists, support staff, and administrators through partnership working. In addition OSSME provides information, training and support in respect of autism to people working in mainstream education and students working towards degree level qualifications.

Located at the Head Office in Liverpool with its own developing resource bank, supplemented by the charity's library, the OSSME service contributes to, and benefits from, a comprehensive training schedule which is available to families and professionals.

The team comprises a Teacher/Co-ordinator, an Advisory Teacher, four Autism Inclusion Practitioners and an Administration/Project officer.

### **Why OSSME was necessary**

The OSSME service was set up in response to needs which had been identified and monitored by Peterhouse School. Parents contacting the school requested information about ASD, or support for their children in mainstream school placements, or asked for help with the transfer of pupils from special schools to mainstream. Some pupils required support to get from home onto a school register.

Education professionals had also contacted Peterhouse to learn about autism specific strategies within mainstream settings. The fact that the parents and professionals were contacting Peterhouse School indicated:

- That parents and professionals were finding it difficult to access information and practical help from elsewhere
- That there was an increasing number of pupils with ASD attending mainstream schools
- That an increasing number of parents wanted their children to be educated in mainstream placements

In Merseyside, appropriate and individualised support in mainstream schools was, and continues to be, limited. Approaches to inclusion for pupils with special educational needs are developing but there are few resources allocated to outreach work - allied to a lack of experienced or skilled staff. Despite this, all Local Authorities promote integration and inclusion in line with current government guidance.

OSSME consequently developed its own service level agreements to address the issues and to accommodate the involvement of all parties. These are known as:

- 5 Steps to Individual Intervention (see fig.1)
- 7 Steps to Service Transition (see fig.2)
- Socialisation in Practice (SIPS) (see fig.3)
- Personal Tutorials (see fig.4)

Personalised resources are produced for each pupil.

We have also developed:

- EarlyBird training (for parents of pre-school children with ASD)
- Project work (needs led and funding dependent)
- Training (bespoke training packages)

OSSME is currently providing general ASD Awareness Training sessions in Primary and Secondary school settings.

Throughout 2007 we provided ASD specific training to over 1300 people. Feedback from the NAS Accreditation report stated:

*'98% (of those surveyed) rated the OSSME trainers 'Excellent or Good' and described the training as 'Cutting Edge'.*

Our staff access Conferences and accredited training to maintain their continuing professional development and to further develop OSSME resources e.g. staff members recently attended TEACCH and workshops delivered by Tony Attwood in the Isle of Man.

Members of the team have presented papers at the Autism World Congress and Autism-Europe in addition to receiving a Walter Hines Scholarship Award.

This year, OSSME celebrates its 10th anniversary!

We work in partnership with concerned parties from the outset of our involvement – young people (when appropriate), parents, carers, educationalists, support staff and professionals from other fields. This collaborative approach ensures success in addressing the needs of all people concerned in the individualised support of the pupil with ASD.

OSSME is the first, and only, stand-alone Outreach Support Service to receive national accreditation.

*"OSSME is vital outreach service. There is nothing like it anywhere else in the country. OSSME is exciting and forward thinking and has achieved numerous good practice points as an indication of the quality and breadth of this groundbreaking outreach service..."*

Gregg McNeish – Director of NAS Autism Quality Programmes

The OSSME team inherently cares for the people they support and are proud of the unique work they carry out. All of our work is tailor-made to address the specific needs of the pupil and how best to facilitate support.

The team provides support for 135 young people in a variety of educational settings ranging from Nursery to University placements. Since its inception, OSSME has provided for over 1000 pupils and staff in a variety of educational settings and the delivery of training from foundation to Masters degree level.

The Service Level Agreements developed by OSSME provide both an effective and transferable framework for the support of the

pupil with ASD. As both the age ranges and the needs of the pupils supported grow, we continue to develop and enhance our services. We are currently developing specific training packages increase the understanding of ASD and its implications within educational/college/work placement settings.

## How OSSME started

In January 1998, Autism Initiatives successfully applied to the National Lottery Charities Board (NLCB) for a grant to facilitate the development of an Outreach Support Service for Mainstream Education. The service was aimed at enabling pupils and students in Merseyside with ASD to access and take full advantage of the opportunities available to them in mainstream educational facilities.

*"I don't know a 'generic child'"*

Claire Curtis-Thomas MP (Crosby)

Autism Initiatives anticipated that the project would enhance the educational choices available to parents, support pupils with ASD in educational settings and ensure that issues relating to knowledge and experience of ASD would be quickly addressed during and following the pilot period.

OSSME is tasked with being self funding through contracts with Local Authorities and other organisations and by seeking additional income, particularly for development and training work, from trusts and charitable bodies. OSSME currently works across each of the Merseyside authorities, complementing and augmenting their provision.

Where conflict may exist between parents and a Local Authority, OSSME is sometimes viewed as being both a mediation service and a catalyst for change.

## OSSME innovative project work

**Creating Autism Friendly Settings (CAFS)** drew together statutory and non-statutory agencies in one Local Authority to assist in a successful project to access mainstream education for five pupils and their families. Service providers worked together to formulate a winning bid for funding from central government.

All participants engaged in the OSSME 7 Steps Transition Agreement as a process for constructing the personalised bridge to enable each of the pupils to move from primary school to secondary school with maximum cooperation from all parties.

At the heart of the project was the need to equip staff, in a variety of job roles, with skills, knowledge and expertise to carry forward developments in ASD provision. The local university evaluated the project and highlighted examples of good practice in creating ASD friendly settings and transitions. The project benefited not only the pupils with ASD by reducing the stress of the transition but also the other pupils being educated with them.

Teachers received support in establishing routines and learning programmes and staff were able to access in-service training in order to support subsequent developments of inclusive provision. The Local Authority was able to extend provision and options for pupils with ASD and to endorse principles and practice to inform the support of pupils placed in mainstream settings.

**Steps to Inclusion for Pupils, Parents and Practitioners (STIPPPS)** applied a 'one sector' approach by engaging the major participants and stakeholders. The project provided pupils with ASD from special schools access to mainstream educational facilities using a flexible, transparent service model which addressed individual needs and demonstrated collaborative planning and working between pupils' parents and practitioners enabling pupils and their families to plan and participate in individually



tailored phased integration to mainstream schools.

The model aimed at collaborative working between all of the participants and stakeholders – pupils, families, Greater Merseyside SEN Partnership; Local Authority representatives; special school and mainstream school based staff; support services; health and social services; parent partnership; University of Liverpool; Partners in Policymaking and Autism Initiatives UK.

**The Facilitating Autism Friendly Socialisation** project was developed as a result of feedback to OSSME from parents/carers and school staff that a significant number of young people with ASD in mainstream schools felt extremely isolated. Some expressed a desire to be put in contact with other young people who were experiencing similar difficulties.

Laptops became the vehicle to network nine young people because some of them were not ready for 'face to face' socialisation. Safety in the use of the Internet was an important consideration for the project.

A successful bid for joint funding for the IT to the European Regional Development Fund (ERDF) and the Health Action Zone (HAZ) enabled the project to achieve its goals. Both bodies realised that, through on-line networking, the risk of isolation would be reduced and that the contact would lead to benefits in socialisation and employability.

*Comments from a participant:*

- I live in a low-budget environment and, when it started, the laptop was the most advanced piece of kit in the family. It enabled me to develop some social skills that would assist me in high school and it made me work MUCH better with computers.
- Comments from parents: The project was the best thing to happen for my son in many years.
- Bringing the gift of a social life is almost the most important thing you could do ... saving children from a life of solitariness is very important indeed.

The project has made such a big difference to her ... she now has eight 'friends' with whom she feels comfortable and happy

Project members and their families highlighted other positive outcomes of the project including increased socialisation and communication, better parent networking and support and improved computer skills (one user tutored her peers).

**The Autism Transition Toolkit (Att)** project is for use with pupils who transition from primary to secondary school at the end of Key Stage 2 (usually at 11 years of age). The Att combines a model of good practice with relevant resources to provide practitioners and families with a 'toolkit' to improve inclusion for pupils with ASD.

The Att project was piloted within a Regional Partnership and aimed to network practitioners from voluntary and statutory agencies in order for them to work collaboratively to form a strategically planned regional pathway for pupils at Key Stage 2. A local university evaluated the project acting as a 'critical friend' and providing ongoing feedback to organisers.

## The role of OSSME within educational settings:

OSSME has developed what has now become known as the 5 Steps to Service Agreement: Individual Intervention which underpins much of the work which takes place with pupils with ASD in their respective schools. As a follow on from that work, the 7 Steps to Service Agreement: Transition has resulted in particular processes being suggested and implemented at any time when a pupil experiences changes in their educational life.



After the initial high-level input from OSSME, the pupil remains on monitoring status to ensure the continued involvement of the OSSME practitioner through termly visits to the educational setting. At all times, families and schools are invited to contact OSSME should they have interim concerns.

**Socialisation in Practice Sessions**, set up in schools by OSSME practitioners specifically to target agreed areas of socialisation. Initially, the OSSME practitioner will devise, plan and implement the Social Group with school staff and give coaching and ongoing support. Approximately 40% of pupils who are supported through OSSME benefit from their inclusion in the Social Groups.

**Personal Tutorials** are an additional and valued service requiring 1:1 sessional work with the pupil. A meeting to outline, plan and agree the Personal Tutorial takes place with OSSME, family and school. Permission is then sought from all parties (including the pupil) before sessions are arranged. There are agreed targets (set at the planning meeting) which may include helping with the pupil's understanding of social situations (e.g. how to start a conversation) or Homework issues

OSSME is currently developing a Work Placement package to support both the pupil and staff by highlighting areas of need at this important transition time.

All OSSME work is independently evaluated at every stage to provide both feedback and points for enhancement of the service. In addition, independent 3rd party evaluations of the OSSME service have been carried out by The National Autistic Society, Liverpool University, Liverpool John Moores University and Sefton (Local Authority).

## Education – In-Service training

From an early stage in the development of OSSME, Local Authorities and other establishments, such as colleges and the private sector providers (for children and adults) have requested accredited training.

All schools which undergo contact with the OSSME service are offered in-service training as an integral part of the service level agreement and school staff determine how that opportunity will be used.

Training may also be requested by special schools catering for the generic needs of pupils or those specialised in fields other than ASD e.g. a whole school inset was requested by a school specialising in visual impairment as one of their pupils also had a diagnosis of Asperger syndrome.

Other voluntary and statutory organisations, such as Scope, Barnardos and Connexions have requested informal training for volunteers and Social Services and Sefton Early Years have had training for nursery staff as part of their own accredited in-service packages.

Local Authorities have consulted with OSSME with regard to resources and staffing needs for prospective units in mainstream schools, and have requested input at conferences and workshops. Additionally, OSSME is integral to the development of, and contribution to, ASD pathways being established in particular Local Authority areas; contribution to Parent Partnership and the training and development required for ASD specific services to enhance best practice.

Indeed, when working with some Local Authorities, it has been almost a prerequisite to be able to train staff before being able to be involved in work with individual pupils. The OSSME service therefore co-ordinates accredited courses, which are assessed up to Master degree level and form part of a pathway to continued professional development for teachers and other professionals. Accredited training modules are delivered on site, in the Autism Initiatives UK training suite and at various venues in the region.

*"We have found the support of OSSME invaluable in enabling us to understand difficulties children with ASD experience in accessing the curriculum, and work toward overcoming these in order to help each child be fully included within the school. Because each child is different it has been extremely helpful to be able to call on the professional expertise of the OSSME team who have experience of children across the ASD spectrum..."*

OSSME is currently providing Pilot Training packages within specific local schools as part of their Service Level Agreements in addition to collaborative working with Sefton Leisure Services to enhance provision and access to facilities for young people with ASD.

## With families

Parents/carers are at the heart of OSSME involvement and planning. Through OSSME service level agreements parents have access to the service on an informal basis as well as part of the Individual Intervention or Transition work which takes place within the school.

OSSME staff members meet parents individually and as part of workshops and in support groups. The newest development is in response to parent requests to meet other parents who have a child with ASD. Some parents live quite close to each other, but never meet because each family is unaware of the identity of others. One family had been told that their son was one of three boys who would all be starting the new school year at the same comprehensive, and it was to facilitate that contact that the OSSME staff produced a newsletter to send to all of the families on the OSSME list, as well as copies to special needs co-ordinators in all schools.

Parent feedback as part of a NAS Accreditation evaluation included:

*"...we feel very much part of the process ... a friendly yet most professional service"*

*"... observations have been thorough and perceptive. The OSSME Keyworker has been friendly, approachable and professional throughout our contact with her. We feel, as parents, that we have been kept informed and very much included in the whole process. "We are sure he would not have achieved this much without continued support from you and the whole team at OSSME. We really appreciate everything that you have done for him over the past four years"*

87% of parents described the OSSME service as 'good/outstanding'

When talking about the OSSME service at the launch of the Att project, Claire Curtis-Thomas MP commented:

*"Parents have access to a marvellous resource which will help you with your unique problems..."*

## OSSME SERVICE LEVEL AGREEMENTS: OUTLINING CLEAR PATHWAYS FOR PARTICIPANTS

fig. 1 Individual Intervention Service Level Agreement

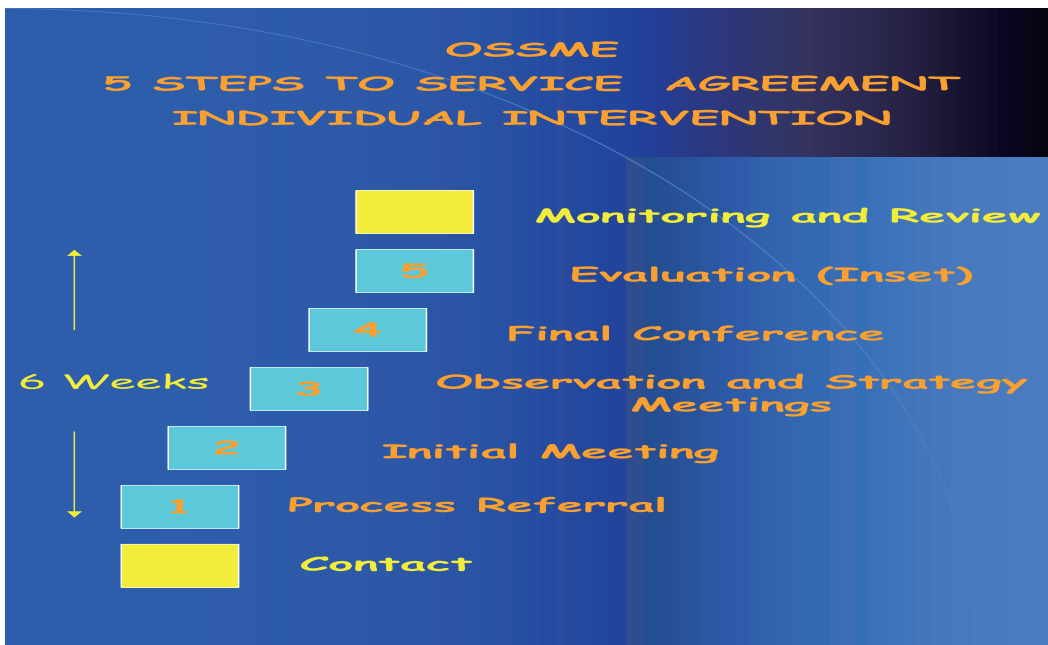


fig. 2: Transition Service Level Agreement

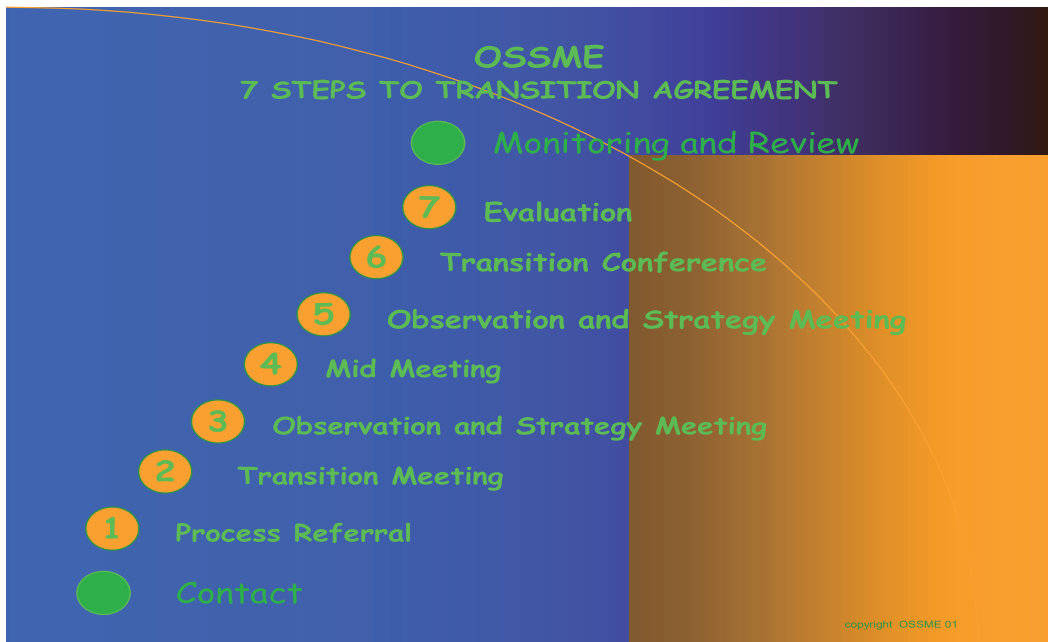
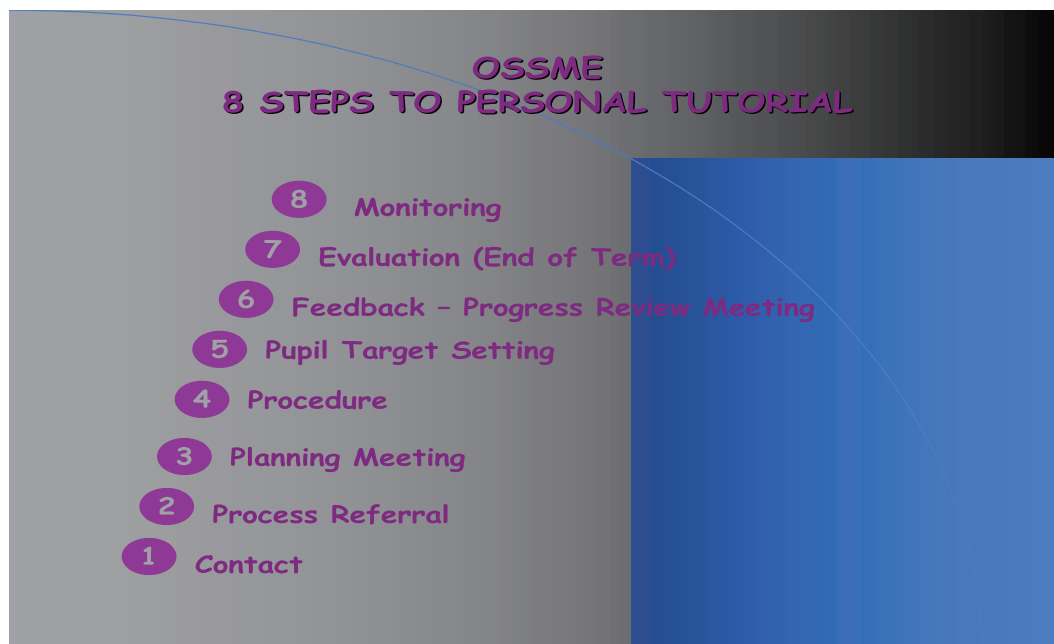


fig. 3: Socialisation in Practice Sessions Service Level Agreement



fig. 4 Personal Tutorial Service Level Agreement



## Contacts

Cindy Tomkinson, OSSME Co-ordinator  
Autism Initiatives UK  
7 Chesterfield Road  
Crosby  
L23 9XL  
Merseyside

phone/fax: 0151 924 5656  
e-mail: [ossme@autisminitiatives.org](mailto:ossme@autisminitiatives.org)

## **Annex 2 : Quality Indicators of Services for Persons with ASD**

### **AUTISM-EUROPE DOCUMENT ON QUALITY OF SERVICES FOR PERSONS WITH ASD**

**With the contribution of the members of the Council of Administration of Autism Europe.**

Special thanks to Ramon Barinaga, Director of the GAUTENA association, Spain, who kindly provided the figures included in this document

### **BACKGROUND**

#### **1. The European context**

##### **1.A The European Union**

The issue of the quality of services for persons with disabilities is high on the EU agenda. In April 2006 the EU Commission adopted a Communication on Social Services of General Interest<sup>1</sup>, taking the specific nature of social services into account at European level and clarifying, to the extent that they are covered, the Community rules applicable to them.

Furthermore, the European Disability Action Plan 2006-2007<sup>2</sup> established as a priority to promote access to quality support and care services, considering that: " promoting quality, affordable and accessible social services and support to disabled people through consolidated social protection and inclusion provisions will be at the core of EU mainstreaming actions... Quality aspects of disability-related social services will also be explored, including the need to promote coordinated delivery of services".

In this context, a thematic dialogue on SSGI to people with disabilities has been engaged by the Disability High Level Group, made up of representatives of all the Member States under the Commission presidency, in order to explore in particular how relevant quality aspects of disability-related social services can be taken into account, including the need to coordinate the delivery of services.

To this aim, the Disability High Level Group with the collaboration of organisations representing people with disabilities, providers of services to people with disabilities and stakeholders in the field, drew up a document on the "Quality of the Social Services of General Interest (SSGI) from the viewpoint of disability". This document was largely inspired by the AE document on the Quality of services for Persons with ASD (2005). Its purpose is to provide guidance and inspiration on how to promote quality social services addressing the particular needs of people with disabilities. It is addressed in particular to actors active in the areas of social protection and social inclusion, including the Member States.

This paper is also to be considered in the context of the European Social Fund programming for 2007-2013, which includes a priority on reinforcing social inclusion of people at a disadvantage, including people with disabilities. The considerations in this paper follow the principle of mainstreaming, which can be defined as the systematic consideration of the specific needs of people with disabilities when designing social inclusion and social protection policies.

<sup>1</sup> Communication from the European Commission "Implementing the Community Lisbon Programme: Social Services of General Interest in the European Union COM(2006)177 final 26.04.2006

<sup>2</sup> Communication from the European Commission on the situation of disabled people in the enlarged European Union COM (2005) 604 final 28.11.2005

## 1.B The Council of Europe

In 2006, the Committee of Ministers of the Council of Europe issued “Recommendations to member states on its Action Plan on disability to promote the rights and full participation of people with disabilities in society”<sup>3</sup>. The Council of Europe Disability Action Plan 2006-2015 is a plan that commits Member States to take action to ensure respect of the human rights of disabled people across all areas of life. It seeks to translate the aims of the Council of Europe with regard to human rights, non-discrimination, equal opportunities, full citizenship and participation of people with disabilities into a European policy framework on disability.

The CoE Action Plan for Disability considers “essential that all policies, services and actions be underpinned by high quality standards... People with disabilities should be the focal point of the services provided. Client satisfaction should be the primary motivation for viable quality policies. It is vitally important that people with disabilities, the service users, should be active participants in quality assurance and monitoring of services.

Training is also an essential element of quality service. This not only includes appropriate training for the personnel involved in service delivery, both disability specific and mainstream services, but also for those who have a role in developing policies which affect the lives of people with disabilities. Training should incorporate awareness of the human rights of people with disabilities”.

## 2. The particular challenges in designing quality services for persons with ASD

ASDs are developmental disorders ranking from severe to moderate, which inevitably result in a significant lifelong disability. This means that persons with ASD need early, lifelong, qualified intervention, lifelong protection at different levels of help, lifelong continuity of services and opportunities for inclusion in the community. The development of their unique potential, as well as their quality of life, depend more on the availability of suitable, appropriate, qualified facilities than on the degree of individual impairment.

Services must support the development of the person from early childhood and their social inclusion in the community by providing special education programmes as early as possible, lifelong training in functional areas such as communication and behaviour, social, work and leisure skills, personal autonomy, and all the support needed for as independent as possible adult life in the community and outside their families. Confronted by an uncertain future, the fears of their families could be dispelled by early planning in how to take care of the child on a daily basis and for the rest of her/his life and depending upon the evolution of the child. The prospect of a dignified future for the child in community-based residential services also provides the most effective emotional support for parents.

This obviously calls for continuous lifelong services that are specific, rigorous, flexible yet consistent. This means also that Quality of the services is not a secondary issue in ensuring the full enjoyment of human and fundamental rights to persons with autism. The availability, reliability and quality of the support services can make the difference between a dignified, significant life and dependency.

Like any other human being, a person with ASD wants to live a full, worthwhile life within their unique possibilities, to benefit from opportunities to achieve independence and a good quality of life in terms of physical, emotional, social and material wellbeing and freedom from abuse or exploitation. In order to achieve their own potential and a meaningful, self-determined life as independently as possible in due respect of human rights and individual freedom, persons with autism need consistent long-term, adequate support.

<sup>3</sup> Recommendation Rec(2006)5, adopted by the Committee of Ministers on 5 April 2006.

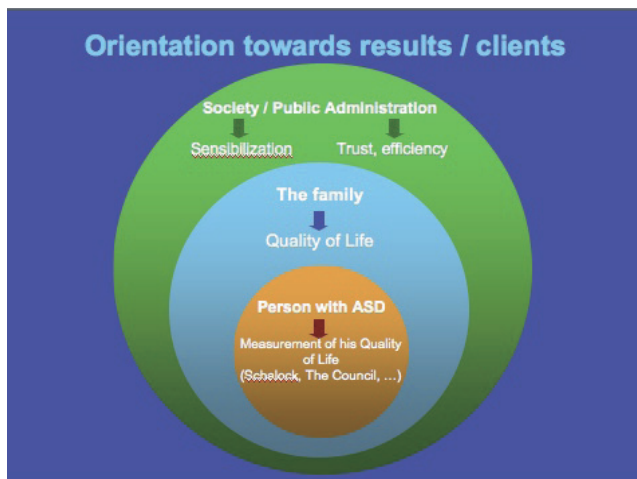
# The Right to Healthcare and Habilitation for Persons with ASD

Such support has to be provided by ensuring:

- Available qualified services organized in a professional way, providing
- persistence and stability of care, as well as
- specific intervention strategies, which are consequent to current, updated knowledge, to meet the specific needs,
- flexible intervention programmes, to meet the individual needs of each user,
- an environment that fosters communication and is adapted to prevent and minimize challenging behaviours,
- ongoing dialogue with families to meet their needs and priorities in the respect of the best interest of the person with ASD,
- active participation of the families in the development, monitoring and review of individual plans.

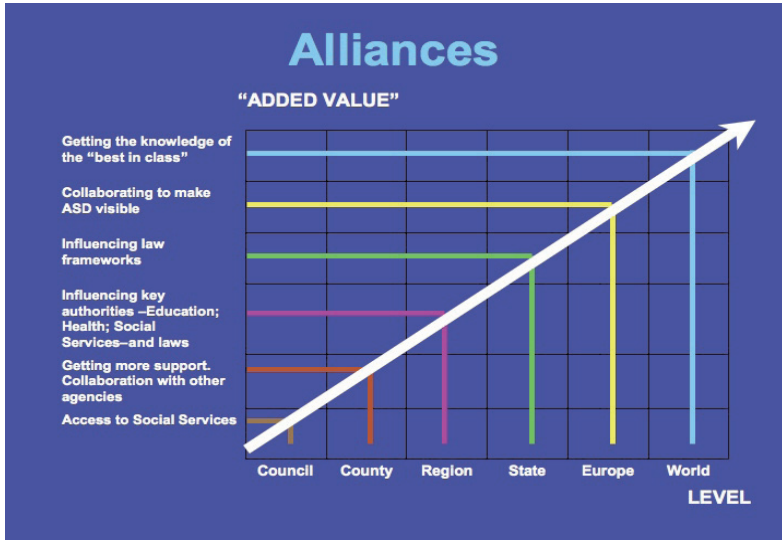
In order to achieve these goals, services should provide specific, qualified intervention in stable and reliable structures that adopt :

- quality standards related to the outcomes, in terms of enjoyment of human rights and quality of life of the users,
- a set of rules defining responsibilities, day-to-day routines and procedures.
- participation of users and their representatives at all stages of the process





# The Right to Healthcare and Habilitation for Persons with ASD



# The Right to Healthcare and Habilitation for Persons with ASD

<b>KEY GOALS</b>	<b>KEY FEATURES</b>	<b>QUALITY CRITERIA</b>	<b>QUALITY INDICATORS</b>
<b>1. What are the pre-conditions to be put in place by the social/health/education systems to ensure that the rights of users with ASD can be exercised in practice?</b>	<b>A. Availability</b>	Provisions and services specifically designed for ASD	Proportion of habilitation and education facilities and support services (compared to the expected rate of persons with ASD)  Proportion of residential services and sheltered units specifically designed for adults with ASD
		Range of educational provisions and services for ASD	Proportion of education facilities for children and adults with ASD  <ul style="list-style-type: none"> <li>• special schools specifically designed for children or adults with ASD included in the education system</li> <li>• special classes specifically designed for children or adults with ASD included in mainstream schools</li> <li>• ordinary educational establishments with provisions for students with ASD</li> <li>• students with ASD included in the mainstream school with qualified support</li> </ul>
	<b>B. Accessibility</b>	Proximity of the services	N° of persons with ASD living in their community of origin
		Transparency of the waiting lists	Rules defining the criteria for admission
		Adapted transport	Ad hoc transport services  Qualified assistance for transfers

# The Right to Healthcare and Habilitation for Persons with ASD

<b>KEY GOALS</b>	<b>KEY FEATURES</b>	<b>QUALITY CRITERIA</b>	<b>QUALITY INDICATORS</b>
<b>1. What are the pre-conditions to be put in place by the social/health/education systems to ensure that the rights of users with ASD can be exercised in practice?</b>		No or minimal financial contribution requested of the users	Financial contribution (if requested) calculated on the basis of the user's incomes (not the family's incomes)  Financial contribution (if requested) calculated on the basis of the evaluation of the needs
	<b>C. Affordability</b>	Range of provisions and services for all ages	Proportion of facilities and services for pre-school children, school aged children, adolescents and adults, including sheltered housing units adapted to the needs of persons with ASD
		Coordinated and consequent delivery of services at all stages in a life-cycle approach	Agreements between Health, Social and Education authorities at national and local level  Counselling and support for transition  Timely planning of transition at individual level  Case manager

# The Right to Healthcare and Habilitation for Persons with ASD

KEY GOALS	KEY FEATURES	QUALITY CRITERIA	QUALITY INDICATORS
<b>1. What are the pre-conditions to be put in place by the social/health/education systems to ensure that the rights of users with ASD can be exercised in practice?</b>	<b>D. Persistence of care</b>	Good governance	Rules defining responsibilities, day-to-day routines and procedures  Card of the service freely available  Transparency and accountability of the financial management  Regular external audits
		Effective and ongoing functional habilitation, education and vocational training programmes	N° of persons with ASD <ul style="list-style-type: none"> <li>• in the open job market (with/without support)</li> <li>• in sheltered workshops</li> <li>• living independently</li> </ul>
		Inclusion in the community	N° of persons with ASD in the mainstream school  Facilities located within the community  Small groups of users in the specialised facilities  Frequency of contacts with peers  N° of users participating in leisure/sport activities in the mainstream on a regular basis  Support to families

KEY GOALS	KEY FEATURES	QUALITY CRITERIA	QUALITY INDICATORS
<p><b>1. What are the pre-conditions to be put in place by the social/health/education systems to ensure that the rights of users with ASD can be exercised in practice?</b></p>	<p><b>D. Persistence of care</b></p>	<p>Free choice</p>	<p>Availability of updated lists of suitable services</p> <p>Availability of updated cards of the provided services</p>
		<p>Ongoing follow-up of the general health conditions</p>	<p>Health professionals in the service</p> <p>General health prevention programmes</p> <p>Qualified staff for accompanying persons with ASD in the general or specialised health facilities</p>
		<p>Reliable detection and diagnosis</p>	<p>Adoption of internationally accredited instruments for detection and diagnosis</p>
		<p>Qualified staff</p>	<p>Qualification and expertise of the recruited staff in the field of ASD</p>
		<p>Trained staff</p>	<p>Structured training opportunities in the field of ASD</p> <p>Annual training programmes concerted with the direction of the service</p>

KEY GOALS	KEY FEATURES	QUALITY CRITERIA	QUALITY INDICATORS
<b>2. What are the conditions to be put in place to ensure that the needs of users with ASD are met?</b>	<b>E. Addressing general needs</b>	Performant staff	Regular measurement of staff satisfaction  Evaluation of the burn-out rate of the staff
		Evidence-based approach	Adoption of intervention strategies based on a sound scientific culture and updated knowledge in the field of ASD (behavioural / cognitive-behavioural strategies)
		Functional intervention	Intervention aimed at developing, improving and maintaining: <ul style="list-style-type: none"> <li>• Social skills</li> <li>• Communication skills</li> <li>• Adaptive behaviour</li> <li>• Personal autonomy</li> <li>• Work skills</li> </ul> Leisure skills
		Choice	Users involved in decisions concerning them  Use of alternative-augmentative communication tools

<i>KEY GOALS</i>	<i>KEY FEATURES</i>	<i>QUALITY CRITERIA</i>	<i>QUALITY INDICATORS</i>
<b>2. What are the conditions to be put in place to ensure that the needs of users with ASD are met?</b>	<b>F. Addressing ASD specific needs</b>	Prevention and treatment of challenging behaviour	Use of alternative/ augmentative communication modes and methods  Use of sound behavioural strategies  Adaptation of the settings
		Individually tailored programmes	Adoption of reliable instruments for individual assessment of capacities, potential and impairments
		Positive approach	Individual programmes consequent to individual preferences, motivation and aptitudes
		Choice	Use of individually tailored alternative-augmentative communication tools  Individually tailored programmes to develop capacity of choice

# The Right to Healthcare and Habilitation for Persons with ASD

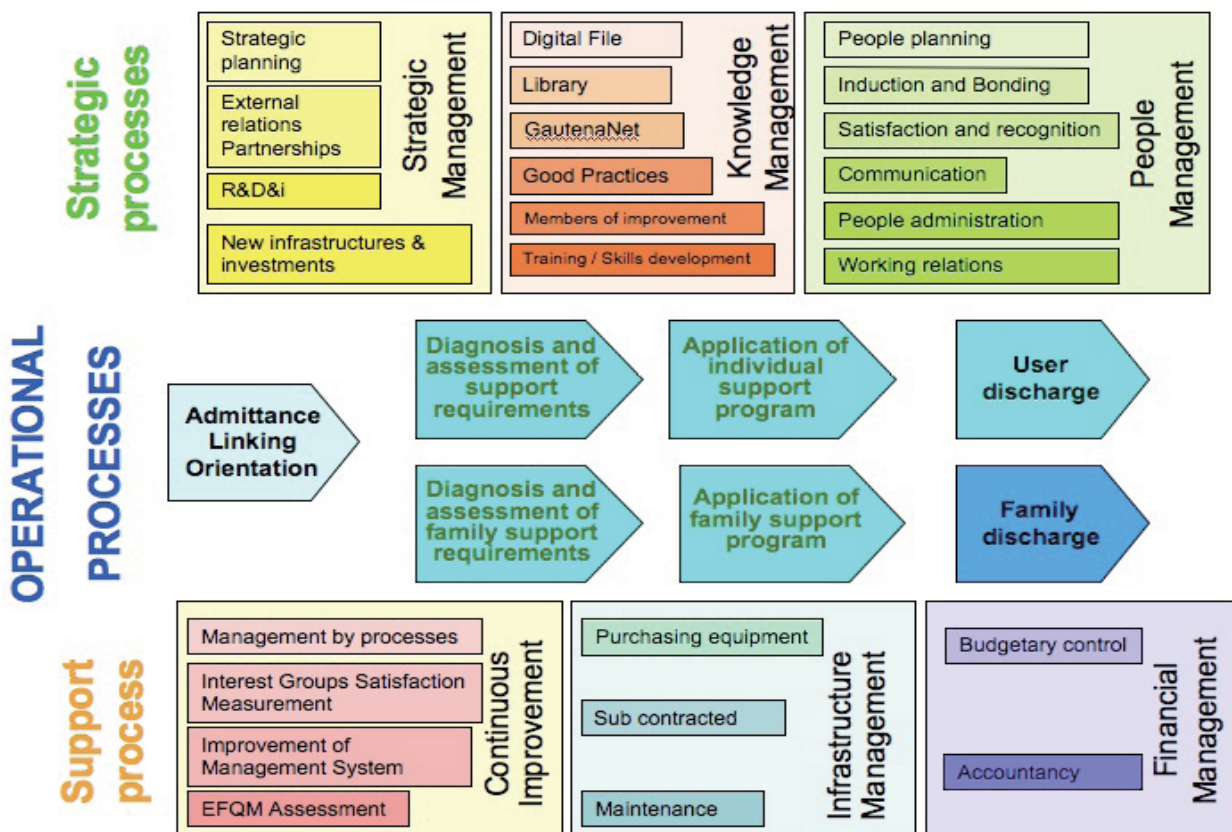
KEY GOALS	KEY FEATURES	QUALITY CRITERIA	QUALITY INDICATORS
<p><b>2. What are the conditions to be put in place to ensure that the needs of users with ASD are met?</b></p>	<p><b>F. Addressing ASD specific needs</b></p>	<p>Functional individual programmes</p>	<p>Concrete, measurable objectives identified in the individual programmes</p> <p>Objectives of the individual programme consequent to:</p> <ul style="list-style-type: none"> <li>• developmental age</li> <li>• chronological age</li> <li>• priorities of the family</li> <li>• environmental resources</li> </ul>
		<p>Flexible individual programmes</p>	<p>Frequency of individual re-assessment of</p> <ul style="list-style-type: none"> <li>• objectives achieved</li> <li>• skills developed</li> </ul> <p>Frequency of adjustments of the individual programme on the basis of the individual re-assessment</p>
		<p>Ongoing assessment of outcomes</p>	<p>Regular administration to users of standardised checklists to evaluate quality of life</p> <p>Regular administration to users and their families of standardised checklists to measure satisfaction</p> <p>Ongoing assessment of challenging behaviour</p>



<i>KEY GOALS</i>	<i>KEY FEATURES</i>	<i>QUALITY CRITERIA</i>	<i>QUALITY INDICATORS</i>
<b>2. What are the conditions to be put in place to ensure that the needs of users with ASD are met?</b>	<b>F. Addressing ASD specific needs</b>	Correct use of medications	Informed consent of the concerned person or of their legal representatives when needed
		Active involvement of the families in diagnosis, assessment and care	<p>Timely communication of the diagnosis</p> <p>Written information on the features of autism</p> <p>Reliable checklists for the assessment of individual development administered to families as part of the individual assessment</p> <p>Detailed written report of the individual assessment timely provided to families</p> <p>Parent priorities and advice collected to draft the individual programmes</p> <p>Availability of parent training programmes</p> <p>Parent training aimed to enable parents to deal with challenging behaviours</p>
	<b>G. Addressing individual needs</b>	Empowerment of families	<p>Written information to families on the rights of their child</p> <p>Contact with representative parent associations</p>

# The Right to Healthcare and Habilitation for Persons with ASD

KEY GOALS	KEY FEATURES	QUALITY CRITERIA	QUALITY INDICATORS
3. What are the conditions to be put in place to ensure that the participation of the users with ASD and/or their families and representatives can be exercised in practice?	H. Active involvement of users and their representatives	Involvement of families in the service management	<p>Assessment of user satisfaction by means of standardised checklists</p> <p>Involvement of representative parent associations in the assessment of the quality of the service</p>



## **Annexes 3 : National Autism Strategy**

### **Medium term services development concept for the period 2008-2013**

#### **NATIONAL AUTISM STRATEGY – GOALS AND ACTIONS**

##### **Table of Contents**

#### **I. INTRODUCTION**

##### **EXECUTIVE SUMMARY**

##### **VISION**

#### **II. MEDIUM TERM ACTION PLAN**

##### **1. Assessment of Current Services and elements of the programmes**

##### **2. Development of Autism-specific Services**

2.1. Ensuring Crisis Services

2.2. Offering Residential Services

2.3. Personal Documentation to Support the Transition of People with Autism between different Services

##### **3. The Provisional Operation of the Autism Professional Workshop**

##### **4. Ensuring Professional Screening and Diagnosis of ASD**

4.1. Improving early diagnosis of autism

4.2. Improving the Diagnostic System for Children

4.3. Diagnosis of Adults

4.4. Assisting the Transition between Child and Adult Psychiatric Services

##### **5. Improving Autism-specific Development and Educational Services**

5.1. Common Strategic Tasks in Education

5.1.1. Establishing and Implementing Autism-specific Qualitative Criteria for Each Level of the Educational System

5.1.2. Offering Accessible Autism-specific Services at Secondary Schools and at Majority Primary Schools is a Priority

5.1.3. Offering Professional Support to schools for the inclusion of pupils with ASD

5.1.4. Adaptation and Dissemination of Psycho-educational Tools Developed for Autism

## 5.2. Special Tasks for Each Educational Level

5.2.1. Early Development, Nursery, Nursery Schools

5.2.2. Primary Education

5.2.3. Improving Access to Secondary Education and Vocational Training

5.2.4. Supporting Students with Autism in Higher Education

## 6. Operating an Adult Training Model Program

### 7. Supplying Autism-specific Professionals

7.1. Preparations for the Training of Autism-specific Professionals, Defining Training Levels, Establishing Training Programs

7.2. Training Trainers

7.3. Organising and Launching the Training of Autism-specific Professionals

7.4. Creating the Body of Autism Professionals

7.5. Supplying Autism-specific Professionals - General Results

### 8. Ensuring Autism-specific Employment

8.1. Establishing and Introducing Standards for the Employment of People with Autism

8.2. Autism-specific Employment and Operating a Labour Market Services Model Program

8.3. Strengthening Alternative Labour Market Services

### 9. Family Support

9.1. Informing Parents and Inclusion of Parents in the Development of the Person with Autism

9.2. Establishing a Mentor Parent Network

9.3. The Opportunity of Employing a Personal Assistant in the Family of the Person with Autism

9.4. Financial Support to Families of People with Autism, Making Existing Services "Autism-friendly"

## Appendix 1. - A Review of Autism

1. Definition of Autism

2. Frequency of Autism

3. Common Needs within the Autism Spectrum

4. General Characteristics of Autism-specific Services

5. Services Offered by Different Sectors to People Living with Autism

6. Legal and Professional Framework of Autism-specific Services in the European Union and in Hungary

## 1. Introduction

The National Autism Strategy (Strategy) was commissioned by the Ministry of Social Affairs and Labour and created by experts as a recommendation for decision making, executive, public administration, interest groups and service providers with reference to the implementation of the new National Programme of Disability Affairs and the Government Decree 1062/2007. (VIII.7.) IV/3. on the medium term implementation schedule of the program for the period 2007-2010.

The Strategy was created in the interest of people living with autism, their families, relatives and the groups of specialists dealing with these people.

The period of the Strategy is 5 years.

### 1. Executive Summary

The creation of the National Autism Strategy is specified in Section IV/3. of the Government Decree 1062/2007. on the implementation of the National Programme of Disability Affairs and the medium term implementation schedule for the period 2007-2010. Therefore the Strategy, as specified in the Government Decree, is a preliminary 5-year development concept which aims to improve the quality of life for the Hungarian population affected by autistic spectrum disorder.

A further reason to create the Strategy other than the legal requirements is the fact that the size of the population affected by autistic spectrum disorder is rising sharply in every country around the world (where the figures are surveyed). Based on the international data on frequency, the size of the Hungarian autistic population is estimated to be around 60,000 persons<sup>4</sup>; and due to the developing diagnostic network the number of young children with autism is growing most quickly. The drastic rise in the number of people living with autism makes it necessary to develop the system as well.

The structure of the Strategy basically reflects the way the facilities and range of services created to cater for the needs of an autistic person during his/her life course are built onto each other, where each element serves as the basis for the subsequent level: early screening and diagnosis, early development, education-development, adult training, employment, family support. A few chapters do not deal directly with the development of the existing system of services available to people with autism but they focus on actions regarding professional policies (Autism Professional Workshop, establishing levels of professional training, launching the training of professionals), and the development of other forms of facilities (Chapter II.2.)

Chapter I. of the Strategy contains the Executive Summary and Vision, and Chapter II. recommends specific actions to be taken.

The definition of autistic spectrum disorder and the national and international principles and professional standards and legislation that give the theoretical background of the Strategy can be found in Appendix I.

The Strategy was created under the guidance of the National Association for People with Autism (AOSZ) by the following experts: dr. Anna Balázs, Gabriella Csillik, Anikó Horváth, László Jakubinyi, Zsuzsanna Kovács, Kinga Marton, Mrs. Mahler Anikó Köfner, Mrs. Tamás Őzsi, Gábor Petri, Csilla Prekop, Mrs. László Schenk, Krisztina Stefanik, dr. Judit Simó, Mrs. Szilágyi dr. Erika Erdős. The Strategy was supervised by the following experts: Gyula Ébner, Csaba Kanyik, Ágnes Tóth J., Balázs Tarnai Phd. (USA).

<sup>4</sup> For detailed research data see Appendix 1.

Throughout the creation of the Strategy, from the preliminary preparation to the final supervised version, the participation of affected parents was ensured at each step. The Strategy was presented to the public and it underwent a social discussion before it reached its final version.

The body of the Strategy contains detailed suggestions, specifying the responsible Ministry for each chapter and the final deadline for implementing all the recommended elements of the given chapter. We also offer recommended deadlines for each action within the Chapter but whether they are adopted or not is the responsibility of the decision maker. The deadlines for each action within a given chapter do not form part of the Strategy but can be found in Appendices II. and III.

The estimated budget of implementing the Strategy can also be found in Appendices II. and III. The costs have been calculated on the basis of currently available data and the aim of the calculation was to give an accurate prediction of what the actual costs would be.

## **Vision**

People living with autism, their families and the specialists and providers offering services to them will experience changes in numerous areas once the Strategy is fulfilled. If the vast majority of the Strategy's goals are fulfilled then the following scenario will unfold by the end of the Strategy's period, by 2013:

- There is a national map of the services available to people with autism and a map of the missing services. These national maps serve as the basis for local councils and fenntartók to plan the forms of required services and their capacities. On the other hand, it would also serve as a basis for the NGOs safeguarding their interests, and it would be a point of reference for their initiatives. The maps will be continuously updated and made public by the interest groups.
- A national network of autism crisis services and residential homes for people living with autism is in operation.
- Tenders issued for residential homes prioritise services specifically offered to people living with autism.
- There is a set of documents which helps the transition of a person with autism when he/she moves from one service to the subsequent one. The documents alleviate the transition of moving from one facility to the other and make the transition easier by offering information and professional knowledge on the personal history of the new "arrival", the given person living with autism. This way the services offered by the new facility can be based on the experiences gathered by the previous one.
- The Autism Professional Workshop creates 3 levels of professional training and further education and trains several dozens of professionals at each level. Due to the fact that these training events are subsidised, the schools and other services can afford to let their colleagues participate in these training events. The training courses are announced each year.
- During the 4 years of its existence the Autism Professional Workshop (APW) has prepared the operating principles and professional requirements for a National Institute on Methodology to be established in the future. Both the system and the APW are prepared to be taken over by one national and seven regional centres.
- Screening autism spectrum disorders is becoming a common aspect of the practices of the general practitioner, midwives and pediatricians, due to the fact that several dozens of professionals have

been trained within each branch of specialists. Early screening creates the opportunity to obtain the diagnosis in time.

- The diagnostic system has also made a significant step forward: the majority of child psychiatric units already have an autism diagnostic team which is able to apply standardised tests. Parents and families have access to a diagnosis more quickly and also closer to their homes.
- The general conditions of psychiatric services for adults have also improved due to the training of professionals. The codes of the OEP (National Health Insurance Fund) have been adjusted.
- The professional standards of autism-specific education has been prepared under the guidance of APW.
- Due to the raised sum of normative subsidy, schools are more willing to accept autistic children (in the educational system) and are also able to offer specialised services. Starting from the school year 2012-13 schools must comply with autism-specific educational standards. In order to achieve this, schools have already made use of a wide range of professional training. Schools had 2 years to bid for funding from tenders to adapt the environment, acquire new tools and pay for costs of the training. As a final result the standard of teaching for students in the specialised groups and for children participating in integrated education has risen significantly.
- Due to the fact that modern psycho-educational tools have been introduced and that professionals have been trained, the quality of individual assessment has improved and better and more professional individual development programs have been established for an increased number of schools.
- A program to safeguard the interest of students with autism in higher education has been launched.
- Due to the range of professional training programs worked out by the Autism Professional Workshop the number of trained professionals has increased at all levels of the service system: carers in residential homes, assistants, teachers, social workers, occupational consultants, psychologists, psychiatrists – and the autism-specific knowledge of each group has improved and therefore has contributed to improve the level of services offered.
- The national model program for autism-specific adult training has ended and therefore has created the opportunity to integrate the experiences in the adult training system.
- The model program for employment has also ended, which serves as a basis for standardised, autism-specific employment programs to be launched in the future. The experiences will primarily be utilised by those NGOs, alternative labour service providers that offer “contractual” labour services to the National Employment Office. The model program and the established set of standards have led to minor changes in legal regulation, and as a result of that the set of criteria for the services in the sector has improved.
- Various changes have occurred in the subsidy system supporting families and consequently, the financial situation of families has slightly improved. Due to the training courses for parents and as a result of a working mentor parent network the quality of life of families has also improved.

The above vision formulates a scenario which could become real to the last detail if all the medium term actions presented in Chapter II. are implemented.

## 2. Medium-Term Action Plan

### 1. Assessment of Current Services and Elements of the System (Responsible: Ministry of Social Affairs and Labour; Deadline: 30<sup>th</sup> September, 2009)

#### Goal

A national survey must be conducted to offer data on autism-specific educational, health and social services.

#### Tasks

Creating a national autism services map and a map of the missing services.

1. **A national autism services map to be prepared** on the basis of international epidemiological studies and the data available on accessible services (developmental, educational, social etc.) for all the possible services required by a person with autism throughout his/her life course. Current data of public institutions (public education information system etc.) and the databases of NGOs (Hungarian Association for People with Autism and Kézenfogva databases) must serve as the basis of the services map with additional data collection if required. The services map must also take into account the qualitative aspects (the level of education of experts, applied methods, environmental conditions, the number of persons/students with autism etc.) of existing services.
2. **A map of the missing services to be prepared** as a supplement, based on the current frequency of autism. The goal of the missing services map is to represent the missing services indicated by the number of potential users for each county. The services map and the missing services map must be made public and the local councils of the areas that have missing services must be contacted and convinced to modify their local services development concepts.  
The existing missing services map must be updated each year starting from the year 2010.
3. The revision and possible modification of legal regulation on social and educational services based on the missing services map (modification of compulsory services).

#### Expected result

The elimination of "black spots", geographical development and improving regional services can be carefully planned on the basis of the services map and the missing services map. Each local council gets the required amount of information in order to modify their own services development concept to meet the demands.

Further than planning the qualitative and quantitative development of the currently available services, designing new forms of services and establishing new facilities/services models can also be launched.

### 2. Development of Autism-specific Services (Responsible: Ministry of Social Affairs and Labour; Deadline: 1<sup>st</sup> January, 2011)

#### Goal

Autism-specific services must be based on the current services and facilities and the current system. They must be supplemented with autism-specific elements and in certain cases new facilities must be created.

#### 2.1. Ensuring crisis services

##### Goal

The crisis affecting the person with autism is complex in its nature. It may affect the person with autism and



also his/her family, can be a health issue and/or a social one as well. Therefore there is a need for a special temporary home that offers housing, health and/or social services in crisis situations for both adults and children living with autism. The long term existence of such a service is only possible if the personal and material requirements are specified in the legal regulation and if appropriate funding is also ensured.

## Tasks

The basis for the financial and standards of these future facilities must be created. In order to achieve this, an **autism crisis facility model program must be launched.**

**The goal of the model program:** The goal of the model program is to offer services as a national crisis facility for people with autism for 2 years. The goal is to work out the standards of autism crisis facilities and also to continuously offer crisis services throughout the duration of the model program.

**Contents of the model program:** The model program must be in operation at a social facility with a national range, a residential facility which is able to offer the carer capacity locally, a facility that already has the necessary physical requirements, where only minor changes (e.g. rearranging the furniture in the rooms) are required for the model program to be launched. The crisis facilities should offer temporary accommodation for 5-8 persons with autism at the same time. The person with autism would get accommodation with full board and his/her family would get social help or family therapy if required in the meantime. In certain cases the crisis facilities must also offer accommodation to members of the family to a limited degree (2-3 persons). The crisis services are offered for a daily fee with a limited duration (number of days). In special cases the opportunity must be ensured to offer the services free of charge for a short period.

The permanent crisis facilities can be launched on the basis of the experiences gained during the model program. Based on the current needs, one facilities for the entire country may be sufficient. The capacity is to be established by the end of the model program but based on experiences it could be launched with an approximate capacity of 10-12 people. The exact figure will be determined by the model program. Following the modelling period it must be considered (according to the principle of subsidiarity) whether there is a need to have two locations in the country to offer crisis services in the medium run.

## Agenda:

- Detailed **elaboration of the model program**, issuing a tender to select the facilities to offer these services, ensuring funds.
  
- **Execution of the model program:**
  - Preparation for ensuring crisis services until 1<sup>st</sup> June, 2009
    - Preparing the selected facilities for the model program: hiring specialists (head of the crisis centre, personal carers, social worker, family assistant), training current colleagues
    - Establishing an appropriate physical environment (furnishing rooms, halls, necessary changes)
    - Preliminary promotion of the services, informing recipients. Shared responsibility with interest protection groups.
  - Services offered continuously between 1<sup>st</sup> June, 2009 and 31<sup>st</sup> December, 2010.

- **Standards for the services offered**, calculations on funding, preparing suggestions for the type of facilities to be established on the basis of the services data and the expected need for the services.
- **Offering crisis services in permanent crisis facilitie(s)**

## Expected results

Crisis services offer families short-term assistance and therefore make it possible for families to mobilise their resources in order to find a solution to the crisis.

A further result to be expected is that the governing public institution in charge of creating strategies will be able to estimate the personal and physical requirements of an autism crisis facility as a permanent solution for the future and will also have the opportunity to make specific plans for establishing a permanent crisis facility.

## 2.2. Offering residential services

### Goal

Widening the range of residential services; the preference of accessible community based residential home solutions within the time span of the Strategy.

### Tasks

The tenders to be issued for residential homes must subsidise the services offered to people with autism, at least to an extent of 33% of the newly created capacity.

At the same time, the types of residential services offered must be established based on international models. The exact form of services offered should also be specified. Each type should offer different levels of services and should be operated in a different manner. Carers should perform given tasks depending on the individual's level of independence.

### Deadline: continuous for issuing tenders

**Responsibility: Ministry of Social Affairs and Labour** and/or the institution issuing the tender; the Autism Professional Workshop is responsible for the system defining the types of residential homes.

**Funding:** requires no additional funding

### Expected results

A growing number of state financed residential homes will be built for people with autism.

## 2.3 Personal Documentation to Support the Transition of People with Autism between Different services

### Goal

The goal is to offer help in the "transition" of people with autism from one service to another by creating a system of references to transmit relevant information.

The goal is to legally ensure that professional information flow would be established between the services that a person with autism encounters during his/her life course, thus making it possible that the services offered meet the individual characteristics of the client as much as possible, irrespective of the fact whether the services offered are short-term intervention, long-term services, partial or comprehensive special services.

### Tasks

A well-structured documentation system must be established to offer the facilities a clear indication of the autistic person's general capabilities as well as his/her abilities and difficulties connected with his/her state, all of which must be taken into account. This would also create the opportunity to monitor and give an overview of the changes in all these areas.

The documentation system which requires the active presence of a "key person" who personally follows the life of the client must contain:

- Details of the multidisciplinary diagnostic results,
- The starting points of special therapy and educational processes,
- A detailed description of the short, medium and long term individual development plans,
- The client's certificates
- Individual information about the person's family or other social environment,
- The client's general health, any associated problems and the experiences gained in offering appropriate autism-specific services to address these needs.

The documentation must be structured in a way that extracts from it could efficiently contribute to the quality of services offered by service providers for the general public (e.g. health intervention) and would offer information without violating the personal rights of the client.

The contents and the general use of the documentation must also be included in the syllabus of professional training for specialists working in the field of autism.

### Requirements

The documentation system should practically be prepared under the guidance of the Autism Professional Workshop. Additional funding requirement is approximately **HUF 2,000,000** (expert fees).

### Expected results

The documentation system makes it possible that services for people with autism at each service provider could be offered without any delay, mistakes, insults or the declining condition of the recipient.

### **3. The Provisional Operation of the Autism Professional Workshop (Responsibility: Ministry of Social Affairs and Labour; Deadline: 31st May, 2009)**

#### **Goal**

It is essential to train an appropriate number of professionals required for the developments defined by the Strategy and to improve the quality of the services. The co-ordination of the large number of development tasks described in the Strategy encompassing various professional fields and containing numerous new elements must be adequately organised. The execution of the tasks must be coordinated and performed at the required professional and quality level.

#### **Tasks**

A provisional comprehensive professional governing and consultation organisation must be in operation for about 5 years (referred to as the **Autism Professional Workshop (APW)** within the Strategy), which would play a professional coordinating role within the time span of the Strategy in order to achieve the following by the year 2013:

- a) Create a coherent system of intensive professional training and further education
- b) Significantly increase the number of trained professionals
- c) Define a system of criteria for the list of autism professionals to be created
- d) Create a financial and organisational basis for a national professional methodology centre and for regional autism centres to be created for each region after the year 2013.

The following professional fields are represented in the APW: health sector (psychiatry, psychology), pedagogy/special needs education and the social sector.

Membership at the APW can be acquired by successful application. A secretariat of 4 persons is recommended (1 head, 2 coordinators and 1 administrator) and roughly 10 commissioned professionals. Members of the secretariat will work full time and members of the professional team will be commissioned for projects. It would be a sensible solution to create a new organisational unit within the framework of the Public Foundation for Equal Opportunities for People with Disabilities (e.g. Autism Professional Workshop Program Unit). The APW has an independent budget to fulfill its tasks which can be supplemented in special cases for specific tasks.

It is a crucial criterion that the supporting organisation, practically the Ministry, be entitled to make use of the methods established, adopted, bought or applied by the APW because this is the only way to ensure that the methods remain "public property", that is the legal opportunity to launch training programs, to reprint professional literature and to use methods and applications in the future would be ensured. The above condition or a guarantee of an equal measure must be included in the contract regulating the operation of the APW.

Recommended tasks of the APW:

- To make a survey of the current training opportunities, establishing, organising and holding training programs.
- Establishing autism-specific quality insurance criteria (services, programs, training)
- Updating professional guidelines, disseminating and making new information accessible and creating a professional development plan (e.g. which new diagnostic and/or therapeutic methods are worth adopting and disseminated).

- Widening the range of scientific and informative literature in Hungarian, translating international scientific literature. It is crucial that only unquestionable and widely acknowledged scientific literature and methods be translated to Hungarian.
- Organising conferences and presenting a summary of each year's achievements to facilitate an open dialogue.
- Defining the set of tasks for the professionals, establishing the set of requirements and the guidelines for operating a professional team, compiling and publishing the list of professionals.
- Establishing and preparing the basis for the development of the system (National Methodology Centre and Regional Services Centres).
- Offering consultation, supervision to social and educational facilities within an appropriate framework.
- Maintaining relations with international organisations, exchanging experiences and information.

## **Expected results**

Achieving the goals specified within the Strategy with an active professional participation in the execution of the Strategy. Offering a modern and reliable professional background to support the "field work" and the appropriate execution of the Strategy.

The most important result to be expected by the end of the Strategy's period, 2013, is that all the requirements and conditions will have been established for one National Methodology Centre and a Regional Methodology Centre for each region to be in operation. By the end of the Strategy's time span the APW will be able to hand over its responsibilities to the National Methodology Centre.

## 4. Ensuring Professional Screening and Diagnosis of ASD (Responsible: Ministry of Health; Deadline: 31st December, 2010)

### Goal

Reliable and adequate diagnostics determine the life course of the person affected by autism (and his/her family) and also improve their quality of life. On the other hand, it clarifies the quantitative and qualitative requirements of supporting this population. Therefore the screening and professional diagnostics of autism spectrum disorder must be ensured.

Given the current framework and the time span of the Strategy, the goal is to improve the reliability of screening and diagnostics and to increase the accessibility of both.

### 4.1. Improving Early Diagnosis of Autism

#### Goal

Early diagnosis leads to early specific intervention and consequently children will have a greater chance of being integrated and greater development can be anticipated in their abilities and their quality of life. It is indispensable for early screening that pediatricians and midwives be well-informed both in terms of the early signs of autism spectrum disorder and in terms of the necessary actions to be taken (e.g. sending them to the right specialist).

#### Tasks

Further training must be established and launched for people working in the following fields:

- Pediatricians,
- Midwives,
- School Doctors,
- General Practitioners – expanding the range of tools for screening (e.g. SCQ<sup>2</sup>).

on the methods applied for early screening (CHAT<sup>3</sup>; M-CHAT<sup>4</sup>), on the professional guidelines on autism spectrum disorder and on new elements of the screening tools (e.g. SCQ<sup>5</sup>) - transmitting relevant information on the age groups encompassed by the given field.

The training and further education for each professional field must be fitted within the educational system based on the credit system and within the training of neonatal and child carer training or as a separate subject or as part of a block of subjects together with other disabilities.

#### Requirements

The training requires a screening protocol to be established, professional guidelines and newsletters to be compiled, the syllabus of 2-day training events to be determined and the training events to be held. The tasks are to be executed under the guidance of the professional team of the APW.

#### Expected results

Training a minimum of 40 pediatricians/midwives and a 20-hour training to be held for a minimum of 30 other specialists in the year 2010.

<sup>2</sup> Rutter, M., Bailey, A., & Lord, C. (2003): SCQ: The Social Communication Questionnaire. Western Psychological Services: Los Angeles, CA.

<sup>3</sup> CHAT – Checklist for Autism in Toddlers; Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *British Journal of Psychiatry* 161, 839-843.

<sup>4</sup> Robins DL, Fein D, Barton ML, Green JA. (2001) The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders* 31(2):131-44.

<sup>5</sup> Rutter, M., Bailey (2003): SCQ: The Social Communication Questionnaire. Western Psychological Services: Los Angeles, CA.

As a result of the training events the set of criteria for the "first screening" level would be established on a national basis. Depending on available funding, the training events could subsequently be held each year in order to increase the number of professionals capable of performing screening tasks.

## 4.2. Improving the Diagnostic System for Children

### Goal

The diagnosis of autism spectrum disorder for children or adults is primarily a psychiatric task, that is the duty of health services. But public education facilities that employ psychiatrists either for children or adults who are also engaged in diagnosis also play a role (professional and rehabilitation committees assessing learning abilities, early development centres).

The following qualitative criteria for reliable and valid diagnosis must be ensured by the end of the Strategy's period:

- interdisciplinary team work (child or adult psychiatrist, psychologist, special needs teacher or a neurologist if justified),
- the use of standardised diagnostic assessment tools (ADI-R<sup>6</sup>; ADOS<sup>7</sup>),
- the use of standardised performance and skills assessment tools,
- defining and controlling the main guidelines of the appropriate therapy, care and services meeting the individual's special requirements, professional assistance in their execution.

### Tasks

The training of professionals must be established and launched in order to improve the level of diagnostic services. The training must focus on standardised diagnostic tools (ADOS, ADI-R) and should be based on professional child psychiatry guidelines.

Further than the training offered, the necessary test equipment must also be made available to them.

The tasks in detail: creating a 20-hour diagnostic course, offering training; ADOS and ADI-R training; ensuring the set of diagnostic tools required for ADOS and ADI-R; maintaining the reliability of standardised tools with follow-up training events; ensuring an autism diagnostic expert/supervisor.

The NM Decree 51/1997. on *Health services and screening tests offered within the national health insurance system to prevent diseases and for early detection* should be modified in order to incorporate the above screening system which would create the opportunity for early diagnosis. The modification should specify the tasks of the pediatrician (screening based on early symptoms with a minimum burden) and the tasks of the designated centre (differentiated diagnostic tasks with the right personal-physical requirements).

### Requirements

A set of appropriately weighted OEP (National Health Insurance Fund) points must be introduced for the use of standardised tools. The required data should be gathered at 2 or 3 selected facilities.

<sup>6</sup> LeCouteur, A, Lord, C., Rutter, M. (2007). Autism Diagnostic Interview-Revised. Kapocs: Budapest

<sup>7</sup> Lord, C., Rutter, M., DiLavore, P. C., Risi, S. (2007) Autism Diagnostic Observation Schedule. Kapocs: Budapest

## 4.3. Diagnosis of Adults

### Goal

Current experiences reveal that the psychiatric services for adults are not prepared to diagnose autism, consequently, this task is often performed by psychiatric services for children – which are not reimbursed by the National Health Insurance Fund – or no reliable diagnosis is established. The aim is to improve and spread the diagnostic skills of adult psychiatric services.

### Tasks

The training and preparation of adult psychiatric units and psychiatric departments at hospitals is identical to the preparation described in Chapter 4.2. :

- further training is required
- the set of tools to be extended to include the standardised screening (SCQ) and diagnostic (ADI-R and ADOS) tests.

### Requirements

A transitional period of 1 year is required for the appropriate preparation of adult psychiatric services. During the transitional period child psychiatric facilities offer these services under clear financial circumstances (code revision).

### Expected results

At least 8 diagnostic teams (2 persons each) have been trained in the field of ADI-R and ADOS and the required set of tools have been ensured. At least 2 follow-up consensus training events held.

## 4.4 Assisting the Transition between Child and Adult Psychiatric Services

### Goal

The transition from child psychiatric care to adult psychiatric care, that is the planned process of transfer must be ensured from early adulthood.

The transition between child and adult psychiatric services is facilitated if the transfer takes place in a systematic manner, that is the adult services is able to take over the role of offering adequate services to the patient at each level (doctor or specialist).

### Tasks

If the goals of Chapters 4.2 and 4.3 are fulfilled then there will be an appropriate number of trained professionals for each level of services. Further training on adult care is required for the specialists of adult psychiatric units. The training program must be established and the training events held.

Training the network of professionals performing the professional supervision of adult doctors is of crucial importance (ORSZI – National Rehabilitation and Social Institute). Specific training is required and must be established for this field as well.



## **Requirements**

The reimbursement of services offered to patients is based on the current professional list of codes (EüM. Decree 9/93.). However, the reimbursed amount paid with reference to the given code does not fully cover the actual costs incurred, standardised diagnostic tests in particular, which require ample time and expertise. Therefore it is essential to initiate the revision of codes (cost analysis and certificates of the number of cases).

## **Expected results**

Selecting and preparing at least 10 adult psychiatric facilities. The quality of services offered will improve on the long run due to the fact that the financing will be adjusted to reflect the actual labour requirement.

## 5. Improving Autism-specific Development and Educational Services (Responsible: Ministry of Education and Culture; Deadline: 30th September, 2013)

### Goal

Children and adults with autism require individualised, disability-specific development, training and education throughout their entire lifetime. In order to ensure services that meet their requirements, services of the Hungarian system must be improved in quantitative and qualitative terms as well.

**Reason:** The frequency of ASD for the entire population is calculated to be 0.6% based on international epidemiological surveys. If we calculate a moderate estimate based on this rate, at least 7,000 children/pupils should have appeared in public educational settings in the school year 2007/2008, irrespective of the fact whether they took part in mainstreamed education or received disability-specific special education. In contrast, only a total of 1276 children/pupils appeared within the educational system according to the national statistics of the Ministry of Education and Culture. The figure in itself by no means represents that pupils with ASD received disability-specific services either in terms of the personal/material requirements or the professional content.

### Children/pupils with autism based on the statistics of public education for the school year 2007/2008. (the data is based on the statistics of educational facilities as of 1<sup>st</sup> October, 2007):

Total (persons):

Data of children/pupils according to disabilities	School years															Total	No. of girls
	Nursery school	E1	E2	1	2	3	4	5	6	7	8	9	10	11	12		
<b>Autistic</b>	<b>306</b>	<b>45</b>	<b>18</b>	<b>163</b>	<b>111</b>	<b>106</b>	<b>80</b>	<b>83</b>	<b>79</b>	<b>77</b>	<b>88</b>	<b>46</b>	<b>33</b>	<b>26</b>	<b>15</b>	<b>1276</b>	<b>231</b>
<b>Participating in integrated education</b>	<b>211</b>			<b>42</b>	<b>22</b>	<b>24</b>	<b>24</b>	<b>12</b>	<b>13</b>	<b>12</b>	<b>13</b>	<b>8</b>	<b>7</b>	<b>12</b>	<b>5</b>	<b>405</b>	<b>77</b>

### 5.1. Common Strategic Tasks in Education

#### Goal

The general conditions for the entire range (special and integrated forms) and the full length of public education must be modified once, in order to meet the needs of reality. The number of professionals and their level of training are both inadequate at current facilities and the normative subsidy of autistic students does not reflect the realistic requirements either. Therefore educational facilities do not get either the required professional or financial support for their tasks connected with autistic children. The goal is to make decisions that would have an effect on the long run, decisions that would help the facilities offer professional services, decisions that would motivate them and at the same time would also create obligations for them.

The distant goal is to raise the professional per child (pupil) ratio to such an extent that it would gradually approximate the ratio recommended internationally, i.e. the ratio in best practices, by the year 2013. As a first step and within the time span of the Strategy, the realistic aim is to reduce the difference between the current professional/child ratio and the international ratio, according to the following:

- To have 1 special needs teacher and 2 assistants for a segregated autistic group of 6-8 children/pupils on average – (currently, in the majority of the institutions there are 2 persons per group, that is the average number must be raised by 1 person).
- At least 1 trained professional per mainstream school and at least 1 assistant for 2 children participating in mainstreamed education.

The financial basis of increasing the professional/child ratio could be the raised sum of supplementary normative subsidy.

**Reasons:** One of the consequences of autism is that the traditional form of education, based on spoken language, social communication and learning in a group, is not appropriate for people with autism in most cases. Autism-specific training/education heavily relies on professionals because assessment, planning and development alike must meet individual requirements. A high number of individual lessons is an indispensable condition of successful learning.

The prevention and treatment of severe behavioural problems frequently associated with autism also make it necessary to have an adequate teacher/child ratio.

## 5.1.1. Establishing and Implementing Autism-specific Qualitative Criteria for Each Level of the Educational System

### Tasks

- The general criteria (professional requirements, professional/child ratio etc.) for a high standard of autism-specific education must be established. The criteria will affect all educational facilities and all the children, pupils with autism participating in the educational system and their families. If possible, the standards should also apply to the dormitories of educational facilities.
- The codification and the implementation of the criteria must start from the school year 2011/2012. Service providers must be made interested in offering a high level of autism-specific services. This can be achieved by allocating a raised sum of normative subsidy or by ensuring funds from tenders, starting from the school year 2011/2012. The new regulations would mean that the facilities that offer services at a certified quality would get a 250% supplementary normative subsidy for their pupils with autism instead of the current 160% supplementary normative subsidy.
- At least two tenders must be issued, starting from 2010, to support and assist changes at educational facilities to reach the required quality standards. By this time, there will be further education programs for professionals. With the help of these trained professionals, the funding from the tenders will assist schools in: training professionals (teachers, assistants); purchasing equipment and creating an autism-friendly environment.

## Common requirements

- The procedures leading to the modification of the OM Decree 3/2002 on *Quality insurance and qualitative improvement of public education*, with the result that the qualitative criteria would be included in the Appendix of the decree.
- The criteria to be included in the Services Quality Management Program (SMIP), in cases when services offered to children/pupils with autism is among the tasks of the facility
- Creating a connection between financing and meeting the criteria – after a certain period only the services that meet the criteria would get extra funding. Modification of the Budget Act.

## Expected results

The results of establishing and applying the criteria will be more standardised services, services offered at a higher level of quality and controlling the services will also be easier. The regional and quality differences between the services will be reduced. Children/pupils diagnosed with autism will receive more adequate services that meet their disabilities to a higher degree and therefore these children/pupils will not drop out of the system and will have the chance of getting adequate development that meets their individual requirements.

Further services in the mainstreamed schools and special service centres will be established.

### 5.1.2. Offering Accessible Autism-specific Services at Secondary Schools and at Majority Primary Schools is a priority

### 5.1.3. Offering Professional Support to schools for the inclusion of pupils with ASD

#### Tasks

Ensuring the professional requirements of mainstreamed schools for the entire length of public education. Teaching the required professional knowledge to majority teachers. We recommend that it be a legal requirement for mainstreamed schools to have at least 1 professional to be trained until 2013 if the school has any pupils with autism.

The minimum requirements for a program supporting integration:

- Information and methodology material to be created;
- Creating training programs;
- Making the professional material supporting integration and training opportunities available to mainstreamed schools.

#### Expected results

Professional services offered to high functioning children/pupils with autism and their complete functional

integration. The acceptance and attitude of the society in mainstreamed settings (parents, professionals, peers) towards people with autism will improve and their understanding of autism will be better. Consequently, it will have a positive overall impact on Hungarian society in general.

## 5.1.4. Adaptation and Dissemination of Psycho-educational Tools Developed for Autism

### Tasks

Ensuring the methods and tools required for the assessment of individual abilities within the methodology for education, training and development. The national adaptation of assessment tools (PEP-3, TTAP) and creating a training program in order to make the adapted autism-specific assessment tools equally accessible for each service offered. Ensuring training and the required tools after the adaptation.

### Requirements

- Regulating the use of the tools in Chapter 6 of Appendix 1 and Chapter 8 of Appendix 2. of the OM Decree 2/2005.
- Ensuring the necessary funding.

### Expected results

Standardised individual assessment of an adequate quality is performed based on specific disabilities, creating the opportunity for professional individual development plans to be prepared. As a result, the effectiveness of the development process can be measured objectively.

## 5.2. Special Tasks for Each Educational Level

### 5.2.1. Early Development, Nursery, Nursery Schools

#### Tasks

Supporting the operation of autism-specific family day care centres. Establishing the professional, personal and financial model for the operation of autism-specific integrated/segregated family day care centres.

Early development and the nursery school normative subsidy should both be available within the services offered to the child with autism, up to a level of 25 hours of early development per week. We suggest that a model for new financing options be established.

Comprehensive, complex and multidisciplinary early intervention is a crucial criterion of efficient professional services. The current hours of weekly services (2 to 6 hours) should gradually be raised to the level recommended internationally (25 hours). State financed services must be available from the moment of the first suspected symptom. The tasks must be elaborated in detail.

## Requirements

- Training an adequate number of trained professionals and ensuring the required amount of lessons per week. Consequently, Section 8. of MKM Decree 14/1994 must be modified.
- Ensuring funding for the new model to be established. The actual sum of the funding can only be estimated once the program has been established.

## Expected results

- Ensuring early, intensive and disability-specific services to infants diagnosed with autism.
- Improving the quality and quantity of the available services. Reducing the number of children who do not get any services.

## 5.2.2. Primary Education

### Tasks

Detailed codification on the operation of special autistic groups (not a system of regular lessons; education based on individual lessons; training and education issues; the question of how to divide and unite groups). More specific legal regulation on the professional and organisational requirements of integration. Creating a comprehensive and coherent administrative and documentation system reflecting the actual operation of services, systems that comply with legal regulations.

### Requirements

- Modifying Appendix 3. of the Act on Public Education regulating *Group sizes and unifications*,
- Modifying the sections of OM Decree 2/2005 referring to autism.

### Expected results

An improved quality of services. Cost efficient, transparent and professional operation.

## 5.2.3. Improving Access to Secondary Education and Vocational Training

### Goal

The common strategic tasks (see Chapter 5.1.) must be applied in secondary education as well.

During the preparation of the Development Plan on public education (Section 88. of the Public Education Act) the local councils that offer services must be responsible for aligning their plans and must reach an agreement on the variety of services offered, in order to ensure that services, including dormitories, will be available in the entire country for the full spectrum of autism. Due to the heterogenous nature of the target group, it is not a sensible solution to offer the entire range of services for the full spectrum of autism in each county. Instead, each county is recommended to specialise and ensure services for a specific subgroup (e.g. a special recipient grammar school for high functioning students, specialised vocational services for autistic people with mental disabilities etc.).

## Requirements

Training an adequate number of professionals.

## Expected results

Creating disability-specific services for students with autism of a secondary school age, which is currently a missing service.

### 5.2.4. Supporting Students with Autism in Higher Education

#### Goal

Offering help and support to students with autism in higher education, preparing higher education facilities.

#### Tasks

Professional assistance and consultancy offered to people with autism studying at higher education facilities to help them fit in.

Offering information and assistance to the person with autism to register him/herself as a student with special needs within the higher education and also to choose the form of help needed. Peer helping programs to be launched where students studying special needs pedagogy, psychology, medicine, social work etc. could play a special role.

#### Requirements

Getting acquainted with foreign best practices and adapting them.

#### Expected results

High functioning people with autism could successfully participate in higher education.

The goals and tasks expressed within this Chapter of the Strategy are closely connected with Sections 3 and 5 of Appendix I. and Section 3 of Appendix II. and Section 3. of Appendix III. of *Government Decree 1062/2007. (VIII. 7.)* and are aligned with Subsection 3.a and 3.f of Section 10 of the *Public Education Act (1993.)* and the *Resolution ResAP(2007)4 on Education and Integration of Children with Autism* adopted on December 12th 2007 by the CoE Committee of Ministers Council of Europe.

## **6. Operating an Adult Training Model Program (Responsible: Ministry of Social Affairs and Labour; Deadline: 30th November, 2008)**

### **Goal**

Creating an opportunity for the target group of autistic people with mental disabilities to have access to training once they are past the schooling age and to give them the opportunity to continuously develop their adaptation skills. In order to ensure this, the adult with autism must have access to both general and vocational training. The vocational training must be available to them within the public educational system and/or within the framework of adult training, i.e. through OKJ training and other forms of accredited training. The vocational training must be market-oriented.

### **Reasons**

In order to create the opportunity for people with autism to make the best use of their skills, it is indispensable to teach them independence skills, prepare them for work and employment by structuring space and time and applying special tools and methods. An appropriate framework must be ensured within the adult training system: tight schedule, general training in an appropriate residential home, preparation for work, ensuring the equipment required for professional teaching, social workers and trained professionals as teachers who have a deep understanding of autism. The adult training system makes it possible to achieve significant progress based on individual training programs.

### **Tasks**

A model program to be launched for autism-specific adult training. The adult training model program must be based on general training (lifelong learning, preparation for independence, developing communication and social skills) and special training aiming development.

1.

Contents of the model program:

- A uniform system of requirements and quality insurance system must be created in order to offer the training material defined by the structure.
- Improving training programs and services, creating a curriculum, teaching aid, workbooks, videos, CD's and DVD's.
- Fitting vocational training programs to the National Educational Registry system (OKJ), accreditation at the Adult Training Accreditation Institute.
- Establishing training programs on autism for teachers of both children and adults offering further training and retraining; creating teaching aids; offering training.
- General training offered in each region, near their residence, to be introduced gradually depending on the number of professionals available.
- Offering training programs, making them accessible and communicating them to the target group.
- A National Integrated Vocational Training Centre to be established with regional education centres and dormitories. Vocational training to be organised nationally with boarding, matching the regional labour requirement.

Tasks of the model program are to be scheduled, the achievements to be monitored and regularly evaluated. The insight gained through the achievements and experiences to be incorporated in subsequent tasks of the program.



## Requirements<sup>8</sup>

- Sufficient funding to be ensured for the detailed elaboration of the program.
- Within the project:
  - Modifying the Vocational Training Act and associated decrees in order to ensure the participation of students with special needs (autistic and mentally disabled adults as well) in vocational training
  - Preparing curriculum, teaching aid, videos etc.
  - Training and preparing professionals
  - Ensuring funds from the New Hungary Development Plan for infrastructural development
  - Ensuring funds for the vocational training of adults with autism through tenders from the Adult Training Fund of the Hungarian Budget starting from the year 2009
  - Ensuring the funds for operation from the Adult Training Fund of the Hungarian Budget starting from 2011
  - Ensuring funds for the training programs in the Budget Act (Ministry of Social Affairs and Labour, Adult training normative subsidy)
- The funds scheduled for each year must be defined in the project proposal.

## Expected results

- General training offers predictability, safety and continuous development for adults with autism and also gives them the basis to live independent and full lives to the limit of their potential, to take part in vocational training and to become active members of society.
- Having participated in market-oriented vocational training, adults with autism will have the opportunity to be active members of the (protected or free) labour market.
- The training offers the basis for employment for the person with autism, an appropriate financial status and safety.
- The way professionals will deal with people with autism will change. They will devote less time on their social welfare and more on their training and independence.
- Families of adults with autism will be integrated in society.

The suggestions expressed within this Chapter are closely connected with the following documents: 2003 Madrid Declaration, the Constitution of the Hungarian Republic, the Adult Training Act 2001/CI. and the OGY declaration 10/2006. (II. 16.) on the new National Programme of Disability Affairs.

<sup>8</sup> Achievements:

December 2007: The Aktiv Műhely Humán Szolgáltató Nonprofit Kft. was founded with the goal to offer general and vocational training to people with autism (and mental disabilities). Uniform accreditation of training programs, creating and establishing the curriculum and teaching aids.

April 2008: Quality insurance introduced in 6 locations (Budapest, Dunaharaszti, Mezőberény, Miskolc, Pécs, Tata)

May 2008: Accreditation of institutions

## 7. Supplying Autism-specific Professionals (Responsible: Ministry of Social Affairs and Labour, Ministry of Education and Culture; Deadline: 31st December 2013)

### Goal

Ensuring adequately trained and capable professionals in order to offer autism-specific services at each level of services and for the entire life course of people with autism.

It is a goal to ensure an adequate number of professionals to meet the requirements of the goals expressed in other Chapters of the Strategy (primarily Chapter 4. on Screening and Diagnosis; Chapter 5. on Development and Educational Tasks; Chapter 6. on Adult Training; Chapter 8. on Employment) and furthermore, to ensure accessible training programs for the professionals working within the range of services offered to people with autism.

### 7.1. Preparations for the Training of Autism-specific Professionals, Defining Training Levels, Establishing Training Programs

#### Goal

The training of autism-specific professionals to be launched at different levels of superior quality. A significant growth (at least an average of 4-5 persons per year for each level in each region) must be achieved in the number of autism professionals. Ensuring that the training of professionals is based on a standard scientific background. Creating the range of training programs based on existing and new programs.

#### Tasks

- Determining the number of professionals required, establishing the training levels /programs, defining tasks.
- The number and qualification of the professionals required for each field must be mapped for every region in order to determine the total number of professionals required. Professionals from each region must be involved in this phase of planning. (The task must be performed simultaneously with the tasks of preparing the services and missing services maps described in Chapter 1. of the Strategy.)
- The number of professionals who had been trained before the start of the Strategy and the value of their qualification must be determined.
- Determining the specialised fields for professionals:
  - Diagnostics, specific development and therapy adjusted to age, areas of public education, employment, adult services, social care, public administration etc.
  - Determining the profession of professionals given specific training: doctor (pediatrician, psychiatrist/ child psychiatrist), psychologist, teacher, special needs teacher, social area (social teacher, social worker, public administration professional), etc.
- Determining the levels of training:
  - **Basic level:** "sensitising", ensuring that there is a basic understanding concerning the nature of the state and the philosophy of intervention.  
Target group: the wider group of people offering services  
Form of training: primarily courses and further education/training  
Tasks: widening the range of the current courses and aligning their curriculum according to the realistic needs (based on a survey)

- **Intermediate level:** offering specific and in-depth knowledge on diagnostics and the wider range of services.  
Form of training: vocational training in diagnostics and services  
Tasks: in an ideal case the training could be form part of the basic training but in a larger quantity and at a higher level of quality with a new curriculum and quality insurance.
- **Advanced level:** ensuring a higher level, a more specific knowlegde of autism, that could serve as a basis for scientific work, for people/leading professionals working at the regional and the national centres.  
Forms of training: masters and postgraduate.

## Expected results

A list of the facilities offering specific training and a list of the forms of training. The training programs will offer the majority of people working in the educational and social field a standard knowledge on autism to be utilised in their work.

## 7.2. Training Trainers

### Tasks

Training the people who will train others (training trainers) is also necessary, which requires Hungarian and foreign further training/education to be held. This also applies for the general training. Professionals should acquire special qualifications in the given programs.

- Spreading and adapting ("acquisition of") the method in Hungary or
- organising foreign training programs in Hungary.

### Requirements

Ensuring funds for

- the training of 10 persons in Hungary
- scholarship program for 5-6 persons to be trained abroad

### Expected results

Launching the training of trainers in Hungary (1 or 2 training events per year), holding foreign training programs in Hungary (1 training event per year).

## 7.3. Organising and Launching the Training of Autism-specific Professionals

### Tasks

Launching regional training and regional courses at the levels described in Chapters 7.1 and 7.2 replacing the current centralised structure (only in Budapest). Making the training programs accessible through normative subsidy or funds from tenders. Training programs must be organised according to the regional requirements and subsequently these local professionals will fulfil further tasks.

### Requirements

- Postgraduate training for at least 30 persons
- Ensuring further funds for Chapter 7.1 and other programs

### Expected results

Ensuring a wide range of autism-specific professionals and that the range of training and further training programs are accessible to educational/social habilitation facilities.

## 7.4. Creating the Body of Autism Professionals

### Goals

Creating the body of professionals at a regional level to act as a supervisor of services and to ensure a professional background.

Compiling the list of professionals on the basis of specific factors, establishing a base of professionals meeting professional criteria.

### Tasks

Enlisting the professionals trained within the programs described in Chapters 7.1-7.3 in the "list of professionals". Creating the body of autism professionals comprising specialists from various fields, with adequate qualifications, extensive experiences, numerous references and possibly scientific publications.

### Expected results

Regional lists of professionals.

## 7.5 Supplying Autism-specific Professionals – General Results

Establishing the training system and launching quality training at various levels and the continuously growing number of professionals at different levels are all crucial factors of implementing the comprehensive Strategy. Even if the financial resources are abundant the lack of trained professionals makes it impossible to offer efficient services. Knowledge enhances the self-confidence of professionals, increases their competency and effectiveness and hopefully, a greater number of professionals will come to the decision

to enter this field rich in challenges. Vocational training and competence both reduce the likelihood of the burnout syndrome, which is quite frequent within this field. Trained professionals – with a sound strategic and financial background – are capable of offering services that make the lives of the clients and that of their families safer throughout their entire lifetime and creates the opportunity and facilitates their social integration.

Basic documents that support the implementation of the tasks specified within this Chapter:

- **Government Decree 1062/2007(VIII.7)** on the implementation of the new National Programme of Disability Affairs and tasks for the years 2007-2010. Basic principles of the program in Chapters III., IV. and V.
- **Government Decree 1062/2007(VIII.7)** on the implementation of the new National Programme of Disability Affairs and the tasks for the years 2007-2010, and the Parliament Resolution 10/2006 (II. 16.) on the new National Programme of Disability Affairs, on the goals connected with making a positive impact on public opinion and on goals connected with rehabilitation.
- UN Convention – "Convention on the Rights of Persons with Disabilities" Sections j) and v) of the Preamble; Article 2; Section d) of the General Principles in Article 3; Articles 26. and 35.

#### **Criteria for modifying legislation:**

Modification of Act LXXIX. (1993) on Public Education; Act CXXXIX. (2005) on Higher Education and Act CI. (2001) on Adult Training and the modification or adjustment of the associated Government and Ministry decrees are required to offer the legal framework for the operation of the National centre and the Regional service centres. The operating funds must be set in the Budget Act within the chapter of expenditures of the Ministry of Education.

## 8. Ensuring Autism-specific Employment (Responsible: Ministry of Social Affairs and Labour; Deadline: 31st December 2009)

### Goal

Improving the employment of people with autism, operating consecutive and passable (from the social employment system to the system of employment endorsed by the labour market and vice versa) forms of employment, matching their specific situation, special needs, individual abilities and skills.

It is a primary task to adequately prepare the people working within the organisations offering social services, dealing with employment, training, assessment of working ability for the special aspects of employing the given target group (communication, co-operation etc.).

**Reason:** Ensuring employment for people with autism is a basic human right and from the social-therapeutic perspective it means that they conform to the social norm. It is a widely acknowledged fact that the employment of people with autism poses significant difficulties, therefore it must primarily be connected with the comprehensive set of social services. Employment can only be ensured if there is a close co-operation with the social services. At the same time, the entire spectrum of employment must be supported and each segment of employment must be passable according to the individual needs; labour market policies must be involved as well.

### 8.1. Establishing and Introducing Standards for the Employment of People with Autism

#### Tasks

A standard (theory and implementation) to be established for the employment of the population living with autism: a heterogenous and diverse group of people, affected and afflicted by numerous factors to a different degree. Certain labour market policies are required to monitor the individuals during the entire length of employment. International experiences must be utilised, adapted and their continuous application must be supported (e.g. farms for autistic people). The standards must define the special tools required to facilitate the employment of the person with autism for each labour market service.

- In order to create an environment where the standards can be adopted and used, the contradictions and barriers of the legal regulation must be eliminated and/or modified to meet autism-specific requirements. E.g.:
  - If the condition of the person deteriorates then he/she must have the option of returning to a lower level of employment. This requires that the Government Decree 112/2006. (V. 12.) *on the Permission of social employment and the subsidies for social employment* must regulate the levels of employment and the number of people employed more flexibly during the process of granting permission.
  - The legal regulation of social employment must be harmonised and must take into account the life course of people with autism which is characterised by individual and special needs. The Government Decree 321/2007. (XII. 5.) *on Complex rehabilitation* must be aligned with the regulation of social services.
  - It must be specified how accredited employers based on Government Decree 176/2005. (IX. 2.) can employ a person in a day care centre and/or a residential facility because strengthening this system may build a bridge between the sheltered workshop and the open labour market. Similarly, it must be clarified how the social services could operate as accredited employers.

## Expected results

The standards will be compulsory for all public and private labour market service providers who take on the employment and support of people with autism and receive Hungarian and European Union funding. Once the legal regulation is modified, it will create a wider range of opportunities for autistic people to be employed.

## 8.2. Autism-specific Employment and Operating a Labour Market Services Model Program

### 1. Goal

Currently there are only a few isolated examples for the long term employment of people with autism and there are few examples of the current practices applied in a different framework. Getting acquainted with the experiences and practices of employing people with autism and establishing the basis for a practice-oriented financing model are required. In order to achieve this, **model programs must be launched** in the entire vertical range of employment for people with autism. The programs must ensure various individualised forms of employment and the autism-specific work orientation and assistance to young autistic people and their parents. The programs must be based on the standards defined in Chapter 8.1. The standards must be put into practice and the results continuously monitored.

### Tasks

The programs must be created in cooperation with the representatives of organisations currently employing or offering labour market services to people with autism. The programs must be in operation for a minimum of 1 year and the experiences of the programs must be monitored continuously. The requirements for the programs are the following:

- The programs must contain elements that prepare the employers for receiving people with autism (adapting the workplace to the individual's skills and needs, e.g.: info-communication accessibility, mentoring, offering information and/or internal training, follow-up, indication system).
- Publications, publicity actions to spread information connected with employment. One of the work groups of the info-communication accessibility project of FSZK TÁMOP 5.4.5. prepares a program to create a social attitude based on acceptance; the opportunities for applying the results of the program must be found.
- In order to assess the autistic person's map of competencies the co-operation of an autism expert and an appropriate assessment tool (e.g.: TTAP and Lantegi working ability assessment tools) are required. The individual employment plan for rehabilitation must be based on the Individual Plan.
- The experiences gained from the projects must be shared with the public and private employers and service providers. Sharing experiences and dissemination must be an integral part of the proposed model programs, which have a minimum duration of 3 years.
- The model programs must be developed to be more market-oriented (possible elements: market research, business plan, training of professionals, sales, marketing, product PR, sensitising, on-line knowledge base, activity pricing, mainstreaming principle etc.)

## Expected results

The opportunity to define and finalise the professional and financial standards for the employment of persons with autism will be possible once the model programs have ended. This will also create the

opportunity to initiate the modification of the necessary legal regulation. The financing government will get a more accurate picture of truly effective autism-specific employment methods and their costs.

### 8.3. Strengthening Alternative Labour Market Services

#### Tasks

Launching the process, creating the opportunity for organisations offering alternative labour market services, primarily NGOs to be accredited and get normative subsidy. The system of accreditation basically means that the service capacity of the National Employment Office is increased. ***The process of establishing the system of accreditation within the framework of TAMOP 2.6.1. for the complete alternative labour market service system (people with altered working abilities) has been started.***

#### Requirements

The funding for creating the system of accreditation has been made available by the TAMOP 2.6.1. program to the National Employment Public Foundation and the work is currently in progress.

#### Documents that support the implementation of the tasks described in the Chapter are:

- Chapter 3.6 of OGY Decree 10/2006 (II.16)
- Section 7, 10 of Chapter 3.; Sections 3, 4, 5 of Chapter 4. of Government Decree 1062/2007



## 9. Family Support (Responsible: Ministry of Social Affairs and Labour; Deadline: 31st August, 2009)

### Goal

The psycho-social and financial support offered to families of people with autism.

**Reason:** The families raising a person with autism are significantly burdened with psycho-social problems and they need special help to be able to resolve them. A support system must be created for them which is both special and general, that is, it is able to manage the psycho-social problems of the family connected with autism and other psycho-social problems.

### 9.1. Informing Parents and Inclusion of Parents in the Development of the Person with Autism

#### Tasks

Extending the parents' knowledge of autism and training parents are both crucial. Informational material and training programs (e.g. general parent training on autism; the opportunities of preparing someone for independence; parent-child groups; self-advocacy; legal awareness) must be created for parents at different levels and with different topics.

#### Requirements

Determining the training topics, curriculum and teaching aids.

- Training an adequate number of professionals is a prerequisite (see Chapter 7. of the Strategy)

#### Expected results

If the goal is achieved then the quality of life for the families will be improved. It is more probable that the family will be able to cater for the needs of the child or student with autism and placing the child in a residential facility can be avoided in many cases. Members of the family can actively take part in the development of the person with autism and this greatly increases the efficiency of therapeutical interventions. The training programs may be funded by NGOs or from current open tender sources (FSZK assistance program for parents) in the future.

### 9.2. Establishing a Mentor Parent Network

#### Goal

The help offered to parents by one another efficiently contributes to the support offered by professionals.

#### Tasks

Parents who take on the role of mentors must be prepared to offer assistance. Mentor parent training programs must be created. The training of trainers must be established based on the training material: training parents who would work as mentors within the mentor parent network and parents who would actively participate in organising training programs in the future.

#### Expected results

The training offered to the family of the person with autism does not merely transmit information to

the family. It also offers psychic assistance which helps them resolve their problems more efficiently and protect their interests. It will also make them capable of supporting their peers.

### 9.3. The Opportunity of Employing a Personal Assistant in the Family of the Person with Autism

#### Goal

There is a need for carers who, other than having sufficient skills in assistance, also have a knowledge of autism, ones who are willing to take on the difficulties associated with the role.

**Reason:** Caring and catering for the needs of a severely disabled person or someone with compounded disabilities or an autistic child/adult is a significant burden for the families. In the majority of cases they cannot get any help due to missing services and the way existing services are targeted. Even accessing the most simple services requires a significant amount of effort from families.

#### Tasks

- Creating an intersectoral work group for the preparations of establishing the services, studying foreign examples (e.g. Slovakia), cost efficiency analysis, transforming existing services.
- Modification of Act 1993. III. to include people with autism in the groups that require special services.

#### Expected results

The personal assistant offers help in: employment; making use of labour market policies; training parents, primarily by creating the opportunity for parents to return to work and to participate in training and retraining.

### 9.4. Financial Support to Families of People with Autism, Making Existing Services "Autism-friendly"

1. The **higher "factor"** to be applied for children with autism for subsidies calculated on the basis of the number of children raised by the family.

**Reason:** The Act on Education acknowledges the raised requirements of autistic children. According to the Act, each child with autism accounts for 3 children when calculating the size of a class. This raised requirement poses needs in various fields of life. Meeting these needs is a basic requirement in order for people with autism and their families to be able to lead at least an approximately "normal" life (e.g. in housing subsidies a separate room is justified for the child with autism; families living in a block of flats are liable to be constantly provoked, intimidated and sued due to the noise etc.)

#### Tasks

- Reviewing and revising the legal regulation of subsidies connected with children
- Writing recommendations

- Realistic calculation of financial requirements for the budget
- Launching an initiative towards Ministry of Social Affairs and Labour
- Codification

2. The **allowances persons with autism could receive** based on the Government Decree on parking allowances **must be examined**. E.g. reduced parking fee, subsidy for purchasing a car, subsidy for adjusting housing conditions

**Reason:** Some of the people with autism are not able to use vehicles of public transportation due to their fears, anxieties or some other reason. Or the person may exhibit behaviour problems of a scale that make it impossible for the person to use public transportation vehicles safely. These people with autism can only be driven by car to the facilities offering education, development, health services or employment. In the absence of a car, the life of the person with autism and his/her family is strictly limited within the walls of the flat that they live in.

The Government Decree 218/2003 (XII.11.) on the parking ID of physically disabled people already specifies autism as a beneficiary for the allowance. Thus acknowledging that a car is not only crucial for people with physical disabilities but also to people with other disabilities in order to make use of their human and citizen rights.

## Tasks

Revision of the legal regulation on the various subsidies, allowances, especially the following:

- Articles 3 and 5 of Government Decree 164/1995 (XII.27)
- Article 9 of Government Decree 12/2001 (I.31)
- Article 4. Sections 5 and 6 of Act 1993. III.
- Modifying the definition of the code to "severely disabled in their movement".

The **raised level of caring fee to be made available** to families who are raising a child with autism exhibiting severe behavioural problems, who is able to eat, get washed or get dressed independently, who is toilet trained and is able to move around the living quarters independently.

## Reasons

Families who would be eligible for the raised level of caring fee due to their child with autism but do not get it because the raised level of need for caring primarily arises from the behavioural problems (e.g. smearing faeces, aggression). Currently it depends on the decision or benevolence of the expert examining the situation whether the family is eligible for the higher sum of caring fee or not. for a child who is able eat and move around independently but may e.g. exhibit aggressive behaviour.

## Tasks

Initiating the modification of Section 43/a. of Act 1993. III. on Social Administration and Social Services.

## Expected results

The raised need for caring is acknowledged in the codification for children who are relatively independent but due to severe behavioural problems require a higher level of supervision. Consequently, the financial

situation of families will be improved.

### **Expected results for the entire Chapter**

- The quality of life for families in real need, raising a child with autism, is improved. Or in certain cases the life of the family becomes more livable.
- Discrimination is reduced within certain services connected with disabilities. The situation of families in real need and the services meeting the needs of the person with autism are improved.

## Annexes I : A review of Autism

### 1. Definition of Autism

Autism is a neurological development disorder which is the result of the permanent disorder of the central nervous system and/or a complex behavioural syndrome characterised by behavioural and developmental differences. It is a lifelong disorder and the basic disorder cannot be influenced by treatment according to our present knowledge.

All the states, (1) *social communication*, (2) *reciprocal social interaction*, and (3) *flexibility of thinking and behaviour* (the triad of autism), that belong to the spectrum are based on and characterised by the developmental delay and deviance of the cognitive skills.

The clinical picture of the given population varies greatly. The severity of autism, the symptoms outside the triad, the intellectual skills (can be at any level), other skills, strengths, disabilities, associated conditions (e.g. speech development disorder, epilepsy) all depend on the personality of the child or the given person and they may vary and change with age.

Despite the characteristic and striking similarities there is no single form of behaviour or a single symptom which would always be present nor is there one that would rule out the diagnosis of autism.

Autism may lower the quality of life of the individual and his/her closest environment by a significant degree.

People with Rett syndrome and all the patients/clients diagnosed with pervasive developmental disorders - excluding, arguably, those with disintegrative disorder - belong to the group of people living with autism or to those with autism spectrum disorder. All of them have common special needs and the services offered to them must be standardised, because all of them require a uniform – disregarding intellectual abilities – but distinct therapeutic-educational approach and care that meets their special needs. (Dr. Anna Balázs 2007)

### 2. Frequency of Autism

Epidemiological surveys (on children) indicate that the frequency of autism is rising. The state that used to be considered especially rare is one of the most frequent developmental disorders today. The most recent data (published within the last few years) of the scientific literature indicates that the combined frequency of all forms of autism is between 0,6% and 1%.<sup>9</sup>

### 3. Common Needs within the Autism Spectrum

The common basic problems of autism spectrum disorders denote common special **requirements** as well, which must be taken into account throughout their entire life course and within all environments:

- It is indispensable to be aware of the consequences of autism and to accept the special perspective of the individual.
- The participation and inclusion of the family is of primary importance in every phase of life. At the same time, services must also continuously be offered to the family.
- Applying cognitive behavioural therapy methods is a basic element of development and the prevention and treatment of behavioural problems.
- In compounded cases autism must be considered the main disorder – the one that determines the methodology of different interventions.

<sup>9</sup> Earlier data: 1950's: 0.03-0.04%; Wing and Gould, 1979: 0,2 %; National Autistic Society UK., 1999: 0,9%. The registered rise in percentages does not apply to the total number of people with ASD but to those diagnosed with ASD. The reason for the change is presumably due to differences in the diagnostic methods, our knowledge of autism, the development of our approach and the fact that the state is more widely known. References and sources:

Fombonne, E.: Epidemiology of autistic disorder and other pervasive developmental disorders: (J. Clin. Psychiatry 2005. Supl. 10:3-8) Frequency: 0,6 %

Baird G. et al.: Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special needs and Autism Project - SNAP (Lancet, 2006 Jul. 15.) ASD frequency: 1,16%

- A multidisciplinary approach is necessary, offering complex rehabilitation.
- The most general distant goal, given the skills and developmental level of the individual, is to achieve the highest quality of life possible; social adaptation; creating the conditions for independence. Compensating for the lack of social, communication and other cognitive skills with specific methods and developing existing skills is the key to achieve the goal.
- Individual assessment, planning and development is required: developing communication and social skills must be in focus.
- Due to the typical difficulty in thinking and the lack of flexibility a special dimension is applied in their development: teaching the application of the skills they have acquired, teaching them how to generalise, the continuous use of skills in order to preserve the skills and teaching alternative problem solving methods.
- The opportunities to motivate the individual must be mapped in each case.
- Ensuring the right number of appropriately trained staff is indispensable.
- Clear, structured, predictable, "autism-friendly" environment must be established.
- Taking advantage of understanding and learning based on visuality and the use of visual aids are essential, as they help stabilise the fragile social world. Supplementing and replacing spoken language with forms of communication that are more accessible to people with autism.
- Offering 24-hour assistance based on the understanding of autism is required throughout their entire lifetime.

#### **4. General Characteristics of Autism-specific Services**

Autism-specific services are based on the common requirements described above and the mapping of individual needs.

In order to create an appropriate therapeutic environment and to create an individualised intervention, the following factors must be assessed: level of social adaptation, mental age, level of intelligence and level of communication. Due to the fact that the profile of skills and abilities and the learning abilities are uneven, individualised development is required. Individual development must also be continuously monitored with an appropriate tool.

The set of tools and methodology applied is based on scientific facts connected with autism.

#### **5. Services Offered by Different Sectors to People Living with Autism**

The competencies of the facilities providing services to people with autism must match the requirements of the given age group. The facilities can be divided into

**Child facilities** offering:

- health
- social habilitation
- social inclusion support
- mainstream education;

**Adult facilities** offering:

# The Right to Healthcare and Habilitation for Persons with ASD

- health
- social habilitation and training (social, communication and adaptive skills training and vocational training)
- social inclusion support (including recreation)
- employment opportunities
- labour market services.

Services can be provided:

- In mainstream services or
- Autism-specific facilities offering one or several kinds of services.

Sectors and services		childhood (0-24 years) child facilities	adulthood (16 years and above) adult facilities
<b>Health</b>	General health	Diagnosis, Prevention, Healing	Diagnosis Prevention, Healing
	Autism specific health	Early detection and diagnosis, early intervention, habilitation	Social habilitation services
<b>Social</b>		Social services Nursery Support to families	Social services
<b>Education</b>		Nursery school Public education Vocational education	Adult training Vocational training
<b>Employment</b>		Creating working abilities and work behaviour	Employment opportunities Labour market services

## ***The services required by a person with autism in different phases of life for each sector***

It is a distant goal to ensure that the system of provisions and the horizontal and vertical system of services would be passable to the person living with autism, that is the person would get to the facility that matches his/her personal needs indicated by his/her state and general circumstances

