

Domestic Laws and National Plans or Strategies for the Protection of the Rights of People with Autism: An Appraisal

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1 Introduction

The recognition of autism in psychiatry in 1943 by Dr. Leo Kanner¹ and Hans Asperger's studies in the mid 1940s marked the beginning of the scientific studies on autism.² In 1979, Wing and Gould introduced the concept of autism spectrum disorder (ASD) covering a range of levels and severities, and characterized by qualitative impairments in social interaction, communication, understanding and imagination.³ The ASD is a complex lifelong developmental disability which impacts on all aspects of individual's life and on several public sectors (education,

¹ See Kanner (1943). Kanner used the expression 'infantile autism' to describe a psychiatric syndrome, characterized by disturbances of social relationships, limited use of language to communicate, and fixed repetitive interests and routines.

² See Asperger (1944). The article was translated into English only in 1991, see Frith (1991). Individuals with Asperger's syndrome have impairments in social interactions but with no significant language or cognitive development delay, nor lack of age-appropriate self-help skills. For these reasons, they may be well integrated in their community.

³ See Wing and Gould (1979). Under the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) published in 2013, ASD is the only overarching diagnosis and Asperger's syndrome is no longer a separate label, see American Psychiatric Association (2013). Differently, under DSM-IV, patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified. The DSM-5 is the manual used in the United States (US) and Anglophone countries by clinicians and researchers to diagnose and classify mental disorders.

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health, welfare, justice⁴ and others). The very nature of its pervasiveness makes the ASD different from other conditions. Indeed, ASD covers a broad group of disorders that share core deficits but with a wide range of differentiated degrees of disabilities and impairments.

The World Health Assembly, the plenary organ of the World Health Organization (WHO), in the Resolution WHA67.8 concerning ‘autism’ of 24 May 2014 has affirmed that ‘autism spectrum disorders are developmental disorders and conditions that emerge in early childhood and, in most cases, persist throughout the lifespan and are marked by the presence of impaired development in social interaction and communication and a restricted repertoire of activity and interest, with or without accompanying intellectual and language disabilities; that manifestations of the disorder vary greatly in terms of combinations and levels of severity of symptoms’.⁵

Currently, ASD is the fastest-growing serious developmental disability in the United States (US) affecting 1 in every 68 children, while in the European Union (EU) 1 in every 150.

A number of studies indicate that behavioral and educational interventions, particularly those that begin in early childhood, lead to positive improvements in children with ASD with regard to behavioral problems, acquisition of new skills and greater social integration.⁶ It is now accepted that the quality of life of individuals with ASD and their families are much enhanced when timely, appropriate and effective support is ensured, and adequate health, education, and social care services are provided.

In some countries these factors have contributed to make ASD an issue of public interest which has impacted on policies and laws. Legislation may play a key role in providing special support and services for individuals with ASD and their families, and in safeguarding autistic people from discrimination and social exclusion on the grounds of disability irrespective of the underlying impairments (whether physical, mental, intellectual or sensory). This role has also been recognized by the World Health Assembly in the above-mentioned Resolution on autism that recommended to Member States ‘to develop or update and implement relevant policies, *legislation*, and *multisectoral plans*, supported by sufficient human, financial and technical

⁴ See, for instance, the Bill introduced in the United Kingdom on ‘Hate Crime (People with Learning Difficulties and Learning Disabilities) Act 2014’. The Bill requires police forces to register hate crimes committed against people with learning difficulties and learning disabilities, including autism.

⁵ The Resolution was co-sponsored by more than 50 countries and supported by all WHO members, including the US. The Resolution, even if not legally binding, is relevant because WHO countries have underlined the importance of addressing autism and other developmental disorders in national policies and legislations, and have established a clear set of actions to be undertaken to support individuals, families and communities affected by them, see more at: <http://www.autismspeaks.org/science/science-news/who-publishes-autism-resolution#sthash.DkJ099LS.dpuf>. For all websites, last access 31 October 2014.

⁶ See National Autistic Society for National Initiative for Autism: Screening and Assessment (NIASA) (2003), p. 89.

resources to address issues related to ASD and other developmental disorders, as part of a comprehensive approach to supporting all persons living with mental health issues or disabilities’.⁷

Similarly, the European Committee of Social Rights (ECSR) in the decision of September 2013 on the case *European Action of the Disabled (AEH) v. France* underlined that having regard to the definition of autism given by the WHO in the ICD-10,⁸ autism is not as a temporary disease, which could therefore be cured, but is a disability which has stable and permanent nature. For the Committee such a nature affects the form of protection that States must accord to people with autism, in the specific case children or adolescents with autism ‘must be educated in citizenship’ and ‘human assistance must be arranged for all or part of their schooling’.⁹

2 The Legal Recognition of Autism in National Laws

At domestic level, national laws protecting the rights of people with disabilities are the first sources of statutory obligations for States to guarantee fundamental rights of persons with ASD and provide them targeted services and support. However, from a legal point of view, the needs of persons with ASD are better satisfied if autism is recognized as a specific form of disability with lifelong impairments. Indeed, the inclusion of autism among the disability categories established by law may be a first step to reinforce the rights of people with autism in the domestic legal order.¹⁰

In the EU, some countries have included autism among the disabilities recognized by law.

In France the Law no. 96-1076 of 1996 amended the Law no. 75-535 of 1975 (‘Disabled Persons Policy Act’) by recognizing autism as a form of disability

⁷ See para 1.2 (italic added).

⁸ See ICD-10 Classification of Mental and Behavioural Disorders adopted by the World Health Organization (WHO) in 1993 (<http://www.who.int/classifications/icd/en/GRNBOOK.pdf>). The ICD-10, widely used in the European countries, is under revision. The French Federation of Psychiatry developed an alternative classification system the CFTMEA (Classification française des troubles mentaux de l’enfant et de l’adolescent), first released in 1983, and lastly updated in 2012. <http://www.psychiatrie-francaise.com/Data/Documents/files/CFTMEA%20-%20R-2012.pdf>.

⁹ See para 80 of the decision.

¹⁰ For the relevance of a normative definition of autism in the field of employment, see the chapter by M. Fasciglione, in this volume.

requiring a multidisciplinary taking care which must take into account the specific needs and difficulties of the person concerned regardless of the age.¹¹ The Law no. 2005-102 of 11 February 2005 ‘For equal rights and opportunities, for the participation and the citizenship of people with disabilities’ does not mention autism but contains a legal definition of disability that reads as follows: ‘a disability constitutes any activity limitation or participation restriction to life in society that a person may undergo in her/his environment, due to a significant, lasting or permanent alteration of one or more functions, be it physical, sensory, mental, cognitive or psychological, due to multiple disability or due to a disabling health condition’.¹² This notion has been criticized to be more restrictive compared with the WHO’s definition according to which ‘disability is the result of the interaction between individual characteristics and that of the environment’ and the concept of disability enshrined in Article 1(2) of the Convention on the Rights of Persons with Disabilities (CRPD) of 2006 modeled on the human rights approach.¹³ With regard to ASD, Autism France has proposed to include in the Law no. 2005-102 ‘autism and ASD as a specific disability’ and to define the ‘cognitive disability and its place within autism’.¹⁴ The critical observations on the notion of disability in the Law no. 2005-102 and the proposal to introduce the concept of autism in the French legislation show the role that normative definitions may play in safeguarding the rights of people with ASD.

The relevance of a broader notion of disability that encompasses autism is also evidenced by the case of Northern Ireland. By the Disability Discrimination (Northern Ireland) Order 2006 and the Autism Act (Northern Ireland, NI) 2011

¹¹ ‘Toute personne atteinte du handicap résultant du syndrome autistique et des troubles qui lui sont apparentés bénéficie, quel que soit son âge, d’une prise en charge pluridisciplinaire qui tient compte de ses besoins et difficultés spécifiques. Adaptée à l’état et à l’âge de la personne et eu égard aux moyens disponibles, cette prise en charge peut être d’ordre éducatif, pédagogique, thérapeutique et social’, see the so called Loi Chossy ‘Loi n. 96-1076 du 11 décembre 1996 modifiant la loi n. 75-535 du 30 juin 1975 relative aux institutions sociales et médico-sociales et tendant à assurer une prise en charge adaptée de l’autisme’.

¹² ‘Constitue un handicap, au sens de la présente loi, toute limitation d’activité ou restriction de participation à la vie en société subie dans son environnement par une personne en raison d’une altération substantielle, durable ou définitive d’une ou plusieurs fonctions physiques, sensorielles, mentales, cognitives ou psychiques, d’un polyhandicap ou d’un trouble de santé invalidant’ (see Loi n. 2005-102 pour l’égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées du 11 février 2005, JO n. 36 du 12 février 2005, p. 2353).

¹³ The French concept of disability seems still to reflect a vision that burdens unequally the individual’s impairment (‘due to ...an alteration of function’), even if it takes into account the various dimensions of disability (impairment, activity limitations, and social participation restrictions) and includes mental, cognitive or psychological conditions, see ANED (2009), p. 4. On the concept of disability in the CRPD see Sect. 3 in this chapter.

¹⁴ See Autism France, Bilan de la loi de 2005 pour l’autisme. www.autisme-france.fr/offres/file_inline_src/577/577_P_21066_4.pdf. It is interesting to recall that also the ECSR in its decision on the merits of 4 November 2003 in the case *Autism-Europe v. France* pointed out ‘the restrictive definition of autism used in French official documents’ (submitted during the procedure) in relation to the definition of autism adopted by the WHO.

the Disability Discrimination Act (DDA) 1995 was amended in order to include ASD within the legal concept of disability. The DDA prohibits discrimination against disabled persons in a range of circumstances, including employment, transport, and the provision of goods, facilities and services. Only ‘disabled persons’, as defined in Section 1 of the DDA and associated schedules and regulations, are entitled to the protection provided under the Act. In particular, Section 1 of the DDA affirms: ‘(1) Subject to the provisions of Schedule 1, a person has a disability for the purposes of this Act if he has a physical or mental impairment¹⁵ which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities. (2) In this Act-disabled person means a person who has a disability’.

Schedule 1, para 4(1) of the DDA establishes that an impairment is to be taken to affect the ability of the person concerned to carry out normal day-to-day activities only if it affects one of the activities listed in the same paragraph. Social relations, which affect in particular people with ASD, were not included. For this reason, the Autism Act (NI) 2011 added in this list the following activities: (a) ‘taking part in normal social interaction; or (b) forming social relationships’.

Through this amendment also social impairments have to be considered under the terms of the Act, allowing people with ASD to fall within the provisions of the DDA and appeal against a form of discrimination. This modification removed the ambiguity, originated by some case law, as to whether ASD could fall within the definition of disability contained in the DDA. The case of *Hewett v Motorola* decided by the United Kingdom Employment Appeal Tribunal in 2004 is particularly significant in this respect.¹⁶

The case involved a person whose Asperger’s syndrome was not considered by an employment tribunal to fall within the definition of disability in the DDA 1995. For the Employment Tribunal of Bristol the Asperger’s syndrome produced on Mr. Hewett adverse effects on his ability to participate in human interaction, social relationships and communication, ‘however, those are not matters listed in paragraph 4 of schedule 1 DDA 1995 and therefore, not matters the tribunal is able to take into account. The tribunal does not find that the condition from which Mr. Hewett suffered had a substantial and long-term effect on his ability to carry out normal day-to-day activities by reference to those matters set out in paragraph 4 of Schedule 1 to the Act’.

Mr. Hewett appealed and the Appeal Tribunal concluded the following: ‘We have not found this an easy case to determine as to whether this experienced

¹⁵ The definition covers both physical and mental impairments. Physical impairments include those affecting the senses such as sight and hearing, heart disease, diabetes, epilepsy. Mental impairments include learning disabilities and mental ill health.

¹⁶ *Hewett v Motorola* 2004, UKEAT/0526/03: http://www.bailii.org/uk/cases/UKEAT/2004/0526_03_1602.html. This is an appeal against a decision of an Employment Tribunal of Bristol of 29 April 2003. The appellant, employed as a Firmware Engineer, claimed to be unlawfully discriminated against in breach of section 5(1) of the DDA 1995 and that the respondents had failed to make reasonable adjustments to the employment arrangements, to provide training supervision and assistance, and to modify the procedures for assessment.

Chairman and Tribunal fell into error in their approach, but after considerable consideration, we are unanimously of the view that their approach to the concept of ‘understanding’ was at fault in failing to acknowledge that someone who has difficulty in understanding normal social interaction among people, and/or the subtleties of human non factual communication can be regarded as having their understanding affected and that concept is not limited simply to an ability to understand information knowledge or instructions. . . In conclusion, therefore, we are of the view that the Tribunal was in error in not accepting that the Appellant’s ability to understand was affected by his impairment’.¹⁷

This case highlights the difficulties in defining the effects of the ASD under the terms of a disability legislation and the necessity to amend the DDA 1995 in order to broaden the scope of the definition of disability in a way which would encompass autism, and avoid the discretion of the courts regarding the interpretation of rules.¹⁸ Also in the United States case law concerning judicial protection against discrimination in the workplace involving people with ASD shows the difficulties of courts to qualify ‘social interaction’ a ‘major life activity’ under the American Disability Act (ADA)¹⁹ and to recognize autism as a disability for the purposes of the ADA.²⁰

In addition to national disability legislations which include autism, definitions are also contained in specific acts and national plans or strategies on autism adopted by some European Member States.

The Autism Act (Northern Ireland) 2011, in the section 4(1) affirms that the term ‘autism’ comprehends ‘autism, Asperger’s syndrome, Rett’s syndrome, Heller’s syndrome or any pervasive developmental disorder not otherwise specified’. The definition is consistent with the ICD-10 classification of Pervasive Developmental Disorders (PDDs-F84) and is broadened enough to facilitate access to services and support provided in the Northern Ireland Autism Strategy (2013–2020). The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales (2008–2018) also contains the concept of ASD which conforms with the ICD-10. According to this definition ‘the term ASD is used to describe the group of PDDs characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities’.²¹ The ASD Strategic Action Plan specifies that there are a number of

¹⁷ See paras 24 and 25 of the judgment.

¹⁸ See also the case of Ireland, the Autism Bill 2012 provides an amendment of the notion of disability contained in the Employment Equality Act 1998 and in the Equal Status Act 2000 in order to include autism.

¹⁹ To be entitled to the ADA judicial protection a person must be found to have ‘a physical or mental impairment that substantially limits one or more major life activities of such individual’. For the definition of disability as amended in 2008, see ADA Amendments Act of 2008, PL 110-325 (S 3406), 25 September 2008. <http://www.eeoc.gov/laws/statutes/adaaa.cfm>.

²⁰ *Morgenthal v. AT&T*, No. 97 Civ. 6443 (DAB), 1999 U.S. Dist. LEXIS 4294, at 8 (S.D.N.Y. Apr. 5, 1999) cited in Caruso (2010), note 192.

²¹ See Chapter 2 of the Strategic Action Plan. <http://wales.gov.uk/strategy/strategies/autism/asdplane.pdf?lang=en>.

definitions of autism but the Welsh Assembly Government for the purpose of the Plan has adopted that of the WHO as ‘the use of the terminology of ASD denotes the fact that there are a number of subgroups within the spectrum of autism’. The Danish National Autism Plan (2008) affirms that ‘ASD is a term used to denote the problems known as PDDs and which include highly differentiated levels of reduced social, verbal and intellectual functional abilities. People with ASD may have other disorders or conditions. This is known as comorbidity and may require special treatment, e.g. medical’.²² In the Hungarian National Autism Strategy (2008–2013), autism is defined as ‘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’.²³ The Scottish Strategy for Autism (2011) refers to ‘autism’ as ‘a lifelong developmental disorder more commonly referred to as autism spectrum disorder (ASD) but also known as autism spectrum condition (ASC). ASD affects people differently with some individuals being able to live independently. Others will need very specialist support’.²⁴ Finally, with regard to England, it is interesting to observe that in the Autism Act 2009 the definition of ASD has not been included because ‘As research and experience refines the understanding of autism, so the range of characteristics will change’. Nevertheless, ‘the intention is that definitional issues will be dealt with in the autism strategy, which, as it has to be kept under continual review, will allow for changes to be made much more quickly in response to new developments than if the definition were to be included in primary legislation’.²⁵ Then, the 2010 Strategy specified that the term ‘autism’, in line with the approach to terminology adopted by key autism representative organisations, was used as an umbrella term for all conditions (autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity), including Asperger syndrome.²⁶

Outside the EU, the Individuals with Disabilities Education Act (IDEA) of 2004, the US federal education law on special services for children with disability, contains the definition of ‘autism’ that reads as follows: ‘(i) Autism means a developmental disability significantly affecting verbal and nonverbal

²² See National Autism Plan—a summary (2008), p. 6.

²³ See Hungarian National Autism Strategy, Annexes I. The Strategy further specifies the triad of autism and its characteristics.

²⁴ See Scottish Strategy for Autism, p. 7.

²⁵ See Autism Act 2009, Explanatory Notes. <http://www.legislation.gov.uk/ukpga/2009/15/notes/division/5/1>. As for the United Kingdom it is important to recall that the concept of ‘impairments’ contained in the Equality Act 2010 includes ASD as specified in the ‘Equality Act 2010, Guidance on matters to be taken into account in determining questions relating to the definition of disability’, p. 9.

²⁶ The updated Strategy for adults with autism in England (2014) affirms that the term ‘autism’ is used to refer to ‘all diagnoses on the autism spectrum, including Asperger syndrome, high functioning autism, Kanner or classic autism’ (Appendix A).

communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. (ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section. (iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied'.²⁷

In order to receive special education and related services children with autism must meet requirements under the IDEA and States' definition of the term autism, not always coincident with the federal one.²⁸

3 Protecting the Rights of People with Autism Through Specific Legislations and the Role of the CRPD

In 1996, the European Parliament adopted, in the form of a written declaration, the Charter for Persons with Autism which states that people with autism should have the same rights enjoyed by all EU citizens, where such be appropriate and in the best interest of the person with autism, and that these rights should be enhanced, protected and enforced by appropriate legislation in each State.²⁹ The Charter recommended that diagnostic services, individualized education, family support, housing, vocational training and lifelong care should have been adequately addressed and appropriate services provided at domestic level.

After 18 years of the Charter's adoption, the protection of the rights of people with ASD within the EU Member States is far from being uniform and satisfying. Among the European countries substantial differences exist with regard to the legal framework in favour of persons with ASD revealing that only a short number of countries has implemented the recommendations of the European Parliament.

²⁷ See Public Law 108-446. Autism was added to the IDEA in 1991, see Caruso (2010), p. 52.

²⁸ For the purposes of special education services, States have adopted national definition of autism. See, for instance, the Nebraska State Definition of Autism, Rule 51 (92 NAC 51.006) contained in the Nebraska state plan for autism spectrum disorders, revised January 2013 <http://www.mindbank.info/item/3935>. For up-date data on the percentage of population with autism by year and age group under IDEA and the national projects addressed to children with autism in the US, see the 35th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2013. <http://www2.ed.gov/about/reports/annual/osep/2013/parts-b-c/35th-idea-arc.pdf>.

²⁹ The Charter was proposed by Autism-Europe that presented it at its 4th Congress (Den Haag, 10 May 1992).

Indeed, only few European countries have developed specific autism legislation or national autism plans and strategies,³⁰ while some EU Member States have adopted *ad hoc* measures in favor of people with ASD in sectoral laws above all relating to education,³¹ health and social care. In general, sectoral laws are more limited in scope than autism plans, for at least a couple of reasons: firstly, they focus only on a specific group of persons with ASD (children, young people or adults); secondly, they address the needs of people with autism only in determinate fields (i.e. education, health and others) even if of great impact on their lives, their families or carers. However, when these laws combine with national autism plans, the domestic legal framework for the protection of people with ASD is more complete and extensive, meeting the needs of a wider range of persons and producing positive effects at domestic level in terms of their inclusion in the society.

As it was rightly observed, ‘the post-modern concept of neuro-diversity, with its promise of inclusion and its philosophical acceptance of variation, may find in autism a perfect home’.³² The full inclusion and participation of disabled persons in the society, including people with autism, is the cornerstone of the human rights approach to disability enshrined in the CRPD. The Convention marks the passage from a medical model of disability to a social one, recognizing that disability is an evolving concept resulting from the ‘interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’.³³ In its articles, the CRPD establishes the human rights and fundamental freedoms of persons with disabilities whose fully enjoyment must be guaranteed without discrimination in order to remove all the barriers that obstacle their participation as equal members of society. In the Preamble, States parties recognize, among others, ‘the need to promote and protect the human rights of all persons with disabilities, including those who require *more intensive support*’,³⁴ such as people with ASD who need lifelong services and support.

Indeed, the CRPD is an international instrument that may contribute at the domestic level to the reinforcement of the rights of people with disabilities, including those of individuals with ASD. Its legal relevance in the field of autism has been also underlined by the World Health Assembly that, in the Resolution on autism of May 2014, has recalled the CRPD, together with the Universal Declaration of Human Rights of 1948, the United Nations General Assembly (UNGA) resolution 62/139 declaring 2 April as World Autism Awareness Day and the UNGA Resolution 67/82 on addressing the socioeconomic needs of individuals,

³⁰ See Sect. 4 in this chapter.

³¹ See the chapter by R. Cera, in this volume.

³² See Caruso (2010), p. 9.

³³ On the concept of disability in the CRPD see, among others, Della Fina (2010), pp. 17 ff.

³⁴ *Italic added.*

families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities.

The role of the CRPD in ensuring the protection of the rights of persons with ASD and their social inclusion in domestic legal orders is confirmed by some best practices concerning EU Member States. In this context, it is worth mentioning the Northern Ireland Autism Strategy (2013–2020) and Action Plan (2013–2016) which have been expressly developed in accordance with the CRPD to support the values of dignity, respect, independence, choice, equality and anti-discrimination for people with autism, their families and carers. The provisions of the Convention have informed the issues, the strategic priorities and the actions provided in the Strategy and in the Action Plan.³⁵ Another relevant case is the Danish National Autism Plan (2008) which recalls the CRPD, pointing out that the Convention requires States parties to set up guidelines and action plans to ensure that people with functional disabilities, such as ASD, are not put in a position of disadvantage regarding their participation in society.

At the national level the CRPD implementation may therefore strengthen the human rights of people with ASD through the adoption of specific laws or plans which should take into account the fundamental rights of persons with disabilities enshrined in the Convention. This aspect may result particularly relevant in the framework of the EU, considering that the Union and most of its Member States ratified the CRPD.³⁶ In order to achieve an effective implementation of the Convention, the EU adopted the ‘European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe’³⁷ focused on eight main areas of action (accessibility, participation, equality, employment, education and training, social protection, health, and external action) having great impact also on the life of people with ASD. The EU Strategy identifies actions at EU level to supplement the national ones with the aim to empower people with disabilities so that they can enjoy their rights, and benefit fully from participating in society and in the European economy.

³⁵ See Sects. 6 and 7.

³⁶ For the EU see Council Decision 2010/48/EC *concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities* of 26 November 2009, O.J. L 23/35. As of 31 October 2014, Finland, Ireland, and Netherlands did not ratify the CRPD.

³⁷ COM(2010) 636 final, Brussels, 15.11.2010.

4 National Autism Plans and Strategies in the EU Member States

In the EU context, autism plans and strategies have been adopted only by few States namely Bulgaria, France, Denmark, Hungary, and within the United Kingdom, England, Wales, Northern Ireland and Scotland.³⁸ All these plans have a legal basis in so far they are provided in a legal act or have been adopted on the initiative of a Government or a department.³⁹

One of the first European countries to adopt rules in favour of people with autism is France. French government has started regulating autism since the mid-1990s by a series of acts of different legal nature.⁴⁰ Following the enactment of the Law no. 2005-102 of February 2005 and the interministerial circular of 8 March 2005 on the Policy for taking care of persons with autism and PDDs,⁴¹ France adopted its first Autism Plan for the period 2005–2007. Later, two additional plans are followed: the Autism Plan 2008–2010 and the third Plan covering the years 2013–2017.

In Denmark, *the National Autism Plan (NAP)* was first published in 2006, only in Danish, as a guide for the new municipalities. In 2007, following the reform and the merger of the municipalities the responsibility to establish and run services for people with ASD was assigned to them.⁴² Some municipalities started to base their

³⁸ In 2008, the Dutch Government requested a report on ASD to the Health Council of the Netherlands which was published in 2009 with the title ‘Autism spectrum disorders: a lifetime of difference’ (<http://www.gezondheidsraad.nl/en/publications/healthcare/autism-spectrum-disorders-lifetime-difference>). On the contents of these plans and strategies in the fields of education and employment see Sects. 6 and 7.

³⁹ Under this aspect, the autism plans and strategies examined differ from those prepared by autism representative organisations. These latter may be an input for policy makers and a useful tool to identify priorities and objectives to be realized at domestic level but they have not a legal status, except in the case they are adopted by a government.

⁴⁰ See the interministerial circular of 27 April 1995 concerning therapeutic, pedagogical, and educational care, and social inclusions of children, adolescents, and adults with autism (circulaire AS/EN n. 95-12 du 27 avril 1995 *relative à la prise en charge thérapeutique, pédagogique et éducatrice et à l’insertion sociale des enfants, adolescents et adultes atteints d’un syndrome autistique*); the Law no. 96-1076 which has recognized autism as a form of disability; the Circulaire DAS/TSIS n. 98-232 du 10 avril 1998 *relative à la formation continue et à l’adaptation à l’emploi des personnels intervenant auprès des enfants et adultes présentant un syndrome autistique*. Other relevant provisions concerning the right to education for people with autism are contained in the Code of Social Welfare Action and in the Education Code.

⁴¹ See Circulaire interministérielle n. DGAS/DGS/DHOS/3C/2005/124 du 8 mars 2005 *relative à la politique de prise en charge des personnes atteintes d’autisme et de troubles envahissants du développement (TED)*.

⁴² Administratively, Denmark is divided into 5 regions and 98 municipality areas. Municipalities are charged with the treatment of and support for people with ASD. The municipalities must maintain and develop an organisation that, in case of suspected ASD, ensures the primary examination, assessment of development and diagnostic considerations. The regions are responsible for specialized assessment of children and young people.

autism policy on the NAP which was published in English as a shorter guide in 2008.⁴³ The Plan is the result of a collaboration between the National Board of Social Services under the Ministry of Social Affairs, Children and Integration,⁴⁴ and autism representative organizations, such as the Danish Autism Society. The NAP adopts a lifelong approach, providing guidelines for best practices in diagnosis, care and treatment for people with autism in all stages of life from children to the elderly.⁴⁵

In Hungary the 5-year *National Autism Strategy* (2008–2013) was commissioned by the Ministry of Social Affairs and Labour and prepared by experts under the supervision of the Hungarian Autistic Society.⁴⁶ The Strategy was provided in Section IV/3 of the Government Decree no. 1067/2007 on the implementation of the National Programme of Disability Affairs and the medium term implementation schedule for the period 2007–2010. The purpose of the Strategy is to improve care for persons with ASD by developing specific services, including those in the fields of education, training and employment.

An advanced legal regime in favour of people with ASD, mainly focused on adults, has been developed in England. The Autism Act 2009 is the first autism specific legislation adopted in Europe. The Act is the legal basis of the *Fulfilling and rewarding lives: the strategy for adults with autism in England* of March 2010 and its updated version of April 2014 (called *Think Autism*), and its guidance, *Implementing fulfilling and rewarding lives: statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy* of December 2010, currently under public consultation.⁴⁷ The Autism Act 2009 specified the statutory duty to prepare and publish the Strategy to meet ‘the needs of adults’⁴⁸ with autistic spectrum conditions by improving the provision of relevant services by local authorities, National Health Service (NHS) bodies and NHS foundation trusts’ (Section 1).

Within the United Kingdom plans to improve services for people with autism have been developed in Wales, Northern Ireland and Scotland. The Welsh

⁴³ Since the publication of the original six NAP reports in Danish, requests for a shorter version in English have been posed, also to share knowledge and experiences internationally, see Danish National Centre for Autism and the National Board of Social Services (2008).

⁴⁴ The National Board of Social Services is charged with ensuring that social and welfare initiatives are put into practice by local authorities, including those addressed to persons with disabilities (<http://www.socialstyrelsen.dk/om-os/about-us>).

⁴⁵ <http://www.autismeurope.org/files/files/link-autism-56-en-lowres.pdf>.

⁴⁶ The English translation of the Hungarian Autism Strategy is published in Autism-Europe (2009). Currently the Strategy is under revision.

⁴⁷ The revised guidance should be published at the end of 2014 after the public ‘consultation on new statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy for England’ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/371869/Autism_Statutory_Guidance_Consultation_Draft_Guidance.pdf.

⁴⁸ The Act extends to (that is, forms part of the law of) England and Wales, but applies only in relation to England. Section 4(1) of the Act specifies that ‘adult’ means a person who is aged 18 or over (and, accordingly, ‘child’ means a person who is under the age of 18).

Assembly Government adopted the *Autistic Spectrum Disorder Strategic Action Plan for Wales* (2008–2018) which sets out specific and measurable actions during a period of 10 years to improve services for children, young people and adults with ASD. The overall objective is ‘to set the direction to improve the commissioning and delivery of services so that individuals with ASD are supported to reach their full potential in all aspects of their lives whatever their age, wherever they live, whatever their gender, social or ethnic background’. As for Northern Ireland, on 26 June 2008 the Health Minister announced his intention to develop a Strategic Action Plan for ASD Services across the nation. Consultation on the draft Strategic Action Plan closed on 12 December 2008 with a positive response. The *ASD Strategic Action Plan* (2009–2011) was published in 2009 covering a broad range of actions aimed at improving health and social care services to meet the need for children, adolescents and adults with ASD, their families and carers.⁴⁹ The Action Plan provided for an ongoing monitoring by the Health and Social Care Board and an evaluation to ensure effective implementation and to inform the need for any future resource allocation from 2011/2012 onwards.⁵⁰ In 2011 the Autism Act (Northern Ireland) was enacted, providing the statutory obligation to develop a strategy for autism not less than two years after the passing of the Act.⁵¹ In 2013 the Autism Strategy (2013–2020) and Action Plan (2013–2016) were adopted. In Scotland the 10-year *Scottish Strategy for Autism*, published in 2011, addresses the entire autism spectrum and the whole lifespan of people living with ASD. The vision at the basis of the Strategy ‘is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives’.⁵²

As for Bulgaria, in 2012–2013 the Ministry of Health prepared a document titled ‘Measures to improve care for helping people with autism and ASD, and their families’ based on an analysis of existing legislation, policies and services for persons with autism. In August 2013 this document was approved by the Minister of Health and is considered a sort of national autism plan. Main priorities of the plan

⁴⁹ Department of Health, Social Services and Public Safety, Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09–2010/11, June 2009. http://www.dhsspsni.gov.uk/asd_strategic_action_plan.pdf. In April 2009 also the multidisciplinary Regional ASD Network Group charged with the implementation of the ASD Strategic Action Plan started working in coordination of Local Health and Social Care Trust (HSCT) ASD networks.

⁵⁰ The Action Plan follows the publication of a series of documents including the Independent Review of Autism Services, the recommendations of the Bamford Review relating to ASD and its Equal Lives Report, and other local, national and international work, see Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09–2010/11, DHSSPS, June 2009, p. 10. Cf. Kelly et al. (2007) and Maginnis (2008).

⁵¹ The Autism Act (NI) 2011, which received Royal Assent on 9 May 2011, came into operation on 9 August 2011.

⁵² The Strategy was developed by the Scottish Government working in partnership with the Convention of Scottish Local Authorities (COSLA), the two national autism organisations, and a wide range of stakeholders.

are: early diagnosis and detection of ASD in the primary outpatient care units; early intervention; providing comprehensive and integrated community services, including education; application of modern therapeutic methods; personnel training and training programs; measures for employment; raising awareness about autism among professionals and the public. The scheduled activities are implemented through an inter-institutional interaction, in partnership with associations of the sector and the involvement of people with ASD and their families. The plan, covering the years 2013–2016, provides mechanisms for its coordination and monitoring.⁵³

It is also worth mentioning the case of Ireland where the Autism Bill 2012 was introduced in the Dáil Éireann (the Assembly of Ireland), with the aim to place a statutory obligation on the Government to adopt an autism strategy to meet the needs of adults with ASD in the accessibility to services, employment and social inclusion, and the needs of families and carers by setting out a clear directive towards family support service development. The Bill proposes a system of accountability and scrutiny relating to ASD service provision, an autism awareness campaign, including an information website, poster campaign, media strategy, and the provision of autism awareness training for all professionals who frequently deal with adults with autism. The Bill also states that the autism strategy shall be published not less than two years after the passing of the Act.⁵⁴

Also in Italy a kind of autism plan called ‘Progetto nazionale autismo’, to be developed at national and regional levels, has been proposed by a national working table on autism set up in 2007 by the Ministry of Health (‘Tavolo nazionale di lavoro sull’autismo’), but to date it has not yet been adopted.⁵⁵

Remaining in the European context, Autism-Europe and other associations⁵⁶ have also proposed a European Strategy for Autism in consideration of the increas-

⁵³ A translated text of the plan is not available. The information has been taken from the Bulgarian Ministry of Health, National Center for Public Health and Analyses. <http://hph-bg.ncphp.government.bg/en/mejd-d-t-2/1020-southeast-european-autism-network,-sean.html>.

⁵⁴ See ‘Proposed Bill provides for first national strategy on autism’. <http://www.thejournal.ie/autism-bill-ireland-823778-Mar2013/>. As of 31 October 2014, the Bill was not passed. The Cabinet Committee on Social Policy, together with Government Departments and the National Disability Authority (NDA), are examining the issues arising from the Bill to ensure that the proposals dovetail appropriately with the actions in favour of people with ASD undertaken under the National Disability Strategy, see Statement from Dr. James Reilly, T.D., Minister for Health on World Autism Awareness Day April 2nd, 2014. <http://www.merrionstreet.ie/index.php/2014/04/statement-from-dr-james-reilly-t-d-minister-for-health-on-world-autism-awareness-day-april-2nd-2014/>.

⁵⁵ For Italy see the chapter by L. Chiappetta Cajola, in this volume.

⁵⁶ On 6 November 2012, Autism-Europe organized the seminar ‘Towards an Autism Strategy for Europe’ at the European Parliament to present successful national strategies for autism and discuss the possibility of a Europe-wide strategy for autism. http://www.autismrpphub.org/sites/default/files/resources/brussels6novreport_jan2013.pdf.

ing incidence of people diagnosed with autism in the continent and the need to coordinate policy approaches at national and European levels.⁵⁷ According to the proponents, the European Strategy for Autism should identify the most urgent needs to be met for people with autism (such as diagnosis, early interventions, and research) and enshrine the fundamental human rights of the persons with ASD in conformity with the CRPD.

In this regard it is important to underline that the EC adopted the European Strategy for Disability 2010–2020 in the form of a communication to the European Parliament, the Council, the European Economic and Social Committee, and the Committee of the Regions.⁵⁸ The European Autism Strategy could follow this precedent for recommending to EU Members States a set of domestic actions to address the needs of people with ASD. From this point of view, a European Autism Strategy may be a useful instrument to enhance the protection of persons with ASD within the EU and the domestic legal orders.

5 National Autism Plans Adopted Outside the EU

In the last years, also outside the EU autism plans have been developed. The cases of the US, Canada and Australia are worth mentioning.

In the US, a federal autism legislation has been developed to regulate relevant fields that impact on the life of people with ASD and their families, such as health, social care, education, research, screening, and treatment.⁵⁹ In 2009, the Interagency Autism Coordinating Committee (IACC), a federal government advisory panel, has released the Strategic Plan for Autism Spectrum Disorder Research

⁵⁷ The European Commission (EC) has specifically included ASD in its public-health work plans since 2005, but the EC actions are mainly focused on providing information on autism, defining indicators and coordinating public health research. http://ec.europa.eu/health/major_chronic_diseases/diseases/autistic/index_en.htm.

⁵⁸ The communications, as it is known, are not legally binding and usually contain action plans or legislative proposals.

⁵⁹ In these last fields, the US legislation may be considered an example of good practice. The Children's Health Act of 2000 (Health Act) explicitly identified autism as a major target of research (Public Law 106-310 Sec. 1004 (2000), Division A, Title I). Then, the Combating Autism Act of 2006, signed by President Bush on 19 December 2006, expanded the activities related to autism research, surveillance, prevention, screening, early detection and intervention, and treatment, with a funding of about 1 billion dollars over five years for ASD. The Combating Autism Act of 2011, signed into law by President Obama on 20 September 2011 (Public Law 112-132), ensured that the programs established under the Combating Autism Act of 2006 continued for an additional three years, authorizing 693 million dollars federal investment in autism research, treatment and services through fiscal year 2014. Lastly, the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2014, signed by President Obama on 8 August 2014, has authorized 1.3 billion dollars for fiscal years 2015–2019 to fund ASD research, services and support activities (Public Law 113-157).

containing recommendations to federal agencies and Congress on needs and opportunities to improve research in the field of autism.⁶⁰

The US Government funds States to develop autism plans to improve services, as well as investing in research, public awareness, and expanding training programs for health professionals.⁶¹ In conformity with federal legislation, national autism plans have been adopted, among others, by Michigan, Nebraska and Texas. In Michigan, the *ASD State Plan* was published in 2012 with the purpose to identify best practice in supporting individuals with ASD of all ages, review practice across key priorities areas, identify gaps, and make recommendations for improving services and outcomes for individuals with ASD and their families.⁶² The ultimate goal of the Plan is to create a solid understanding of the needs of all individuals with ASD, from birth through adulthood, in order to identify, access, and coordinate resources. Among the key priorities areas of the Plan are education and training, and under the focus area ‘Adult Supports and Services’ employment is considered a tool to include adults with ASD in society.⁶³

The *ASD Nebraska State Plan*, published in 2000 and revised in 2013, is limited to the field of education and has the objective to inform education personnel, administrators, parents, educators, and other professionals, on services provided by the Nebraska ASD Network. This latter has been developed by the Nebraska Department of Education to provide consultation, training and technical assistance to local school districts, educational service units and parents of children with ASD.⁶⁴ The *Texas State Plan for Individuals with ASD* (2010–2014) was adopted by the Texas Council on Autism and PDDs in 2010.⁶⁵ The State Plan has the purpose to create a statewide infrastructure that promotes the coordination of research and the delivery of timely, appropriate and cost-efficient services to people

⁶⁰ <http://iacc.hhs.gov/strategic-plan/2009/index.shtml>.

⁶¹ http://www.hhs.gov/autism/factsheet_autism_support.html.

⁶² Key priorities areas are: infrastructure-system, service, and resource coordination; family engagement and involvement; early identification and intervention services; educational supports and services; adult supports and services; physical, mental, and behavioral health care; training and professional development. http://www.michigan.gov/documents/autism/ASDStatePlan_2_19_13_Final_414143_7.pdf.

⁶³ The Plan recommends to give people with ASD access to a variety of employment opportunities, including supported, competitive and customized employments (see the Plan, p. 42).

⁶⁴ Nebraska school districts must assure that all children with ASD have a free and appropriate public education (FAPE) under IDEA, which includes special education and related services that meets their unique needs. In 2002, five ASD Regions were established across Nebraska to provide support for schools and families impacted by ASD.

⁶⁵ The Texas Council on Autism and Pervasive Developmental Disorders (TCAPDD) was established by legislation in 1987 adding the Chapter 114 to the Human Resources Code (Interagency Council on Autism and Pervasive Developmental Disorders Act of 1987). Its mission is to advise and make recommendations to State agencies to ensure that the needs of persons of all ages with autism and other PDDs and their families are addressed and that all available resources are coordinated to meet those needs.

with ASD.⁶⁶ The Plan follows a practical approach and is structured under four goals: (1) services to children to age 5; (2) services to individuals ages 6–22; (3) services to individuals age 23 and older; and (4) research and statewide infrastructure. For each goal specific objectives and strategies are identified, including those in the fields of education and employment.

In Canada individual members of the Senate requested an enquiry on federal funding for ASD treatment and the need for a national ASD strategy at federal level. In the final report of the enquiry published in 2007, the Standing Senate Committee on Social Affairs, Science and Technology recommended that ‘The federal government, in collaboration with the provinces and territories, establish a comprehensive National ASD Strategy; all stakeholders, including individuals with autism, be consulted on the components that should be part of the Strategy, such as treatment, research, surveillance, awareness campaigns, community initiatives, education, respite care for families, etc.; and, the Strategy include child, adolescent and adult treatments and supports’.⁶⁷

After the publication of the Report also Autism Society Canada, together with other associations, asked the Federal Government to build a National Autism Strategy in order to provide minimum standards such as: establish a national surveillance mechanism to effectively track individuals with ASD; define minimum standards of service and treatments and professionals across the country to ensure equal access to services across Canada; promote autism awareness through a national awareness campaign targeted at individuals, health care professionals, and first responders (fire, ambulance, and others).⁶⁸

A federal ASD Strategy has not yet been adopted, but since Canadian provincial and territorial governments are responsible for delivering health and social services within their respective jurisdictions, some provinces have developed autism plans. These are the cases of the *Nova Scotia ASD Action Plan* (2011) and the *Manitoba five-year Plan to help Manitobans with ASD and their families* (2011). In April 2011, Nova Scotia adopted the Plan designed to support children, youth and adults with ASD and their families through a phased-in approach. The Plan is focused on five key areas: (1) intervention and support services for families with preschool children diagnosed with ASD; (2) supports for school-aged children with a diagnosis of ASD; (3) supports for adults with ASD and their families; (4) skills training and awareness; and (5) partnerships to support programming and services.

⁶⁶ The State Plan was reviewed and approved by the Texas Council on Autism, its ex-officio state agency members and Regional Advisory Task Force in 2010.

⁶⁷ See Standing Senate Committee on Social Affairs, Science and Technology (2007), point I of the Final Report.

⁶⁸ See ‘Collective Voice of the Autism Community in Canada Calls on Government to Take Steps to Establish National Autism Strategy’ (Ottawa, Ontario, Nov. 5, 2007). Autism Society Canada is a national umbrella organization of provincial and territorial societies and has proposed to collaborate with the Federal Government to outline a National Autism Strategy. http://www.parl.gc.ca/Content/HOC/Committee/411/FINA/WebDoc/WD5138047/411_FINA_PBC2011_Briefs%5CAutism%20Society%20Canada%20E.html; <http://www.autismsocietycanada.ca/>.

Furthermore, the Plan has provided a funding of 4 million Canadian dollars for intervention and support services in the field of education.⁶⁹ The Manitoba ASD Plan, launched by the Manitoba government in June 2011 for a period of five years, is focused on support and services for children with ASD and their families. It also provides services for young people and adults in order to ensure them access to education and employment training programmes, promote opportunities for developing life skills, help to find and keep jobs, and live independently.⁷⁰

Also in Australia the Federal Government has adopted specific autism legislation providing public resources to fund initiatives in support of children with ASD and their families.⁷¹ Currently, each State has developed its own legislation including, in some cases, autism national plans. The Victorian Government committed to outline an Autism State Plan during the State election in 2006. In that occasion, with *Addressing Disadvantage*, the Victorian Government undertook to ‘develop an Autism State Plan in partnership with Autism Victoria, to build new and better approaches across government for meeting the growing and complex needs of people with autism and ASD’.⁷² In 2009, the Victorian Government adopted an Autism State Plan, in recognition that ASDs are becoming more prevalent and demand on services and support is growing, and that ASDs have particular features that distinguish them from other conditions. The Plan identified six priority areas for the next ten years to be addressed in short, medium, and longer term Plan’s implementation: (1) make it easier to get support; (2) strengthen the ASD expertise of the workforce; (3) extend and link key services and supports especially during transition; (4) enhance and provide appropriate educational opportunities; (5) facilitate successful participation in the community; and (6) develop a robust evidence base about ASD.⁷³ In 2013, the Government also issued the Victorian State Disability Plan (2013–2016) in which one of the strategies provides better support for people with ASD.⁷⁴ Also the Queensland Government announced the intention to develop an autism plan but, at the current stage, it has not been released.⁷⁵

⁶⁹ See Autism Spectrum Disorder Action Plan. Progress Report-Spring 2012. http://www.ednet.ns.ca/files/reports/Autism_Report_final.pdf.

⁷⁰ See Thrive! A 5-year Plan for helping Manitobans with autism spectrum disorder and their families. The text is available in the website of the Plan <http://www.gov.mb.ca/fs/thrive/>.

⁷¹ For a synthesis of autism federal initiatives, see Roth (2013). Concerning services and support to people with ASD and their families in Australia, see O’Reilly and Wicks (2013).

⁷² See Autism State Plan, May 2009, p. 9.

⁷³ The Plan was developed after a statewide consultation undertaken in October and November 2007.

⁷⁴ http://www.dhs.vic.gov.au/__data/assets/pdf_file/0009/749862/Victorian-state-disability-plan-2013-2016-180113.pdf.

⁷⁵ See Roth (2013), p. 25.

6 National Autism Plans and Strategies in the EU Member States: Actions and Services in the Field of Education

From the consultation processes preceding the adoption of the national autism plans and strategies it is emerged that people with ASD face a variety of common challenges for accessing services arising across a wide range of fields, including education and employment. For their relevance in terms of inclusion of autistic people in society such sectors are priority areas in all national autism plans and strategies, although it is evident that actions and services to address the needs of people with ASD differ depending on the domestic legal order and the existing network of social, health, and educational services in each Member State. It is therefore necessary to analyze each autism plan and strategy in order to identify good practices.

The autism plans and strategies will be examined according to the chronological order of adoption.⁷⁶

6.1 Denmark

The *Danish NAP* of 2008 contains a series of recommendations to municipalities to meet the needs of people with ASD during their lifetime. The approach followed is based on the respect of human rights of persons with ASD as enshrined in the CRPD ratified by Denmark in 2007, in particular the right to inclusion and participation in society that should be guaranteed through adequate services. The NAP recognizes that efforts for people with ASD should be based on the fundamental respect for the individual and, in the case of relatively high functioning people with ASD, personalized support in relation to employment and education.

The needs of people with ASD changes during lifetime, for this reason the NAP identifies the following phases: preschool age, 0–6 years old; school age, 6–17 years old; youth, 15–35 years old; adult life, 20–65 years old; and old age, from 60 years old. For each phase, recommendations are given.

With regard to children with ASD before the age of 6, the NAP emphasizes that they often have quite severe difficulties and need a substantial support. The pedagogical efforts are therefore based on specialized services, in the form of specialized day-care institutions, special groups in the framework of the day-care or individual support in a normal day-care institution. In these cases, the NAP recommends early interventions to be initiated as soon as possible after ASD has been identified. In recognizing that to date there is no documentation concerning a particular form of treatment or method that is more effective than others, the Plan recommends a structured pedagogical, learning and behaviour oriented approach.

⁷⁶ The chronological order will be also used in Sect. 7 in this chapter. The Bulgarian plan has not been examined because a translated text in English or French was not available at the time of writing.

Interventions should be intensive with an individually organized specialist-pedagogical effort on a daily basis and an important role of family. According to the NAP, counseling in the home and courses on ASD should be offered to the parents and the family should be an important partner for the municipality. In the evaluation of the child's need for support the NAP requires to take into account the child's functional level, while all interventions for preschool should be carried out only by professionals with specific knowledge of autism.⁷⁷

As for school age, the NAP outlines that the number of children with ASD is significantly higher in the later school years than during the early years of schooling because most children are not diagnosed until they reach school. At the same time, the school age is the phase of life in which the need for support varies more.⁷⁸ For these reasons, the NAP recommends that many different types of services should be made available for children with ASD, both in the framework of school, spare time, respite care and residential homes, and that services should be highly individualized and specifically adapted. The NAP gives a series of detailed advices on the methods to follow concerning the relationship with autistic children, pointing out that all pedagogical efforts should be based on the understanding of the cognitive nature of the functional disability and attention should be paid to the development of independence in all regards.

Concerning youth, the NAP specifies that is a phase of life during which a person usually develops his/her identity and gains independence, but a high number of people with ASD never achieve these objectives. However, also for persons with autism youth often represents a period of changes (i.e. changing in daily activities from school to work or day-initiatives, education at all levels) and for these reasons the NAP recommends to ensure to young people with ASD the necessary support to be evaluated on the basis of the individual's functional level. A mentor or a support/contact person (often parents) may represent the right way to compensate the difficulties young people with ASD encounter in this phase of life. As for education, the Plan requires that young people with ASD should have the possibility of a flexible course of education, regarding both duration and contents, because many young people with ASD try out several educations before deciding on one.

⁷⁷ See also the recommendations concerning assessment (NAP, pp. 12–13).

⁷⁸ The Public School Law, LBK no. 521 of 27 May 2013 has no specific chapter on special education, instead it is mentioned in most of the chapters (sections 3, 4, 12, 19, 20, 21, 22, 40, 42, 44, 47, 49, 51 and 57 of the Public School Law). Special education is an integrated part of the Danish public school system. However, in 2008 the Danish Ministry of Education launched the school development project 'Less special education, enhanced professionalism and increased inclusiveness' with the aim to maintain pupils in mainstream education and reduce the reference to special education. An Appeal Board for special education was set up as an independent authority, acting on complaints of every kind concerning local special education for pupils who need extensive support in the teaching or instruction in special classes or schools.

With regard to adult life, according to the NAP education institutions should ensure the necessary adjustments and support for persons with ASD as provided by law.⁷⁹ Furthermore, access to education and continuous learning should be guaranteed and individuals with ASD should have the right to try their possibilities on the regular labour market.⁸⁰

6.2 Hungary

The *Hungarian National Autism Strategy* (2008–2013) aims at improving the quality of life of the population affected by ASD by setting out medium-term targets and tasks in the following fields: early screening and diagnosis, education, adult training, employment, and family support. The Strategy requires, first of all, a national map of autism accessible services and a map of missing services in several sectors, including education, in order to improve regional services and design new forms of services.⁸¹

In the framework of the Strategy training an appropriate number of professionals has a key role in order to improve the quality of the services.⁸² The professional training is strictly linked with the field of education to which the Strategy dedicates the Chapter 5 entitled ‘Improving Autism-specific Development and Educational Services’. The Strategy points out that children and adults with autism require individualized, disability-specific development, training and education throughout their entire lifetime. In order to meet these requirements, the Strategy recommends an improvement of services both in quantitative and qualitative terms. It is recognized 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 must meet individual requirements and a high number of individual lessons is indispensable for successful learning. For these reasons, the Strategy recommends to increase the professional per child ratio in order to have one special educational needs teacher and two assistants for a group of six to eight pupils with ASD, and at least one trained

⁷⁹ Law on Vocational Education (LBK no. 439 of 29 April 2013) in Section 29 provides for students who need it, special education and other special educational assistance. The more detailed Guidance rules (chapter 4) establish that students are entitled to have their ongoing support needs identified and relevant actions implemented throughout their schooling.

⁸⁰ For the NAP’s recommendations in the field of the employment see Sect. 7 in this chapter.

⁸¹ The national autism services map must take into account the qualitative aspects of the existing services that, in the sector of education, are indicate in the following: level of education of experts, applied methods, number of students with autism and others.

⁸² To this purpose in the Chapter 3 it is envisaged to set up an Autism Professional Workshop (APW), a provisional consultation organization charged with the creation of a system of intensive professional training and further education. In the APW the health sector (psychiatry, psychology), pedagogy/special needs education and the social field are represented.

professional per mainstream school and one assistant for two children participating in mainstreamed education.⁸³

Furthermore, the Strategy requires the codification and the implementation of ‘autism-specific qualitative criteria for each level of the educational system’ that is the establishment of general criteria (professional requirements, professional/child ratio and others) for a high standard of autism-specific education. These criteria should lead to more standardized and better monitored services, higher level quality of services, a reduction of regional and quality differences between the services, more adequate services that meet the individual requirements of children with autism.

In the field of education, the Strategy considers a priority to offer accessible autism-specific services at secondary and primary schools and requires professional support to schools for the inclusion of pupils with ASD in mainstreamed schools for the entire period of public education. In order to realize this objective special tasks for each educational level are identified.

As for ‘Early Development, Nursery, Nursery Schools’, the Strategy points out that a comprehensive, complex and multidisciplinary early intervention is crucial and recommends to raise to 25 h (instead of 2–6 h) the weekly professional services. The objectives are to ensure early, intensive and disability-specific services to infants diagnosed with autism, improve the quality and quantity of the available services and reduce the number of children who do not get any services. For Primary Education the tasks are identified in the following: 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; creation of a comprehensive and coherent administrative and documentation system.

With regard to ‘Improving Access to Secondary Education and Vocational Training’, the Strategy refers to the above-mentioned ‘common strategic tasks in education’ that must be applied in secondary education as well. The purpose is the creation of disability-specific services for students with autism of secondary school age which are missing. As for ‘Supporting Students with Autism in Higher

⁸³ Regarding education and training of disabled persons in the Hungarian legal system, the Equal Opportunities Act (Act XXVI of 1998) in the Section 13 states: (1) ‘It is the right of the person living with disability to take part in early development and care corresponding to his or her condition and depending on age, to kindergarten training, school training and education and development preparation for such education, in keeping with the provisions of the Act on Public Education’; (2) ‘If it is advantageous for development of the capabilities of the person living with disability - in keeping with the opinion of the expert and rehabilitation committee set up for this purpose - the person living with disability shall take part in kindergarten training and school education together with other children and pupils, in the same kindergarten group or school class’. The Act on National Public Education (Act CXC of 2011) provides two choices for children with disabilities: education in special schools or in regular pre-schools and schools. The Act addresses to children/students with special education needs, including those having autism spectrum disorder (Section 4, para 23).

Education’, the goal is to offer help and support, preparing higher education facilities. Consequently, a series of tasks are identified such as: 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 as a student with special needs within the higher education and to choose the form of help needed; and peer helping programs. It is interesting to observe that the Strategy emphasizes that the goal and the tasks of this chapter conform with the Resolution ResAP(2007)4 on *Education and Integration of Children with Autism* adopted on 12 December 2007 by the Committee of Ministers Council of Europe that recommended to Member States to take into account in their policies, legislation and practice a set of principles, listed in the Annex of the Resolution, to ensure social inclusion and inclusive education to children and young people with autism.⁸⁴

In the Chapter 6 entitled ‘Adult Training’ the Strategy aims at creating an opportunity for the target group of autistic people with mental disabilities to have access to training once they terminate the schooling age and giving them the opportunity to continuously develop their adaptation skills. In order to realize these objectives, the Strategy requires that adults with autism must have access to both general and vocational training. This latter must be available within the public educational system and/or within the framework of adult training and market-oriented. Training has the objective to teach adults with autism independence skills, and prepare them for work and employment. In this field, the Strategy also foresees the launch of a model program for autism-specific adult training based on general training (lifelong learning, preparation for independence, developing communication and social skills) and special training.⁸⁵

Finally, in order to meet the requirements in the fields of education and training the Strategy recommends to train autism-specific professionals, define training levels, and establish training programs (Chapter 7).

6.3 Wales

The *Autistic Spectrum Disorder Strategic Action Plan for Wales* (2008–2018) has the purpose ‘to set a clear direction of travel for the development of services in

⁸⁴ See also Recommendation CM/Rec(2009)9 of the Committee of Ministers to Member States *on the education and social inclusion of children and young people with autism spectrum disorders* adopted by the Committee of Ministers on 21 October 2009.

⁸⁵ The Strategy also lists the contents of the model program. In 2010, in Hungary the education system was changed, including all sectors of education and training general/public education, vocational education and training (VET), higher education. VET is now governed by the Act CLXXXVII of 2011 on Vocational education and training and by the Act LXXXVII of 2013 on Adult Training (<http://www.eqavet.eu/gns/what-we-do/implementing-the-framework/hungary.aspx>).

Wales by ensuring that specific and measurable actions are undertaken and, on the basis of evidence of prevalence and need, commissioning interagency services at local, regional or national levels as appropriate. It also aims to broaden the understanding of ASD and its prevalence in Wales'.⁸⁶ The approach followed is to improve services, offered by government and the voluntary sector, for children, young people and adults with ASD, and their families, in the fields of health, social services and education.

The Strategic Action Plan (Action Plan) builds on a wide range of existing policies, strategies, and guidance for people with ASD in Wales. In the field of education, the Education Act 1996 states children's right to inclusive mainstream education if it is appropriate and parents agree.⁸⁷ In 2002 the Welsh Assembly Government issued the Special Educational Needs (SEN) Code of Practice for Wales based on the principle that the SEN of children will normally be met in mainstream schools or early education settings.⁸⁸ Within the Action Plan the publication 'Quality Standards in Education for Pupils with ASD' by the Welsh Assembly Government is considered a key action point. In 2010, a small task and finish group (comprising representatives of local authorities, special schools, voluntary organizations and parents) was established to update the original draft document in order to ensure compliance with the Action Plan. The Welsh Assembly Government is still working to deliver it.⁸⁹

The Action Plan also provides measures to raise awareness of ASD in the schools and to train teachers to improve ASD awareness. Raise awareness and

⁸⁶ The actions outlined in the Plan cover a number of key broad areas: (1) mapping prevalence, needs and services; (2) commissioning services; (3) transitional arrangements; (4) services for adults; (5) awareness raising, information and training; and (6) resources.

⁸⁷ See also Education Act 2002 and Education Act (Wales) 2014.

⁸⁸ The Code defines SEN as follows: 'Children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them'. The Code suggests the adoption of a range of strategies that recognize the various complexities of needs, the different responsibilities to assess and meet those needs, and promotes common recognition of the continuum of SEN' http://www.npt.gov.uk/PDF/sen_sen_summary.pdf. See Welsh Assembly Government (2007), p. 22. The Welsh Government proposed a reform of the current Special Educational Needs framework. In May 2014, a White Paper was published to set out proposals to introduce a new legislative framework for supporting children and young people with 'additional learning needs' (see <http://wales.gov.uk/topics/educationandskills/schoolshome/curriculuminwales/additionaleducationalneeds/additional-learning-needs-reform/?lang=en>). With regard to funding for education, the Welsh Assembly Government has secured 1.5 million pound, commencing 2008/2009, to provide support to children and young people with SEN, including those with ASD, as they move through school and to further education or the workplace. In 2007/2008, £1.7 million (recurring) was allocated by the Welsh Assembly Government to local authorities to children with SEN and children's social services. This funding remains year on year for local authorities to draw on.

⁸⁹ The Standards should include an overview of ASD, Local Education Authority (LEA) policy; identification and assessment; multi-agency support and collaboration; intervention; pupil participation; supporting parents and carers; education provision including managements and training; self-evaluation tool for schools. See Thomas (Deputy Minister for Social Services) (2010).

understanding of ASD are one of the key elements in ensuring that individual's needs are fully identified and assessed. In this regard, the Action Plan emphasizes that assessment is an ongoing process that is designed to identify each person's individual strengths as well as difficulties. For children, social services are the lead agency in the 'Framework for the Assessment of Children needs and Their Families', issued by the National Assembly for Wales on 2001 in order to provide a systematic basis for collecting and analyzing information to support professionals on how to help children and families, and the SEN Code of Practice should also be used where appropriate.⁹⁰

The Action Plan contains a specific part dedicated to 'Transition planning and preparation for adulthood and employment' (Chapter V, Part B) where, under 'Transitions for children and young people', it is recognized that 'transition, and the associated changes in life circumstances, can provoke extreme anxiety in people with ASD, and their families and carers. Existing policies outline a number of approaches authorities may adopt to seek to ensure a smooth transition between pre-school services, mainstream school and special school and post school learning and adult services'.⁹¹ As for transition from primary to secondary education, the Action Plan specifies that it tends to have an educational focus in conformity with the procedures outlined in the SEN Code of Practice for Wales. With regard to 'Transition from school to further education', the Action Plan requires a partnership between schools, Careers Wales⁹², further education and higher education institutions, employers and carers. Transition should be planned well in advance and the plans should have regard to the views of pupils and parents in leading to an assessment of individuals' needs. For pupils with ASD this may involve using a phased or gradual move to the new service or provision. Specific measures are indicated for the transition of young people (or adults) from school to further and higher education⁹³ which requires cooperation among schools, Careers Wales, post-school education, training providers, employers and carers. In this context, the 14–19 Learning Pathways⁹⁴ aim to ensure that all young people, including those

⁹⁰ See Action Plan, Chapter 5, point A 'Services for Children and Young People'.

⁹¹ The Action Plan recalls that the Welsh Assembly Government has convened a Multidisciplinary Transition External Reference Group to take forward the recommendations made by the Education, Lifelong Learning and Skills Committee in their review of SEN, with part three focused wholly on transition. Also the National Service Framework for Children, Young People and Maternity Services (Welsh Assembly Government 2005) contains a specific chapter on transition.

⁹² Career Choices Dewis Gyrfa Ltd (CCDG) is a subsidiary of the Welsh Government, established on 1 April 2013, to provide all age, independent and impartial careers information, advice and guidance service for Wales (<http://www.careerswales.com/en/>).

⁹³ The Adult Task and Finish Group, set up in October 2008 in conformity with the Action Plan (para 11.1) is charged to explore and make recommendations on a series of priority areas for adults, including, employment, higher and further education. The Report of the Group of October 2009 is available at http://www.asdinfo.wales.co.uk/resource/p_a_Adults_Task__Finish_Group_Report_For_matted_English_Version_February_2010.pdf. See also http://www.assembly.wales.org/NAfW%20Documents/specialist_provision_-_e.pdf%20-%2024052010/specialist_provision_-_e-English.pdf.

⁹⁴ See Welsh Assembly Government, 14–19 Learning Pathways Guidance, 2006. www.learning.wales.gov.uk.

with learning difficulties, receive learning provision that is flexibly tailored to meet their individual needs and aspirations.⁹⁵

Finally, it is important to recall that all the 22 Local ASD Action Plans adopted in implementing the Action Plan for Wales include a focus on education and address the need for a range of educational provision locally.⁹⁶

6.4 England

The Strategy for adults with autism in England (2010) was underpinned by the fundamental principles of equality and human rights and based on the Government's vision for transforming the lives of and outcomes for adults with autism which affirmed: 'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents'.⁹⁷

Government reaffirmed this vision in the updated version of the Strategy published in 2014 (2014 Strategy) which takes into account the progress made in improving support for adults with autism in England since 2010, the legislative developments in relevant sectors, such as special educational needs (SEN), and the results of the review of the Autism Strategy undertaken in 2013/2014 in conformity with Autism Act 2009.⁹⁸ The 2014 Strategy identifies 15 Priority Challenges for Action listed under three wide themes: (1) An equal part of my local community; (2) The right support at the right time during my lifetime; and (3) Developing my skills and independence and working to the best of my ability.

The field of education is firstly treated under the Priority Challenge for Action no. 4 with regard to the reasonable adjustments that all public organizations, as schools, are required to make in order to ensure that services are accessible to

⁹⁵ Working with local education authority (LEA) networks, the 14–19 Learning Pathways set out to provide appropriate opportunities and experiences for young people of all abilities to develop necessary core life and vocational skills, with the help of personal and learning coaches support and career guidance.

⁹⁶ See Welsh Assembly Government (2011), p. 45.

⁹⁷ The 2010 Strategy focused on five core areas of activity: (a) increasing awareness and understanding of autism among frontline professionals; (b) developing consistent pathways for diagnosis in every area, followed by the offer of a personalised needs assessment; (c) improving access to the services and support which adults with autism need to live independently; (d) helping adults with autism into work, and (e) enabling local partners to plan and develop appropriate services for adults with autism.

⁹⁸ See 'Think Autism – Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update, 2014'. This updated Strategy specifies that requirements for local authorities and NHS bodies from the 2010 Strategy still apply. Indeed, *Think Autism* does not replace the original Strategy but rather it is build on its themes (see para 1.8).

persons with disabilities, including people with autism.⁹⁹ The 2014 Strategy recognizes that without reasonable adjustments many services can be inaccessible for adults with autism, for this reason some good practices are recommended also for educational settings, such as providing quiet or low-light areas.¹⁰⁰ The 2014 Strategy also recalls that the Disabled Student Allowance (DSA) supports people with autism with the academic aspects of university life, in particular funding a note-taker for lectures, electronic equipment and software, social skills training, travel training, and 1:1 support.¹⁰¹ The 2014 Strategy also recommends reasonable adjustments for physical environment and for services and behavior of frontline staff who must be trained to this purpose.¹⁰²

In the Priority Challenge for Action no. 11, the 2014 Strategy points out that the needs of adults with autism may be significantly influenced by their experiences within education and children's services. Indeed, the Strategy recognizes that 'transition from school to college and beyond into adult life from children's services into adult services is an important time for many young people with autism and their families'. Consequently, it recommends that good transition planning developed by schools should bring together education, health and social care staff when a young person has complex need, while better transition planning for the move to further education and universities should be developed to support people with autism to lead independent lives and fulfill their potential. In this context, the 2014 Strategy recalls the legal changes introduced by the Children and Families Act 2014 that improves transitions from adult life for young people with special educational needs and disabilities (SEND), by providing new forms of protection for those with SEN in further education. The Act introduces a single Education, Health and Care (EHC) plan for 0–25 year olds, in place of the statements of SEN (mentioned in the 2010 Strategy) and Learning Difficulty Assessments.¹⁰³ When a young person with an EHC plan is expected to leave education, the local authority must agree the support he/she needs to engage with adult services and provision. The Act also includes duties on local authorities to maintain support for young

⁹⁹ Under the Equality Act 2010, educational and training institutions may not discriminate on the ground of disability and are required to make 'reasonable adjustments'.

¹⁰⁰ In the communications, a reasonable adjustment could be avoiding ambiguous questions, not pressurizing adults with autism in conversation and being aware of sensitivity to touch, ensuring essential documents and forms are available in accessible formats, in particular, easy read and formats that take account of sensory issues, in their choice of colours.

¹⁰¹ For the services offered by the DSAs see <https://www.gov.uk/disabled-students-allowances-dsas/overview>.

¹⁰² The 2014 Strategy recommends that quality autism awareness training should be included within general equality and diversity training programmes across all public services. Autism awareness training is set out in the Priority Challenge for Action no. 9 (see the 2014 Strategy, pp. 27–28).

¹⁰³ EHC plans are more person-centered and put greater emphasis on long term outcomes for young people. The annual reviews of support have to consider progress made against agreed outcomes within the plan, and from year 9 onwards must include a focus on preparing for adulthood.

people with EHC plans who become NEET (not in education, employment or training), and reengage them in education.¹⁰⁴ Furthermore, the Act improves the transition of young people with autism from school, through college and into adult life.

The 2014 Strategy also recalls that further education colleges and providers can also arrange an assessment for those people aged 19 and over who do not have an EHC plan but who self-declare a learning difficulty and/or disability.¹⁰⁵ The Department for Business Innovation and Skills (BIS) provides Learning Support funding to colleges and providers to help them meet the additional needs of people with learning difficulties and/or disabilities so that they can participate fully in education and training. The role of education is also emphasized under the Priority Challenge for Action no. 14 with regard to the development of skills and independence of adults with autism where it is underlined that education and training have a direct impact on the skills and ability to live independently, to enter into and remain in employment and to lead a socially inclusive life.¹⁰⁶ To this purpose, some colleges and universities provide appropriate services. Further education and training have also a key role in enabling adults with autism to improve their life skills and be as independent as possible.

6.5 Scotland

The 10-year *Scottish Strategy for Autism* (2011) is build on the idea that a strategic action is needed both nationally and locally because autism impacts on the whole life experience of people and their families who need to be supported by a wide range of services such as social care, education, housing, employment and other community based services. The Scottish Strategy is underpinned on some relevant

¹⁰⁴ The Department of Education (DfE) funds the Autism Education Trust (AET) with £1.5 m over two years from 2013 to 2015, to provide tiered training across early years, schools and further education. The Autism Education Trust is dedicated to coordinating, supporting and promoting effective education practice for all children and young people on the autism spectrum (<http://www.autismeducationtrust.org.uk/about-aet.aspx>).

¹⁰⁵ A learning difficulty means that a person has difficulties in a specific area (see the case of dyslexia) while a learning disability may affect all aspects of life (<http://www.autism.org.uk/about-autism/related-conditions/learning-disabilities.aspx>). DfE funds ‘Ambitious about Autism’, with £660,000 over two years from 2013 to 2015, to work with the Association of Colleges and four general further education colleges on transitions into further education for young people with autism (para 11.3 of the 2014 Strategy).

¹⁰⁶ Under the Equality Act 2010, educational and training institutions may not discriminate on grounds of disability and cannot refuse trainees on this ground alone. Training providers (including employers) are required to make ‘reasonable adjustments’ and must not to treat disabled learners ‘less favourably’. There are wide variety of providers, including mainstream and special colleges, specific residential vocational training courses, apprenticeships and other work-based schemes.

values that are considered to be at hearth of the act and must address the behaviour of all those who are responsible for implementing it, such as: dignity, privacy, choice, safety, realizing potential, equality and diversity. It is important to observe that all the mentioned values conform with the principles enshrined in the CRPD that the Scottish Strategy expressly recalls under the issue ‘Independent living’.

The Strategy identifies 13 goals divided into 3 parts: (1) Foundations (by 2 years) with five goals; (2) Whole-life journey (by 5 years); (3) and Holistic-personalised approaches (by 10 years) with respectively four goals.¹⁰⁷ Education is expressly mentioned in the goal no. 3, under the second part ‘Whole-life journey’, which requires ‘Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas’.¹⁰⁸ In the recommendation no. 18 the role of education is linked with the transition planning. In particular, it is recommended that ‘good practice transition guidance is developed, building on from existing educational guidance, in order to support the lifelong challenges facing people with autism as they make daily and life-stage transitions’.

Education is then treated in the Chapter 2 of the Scottish Strategy under the item ‘Autism Lifelong: the school years’ where it is underlined that when changes concerning the various stages of schooling or day-to-day transitions involve a child or a young person with additional support needs, the education authority and other agencies should take into account the way in which these changes affect the provision of additional support. To this regard it is important to recall that the Standards in Scotland’s Schools Act (2000) places the duty on education authorities to secure ‘that the education is directed to the development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential’ (Article 15). This Act establishes that education must be provided in mainstream schools, except in certain defined circumstances listed in Article 15 (3). Moreover, with the Education (Additional Support for Learning ASL) (Scotland) Act (2004) the concept of ‘additional support needs’ in substitution of ‘special educational needs’ has been introduced in the Scottish legal order.¹⁰⁹

¹⁰⁷ The Strategy lists 26 recommendations for improving services and access to services for people with autism to be implemented at national and local levels.

¹⁰⁸ An inspection on educational provision for children and young people with ASD across Scotland has identified good practices in relation to the work of education authorities and schools and other professional practice supporting pupils with ASD. However, the inspectors suggested to pay more attention to approaches to learning and teaching, and to targets set out in individualised educational programmes. Furthermore, those with responsibility for delivering services to pupils with ASD should ensure consistency in the quality of services provided, and teachers and support staff should be provided with high quality training to enable them to meet the needs of pupils with ASD (see the Scottish Strategy, p. 53). In order to fill the gaps concerning training of professionals involved in the education, health care and support of people with autism, Scotland has developed several initiatives and projects since 2004 (see the Scottish Strategy, p. 55).

¹⁰⁹ Under Article 1 ‘A child or young person has additional support needs for the purposes of this Act where, for whatever reason, the child or young person is, or is likely to be, unable without the provision of additional support to benefit from school education provided or to be provided for the child or young person’. See also ‘The Supporting Children’s Learning Code of Practice’ of 2005

As for transition of children and young people, the Scottish Strategy recommends to ensure early and timely planning in conformity with the Supporting Children's Learning Code of Practice which sets out detailed guidance on the matter and outlines the duties on education authorities and the time frame within which these duties should be carried out.¹¹⁰ Furthermore, the Scottish Government through the Project '16+ Learning Choices' supports young people to stay in learning after 16 years for ensuring their long term employability.¹¹¹

Also the transition to adult life presents difficulties, therefore the Scottish Strategy recalls that Education (Additional Support for Learning ASL) (Scotland) Act (2004 and 2009) requires education authorities to plan in advance when a young person with additional support needs is preparing to leave school. Under the Act, the education authorities have the duty to identify, meet and keep under review the additional support needs of all pupils, including those with ASD.¹¹² Furthermore, the Act extended the jurisdiction of the Additional Support Needs Tribunal for Scotland to include complaints in relation to an alleged failure of an authority to comply with any of its duties in relation to post school transitions.

The Scottish Strategy also mentions a series of specific Government's initiatives to support inclusion in education, such as the National Framework for Inclusion which promotes the principle that achieving inclusion is the responsibility of all teachers in all schools. Also learning and teaching materials have been developed to allow teachers make their learning in the classroom more inclusive for pupils.¹¹³

which sets out detailed guidance of the Act 2004. The Education (Additional Support for Learning) (Scotland) Act 2009 amended the Act 2004, reinforcing the rights of parents, including increased parental rights in respect of access to the Additional Support Needs Tribunals for Scotland (ASNTS). See Meikle and Watt (2013), pp. 107–111.

¹¹⁰ This recommendation is consistent with other key national policies developments such as *Getting it Right For Every Child* (GIRFEC, 2010) which is the Scottish Government's child-centred approach to children's services, including those supporting children with disabilities.

¹¹¹ The Government appointed a national transitions officer to work with local authorities and partners to support transition pathways for young people who are most at risk of missing out on education and training opportunities, including those with autism.

¹¹² See Alexander and Inch (2013), pp. 37–46.

¹¹³ See also the Inclusive Practice Project at the University of Aberdeen to develop inclusive education principles within teacher training and the Autism Toolbox commissioned by the Scottish Government and published in 2009 with the aim to support education authorities in their planning of services for children and young people with ASD and practice in the classroom (see Scottish Strategy, p. 63).

6.6 Northern Ireland

In the *NI Autism Strategy* (2013–2020) the issue of education is one of the 11 key themes and one of the 16 strategic priorities.¹¹⁴ This aligns with the Autism Act (Northern Ireland) 2011 which prescribed, among others, that the Strategy had to ‘set out how the needs of people with autism are to be addressed throughout their lives including (but not limited to) their *educational*, health and social needs’.¹¹⁵

In the Theme 5 entitled ‘Education’, it is affirmed: ‘There is one strategic priority within this themed area aiming to ensure that children and young people with autism are provided with high quality education services which meets their needs appropriately’. In the field of education the Strategy identifies the following cross governmental actions: (1) continue to build capacity in schools to effectively meet the needs of children and young people with autism; (2) provide effective support to parents and carers of children and young people with autism to ensure they are involved and informed regarding their children’s education; (3) formalise collaboration between health and social care and education sector to help improve support, including specialist support; and (4) expand trans-disciplinary assessments, interventions and support for children and young people with complex needs.

The Strategic Priority 8 entitled ‘education’ has the objective to ‘ensure that children and young people with autism receive a high quality education that prepares them for life and work and enables them to fulfil their potential’. It is important to underline that this Strategic Priority is consistent with the Article 24 of the CRPD expressly recalled in the Strategy where it is pointed out that this norm provides access to an inclusive education system at all levels and to lifelong learning. This is a further confirmation of the role that the CRPD can play at the domestic level to reinforce the rights of persons with autism and their inclusion in the society. Also the UN Convention on Rights of the Child of 1989 is recalled in order to conform the Strategic Priority on education with the rights and obligations enshrined in this treaty.

The Strategic Priority 8 must be assessed in the context of the NI educational legislative framework. In particular, the Disability Discrimination Act (1995) (DDA) enshrines disabled people’s rights to participate in civil society by placing duties on employers, service providers, landlords, schools and colleges, while Part IV contains some provisions on special educational needs.¹¹⁶ This Act has been completed by the Special Educational Needs and Disability (Northern Ireland) Order 2005, which has amended the existing legislation contained in the Education (Northern Ireland) Order 1996, and the Education (Northern Ireland) Order

¹¹⁴For each of the 11 key themes, the Strategy sets out cross governmental actions to be implemented. These latter form the basis for the Action Plan (2013–2016).

¹¹⁵Italic added.

¹¹⁶The Act was amended by the Disability Discrimination (NI) Order 2006 and by Autism Act (NI) 2011. See Sect. 2 in this chapter.

2006.¹¹⁷ As for children's services, under the Health and Social Care (Reform) Act (Northern Ireland) 2009, they are commissioned by Health and Social Care Board and provided by five Health and Social Care (HSC) Trusts: Belfast, South Eastern, Southern, Northern and Western.¹¹⁸

Education provision for children and young people with ASD is made under the special educational needs legislative framework and the statutory Code of Practice (and Supplement) on the Identification and Assessment of Special Educational Needs (SEN) of September 2005.¹¹⁹ In this context, it is also relevant the 'Strategy to improve the lives of people with disabilities 2012-2015' which sets out a framework to improve the health, well-being and life opportunities of all children and young people and their families particularly those who are most in need.

As for the institutional level, the Department of Education's (DE) has the primary statutory duty to promote the education and ensure effective implementation of education policy. The DE main statutory areas of responsibility are: age 0-4, primary, post-primary, special education and the youth service.

With regard to the education support to children with ASD, the Strategy highlights that many schools have tailored the classroom environment and educational programmes to meet their individual strengths and needs and the DE promoted the publication of materials to be used by school staff in supporting pupils with SEN. Another good practice in the field of education support mentioned in the Strategy is the Middletown Centre for Autism, established in 2007 and funded jointly by the DE and the Department of Education and Skills in the Republic of Ireland (RoI), to work with children and young people whose needs are more persistent, challenging and complex and to provide training to professionals and parents, and research services.

¹¹⁷ The Special Educational Needs and Disability (Northern Ireland) Order 2005 regulates, in Part II, the 'Education in ordinary schools of children with special educational needs' ('Duty to educate children with special educational needs in ordinary schools') and the 'Education otherwise than in ordinary schools'. See also the Children (NI) Order 1995 which is the primary piece of legislation in respect of children.

¹¹⁸ The Strategy lists the series of services for 'children in need' and their families. In particular, the Understanding the Needs of Children in NI (UNOCINI) framework is the primary service pathway for children's services within the HSC and for key agencies involved with children and young people; the Children and Young People's Strategic Partnership (CYPSP) leads integrated planning and commissioning of support and services aimed at improving outcomes for children and young people across the province. The CYPSP includes a number of regional sub-groups which aim to improve outcomes for specific groups of children and young people at a particular disadvantage, and their families, across NI.

¹¹⁹ On May 2012 the Education Minister presented to the Education Committee a Policy Memorandum Paper on the Review of Special Educational Needs (SEN) and Inclusion. One of the proposals is 'to introduce a new inclusive model based on the concept of Additional Educational Needs (AEN), which promotes a whole school ethos of inclusion and responsibility for children who face barriers to learning'. http://www.deni.gov.uk/summary_of_key_proposals_july_2012.pdf. All documents are available at the DE website http://www.deni.gov.uk/review_of_special_educational_needs_and_inclusion.htm.

In line with the Strategic Priority 8 and the above-described legislative framework, the DE has identified the following key aspects for ‘education’: (1) schools, in partnership with parents, and supported by the ELBs/ESA¹²⁰ and other agencies, should improve identification, assessment and appropriate early intervention to support pupils who may have autism; ELBs/ESA, in collaboration with health and other agencies, should provide support to schools (including the continuing professional development of staff providing autism support) to identify good practice in meeting the needs of their pupils with autism; the Middletown Centre for Autism should continue to provide a range of support and intervention to professionals, parents and children with autism; schools, supported by ELBs/ESA, working in collaboration with health and other agencies, should help parents and carers in supporting their child’s education and providing appropriate autism interventions; and ELB youth services should provide a wide range of youth activities for groups with specific and general disabilities as well as training to assist youth workers in providing services for them.

Further Education (FE) and Higher Education (HE) are treated under ‘Employment and Learning’ section because the Department for Employment and Learning (DEL) is responsible for FE and HE, training and skills, and employment programmes. DEL and its key delivery partners such as colleges, universities and training providers, offer a range of programmes and services to support people with autism. With regard to FE, the Strategy recalls that colleges are responsible for responding to the educational and vocational needs of the local population. Moreover, under the Special Educational Needs and Disability (NI) Order 2005, further education colleges have a duty to make reasonable adjustments to enable students with autism to access the mainstream curriculum (Article 37). All students with autism enrolling in colleges undergo an assessment of needs in order to help identify appropriate additional levels of support.¹²¹ As for HE, DEL’s strategic goal is widening participation for students with learning difficulties and disabilities, and to this end a specific Regional Strategy called ‘Access To Success’ was published in 2012.

As for the implementation of the cross governmental actions in the field of education, the Action Plan (2013–2016) attached to the Strategy (Section 5) sets out actions, outcome required/performance indicator, responsibility, and timescale.¹²²

¹²⁰ Following the education reform, the Education and Skills Authority (ESA) is the single authority for the administration of education, subsuming the functions, assets and liabilities of the five Education and Library Boards (ELBs), and other organs (<http://www.deni.gov.uk/index/about-the-department/8-admin-of-education-pg/education-and-skills-authority.htm>).

¹²¹ Colleges can access annual funds to help meet the cost of any additional support required.

¹²² See Action Plan (2013–2016), pp. 97–98.

6.7 France

The Third Autism Plan adopted in France, covering the period 2013–2017, is build on five main strands: (1) earliest detection and diagnosis; (2) strengthening and adaptation of support on a lifelong basis; (3) support for families; (4) continued research; and (5) awareness raising and training for all professionals involved in caring for and supporting people with autism.¹²³ For each strand, the Autism Plan identifies measures and actions to be implemented through a cooperation among different sectors, such as research, health, medico-social and educational fields, and with the involvement of persons with autism and their families.¹²⁴

The role of education is first of all recognized under the issue ‘early interventions’. The Autism Plan recalls that in 2012 the National Higher Authority for Health has recommended tailored, comprehensive and coordinated interventions which are considered to be more effective if provided at early stage.¹²⁵ The same Authority has also recognized the relevance of the educational, behavioral and developmental approach to support children diagnosed with autism since the age of 18 months. Indeed, this support helps children with autism to improve a set of sensory, motor, linguistic, and cognitive capacities, facilitating their integration in primary schools and, then, in ordinary secondary schools. The Autism Plan recognizes that this kind of support is also relevant for the transition into adulthood in so far as it helps to gain more autonomy.

In order to develop early diagnosis, the Autism Plan, among other measures, recommends the creation of a national network for detection and diagnosis since the age of 18 months, with the involvement of physicians, professionals of early childhood (such as pediatricians, nursery schools’ assistants) and tutors (Action Sheet no. 1). The national network should be completed by regional poles of early intervention and teaching units established at nursery schools. These latter are composed of teachers and socio-medical professionals and provide educational and healthy interventions with the purpose to increase the capacities of inclusion and learning of children with PDDs.¹²⁶ Strictly linked with these measures, it is the training on cognitive and behavioral problems that the Autism Plan extends to all people involved in the educational field (teachers, psychiatrics, physicians and nurses of the National Education).

¹²³ In the Autism Plan training is considered a tool for changing professionals’ practices and improve the quality of the taking care of people with autism. For these reasons, the Plan extends training to all stakeholders, see *Troisième Plan Autisme (2013–2017)*, pp. 26 ff.

¹²⁴ At central level the Secretary General of the Interdepartmental Disability Committee is charged with the Plan’s implementation with the involvement of all the stakeholders represented in the National Autism Committee (CAN).

¹²⁵ See Haute Autorité de Santé/ANESM (2012).

¹²⁶ The Autism Plan provides the development of the research in human and social sciences and the carrying out of research projects concerning specific pedagogical and educational approaches or the assessment of intervention practices on persons with autism, both children and adults.

With regard to the education of children with autism in France, it is important to recall that according to government data only 15–20 % of school-aged children with PDDs have access to school.¹²⁷ These data contrast with the Law no. 2005-102 which provides an express obligation on the State to ensure education of all disabled children in mainstream school and parallel rights of children with disabilities to access to local mainstream schools and to a personalized educational project.¹²⁸ The Autism Plan tries to reverse this negative trend providing additional 550 places in special education and home care services (SESSADs) in order to support the mainstream schooling for children with autism and other PDDs and their transition to young people.¹²⁹ To this purpose, the Autism Plan provides for a better organization between the educational and socio-medical sectors which are required to work jointly to achieve a series of objectives listed in the Action Sheet no. 5 entitled ‘Schooling of children and adolescents with PDDs’. Among these objectives, the Autism Plan mentions the following: support to adapted education through the development of SESSADs, in continuity with the French Second Autism Plan; strengthening of the territorial network of support to mainstreaming schooling, with pupils notably at ‘Classes d’intégration scolaire (CLIS)’ in primary schools and at ‘Unités Pédagogiques d’Intégration (UPI)’ in secondary schools; reinforcement of SESSADs to support the transition from adolescence to adulthood (16–25 years of age).

The Third Autism Plan seems to make some improvements to the French methods of care of children with autism whose inappropriateness was emphasized by the ECSR in the decision on the complaint *Action européenne des handicapés (AEH) v. France*. In condemning France for the violation of the European Social Charter the Committee affirmed the following: ‘. . .France is not fulfilling its obligation, under Article 15(1), to ensure that, in the context of care provision for children and adolescents suffering from autism within specialised institutions such as IMEs or day-hospital units, the work done by these institutions and the working methods they utilize are predominantly of an educational nature. In this respect, the Law (Article L112-1, §7) only foresees educational provision within these institutions as a subsidiary element amongst a number of other activities (pedagogical, psychological, social, medical and paramedical)’.¹³⁰

¹²⁷ See Plan Autisme 2013–2015. Diversification des parcours d’inclusion et de scolarisation des enfants avec troubles du spectre autistique (TSA). Note technique. http://www.autismefrance.fr/offres/file_inline_src/577/577_A_16315_1.pdf.

¹²⁸ See also Code of Education, article L112-4. The legal system allows parents to place their child also in a special school.

¹²⁹ The Autism Plan also provides an increase of 100 teachers in nursery schools with a cost of 6 million euro a year.

¹³⁰ See Resolution CM/ResChS(2014)2, *Action européenne des handicapés (AEH) v. France*, Complaint No. 81/2012, adopted by the Committee of Ministers on 5 February 2014. In France autism is considered a mental illness, or a psychosis, to be treated with the methods of psychiatry; this approach is criticized by parents and associations. In May 2013, the Minister Marie-Arlette Carloti delegate for disabled people and the fight against exclusion in a interview said that ‘in the

The ECSR also criticized the lack of action to consolidate the applied behavior analysis (ABA) method employed in about 30 new institutions on an experimental basis.¹³¹ The Third Autism Plan in Action sheets no. 7 and no. 8 (Cross-sectoral external review of experimental facilities) makes provision for such method in 28 experimental facilities which are under evaluation.

7 National Autism Plans and Strategies in the EU Member States: Actions and Services in the Field of Employment

As for education, also in the field of employment each national autism plan and strategy follows its own approach based on the domestic legislative background and the existing services.

7.1 Denmark

The *Danish NAP* (2008) deals with employment, in particular, under the sections ‘adult life’ and ‘old age’ affirming that adults with ASD should have the possibility of choosing occupation or daily activity based on their needs and abilities, that access to education and continuous learning should be ensured and the person should have the right to try out his or her possibilities on the regular labour market.¹³²

To this end, the NAP recommends to develop meaningful daily activities, ranging from day centres with no requirement of productivity to actual jobs, mentor and support schemes for people with ASD in regular jobs. It is also recommended that large firms should employ or make use of job consultants with autism specific knowledge to guide and structure the work for people with ASD, including the ordinary working conditions and cooperation with colleagues. Also mentors to strengthen the introduction to a workplace and personal assistants are highly recommended. In this context, the NAP recognizes the role of relatives that in the field of employment may collaborate with professionals, if adults with ASD so desire and under a clear agreement on what is included in this collaboration.

upcoming years, ranging from 2014-2017, France would be rolling out new methods of treatment and no longer consider autism a mental illness. The plan includes more Americanized models of treatment such as behavioral modifications and teachings’. <http://www.autismdailynewscast.com/documentary-influences-a-change-in-frances-autism-policy/77/richardjames/>.

¹³¹ ABA is recognized an essential and scientifically valid method of educating and managing children and youth with ASD, but around this method a debate is open concerning diverse aspects, see Simpson (2001) and Foxx (2008).

¹³² The Danish Law on Equal Treatment in the Labour Market (LBK no. 1349 of 16 December 2008) forbids employers and labour market agreements to discriminate on the basis, among others, of disability.

The NAP also suggests occupation for elderly people with ASD in order to avoid passivity, stereotypical activities and depression. For this group of people, practical employment similar to light employment with pension is recommended. The NAP specifies that elderly people with ASD are not trained in structural environment as children, for this reason they have a more individual need for structure and predictability than other age groups with ASD.

7.2 *Hungary*

The *Hungarian National Autism Strategy (2008–2013)* dedicates the Chapter 8 to ‘Ensuring Autism-specific Employment’ with the goal to improve the employment of people with autism matching their specific situation, special needs, individual abilities and skills. The Strategy recognizes that employment for people with autism is a basic human right that can be ensured only through 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 and labour market policies must be involved.

The Strategy also requires to establish ‘Standards for the Employment of People with Autism’ in order to define the special tools required to facilitate the employment of the person with autism for each labour market service. These Standards should 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 EU funding. Moreover, they should be the basis of the ‘Autism-specific Employment and Operating a Labour Market Services Model Program’ that according to the Strategy should be prepared in cooperation with the organizations employing or offering labour market services to people with autism and should ensure individualized forms of employment and autism-specific work orientation and assistance. The Strategy also suggests the contents of the Model Program such as: elements that prepare the employers for receiving people with autism (adapting the workplace to the individual’s skills and needs, e.g.: information accessibility, mentoring, offering information and/or internal training, follow-up, indication system); actions and publications to spread information connected with employment; co-operation of an autism expert and an appropriate assessment tool in order to assess the individual map of competencies; sharing experiences gained from the projects and dissemination; be market-oriented. The Strategy also foresees the opportunity for organizations, such as NGOs, to offer alternative labour market services to people with ASD.

7.3 Wales

The *Autistic Spectrum Disorder Strategic Action Plan for Wales* (2008–2018) provides that all young people leaving school at 16 plus should have the opportunity to engage in employment or training. Careers Wales has a key role in ensuring that unemployed young people up to the age of 18 receive timely and effective help to secure and retain suitable placements in education, training and employment.¹³³

As for adults, the Action Plan outlines that only 11 % of adults with ASD are in full time employment; it is therefore necessary to help and support them to find work and stay in work. In this context, Job Centre Plus Disability Employment Advisers have a key role in providing specialist support, such as the Employment Assessment, which can help people with ASD to find out how their condition might affect the type of work or training they like.¹³⁴ With regard to training and employment for adults, the Action Plan outlines that ‘people with ASD should have equal access to the full range of government funded programmes including education and life-long learning services and other training opportunities. The principle is that all people with ASD should be able to use services that are likely to assist them in their personal development, or provide career opportunities or secure their employment and which should be based on an understanding of their learning patterns’. The Action Plan suggests the ‘supported employment’ for adults who do not achieve the criteria for entry to training or educational services. In such cases, the Action Plan recommends a co-operation among local employers, supported employment services, social services and mainstream Wales employment services. Of paramount importance is the ASD awareness training for all professionals who may come into contact with people with autism, such as professionals of Job Centres, Careers Offices and Employment Training Agencies.¹³⁵ Finally, the Action Plan recognizes the key role of specialist employment training programmes such as those offered by specialized agencies outside Wales: ASPIRE (Autism West Midlands) and for adults with Asperger syndrome, PROSPECTS (NAS).

¹³³ Careers Wales works with partners as part of the transition planning process from the age of 14, draws together relevant professional information and assessments to produce a Learning and Skills Plan which sets out the post 16 educational needs of the client and the provision required to meet them.

¹³⁴ In Wales, there are over 100 different employment support services that young people with autism could use, the problem is that not all young people with autism know about these services, or use them. <http://www.asdinfo.wales.co.uk/resource/140602-employment-young-people-autism-easy-read-summary2-en.pdf>.

¹³⁵ In Wales the partnership with the Institute of Directors (IOD) led to the appointment in 2010 of Robert Lloyd Griffiths, IOD’s Director in Wales, as *Wales Autism Employment Ambassador* charged with raising awareness of how people with ASD can bring benefits from the talents, skills and knowledge, to enterprises across Wales http://www.asdinfo.wales.co.uk/home.php?page_id=5997.

7.4 *England*

As for England, in the Ministerial Forward to the 2014 Strategy it is affirmed: ‘we must do more to ensure that people with autism have the opportunity to achieve their aspirations in employment’ because many persons have skills to offer but they are not being put to good use. Employment is considered of paramount importance to social inclusion of people with autism and to be part of their communities,¹³⁶ for this reason under the key area ‘Promoting Innovation and Awareness’ the 2014 Strategy recommends to promote innovative local ideas, services or projects which can help people in their communities, including those aimed at finding employment, and to make proposals in the field of employment, particularly involving the use of apprenticeships. The 2014 Strategy suggests some characteristics of these proposals, such as: (a) involvement of people with autism; (b) innovation, including either technology or innovative service design or provision; and (c) partnership, that is an integrated approach to local services and/or partnership with local businesses, employers or other services.¹³⁷

In conformity with these indications, in the Priority Challenge for Action no. 11 it is affirmed that Government sees apprenticeships as an important tool for social mobility and a great opportunity for people with autism of all ages and backgrounds to secure a job with excellent training and real career prospects (para 11.8). Following a practical approach, the 2014 Strategy gives a series of information concerning apprenticeship such as national initiatives and funds, websites where it is possible to get information or ask for support. In this context, the Strategy mentions the ‘supported internships’ which are study programmes for young people aged 16–24 with a statement of SEN, a Learning Difficulty Assessment or an EHC plan who want to move into employment and need extra support. These internships enable young people with complex learning difficulties to achieve sustainable paid employment by equipping them with the skills they need for work, through learning in the workplace.¹³⁸

The 2014 Strategy develops the field of employment under the Priority Challenge for Action no. 15 entitled ‘I want support to get a job and support from my employer to help me keep it’, starting from these considerations: ‘Most people with

¹³⁶ The Equality Act 2010 sets out the rights of disabled people in workplaces and wider society, and states a legal duty on employers to make reasonable adjustments with regard to most aspects of the employment process and working conditions.

¹³⁷ For 2014/2015 a revenue and capital funding of £4.5 million are available to support the delivery of some of the key priorities set out in the 2014 Strategy, including local innovation and awareness (para 3.5). An Autism Innovation Fund was established to fund projects in four areas, including employment (para 3.6) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/338199/autisminnovationfundfinaljuly__3_.pdf.

¹³⁸ DfE’s supported internship trial in 2012/2013 allowed young people with the most complex needs to show employers what they can do. It resulted in an employment rate of 36 %, against a national average employment rate of 7 % for people with complex learning difficulties (para 11.11 of the 2014 Strategy).

autism want to work and have skills and talents that would be useful in the workplace. With support, people with autism can both get and keep a job'. Currently, adults with autism are significantly underrepresented in the labour market with negative consequences on social inclusion and personal financial situations. In this regard, the 2014 Strategy recalls all relevant measures adopted by the Department for Work and Pensions (DWP) in implementation of the 2010 Strategy to increase the number of people with autism in work, such as: the 'Work Programme' and the 'Work Choice and Access to Work' introduced with the purpose to help people with disabilities, including persons with autism, to find employment and stay in work; the Disability Employment Advisers (DEAs) who are specialists working with people facing complex employment situations because of their disability or health condition, including persons with autism, and who receive training in awareness of autism; training for DWP staff; the Hidden Impairment Toolkit designed to offer practical guidance to Customer Care Officers (security staff) on how best to support individuals with hidden impairments, including reasonable adjustment solutions; 'One Stop Shop' service to support employers in employing disabled people; 'Untapped Talent', a guide for employers to help them to practice autism-friendly recruitment and to better support the people with autism in their workforce; the 'Think Autism awareness programme' in partnership with DH to promote autism-friendly practice in working.

Another relevant initiative that may be considered a good practice in the field of inclusion of people with ASD in the employment is 'The Disability and Health Employment Strategy: the Discussion so far' of December 2013 which sets out a more personalised and tailored approach to employment support for disabled people, including persons with autism. This strategy provides for a national network of specialist advisers who will be responsible for pre-employment support, job matching, work entry and sustained in work support, ensuring that people with disabilities, including those with autism, make a smoother transition into work and receive adequate in-work support. Further improvements to better access to job opportunities for people with autism will rise from the Action plan that DWP will present to the Autism Programme Board by the end of 2014.¹³⁹

In supporting adults with autism to gain employment, local authorities play a key role. The 2010 Autism Strategy and the statutory guidance (2010) recommended to establish an Autism Partnership Board (APB) in every local area with the involvement of all relevant stakeholders, people with autism and their families and senior commissioners of health and care services, with the task to help identify local need and develop local plan of appropriate services and support. The 2014 Strategy reaffirms the role of local authorities and recommends as good practice that they should take into account the employment support needs of the local population of adults with autism, and that representatives from Jobcentre Plus as well as

¹³⁹ On the Board see Sect. 8 in this chapter. The Action Plan will be based how the outcomes of the workshop of 3 March 2014 — held by DWP, DH and NAS together with stakeholders and people with autism — to hear about their experiences in the labour.

employers join the local Autism Partnership Board.¹⁴⁰ In this context, the Care Act 2014 is particularly relevant because it provides new duties for local authorities, including to prevent, delay or reduce adults needs for care and support. In conformity with the Care Act, the 2014 Strategy recommends to local authorities the development of employment support services as a tool to meet the prevention duties.

Finally, the 2014 Strategy recommends key actions to local authorities to support increased employment such as: (1) ensuring that transition plans for young people with autism include employment as a key outcome, in conformity with the Children and Families Act 2014 requiring employment to be part of the new SEN local offer (Article 30); (2) assuring that the work of the local authority in relation to promoting employment effectively addresses the needs of people with autism and promoting apprenticeship schemes; (3) guaranteeing that the care planning process for adult social care needs considers employment as a key outcome, as appropriate, and looks particularly at whether personal budgets can be used to support adults with autism to become work ready;¹⁴¹ (4) ensuring that the assessment process for adult social care includes signposting, as appropriate to Access to Work for interview support,¹⁴² other appropriate benefits and agencies that can help people with autism to find and keep a job; and (5) setting the example locally and becoming an autism friendly place to work.

7.5 *Scotland*

The *Scottish Strategy for Autism* of 2011 recognizes that ‘there are many people with autism who would like to work but who face significant barriers to getting and sustaining a job. We will support them through training, creating opportunities and improving access to the workplace’. Consequently, ‘it is recommended that the supported employment framework for Scotland is evaluated in terms of its impact on employment and employability for people with autism’ (recommendation no. 26).

The sixth aim of the Strategy concerning ‘Wider opportunities’ outlines that the Scottish Government is committed to removing barriers which prevent an effective transitions into employment and has developed, together with the Convention of Scottish Local Authorities (COSLA), a Supported Employment Framework for Scotland with the aim to provide the necessary mechanisms to support a disabled

¹⁴⁰ Jobcentre Plus manages a national network of local Job Centres charged to assist unemployed people to find jobs, including disabled people, and also deal with welfare benefit applications.

¹⁴¹ Personal budget is money from the local authority that a person of 18 years or over, eligible for social care support, may spend for services and support. Personal budgets can be used to buy support from both the council and other providers such as domiciliary care agencies.

¹⁴² See the website ‘Access to Work’ of the United Kingdom government. <https://www.gov.uk/access-to-work/overview>.

person's move to paid employment in the open labour market. In order to ensure that the needs of people with autism are taken into account an ASD representative is member of the Employment working group which focuses on employment for people with learning disability and ASD. Also a Scottish Autism Services Network (SASN) Employability Network is active, while the Employability team has funded a national project at the Scottish Consortium for Learning Disability (SCLD) to consider the job opportunities available to people with ASD.

It is interesting to observe that in the Scottish Strategy a link is made between the economic cost of autism and work of people with ASD. In fact, 'it is recommended that Knapp's work on the economic costs of autism is analysed and applied to the Scottish context to inform strategy and planning on what interventions lead to positive impacts both for individuals and for the economy as a whole.¹⁴³ Particular attention should be paid to his 'invest to save' assertion that if 4 % of those with Asperger's were given appropriate support into work this would ultimately mean that those individuals may not require services and could contribute to the economy' (recommendation no. 5).

In the explanation of this recommendation, the Scottish Strategy outlines that work for people with ASD is a tool to realize their inclusion in society. In particular, the Strategy recognizes that 'people with ASD have a right to the information, equipment, assistance and support services necessary to live a fully productive life with dignity and independence of choice, and to feel included in society'.¹⁴⁴

7.6 Northern Ireland

In the *NI Autism Strategy* (2013–2020) to the issue of employment one of the 11 key themes and two of the 16 strategic priorities are dedicated. The Theme 7 'Employability' affirms 'There are two strategic priorities within this themed area aiming to increase opportunities for people with autism to access employment, training, lifelong learning and to attain skills'. Consequently, the Strategic Priority 10 requires to 'increase the number of people with autism entering all levels of employment and safeguard the rights of those people with autism already in work', while Strategic Priority 11 requires to 'increase the opportunities for people with autism to attain skills and qualifications through access to appropriate training and lifelong learning opportunities'.

The contents of these priorities conform respectively with Article 27 of the CRPD on the right to work and employment of persons with disabilities on an equal basis with others, and Article 24 of the CRPD on education of persons with

¹⁴³ Knapp et al. (2009), pp. 317–336. The study focuses on individuals across the autism spectrum, and a prevalence rate of 1 % was used (100/10,000). On the basis of these elements and a wider range of other factors the annual cost of autism in the UK was estimated to be £28 billion. Cf. MacKay et al. (2013), pp. 101–106.

¹⁴⁴ See the Scottish Strategy, p. 27.

disabilities which provides for access to an inclusive education system at all levels and lifelong learning. Indeed, the Strategy expressly refers to these provisions in relation to the two priorities.

Employment and employability are issues which require a number of government departments to work together to support people with autism to gain and retain employment. Under theme 7, the Strategy identifies the following cross departmental actions: (1) increase awareness about the support available to people with autism to help access opportunities for employment, training, and life-long learning; and (2) promote opportunities to access and attain employment, training and life-long learning for people with autism.

As already mentioned, at the institutional level the Department for Employment and Learning (DEL) is responsible of the field of employment and through its partners (colleges, universities and training providers) offers services to assist individuals with ASD to obtain and sustain work, move towards employment, or develop new/existing skills. For people with autism DEL's services cover four main areas: (1) Employment Support with a range of vocational and pre-vocational programmes to meet the needs of people with autism and services;¹⁴⁵ (2) Careers Advice and Guidance which provides careers information through a network of professionally qualified advisers trained to work with clients with autism;¹⁴⁶ (3) Further and Higher Education;¹⁴⁷ and (4) Professional/Technical Training, including Apprenticeships.¹⁴⁸ Moreover, DEL has developed a range of strategies which guide the delivery of its services across these key areas and the DEL's Disability Employment Service helps to raise awareness with employers on the benefits of employing people with autism and provide tailored support for them.

In line with the two strategic priorities and building on existing employment policies and programmes, DEL has identified the following key aspects for the 'employment' theme: increase awareness of DEL's services amongst people with

¹⁴⁵ They include: employment assessments carried out by a team of occupational psychologists; specialist support to find and keep suitable employment; residential training for those disabled people who are not ready to access mainstream training; and menu-based employment support to better target individuals' barriers to employment via 'Steps to Work' and new 'Work Connect' programmes.

¹⁴⁶ The Careers Service has arrangements in place with 99 % of post-primary schools to support the schools' careers education programmes. Through the partnership agreements the schools' careers advisers are invited to attend transition planning meetings at year-10 and subsequent annual reviews until a young person leaves post-primary education.

¹⁴⁷ See Sect. 6 in this chapter.

¹⁴⁸ DEL's Training for Success (TfS) Programme provides training for young people with autism up to the age of 22 who have not yet found full time employment. The TfS Programme provides training to address personal and social development needs, develop occupational and employability skills and, where necessary, essential skills. It is delivered through two components: (1) 'Skills for Your Life' to address the personal and development needs of young people who have disengaged from learning and/or have significant obstacles; and (2) 'Skills for Work' to help young people gain skills and a vocational related qualification at Level 1 to be able to gain employment or to progress to higher level training.

autism, their parents and carers; provide effective support in higher education for people with autism through the delivery of the Access to Success Strategy; improve employment prospects of people with autism through the delivery of an Economic Inactivity Strategy; deliver the Pathways to Success Strategy to improve participation in employment, education and training by young people with autism; and provide individual support for students with autism in further education. These aspects are then listed in the Autism Action Plan (2013–2016) under the column ‘Outcome Required/Performance Indicator’ with the indication of the timescale and the lead responsibility of LED as for implementation.¹⁴⁹

7.7 France

In the Third Autism Plan, the field of the employment is treated with reference to the condition of adults with autism and other PDDs. In the Action Sheet no. 10 entitled ‘Scheme of actions for adults’ the Autism Plan underlines that, actually, inadequate care pathways are offered to adults with autism in France, as reported by a study carried out in three regions in implementation of the Second Autism Plan.¹⁵⁰ Indeed, in France most adults with autism are institutionalized with low self-care skills as a result of failed educational policies and lack of access to work.¹⁵¹

The Third Autism Plan foresees the improvement of pathways and quality of life of adults with autism through adapted interventions and a multifaceted offer, and the involvement of families. In this context, it is recognized that access to work contributes to the autonomy and to the improvement of life of adults with autism and other PDDs and that measures to be developed are the same of those required for disable people, but with the necessary adaptations.¹⁵²

In order to achieve the objectives concerning the improvement of the pathways and quality of life of adults with autism and other PDDs and to create the necessary conditions to support them in employment, the Autism Plan also lists a set of interrelated actions to be implemented (Action Sheet no. 10). Among these

¹⁴⁹ See Autism Action Plan (2013–2016), pp. 99–100.

¹⁵⁰ See Baghdadli et al. (2011).

¹⁵¹ <http://www.thinkingautismguide.com/2012/01/culture-of-abuse-autism-care-in-france.html>.

¹⁵² As for the French legal framework in the field of employment of persons with disabilities see the following acts: the Law no. 90-602 of 12 July 1990 regarding the protection of persons against discriminations because of their health state or disability, the Law 2005-102 of 11 February 2005 which extended the principle of non-discrimination according to the EU Council Directive 2000/78/EC framework for equal treatment in employment and occupation. In parallel with anti-discrimination legislation, a 6 % quota of employees with disabilities within the workforce should be respected by employers of at least 20 employees in both the private and public sectors. Furthermore, in 2009 France adopted a National Employment Pact for People with Disabilities (‘Pacte national pour l’emploi des personnes handicapées’).

measures, the Plan mentions the following: raising awareness and training for staff in the field of employment dealing with adults with autism or PDDS, autism specific training programmes for professionals of ‘Cap Emploi’ and ‘Services d’Appui au Maintien dans l’Emploi des Travailleurs Handicapés (SAMETH)’, and pooling socio-medical and employment interventions. It should be noted that vocational training and lifelong learning are not included in the actions, and even a reference to tertiary education is lacking.

8 National Autism Plans and Strategies: Implementation, Monitoring and Revision

Implementation, monitoring and revision are distinguishing aspects of all autism national plans and strategies that have been examined. These phases are interrelated and involve central and local organs, together with *ad hoc* organisms often set up for these purposes and stakeholders. Just to highlight some aspects of these phases we can refer to the Strategy for adults with autism in England (2010, updated in 2014) and NI Autism Strategy (2013–2020). Both have a legal foundation in primary legislation and their implementation, monitoring and revision are regulated respectively in the Autism Act 2009 and the Autism Act (Northern Ireland) 2011.

Concerning England, under Section 1 of the Autism Act (2009) the Secretary of State must keep the autism strategy under review, may revise it, and must publish it as revised. Moreover, the Secretary of State must consult and seek the participation of such persons considered appropriate in revising it. Under Section 2, the Secretary of State is required to issue a guidance to local authorities, NHS bodies and NHS to implement the Strategy and to keep the guidance under review.¹⁵³ Subsection (5) contains a non-exhaustive list of matters that must be addressed in the guidance, while Subsection (6) requires the Secretary of State to consult and seek the participation of local authorities, NHS bodies and NHS foundation trusts before issuing guidance and before making substantial changes to the guidance once issued. A relevant legal aspect which is worth mentioning concerns the remedies that English legal order offers in case of failure to comply with the guidance. Under Section 3 of the Autism Act (2009) local authorities and NHS bodies have a ‘duty to act under guidance’, if they fail to comply and have ‘no reasonable excuse’,¹⁵⁴ they are subject to judicial review or default action by the Secretary of State.¹⁵⁵

¹⁵³ For the Guidance see Sect. 4 in this chapter.

¹⁵⁴ To have a reasonable excuse local authorities can prove they are providing an equivalent or better alternative service.

¹⁵⁵ Under Section 7D of the Local Authority Social Services Act 1970 the Secretary of State for Health has the power to step in when a local authority fails to comply with its statutory community care duties and has ‘no reasonable excuse’ for this failure. Moreover, each local authority in England, Northern Ireland, Scotland and Wales has a complaints procedure and a citizen may

Under the 2010 Adults Autism Strategy the Autism Programme Board was charged with the duty to oversee the progress on delivering the Strategy and provide overall direction and governance at national level (para 1.8). The Board, currently chaired by the Minister of State for Care and Support, has been confirmed in its role by the 2014 Strategy and carries out the following activities: monitoring general progress in implementing the Strategy; providing challenge and support to government departments, the NHS and local authorities on their contributions to the adult autism agenda; considering and acting upon issues raised by key stakeholders. Moreover, the 2010 Adults Autism Strategy recognised that ‘effective local leadership is essential to ensuring the needs of adults with autism are met in each area’, and, consequently, recommended a range of measures to ensure local leadership, among which, to set up local Autism Partnership Board bringing together different organisations, services and stakeholders locally (para 6.12).¹⁵⁶ The 2014 Strategy reaffirms the role of local planning and leadership in the provision of services, taking into account the progress made at local level in implementing the 2010 Strategy.

With regard to Northern Ireland, under Section 2 of the Autism Act (NI) 2011 the Department of Health, Social Services and Public Safety (Department) has the following duties: to keep the autism strategy under review and publish a revised version at intervals of not more than 7 years; to monitor the implementation of the autism strategy by the Northern Ireland departments;¹⁵⁷ to implement that part of the autism Strategy which falls within its responsibilities; to prepare a report on implementation of the autism strategy by the Northern Ireland departments and the same Department not more than 3 years after the publication of the autism strategy, and at intervals of no more than 3 years thereafter. Under the same Section, the Northern Ireland departments must co-operate with the Department in relation to the preparation, review and implementation of the autism strategy and effectively implement the parts of the autism strategy that fall within their areas of responsibility.

The NI Autism Strategy (2013–2020) completes the provisions of the Act in Section 4 entitled, ‘Implementing Approach’ where the implementation structures, monitoring and reporting arrangements to ensure the delivery of the initial Action Plan (2013–2016) are set out. In particular, the Strategy underlines the role of the Regional Autism Co-ordinator and establishes the tasks and responsibilities of the various organs.

The implementation of the autism plans and strategies and its monitoring are two relevant steps which are necessary to identify new priorities and actions to meet the

lodge a complaint if a service hasn’t been delivered. After the local council’s complaints another remedy is to complaint to local ombudsman.

¹⁵⁶ As set out in the Strategy, in each local authority local lead commissioner/senior manager has been appointed. They have a key role in developing local commissioning plans and in making sure that adults with autism and parents/carers are involved in the development of local services (through working with autism partnership boards).

¹⁵⁷ Section 4 of the Act lists the NI Departments.

needs of people with ASD as well as gaps in the delivery of services that must be filled. The revision of autism plans and strategies passes through an in-depth evaluation of the outcomes obtained¹⁵⁸ and the objectivities achieved with the involvement of all stakeholders and, in particular, of autism representative organizations. The case of the Autistic Spectrum Disorder Strategic Action Plan for Wales (2008–2018) whose refreshing is currently underway shows the key role that autism associations may play in this context. In order to update the Strategic Action Plan a public consultation took place in November 2012 in partnership with the voluntary sector organizations and a set of priorities has been identified for the final refreshed Strategic Action Plan and the Delivery Plan, whose implantation should start in 2015.¹⁵⁹ It is interesting to observe that an ASD Stakeholder Advisory Group¹⁶⁰ has been established to provide expert advice and guidance, and small consultation workshops have been organized to discuss directly with stakeholders and ASD leads at local level.¹⁶¹

Feedbacks from all stakeholders and public consultations are relevant elements in all processes of revision and are one of the strengths of autism plans and strategies.

9 National Autism Plans and Strategies: An Appraisal

The number of national autism plans and strategies adopted in the last few years, both in the EU countries and outside Europe, shows a growing awareness of public institutions towards the challenges that confront people with ASD and their families. Governments are slowly becoming aware of their key role in safeguarding and protecting the rights of the individuals with ASD, and in guaranteeing their inclusion and participation in society. In this perspective, national autism plans and strategies are instruments through which States provide tailored services in key

¹⁵⁸ The Scottish Autism Strategy has identified ten indicators to be used to identify outcome-focused actions ‘that may be achieved over the two, five and ten year timeline of the autism strategy, as agreed locally’ (pp. 11–13).

¹⁵⁹ The Welsh Government has allocated additional £2.1 m over the 3 years 2014/2015–2016/2017 to support the refresh of the Strategic Action Plan. <http://wales.gov.uk/about/cabinet/decisions/dl2014/aprjun1/health/gt0837/?lang=en>.

¹⁶⁰ Membership includes a parent carer representative, a person with Asperger Syndrome, senior representatives from the statutory services and the voluntary sector working to support people with autism.

¹⁶¹ Wales has developed a solid infrastructures to implement the Strategic Action Plan. At a national level there is an ASD Implementation Manager based in the Welsh Assembly Government. At a regional level there is a small ASD Regional Support Team, based in the Welsh Local Government Association (WLGA), which supports local areas to work together and develop regional initiatives. At a local level each Local Authority area has an ASD Lead and has developed an ASD Local Action Plan to be implemented and reviewed via a Local Stakeholder Group. http://www.asdinfo.wales.co.uk/home.php?page_id=5998.

areas having a great impact on the life of people with ASD, such as health, education and employment. Furthermore, these plans and strategies are consistent with the recent indications of the World Health Assembly that, as already mentioned, has recommended to develop national policies, legislation, and *multi-sectoral plans*, supported by sufficient human, financial and technical resources to address issues related to ASD.

Autism plans and strategies could be therefore the proper way to support and improve the quality of life for people with ASD and their families. Indeed, practice shows that in general they have positive impacts at domestic level even if the objectives envisaged in a plan may not always be fully achieved¹⁶² and the adoption of these instruments does not guarantee that the rights of people with ASD will be effectively protected by the State concerned. The case of France is emblematic in this regard. Notwithstanding three autism plans, the ECSR condemned twice the State for the violation of the right to education of children with autism as guaranteed by the European Social Charter (revised) and a petition against France was presented to the competent Committee of the European Parliament in 2013.¹⁶³ In the above-mentioned case *Action européenne des handicapés (AEH) v. France*, the ECSR reached the conclusions that France violated the European Social Charter concerning the right to education of children and adolescents with autism also considering the ground of the limited funds in the State's social budget for this field as emerged from the second Autism Plan (2008–2010) whose measures were not fully implemented.

However, it should be noted that the analysis of the national autism plans and strategies has revealed that these instruments are characterized by some distinguishing aspects. First, they follow a practical approach that allows to identify the real needs of the people to whom the plan addresses (children, young people, adults with ASD, but also families and carers) and, accordingly, the key areas of intervention and the necessary services. In this context, it is important to underline that all national autism plans and strategies adopted by the EU Member States have been outlined in partnership with autism associations and, in most cases, after a public consultation. The information gathered from consultations, the involvement of autism representative organizations and families demonstrate that the plans are developed with the contribution of those who have a direct knowledge and experience of the ASD. In some cases, autism representative organizations lobby Governments to have an autism plan as a way to coordinate national efforts to meet the complex needs of people with ASD (as for the case of Canada). The active involvement of autism associations in developing autism plans and strategies is a very positive aspect and a substantial added value for these instruments.

¹⁶² See, for example, the evaluation concerning the implementation of the Adult Autism Strategy for England in the field of employment, cf. López and Keenan (2014).

¹⁶³ See petition 0031/2013 to the Committee on Petitions of the European Parliament by Marie Bradot (French), on behalf of the 'Diamant association' on the right to education of persons with autism in France (Commission reply of 28 February 2014). On these cases see the chapter by G. Palmisano, in this volume.

Second, autism plans and strategies have a flexible nature that allows their revision without recurring to formal procedures. This flexibility is strictly linked with their implementation and monitoring which are fundamental elements for all autism plans and strategies.¹⁶⁴ Competent Ministries or Departments are usually charged with the task of autism plans' implementation and updating, often with the collaboration of specific organs or networks at national and local levels, and autism associations. For the autism plans and strategies adopted in the EU Member States having a legal basis in primary legislation, such as the above-mentioned cases of England and Northern Ireland, the relevant Acts contain both the broad legal framework of the strategy and 'the enabling clause' that confers the power to an administrative branch to issue and revise it.¹⁶⁵ In this way, it is possible to reformulate objectives and priorities, and identify new actions and challenges to include in a updated plan.

Third, autism plans set out strategic direction and co-ordination of services at national and local levels, mapping out the existing services, identifying the priority areas of intervention and the organs responsible to provide the services and carry out the actions. In some cases, they have also recommended a rationalization of services thus ensuring saving of public money.

The last common aspect concerns public funding. All autism plans and strategies adopted in the EU Member States have the support of Governments that should assure the necessary resources to implement these instruments. France allocated 205.5 million euros to fund the third autism plan (2013–2017), additional 18 million euros than the second autism plan.¹⁶⁶ At the launch of the Scottish Strategy for Autism on 2 November 2011, the Minister for Public Health announced that the Scottish Government would provide £13.4 million over four years, until March 2015, to support implementation of the Strategy.¹⁶⁷ Moreover, the Scottish Strategy (2011–2021) recommends that existing studies on the economic costs of autism should be applied to inform the Strategy leading to positive impacts both for individuals and for the economy as a whole (recommendation 5). In Northern Ireland, before the adoption of the Autism Strategy (2013–2020) and its Action Plan (2013–2016), the Government commissioned a report concerning the costs of ASD in order to provide policymakers and public representatives with background financial information on public expenses for ASD.¹⁶⁸ As already mentioned, also in Canada individual members of the Senate requested an inquiry on funding for ASD, an issue linked with the proposal of a national autism strategy.¹⁶⁹

¹⁶⁴ On the implementation of autism plans and strategies see Sect. 8 in this chapter.

¹⁶⁵ See Sect. 8 in this chapter.

¹⁶⁶ <http://www.social-sante.gouv.fr/actualite-presse,42/breves,2325/presentation-du-3eme-plan-autisme,15797.html>.

¹⁶⁷ <http://www.autismstrategyScotland.org.uk/development-fund/autism-development-fund.html>.

¹⁶⁸ See Autism NI-PAPA (2007).

¹⁶⁹ See Sect. 5 in this chapter.

Having a clear picture of autism costs is of paramount importance in the current world economic situation where every public sector is facing budget restrictions and the austerity measures introduced by many European Governments have impacted above all on disabled people and their families. A recent study led by the London School of Economics and Political Science (LSE) published in June 2014 has estimated that autism costs in the United States and United Kingdom. Its results are the following: the cost of supporting an individual with ASD and intellectual disability during his or her lifespan was \$2.4 million in the United States and £1.5 million (US\$2.2 million) in the United Kingdom. The cost of supporting an individual with an ASD without intellectual disability was \$1.4 million in the United States and £0.92 million (US\$1.4 million) in the United Kingdom. The largest cost components for children were special education services and parental productivity loss. During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs. Medical costs were much higher for adults than for children.¹⁷⁰ The conclusions reached through this study are worth mentioning. Researchers have emphasized ‘the need to continue to search for effective interventions that make best use of scarce societal resources. The distribution of economic effect across many different service systems raises questions about coordination of services and sectors. The enormous effect on families also warrants policy attention’.

These are relevant aspects to be considered by States in developing autism plans and strategies. A better coordination of services at national and local level is of paramount importance in order to have more efficient delivery of services for people with ASD and avoid the waste of public money.

10 Conclusions

In the Resolution 67/82 of 19 March 2013, the UNGA recommended to Member States ‘to enhance access to appropriate support services and equal opportunities for inclusion and participation in society by providing, as appropriate, training to public administrators, service providers, carers, caregivers, families and non-professionals on the needs and rights of persons with autism spectrum disorders, developmental disorders and associated disabilities’ (para 1).

At the same time, the UNGA recognized that, in order to develop and implement feasible, effective and sustainable intervention programmes for addressing ASD, developmental disorders and associated disabilities, an innovative, integrated approach would benefit from a focus, *inter alia*, on: (1) increasing public and

¹⁷⁰ See Buescher et al. (2014). The objective of the research was to update estimates of age-specific, direct, indirect, and lifetime societal economic costs, including new findings on indirect costs, such as individual and parental productivity costs, associated with ASD. A synthesis of the results are available at <http://archpedi.jamanetwork.com/article.aspx?articleid=1879723>.

professional awareness of ASD; (2) enhancing and increasing research expertise and service delivery, including through international collaboration, by training researchers, service providers, as well as non-professionals, in early diagnosis and interventions within health and other relevant sectors; (3) enhancing inclusive educational programmes suited to infants, children and adults, with autism; (4) emphasizing the unique needs of each person with autism across a spectrum of different characteristics and experiences; and (5) increasing awareness of the advantages of the inclusion of individuals with ASD in society through occupational and leisure activities.

These recommendations aim at addressing the conducts of Member States towards the inclusion of people with ASD in the different fields of society, with particular emphasize on education and employment, and at improving services to meet their needs. In this perspective, the UNGA's Resolution completes the principles enshrined in the CRPD having regard to the specific needs of people with autism. It is interesting to observe that national autism plans and strategies adopted by the UE Member States that have been examined, in most cases, are consistent with the UNGA's recommendations. Indeed, within these instruments the lifelong needs of people with ASD are met through the recognition of the role of early diagnosis, tailored services and support for individuals with ASD, parents and carers (advice, guidance, information, training, and others); autism awareness; inclusive education, employment and training.

National autism plans and strategies are flexible instruments that address the needs of people with ASD setting out adapted, life-long support and services to enable them to enjoy full inclusion and participation in relevant social fields. In particular, the national autism plans and strategies developed in the United Kingdom which take into account the needs of people with autism from childhood to adulthood are more respondent to the international recommendations and to the rights enshrined in the CRPD whose overall aim is the inclusion and full participation of persons with disabilities in all aspects of life. In this framework, a good practice is the Northern Ireland Autism Strategy (2013–2020) and its Action Plan (2013–2016) modeled on the CRPD which is expressly recalled as a legal source to which the strategic priorities are conformed and an instrument to reinforce the human rights of persons with autism in the domestic legal order.

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