Parliamentary Assembly
Assemblée parlementaire
http://assembly.coe.int

COUNCIL OF EUROPE
CONSEIL DE L'EUROPE

Provisional version
21 October 2020

Committee on Social Affairs, Health and Sustainable Development

Supporting people with autism and their families

Rapporteur: Ms Sevinj Fataliyeva, Azerbaijan, EC/DA

Draft report[1]

I. Draft resolution[2],[3]

1. Autism is a generally life-long disability emerging in early childhood which is estimated to affect 1 to 1.5% of the population. It also strongly impacts the families of the affected. According to the definition advanced by the World Health Organization, autism is 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. Manifestations vary greatly in terms of combinations and levels of severity of symptoms. The neurological differences can involve areas of strength, such as attention to and memory for detail, and pattern-recognition or systemising.

2. Autism can be understood as a natural variation of human diversity, as well as a disability. In any case, it is clear that people with autism need support – and have a right to support – in order to reach their full potential and access their rights. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has brought about a paradigm shift: Article 4 of this Convention requires that "States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability". At European level, the Convention has inspired the Council of Europe's Disability Strategy (2017-2023), which aims at guiding and supporting the work and activities targeted at implementing the CRPD.

3. Unfortunately, people with autism still face widespread stigma, lack of awareness and inadequate support structures, more than 75 years after autism was first diagnosed. All around the world, including in Europe, people with autism clearly have difficulties in accessing their rights, and often suffer from discrimination. Problems abound related to a lack of understanding of autism across the board, by professionals and the general public alike, including: late or incorrect diagnosis, lack of support after diagnosis, difficulties in accessing education, social and health care services, difficult transitions from childhood to adulthood, barriers to getting into and staying in employment, poor mental health and inappropriate practices (such as involuntary placement and treatment in psychiatric wards), problems when interacting with law-enforcement and the justice system.

4. People with autism are frequently excluded, not only from their communities, but also from all debates related to autism. Furthermore, their loved ones systematically carry substantial emotional, economic and care burdens – autism impacts not only the person with the condition, but also their families, so the number of affected people is much higher. The Parliamentary Assembly believes the time has come to make the world more "autism-friendly", and to guarantee full implementation of the rights guaranteed by the CPRD to people with autism, in particular by providing the necessary support to people with autism and their families.

5. The Assembly thus recommends that Council of Europe member States, inspired by good practice examples:

   5.1. adopt specific legislation on autism, as well as national autism strategies and action plans that are in line with the CRPD and take a "whole government", holistic approach, and regularly review and adjust them;

---

[1] Reference to Committee: Reference no. 4374 of 27 April 2018.

[2] ***Amendments agreed to by consensus by the Committee at its meeting on 9 October 2020 are in bold italics font.***

[3] Draft resolution unanimously adopted by the Committee on 21 October 2020.

5.2. involve all stakeholders in policy development, review and implementation, including people with autism and their families;

5.3. stamp out stigma, negative stereotyping and discrimination against people with autism and their families:

5.3.1. by properly training all professionals who come into contact with autistic people and their families, especially in the health, social care and education sectors – ideally by embedding mandatory autism training in the relevant curricula of training (e.g. for social workers, teachers, medical professionals, police officers, legal professionals, etc);

5.3.2. by running effective and evidence-based awareness-raising campaigns on autism amongst the general public;

5.3.3. by paying particular attention to addressing possible intersectional discrimination based on gender, ***gender identity, sexual orientation, ethnic origin,*** minority or migration background, poverty or class;

5.4. provide person-centred and life-long support to people with autism and their families, with a particular emphasis on meeting the needs of children (including in their transition to adulthood), and of people diagnosed in adulthood, including through the establishment of specialist autism teams:

5.4.1. by ensuring that autism diagnosis for children and adults is swift and thorough, with appropriate support offered immediately after diagnosis;

5.4.2. by providing the necessary support in educational settings (including for integration into mainstream schooling if appropriate, ***as well as funding for specialist teachers and facilities***);

5.4.3. by involving parents in the educational and social progress of their child and providing necessary support by way of information and support groups;

5.4.4. by facilitating the transition to adulthood, and getting into and staying in employment;

5.4.5. by paying special attention to the mental health needs of people with autism: ensuring effective and speedy access to mental health services, and adapting mental health treatment to autistic children and adults, while avoiding involuntary measures in psychiatry;

5.4.6. by putting special safeguards in place when autistic people come in contact with the police and/or the justice system;

5.4.7. by providing the necessary social care, including respite care for family carers.

6. The Assembly recognises that people with autism and their families have been heavily and disproportionately affected by measures taken to combat the novel coronavirus in the current pandemic. It thus calls on Council of Europe member States to pay special attention to their needs in these circumstances.

7. The Assembly underlines the importance of the involvement of parliaments, and calls on them to adopt legislation in line with the CRPD, ensure the appropriate budgetary allocation, promote the adoption by governments of appropriate national strategies and action plans, and hold them to account when it comes to their effective implementation. It furthermore encourages them to contribute to awareness-raising efforts.

II. Explanatory memorandum by the Rapporteur, Ms Fataliyeva

1. Introduction

1. In January 2018, my colleague Dame Cheryl Gillan (United Kingdom, EC) and 45 other Assembly members tabled a motion for a resolution on “The treatment of people with autism and their families”.[4] Referring to research indicating that approximately 75 million people could have autism worldwide, the motion stresses the stigma and stark inequalities people with autism continue to face in everyday life, in terms of access to education, employment and public services, as well as within the justice system. It therefore proposes the elaboration of a report recommending to member States ways to increase support to and understanding of people with autism and their families. The motion was referred to our Committee and I was appointed Rapporteur on 28 June 2018.

2. The Secretariat distributed a survey on legislation and practice concerning the support provided to people with autism and their families, through the European Centre for Parliamentary Research and Documentation (ECPRD) network in June 2019. It received 33 replies, from the parliaments of 29 member States and from two observer parliaments.[5] The questionnaire aimed at determining:

- the attitudes and prejudice about people with autism, and inequalities that they face;
- good practice examples to address these inequalities, in particular regarding access to a diagnosis, inclusive education adapted to their needs, employment and person-centred and life-long support;
- possible areas of action to reinforce support for people with autism and their families.

The questionnaire thus included questions on legislation, prevalence and awareness, education, and support to people with autism and their families. The responses received have informed the corresponding chapters in this report.

3. On 30 January 2020, the Committee held a public hearing with experts[6]. A fact-finding visit to the UK was originally foreseen for the end of March but had to be postponed due to the coronavirus epidemic. It took place virtually on 10-11 September 2020 – the first virtual fact-finding visit I have ever undertaken. I would like to extend my sincere thanks to the Secretariat of the UK delegation for organising the visit so well in these difficult circumstances. Particular thanks also go to Dame Cheryl Gillan and Lord Don Touhig, Chair & Vice Chair of the UK All Party Parliamentary Group on Autism (APPGA), as well as to Sir Roger Gale, Chairperson of the delegation, and all the other interlocutors who took the time to speak to me. It was very useful to get different perspectives on the situation in the UK: from fellow parliamentarians, government officials (working in the ministries of education and health), a variety of NGOs, from researchers and academics, people with autism and their families, and professionals working with people with autism and their families. I will be integrating the findings of this visit into the different thematic chapters, since the UK illustrates well which problems can remain even in a country with a lot of good practice.

4. The report was considered by our Committee at its meeting on 9 October 2020, and a revised version (including the amendments agreed to by consensus at that meeting) will be considered by the Committee at its meeting on 21 October 2020, with a view to presenting it to the Standing Committee meeting to be held on 17 November 2020.

2. Autism: an attempt at a definition

5. In 1943, an Austrian-American psychiatrist at Johns Hopkins University School of Medicine (Leo Kanner) described “infantile autism” as a distinct syndrome instead of previous depictions of such children as feeble-minded, retarded, moronic or idiotic. Kanner classified his description of autism as independent from the psychotic disorder, explaining how autism was not a precursor to schizophrenia, and that the symptoms of

---

[4] Doc. 14489.

[5] Albania, Austria, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Ireland, Latvia, Lithuania, Montenegro, Republic of Moldova, the Netherlands, Norway, Poland, Portugal, Romania, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom, Canada and Israel. (Some parliaments are bicameral and thus sent more than one reply).

[6] Mr Daniel Morgan Jones, “The Aspie World”, UK, and Ms Olivia Cattan, “SOS Autisme”, France. The minutes of the hearing are available here: http://www.assembly.coe.int/LifeRay/SOC/Pdf/DocsAndDecs/2020/AS-SOC-2020-PV-01-ADD2-EN.pdf.

the former appeared evident and present at birth[7]. Just one year later, paediatrician Hans Asperger, at the University of Vienna in Austria, wrote an article describing a group of children in his clinic who shared many of the same features, coining the name "autistic psychopathy" for his group of patients.[8]

6. In 1979, Lorna Wing and Jacalyn Gould introduced the concept of autism spectrum disorder (ASD) covering a range of levels and severities, and characterised by qualitative impairments in social interaction, communication, understanding and imagination. Today, ASD is considered to be a complex lifelong developmental disorder which includes symptoms such as intense focus on one item, unresponsiveness, lack of understanding of social cues (like tone of voice or body language), repetitive movements, or self-abusive behaviour like head-banging.[9] Other possible symptoms include learning to speak relatively late, not playing interactively with other children, avoidance of eye contact, lack of empathy, and social withdrawal, dislike of small talk and reliance on routines and rituals, restricted range of activities and interests, aversion to change, perfectionism, dislike of being touched, sensory overload, and co-ordination issues. The severity of the symptoms varies widely among affected individuals. People with autism may be introverted or extroverted. Some of them have an exceptional memory, and many are highly intelligent.[10]

7. For the needs of this report, the understanding of ASD will be based on the definition of the World Health Assembly of the World Health Organization (WHO). Accordingly, the term ASD refers to "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; manifestations of the disorder vary greatly in terms of combinations and levels of severity of symptoms".[11] [12] At the same time, it has to be acknowledged that different autism rights organisations in many countries consider autism more as a natural variation of human diversity rather than as a disease that needs to be cured.[13]

8. During my virtual fact-finding visit to the UK, I was made more aware of the importance of language in describing autism – in particular that the use of the term ASD is often felt to be stigmatising, as it includes the term 'disorder'. The Autism Research Centre at the University of Cambridge explains well why a distinction should be made between the terms 'disability', 'difference', 'disease', and 'disorder'.[14] Autism always entails disability (which is the reason why a diagnosis is needed) and a difference, but these differences can involve areas of strength (e.g., in attention to detail, memory for detail, and pattern-recognition or systemising). The Autistic Research Centre thus does not seek a cure for autism, as it sees autism as a part of a person's genetic make-up, part of their identity as a person, and involving a mix of strengths and challenges. For the same reasons the Centre does not seek to prevent or eradicate autism. However, it does promote evidence-based interventions that target aspects of disability for which the autistic person and their parents are seeking support.[15]

9. So how exactly does autism develop? Research suggests that autism develops from a combination of genetic and nongenetic, or environmental, influences. The experts agree that genetic factors predominate.

---

[7] However, he also described the parents of children with autism as "cold and unemotional types", laying the groundwork for blaming "toxic parenting" as the cause of autism, according to the review by Simon Baron-Cohen of the book "Neutotribes" by Steve Silberman in the Lancet on 3 October 2015: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)00337-2/fulltext.

[8] It appears that Leo Kanner had known of Hans Asperger's work as early as 1938, when the chief diagnostician of Asperger's clinic, Georg Frankl, came to work in Kanner's clinic; the original "discoverer" of autism may thus well have been Asperger rather than Kanner. Asperger was apparently also "half a century ahead of his time in designing a school for the children he saw that suited their differently wired cognitive style, playing to their strengths rather than focusing on their difficulties". Ibid. However, Asperger also seems to have colluded with the Nazis (https://www.autismresearchcentre.com/research/what-is-autism/).

[9] "Autism Spectrum Disorder"*,* National Institute of Mental Health, United States, March 2018. http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml.

[10] "Autism: We are the one percent", Autistic Minority International, http://www.autisticminority.org/autism.

[11] "Comprehensive and coordinated efforts for the management of autism spectrum disorders", Sixty-seventh World Health Assembly, WHA 67.8, World Health Organization, Geneva, 19-24 May 2014.

[12] Research suggests that only 20-30% of autistic individuals also suffer from co-occurring intellectual disability and/or language delay (https://www.autismresearchcentre.com/research/what-is-autism/).

[13] E. Saner*, "*It is not a disease, it is a way of life", The Guardian, August 2007.

[14] https://www.autismresearchcentre.com/research/what-is-autism/

[15] Examples might be psychological interventions such as music or speech therapy, tailored educational approaches, or Lego Therapy for promoting social skills and confidence. The Centre will also evaluate pharmacological treatments that target unwanted symptoms of autism (e.g., epilepsy, gastrointestinal pain, anxiety, or suicidality). Ibid.

The heritability of autism, however, is complex, and it is typically unclear which genes are responsible.[16] In rare cases, autism is strongly associated with diverse birth complications. Many other causes have been proposed, such as childhood immunisations, but numerous epidemiological studies have shown no scientific evidence supporting any link between vaccinations and autism.[17] [18] Behavioural and educational interventions, particularly those that begin in early childhood, lead to positive improvements in children with autism with regard to behavioural problems, acquisition of new skills and greater social integration[19].

10. In January 2008, autism was brought widely to international attention, when the United Nations General Assembly designated 2 April as World Autism Awareness Day.[20] On that day five years later, UN Secretary-General Ban Ki-moon said: “This international attention is essential to address stigma, lack of awareness and inadequate support structures. Now is the time to work for a more inclusive society, highlight the talents of affected people and ensure opportunities for them to realize their potential.”[21] In May 2014, the Sixty-seventh World Health Assembly adopted a resolution entitled “Comprehensive and coordinated efforts for the management of autism spectrum disorders”, which was supported by more than 60 countries. The resolution urges the WHO to collaborate with member States and partner agencies to strengthen national capacities to address ASD and other developmental disorders.[22]

3. Aim and scope of the report

11. All around the world, people with autism clearly have difficulties in accessing their rights. They are often discriminated against and stigmatised, including in health and education services. For example, between 2004 and 2014, France was condemned five times by the Council of Europe for discrimination against people with autism.[23] Almost 80% of children with autism in France do not have access to mainstream education, a situation which the European Committee of Social Rights has repeatedly found to be in violation of the European Social Charter in its decisions taken within the framework of the collective complaints’ procedure.[24] [25]

12. People with autism are frequently excluded, not only from their communities, but also from all debates related to autism. Generally, people with developmental disorders have inadequate access to services and support which are theoretically destined for them. Furthermore, their loved ones systematically carry substantial emotional, economic and care burdens. Although the statistics talk about 75 million people with autism, we should remember that autism impacts not only the person with the condition, but also their families, so the number of affected people is much higher.

13. In all countries, at varying levels, people with autism and their families have similar difficulties in accessing a diagnosis, inclusive education adapted to their needs, employment, person-centred and life-long support, and lack services to assist them in moments of transition throughout their lifespan. 75 years after the first publication regarding autism in its modern sense, we still have not defined a common strategy within Europe. Only few European countries have so far developed specific autism legislation and national strategies. The lack of awareness often leads to late diagnosis and an extensive range in treatment with mostly no evidence of efficacy. While WHO is talking about ASD in terms of an epidemic, there is so far a very poor or non-existing prevalence of this spectrum mainly in low- and middle-income countries. Indeed, the statistics

---

[16] CM. Freitag. The genetics of autistic disorders and its clinical relevance: a review of the literature. *Molecular Psychiatry*. 2007;12(1):2–22.

[17] A. Doja, W. Roberts. Immunizations and autism: a review of the literature. *Canadian Journal of Neurological Sci*ences 2006;33(4):341–346.

[18] The French approach to autism is dominated by a certain school of psychoanalysis. According to this school of thought, autism is considered not as a neuro-developmental disorder but as a “psychologically-generated condition originating in a disturbed family environment – specifically, problems in the child’s relationship to its mother”. R. Bates, France's problem with autism – and its roots in psychoanalysis, The Conversation, April 2018. https://theconversation.com/frances-autism-problem-and-its-roots-in-psychoanalysis-94210.

[19] For an example of a comprehensive overview of evidence-based therapies and supports please see the website of the government of Canada: https://www.canada.ca/en/public-health/services/diseases/autism-spectrum-disorder-asd/support-autism-spectrum-disorder-asd.html

[20] Resolution A/RES/62/139, UN

[21] D. Rochkind, “World Autism Awareness Day: UN urges early interventions for people on autism spectrum”, UN News, April 2013.

[22] See op. cit. footnote 8.

[23] Press release about the fifth verdict against France by the Council of Europe (« Communiqué sur la 5e condamnation de la France par le Conseil de l’Europe »). *Autisme France*.

[24] “Respecting the human rights of persons with psychosocial and intellectual disabilities: an obligation not yet fully understood”, Commissioner for Human Rights of the Council of Europe, Strasbourg, 24 August 2017.

[25] The French system was also severly criticised by Ms Olivia Cattan of “SOS Autisme” during the hearing held in January 2020.

available online show an important disparity in autism rates across the world.[26] It is precisely this disparity in consciousness about autism and access to specialised services that point to the urgent need for a cohesive European autism plan.

14. Growing awareness of autism could lead to higher acceptance, recognition and respect towards those who are concerned. It could also lead to changing the omnipresent strategy of showing people with autism how to be less different from the society, to rather teaching them more self-confidence and how to advocate for themselves. 46 member States of the Council of Europe have ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD)[27]. Article 4 of this Convention requires that "States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability". Similarly, the Council of Europe's new Disability Strategy (2017-2023) aims at guiding and supporting the work and activities targeted at implementing the UNCRPD and carried out by the Council of Europe, its member States and other stakeholders both at national and local levels. The strategy is based on five priority areas: equality and non-discrimination, awareness raising, accessibility, equal recognition before the law and freedom from exploitation, violence and abuse.[28] Moreover, regardless of health condition, everybody has a fundamental right to participate in society just like everyone else. I think this should be our starting point.

15. This report will look at the attitudes and prejudice about people with autism, and inequalities that they face. The report will provide good practice examples to address these inequalities, prejudices and stereotypes, searching for possible areas of action to propose several recommendations to member States on how to better understand people with autism and their families and to reinforce support for them.

4. Legislation, strategies and action plans

16. While most countries have legislation, strategies and action plans to address the needs of persons with disabilities, which also include persons with autism, few countries have specific legislation concerning people with autism:

- **France** included the relevant provisions of its 1996 stand-alone law into new, integrated, legislation in 2005[29];

- **Romania** adopted Law no. 151 on 12 July 2010 on health, education and social specialised integrated services addressed to people with autism spectrum disorders and associated mental health disorders;

- **Slovenia** has legislation governing the education of children with autism;

- the **United Kingdom**'s Autism Act 2009 places a legal duty on the Government in England to publish a strategy on improving support services for adults with autism.

17. During my virtual fact-finding visit to the UK, everybody I spoke with seemed to agree that adopting specific legislation (the Autism Act) in 2009 really spurred on developments and led to more accountability, without politicising the subject. Specific legislation does not have to be comprehensive – indeed, the Autism Act only puts the onus on the government to develop a national autism strategy – but it puts a spotlight on the subject and thus can get different parts of government moving together towards the same goal in a co-ordinated way, through a specific strategy or action plan.

18. More countries have developed specific strategies or action plans addressing the needs of people with autism:

- **Croatia** has put in place a national framework for screening and diagnostics of ASD in children from 0 to 7 years;

---

[26] R. Charron, Autism Rates across the Developed World, Focus for Health, https://www.focusforhealth.org/autism-rates-across-the-developed-world/.

[27] All Council of Europe member States with the exception of Liechtenstein.

[28] Human rights: a reality for all - Council of Europe Disability Strategy 2017-2023, Council of Europe.

[29] French law n° 2005-102 (11 February 2005), within title IV "Handicapped individuals" of the Social Action and Family Code (CASF), includes a chapter (VI) on "Persons suffering from autism spectrum disorder", of which article L. 246-1 stipulates: "Any person who is handicapped due to autism spectrum disorder and the difficulties which the disorder entails is entitled to multidisciplinary care which takes into account his or her specific needs and challenges, whatever his or her age. Adapted to the condition and the age of the person, this care may be educational, pedagogical, therapeutic and social. The same applies to persons suffering from multiple handicaps."

- in **Cyprus**, the Ministries concerned have drawn up an action plan establishing a Centre for Family Intervention and Support of Persons with Autism, to address the needs of 300 children with autism and their families that include, among other, psychological support services and counselling, home schooling and educational support services as well as social support services;

- the **Czech Republic** is preparing a new strategy, following the "Initiative to solve the situation of life of people with autism and their families", a document which detailed problems and suggested solutions, including in the area of education of the public, early screening, diagnostics, therapies, financial help assessment, education, social services, employment, crisis situation and statistics;

- in **France**, the government elaborates four-year national strategies (the current, fourth, one runs from 2018 to 2022, with a 344 million Euro budget)[30];

- in **Germany**, the state (*Land*) of Bavaria has started a project to design a specific strategy[31];

- in **Lithuania**, there is an action plan 2019–2020 to help children which have a diagnosis of autism or other developmental disorders. This plan was approved on April 25, 2018, by joint order of three ministers – minister of health, minister of education, science and sport, minister of social security and labour. The purpose of the plan is to provide high quality, systemic, complex and integrative health care, social assistance and inclusive education for children with an autism diagnosis[32];

- in the **Republic of Moldova**, by Government Decision No. 234 of 24.04.2019, the state approved the Framework Regulation on the Organisation and Functioning of the Specialised Center for Intervention in Autism Spectrum Disorders and the Minimum Quality Standard;

- in the **Netherlands**, the Youth Health Care Directive Autism (2015)[33] includes the consultative offices and GGDs and can play an important role in the early recognition of autism spectrum disorders; the Guidelines for the diagnosis and treatment of ASD in children and adolescents (2009)[34] are nationally applicable, and give an optimal description of the best possible care for children and adolescents with a (suspected) autism spectrum disorder, intended to support caregivers in clinical decision making;

- in **Romania**, the Minister of Health approved the Methodological Norms for the implementation of the 2010 Law in August 2016. The National Programme of Mental Health and Prophylaxis in Psychiatric Pathology includes, from June 2019, two subprogrammes:
    - increasing the level of skills of specialists working with people with autism spectrum disorders and associated mental health disorders and the quality of medical services provided to them;
    - increasing the level of skills and knowledge of parents and families of people with autism spectrum disorders and associated mental health disorders;

- in **Slovenia**, the Ministry of Labour, Family, Social affairs and Equal Opportunities issued a by-law according to which parents of children with autism are entitled to child-care allowances;

- in **Spain**, in 2015, the Ministry of Health, Consumption and Social Welfare issued the Spanish Strategy on Autism Spectrum Disorders. This strategy is the frame of reference in the definition of state, autonomous and local policies and actions on people with autism spectrum disorders. The work plans and the objectives set out in the Strategy are aimed at promoting respect for independent living, autonomy, full participation and inclusion, equality, accessibility and non-discrimination. These plans constitute the essential support to improve social inclusion, quality of life and protection of the rights of people with autism spectrum disorders. In this sense, the Strategy contemplates fifteen strategic plans[35]

---

[30] https://handicap.gouv.fr/archives/ancienne-rub-autism/strategie-nationale-pour-l-autisme-2018-2022/

[31] https://www.stmas.bayern.de/aktuelle-meldungen/pm1806-440.php

[32] Amongst the measures envisaged are: strengthening diagnostics, setting up the department at the Center for the Blind and Visually Impaired for autistic children's consultations and methodical help, as well as enhancing supply and delivery of technical equipment for providers of specialised education. The plan also foresees further development of social day care services for autistic children and assistance for their families. It is intended to carry out projects to promote public tolerance towards peoples with autism.

[33] Jeugdgezondheidszorg richtlijn autisme (2015)

[34] Richtlijn diagnostiek en behandeling ASS bij kinderen en jeugdigen (2009)

[35] Four of the plans are transversal. They are dedicated to awareness-raising, seeking to favour the inclusion of people with ASD and to promote a positive and real image of their abilities; to accessibility, which aims above all to reduce difficulties in understanding information; to research, favouring the co-ordination of resources, development, innovation and the transfer of knowledge; and to the training of professionals who intervene in the entire life course of people with

with defined objectives that will serve as a guide for the development of concrete measures. For the implementation of the Strategy, an Action Plan will be drawn up, containing the specific measures and actions to meet the objectives, the agents involved in its implementation, the calendar of actions to be developed, the necessary resources for the development of the actions and a method of evaluation by means of indicators;

- in **Switzerland**, in October 2018, the Federal Council (the Swiss government) adopted a strategy to help people with autism spectrum disorders (ASD) to complete vocational training. At its meeting on 17 October 2018, the Federal Council approved a report that provides various measures for the strategy. The Federal Council intends to support people with autism spectrum disorders to help them to play the fullest possible role in society. It also identified three priority areas: early detection and diagnosis, consultation and co-ordination, and early intervention[36]. In this context, a pilot test (2019-2022) was launched for intensive early intervention for children with infantile autism;

- in **Turkey**, there is a “National Action Plan For Individuals That Have Autism Spectrum Disorders (2016-2019)”, and there is also a “Regulation on Special Education Services”;

- in the **United Kingdom**, the first Autism strategy, Fulfilling and rewarding lives, was published in 2010 and provided a framework for public sector services working with adults with autism. An updated Autism strategy, Think Autism, was published in 2014, building on the 2010 strategy; a new one is expected to be published soon, which will include a focus on children as well as adults with autism;

- in **Israel**, in 2013, the Cabinet approved the appointment of an inter-ministerial team to deal with the treatment of individuals with autism in Israel. The aim of the team was to formulate recommendations on defining and meeting the main needs of individuals with autism – and their families – in Israel.

19. I would like to underline that the involvement of all stakeholders, including people with autism and their families, in policy design and implementation was seen as a strength in the UK. People with autism and their families know best what their needs are and can draw attention to the areas which are most in need of improvement. This is why it is important that strategies and action plans are revised regularly, and that the opinion of people with autism and their families is sought also at the evaluation stage.[37]

5. Prevalence, diagnosis, awareness and understanding

20. 15 of the countries who replied to the ECPRD questionnaire have statistics on the prevalence of people with autism in the population: The average overall was situated between 1 and 1.5% of the population.

21. Only a few countries were able to indicate an average age of diagnosis. In Cyprus, France and Georgia, it is estimated at before the child reaches the age of 3. In Norway, the average age of diagnosis is 4,9 years, while in Croatia, it is between 5 and 7 years. In Hungary, even though there is no official information or data, research undertaken in 2009 by the National Autism Society shows that, despite early indication by parents, only 11% of autistic children have been diagnosed before the age of 3 and 40% aren’t diagnosed until after they are 5 years old. In Canada, 59% of children are diagnosed before the age of 6, and 72% before the age of 8.

22. Many of my interlocutors in the UK stressed the importance of early diagnosis. Unfortunately, in many countries, the time lag between first suspicions occurring and formal diagnosis (which, in turn, opens up access to relevant support services), can be several years. Indeed, insufficient training of professionals – for example, in the education and medical field – can lead to children being misdiagnosed or expelled from school. Older adults may find it particularly hard to get diagnosed. We took evidence from one person with autism for whom

---

autism. The remaining eleven strategic plans deal with health, with proposals that favour the early detection of ASDs, access to a diagnosis and specialised comprehensive interventions, as well as early advice and care after confirmation of the diagnosis. In the educational field, objectives are to promote school inclusion and educational success of students with ASD through specialisation, innovation and flexibility of schooling modalities throughout all stages of life. With regard to employment, measures include strengthening employment guidance services and facilitating both private and public employment. In the area of social inclusion, participation and independent living, providing resources for adult life, services for the promotion of personal autonomy, improvement of the associative fabric, support for families and access for people with ASD to community resources are aimed at. And finally, there are proposals that promote justice and the empowerment of rights or the consolidation of the quality, equity and sustainability of the support provided.

[36] https://www.admin.ch/gov/fr/accueil/documentation/communiques.msg-id-72537.html

[37] This was done, for example, by the UK All Party Parliamentary Group on Autism, whose 2019 report “The Autism Act, 10 Years on” is an excellent resource which includes findings as well as recommendations (https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf).

the diagnosis (in her late thirties) was eye-opening and explained many of the problems she had faced. Girls may also find it particularly difficult to be diagnosed and are often misdiagnosed with depression or anxiety.

23. Intersectional discrimination is another flashpoint. We took evidence from one mother from a minority background who explained that she had simply not been taken seriously by professionals when she sought a diagnosis for her child, and was instead "talked down to" – as if her parenting skills had been at fault, and responsible for her child's autistic behaviour. Negative stereotyping of single mothers, people with a minority or migrant background, or on the basis of gender, gender identity, sexual orientation, ethnic origin, poverty or class, can also make it more difficult to access diagnostic and support services. In addition, awareness and understanding of autism can also lag in minority communities, creating a vicious circle of families not asking nor being offered any help.

24. Most countries organise awareness-raising activities on autism, especially on the occasion of World Autism Awareness Day (2 April). These activities are organised by the governments themselves, organisations and NGOs, social associations, educational institutions, universities or health-care providers, or at professional conferences. However, as I have already pointed out, autism is still often misunderstood by the general public and by professionals alike. Though, for example, polling from the National Autistic Society in the UK in 2015 suggests that 99.5% of people have heard of autism, just 16% of autistic people and their families feel the public understands what it means to be autistic.[38] I believe the time has thus come to move from awareness-raising to promoting real understanding – by the general public, and by professionals.

25. Most countries organise training for kindergarten and schoolteachers to spot signs of autism in children. This training can be specialised classes during future teachers' education (Austria, Germany and Hungary) or organised from time to time afterwards by other organisations specialised in autism (Estonia, Germany, Ireland, Lithuania and the Netherlands), and also includes guides which are available on-line (Cyprus and France). In Ireland, teachers are encouraged and supported by the government to attend training courses which are not mandatory. In the Netherlands, there are continuing education projects for teachers, in accordance with the new Inclusive Education Act (*Wet Passend Onderwijs*), since the passage of which more children with autism frequent regular primary education.

26. Training professionals who interact with autistic people (in particular, those who interact with autistic children) is key. In the UK, professionals who have not been adequately trained to understand autism are one of the key concerns raised by autistic people, as reported to me during my virtual fact-finding visit. This should come as no surprise, since the consequences of such misunderstanding can be misassessing – a particular concern when it comes to access to education, health care, social services, or benefits. Such misunderstanding by a police officer offer or a judge can lead to even graver consequences, such as unwarranted arrest, pre-trial detention or even prison time. Misassessment by medical personnel can also lead to unwarranted sectioning and involuntary psychiatric placement and treatment. It is relatively easy to avoid these human rights violations by adequately training professionals, ideally by embedding autism training in the relevant curricula of training (e.g. for social workers, teachers, medical professionals, police officers, legal professionals, etc).

27. I have received an interesting briefing note on the intersecting issues of autism and lesbian, gay, bisexual, transgender, and intersex experiences comprised of inputs from 10 organisations in Europe[39]. According to the submission, this intersection bears unique challenges for LGBTI people with autism, including social isolation, limitations in access to medical care, and ableism in LGBTI communities. I must admit that I was unaware that some studies indicate that there is an increased co-occurrence of the two experiences compared to the general population[40]. I would thus agree with one of the conclusions of the briefing note, that it is important to develop awareness and build bridges between LGBTI and autistic communities, in particular amongst young people, but also to raise awareness in the general population about these facts.

6. Education

28. Almost all countries which replied to the questionnaire indicated that people with autism are included in mainstream schools. The decision to include people with autism in mainstream schools can be made on a case-by-case basis (Austria and Latvia) or can depend on the severity of the condition, as well as on the parents' preferences (Estonia). Furthermore, in three countries, people with autism are generally integrated in

---

[38] UK All Party Parliamentary Group on Autism report "The Autism Act, 10 Years on", p. 8 (https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf).

[39] Including four autism organisations, five LGBTI organisations, and one LGBTI and autism organisation.

[40] For example, one study found that children with autism were four times as likely as the general population to experience gender dysphoria: Elizabeth Hisle-Gorman, Corinne A. Landis, Apryl Susi, Natasha A. Schvey, Gregory H. Gorman, Cade M. Nylund, and David A. Klein, LGBT Health, April 2019. Available from http://doi.org/10.1089/lgbt.2018.0252

mainstream education, unless they have severe mental retardation (Finland, France and the Netherlands). Most countries also have special education programmes for people with autism. In the UK, about 70% of autistic children are integrated into mainstream schools, while 30% go to special education schools.[41]

29. In most countries, teachers can receive training to teach children with autism, but they are generally not mandatory. For example, in Austria, there is an emphasis on inclusive teaching in kindergarten and schools, and thus also further training available to improve teachers' competencies and skills in dealing with autistic pupils. Similarly, in Finland, integrated learning is promoted, so that only severely autistic pupils, who often also have severe mental retardation, study in special groups. In France, the new national strategy priorities early intervention (in early childhood), better integration of both children and adults in society, and inclusive, integrated education. In the UK, initial basic teacher training has included a module on autism since 2018, and a further 150.000 teachers have been trained while on the job by the voluntary sector.

30. In Ireland, early intervention ASD classes are funded, and funding is provided for teachers to receive training in specific interventions for students with ASD. In addition, a home tuition scheme is funded for younger children with ASD from 2.5 – 3 years, and for those children with ASD awaiting a place in a special class or school if this is needed[42]. Special needs assistants are allocated to primary, post-primary and special schools to support students with a disability who also have significant care needs. The National Council for Special Education produces a guide for Supporting Students with Autism Spectrum in Schools (for parents). It also compiles resources for schools related to autism for the purpose of awareness raising, as well as compiles a Continuing Professional Development resources and training for teachers directly related to autism.

31. In Montenegro, inclusive education in mainstream schools is supported by resource centres (including Early Development Centres) which provide advice and expertise; teacher training and training of expert assistants to work with children with special needs in education; use of sign language; preparation, adaptation, design and training on the use of specialised textbooks and other specialised teaching aids. Further good practice examples regarding education come from Slovakia, Slovenia, Poland and Portugal.

32. However, delivering the inclusive and integrated education aimed at *de facto* seems to remain a challenge in many countries. Thus, for example, even in Israel – which is generally recognised as a good practice example – in 2018, only about one-third of pupils with autism were integrated into mainstream schools. In Hungary, the Commissioner for Fundamental Rights, in his 2017 report[43], drew attention to the need for integrative and tailor-made kindergarten education of special needs children and disclosed instances of negligence and practices that violate the law in the access to education of children with special needs, i.e. a lack of experts and the impossibility of such children to get to the school[44]. While it is often clear what needs to be done[45], lack of financial and human resources, late diagnosis, or unclear responsibilities, can hinder effective access of autistic children to the educational services they need and are entitled to. It often seems to require the involvement of independent institutions such as Ombudspersons to remedy shortcomings.

33. Innovative solutions have been found by some countries, which are increasingly turning to ICT tools to help deliver educational or other services to people on the autism spectrum. For example, Hungary is running the so-called DATA project (Digital Autonomy-Support on the autistic spectrum), targeting social integration of people with autism, until 31 December 2020, whose aim is to develop a mobile application which helps persons with autism in their everyday life.

34. The effect of the Covid-19 pandemic on education access for autistic children has been mixed. While in the UK, for example, most schools stayed open for children with recognised special needs, this was not the case for all schools (including some specialist schools for children with autism, at least one of which never

---

[41] It was interesting to learn from Alison Worsley, of Ambitious about Autism (UK), that the two specialist schools for autistic children run by the organisation are very different: one serves children with complex needs and learning disabilities, while the other takes in academically able children who have been excluded from mainstream education (usually because of behavioural issues).

[42] It should be noted that while a presumption in favour of including students with special educational needs in mainstream education is enshrined in Irish legislation, these students are served by a continuum of provision ranging from full-time enrolment in mainstream classes to full-time enrolment in special schools, with a variety of options in between.

[43] https://www.ajbh.hu/documents/10180/2811425/AJBH+beszámoló+2017/60b3d968-ac8e-d28e-058b-64d0eb7e6d69?version=1.2

[44] In his 2015 report, the Commissioner had come to the conclusion that the psycho-diagnostic, pedagogical diagnostic preparedness of expert committees with regard to autism spectrum disorder was not always satisfactory. The Commissioner declared himself satisfied with the measures proposed by the State Secretary for Higher Education to remedy the shortcomings identified (e.g. extending the Klebelsberg Scholarship to special education teachers, and shortening procedural deadlines which were dragging out procedures to the detriment of the children concerned).

[45] See, for example, in Hungary, the 2016 Recommendation to the special basic services provided to persons living with autism in the field of public education, minimum and optimal conditions to its function.

reopened). Many autistic children also suffer from co-morbidities and thus had to shield at home, even if their schools could have received them. On the one hand, many autistic children find routine incredibly important, and thus very much missed school, and became very anxious and difficult to care for. On the other hand, some autistic children found it easier to engage virtually rather than face-to-face. In all cases, however, it appears that the added burden on families was enormous.

7. Employment

35. Getting (and staying in) a job is an important milestone for all adolescents in their transition to adulthood. While it is estimated that 20 to 30% of autistic people would not be able to get a job on the labour market due to intellectual and language disabilities, the labour force participation of the other 70% to 80% is very low, as well. In France, only about 1% of autistic persons are employed, and in the UK, on the tenth anniversary of the National Autism Act in 2019, there were still some 85% of autism-affected persons who could never get a job.[46] As Mr Jones confirmed during our hearing in January 2020, getting a full-time job was a tremendous challenge for an autistic person (even for a university graduate such as himself). Some would pass interviews successfully and face refusals once on the job.

36. To fill the gap between working and not working, both autistic persons and potential employers need specialised training, and possibly matching up and accompanying during the first months. Another possibility is to encourage the certification of virtuous employers. Good practices include the example of *“Specialisterne”*, which is a social enterprise that began in Denmark and has been active in Austria since 2011. It is specialised in preparing people from the autism spectrum for suitable jobs, using a mixture of training, coaching, and support measures[47]. Similarly, Finland ran a career opportunities project for people with partial work ability (2016-2018), and Switzerland developed a strategy in 2018 to help persons with autism complete vocational training. Hungary has been contemplating classifying the refusal to meet the requirement of reasonable accommodation of a disability as a form of discrimination.

37. As Lord Touhig rightly reminded me, employment opportunities for autistic people should also be created by the state, not just the private sector.

8. Support to people with autism and their families

38. All countries which answered the ECPRD questionnaire provide some kind of assistance to people with autism and their families, ranging from financial aid and support programmes to practical assistance (e.g. to find employment or in moments of transition throughout their lifespan) and respite care for family carers[48]. However, such social support services have been severely stretched – sometimes up to breaking point – during the current pandemic of the novel coronavirus.

39. It is important to recognise the extreme burden caring for an autistic child can put on family members, in particular mothers (who are often the ones left “holding the baby”). When a child suffers from a developmental problem co-occurring with autism, his or her parents are much more likely to suffer psychological distress. Every study measuring the health of mothers of autistic children has shown that they suffer from very high levels of stress, distress and depression; these levels vary from 50% to 80%, rates higher than those seen in the parents of children suffering from conditions such as down syndrome or cerebral palsy.[49] For many families, dealing with distressed behaviour by autistic children is their top challenge.[50]

---

[46] See the minutes of the hearing held on 30 January 2020.

[47] *“Specialisterne”* has a success rate of 90%, as it recognises and helps develop the strengths of a particular group of people with disabilities (those with ASD) that struggle in the labour market. It takes targeted and personalised measures to make these individuals job-ready, and coaches firms to implement inclusive structures and processes within their organisation. It connects individuals and firms, utilising a long-term follow-up strategy to ensure that both parties are a good match for each other. It caters to candidates with different needs, offering gainful employment in an alternative setting with extra flexibility. It represents a highly cost-effective measure to empower long-term unemployed people with ASD to (re)enter the labour market.

[48] In addition, in Hungary, employees who have children with disabilities are entitled to extra vacation time (two working days per child) and to unpaid leave for providing care for a relative during any extended period. In the Slovak Republic, employees have the right to prolonged parental leave of 3 to 6 years. In Ireland, support includes additional allowances, school transport and parking cards.

[49] There are many publications on this issue, in particular in Canada (Québec).

[50] According to a recent survey of 12.000 autistic people and their families by the UK National Autistic Society, as cited by Ms Jane Harris.

40. The burden on families can also include financial stressors: In France, for example, most support for autistic persons is only partially covered by the public system (with only speech therapy fully covered), and much of the necessary support is not covered at all. Some families with autistic children are reported to have out-of-pocket expenditure for specialised services totaling over €3000 per month.[51] Many of our interlocutors in the UK also stressed the need for better access to social care, as well as earlier diagnosis and support. One often heard complaint was that families had to “fight” for everything, also because resources were so scarce, they were only deployed when crisis-point had been reached.

41. Making the world more “autism-friendly” in general is also an often-heard wish. As explained by Mr Jones during the hearing, autism usually involves a sensory processing disorder whereby some ordinary sounds and smells overwhelm the persons concerned. Crowds can lead to a sense of oppression, which make it difficult for some autistic persons to travel, to shop, or impair their ability to work or access public services. Many places are adapted to serving persons with physical disabilities, but hardly anything is foreseen for those with enhanced mental needs, such as in the case of autism. In the UK, a street-project of a “sunflower lanyard” has been put in place to foster public awareness and assistance to autistic persons, in order to help autistic people navigate airports, for example.[52]

42. The global coronavirus pandemic has hit the UK particularly hard and has disrupted many support services for autistic people in the country. In addition to disruption in the education sector (see above), health-care routines have suffered, and appointments have had to be cancelled – leading to longer waiting times for a diagnosis, for support after a diagnosis, or for mental health needs made acute by the crisis. Public transport is difficult to use for autistic people at the best of times, and can be even more of an issue during the pandemic. As the National Autistic Society in the UK has pointed out, autistic people and their families have been heavily and disproportionately affected by measures taken to combat the virus.[53] While the coronavirus outbreak and ensuing lockdowns/shutdowns changed everyone’s lives and daily routines, it has led to many autistic people and their families feeling “completely stranded”.[54] This is likely to be the case not just in the UK, but everywhere the coronavirus hit this year.

9. Mental health

43. The importance of properly training mental health professionals in contact with autistic people cannot be overstated. I have already mentioned the risk of misdiagnosis of autism versus mental health conditions in a previous chapter. Just because someone is autistic, however, does not need mean that he or she cannot develop a mental health condition, such as depression or anxiety – on the contrary, research suggests that up to 70-80% of autistic people will need mental health support at one point in their lives.[55] Indeed, the higher rates of suicide of autistic people versus the general public are testimony to the fact that it is often difficult for people with autism to access mental health services on time[56] [57]. It is also important to adapt mental health treatments to the needs of autistic children and adults – thus, for example, “talking therapy” or group therapy can be difficult for people with autism.

44. This Assembly has already taken a strong stand twice in recent years against the involuntary placement and treatment in psychiatry of people with disabilities.[58] My colleague Reina de Bruijn-Wezeman (Netherlands, ALDE) has just started working on a new report to promote deinstitutionalisation of persons with disabilities.[59] In too many countries, too many autistic people end up unnecessarily in inpatient mental healthcare, often against their and their families’ will. The UK APPGA report (2019) describes well the dilemma autistic people and their families face: “So, when people ask for mental health support early on, they are too

---

[51] See the minutes of the hearing held on 30 January 2020.

[52] Ibid.

[53] See the report by the National Autistic Society of September 2020 entitled “Left stranded”, and evidence submitted to the Joint Committee on Human Rights of the UK parliament, both accessible here: https://www.autism.org.uk/what-we-do/news/coronavirus-new-parliamentary-report-highlights.

[54] Ibid.

[55] Ms Antonia Williams, Department of Health (UK).

[56] 82% of autistic adults and 86% of families told the UK APPGA in 2019 that the process of getting support from mental health services took too long. https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf, p. 28.

[57] Ms Georgia Harper, of Autistica (UK), cited research in Sweden and the UK which shows that autistic people are seven times more likely to commit suicide than non-autistic people (with more women and girls committing suicide than men and boys, in inverse relation to non-autistic people).

[58] Recommendation 2158 (2019) on Ending coercion in mental health: the need for a human rights-based approach, and Recommendation 2091 (2016) on The case against a Council of Europe legal instrument on involuntary measures in psychiatry.

[59] Motion for a resolution, Doc. 15106, Deinstitutionalisation of persons with disabilities.

often turned away because they are autistic. But equally when people do not require mental health services, many are forced into them – also because they are autistic."[60]

45. Again, the coronavirus pandemic seems to have exacerbated problems: The impact on people with autism living in care homes who have been separated from their families and subject to blanket visiting bans can be devastating, and affect both their mental health and their emotional wellbeing in a particularly acute manner. The closure of mental health hospitals to the outside world during the pandemic also increases the risk of people's human rights being breached.[61] It follows that countries should pay special attention to the mental health needs of people with autism, in particular in pandemic times: ensuring effective and speedy access to mental health services, and adapting mental health treatment to autistic children and adults, while avoiding involuntary measures in psychiatry in the first place.

10. Law-enforcement and the justice system

46. To cite my British parliamentary colleague Anne-Marie Trevelyan: "The vast majority of autistic people are law abiding citizens. In spite of this, autistic people may come into contact with the justice system for a number of reasons, as a victim, a witness or defendant. Some autistic people may be more vulnerable to criminal acts against them or become unwitting accomplices to criminal activity. Whichever of these situations apply, autistic people have a right to be understood by the justice system."[62]

47. Interactions with law-enforcement and the justice system are anxiety-inducing for neurotypical people, as well, but for autistic people, they are even more so. This can lead to grave miscarriages of justice. Unfortunately, it appears that awareness of the problem is underdeveloped in Europe – and even countries which are aware of the problem, such as the UK, are having difficulties addressing it. It comes back to a basic misunderstanding of autism – which could be rectified, it is hoped, by mandatory autism training for law enforcement officials and legal professionals.

11. Conclusions and recommendations

48. While working on this report, I realised how much society in general is still influenced by stereotypes of people with autism. Discrimination based on these stereotypes is still very widespread, as well. Even politicians sometimes feel challenged by the way people with autism can view and communicate with the world, as is evident from the reaction of some politicians to Greta Thunberg, who first became known for child activism in August 2018 when, at age 15, she began spending her school days outside the Swedish parliament to call for stronger action on climate change. In fact, the voices of many children with autism are not heard at all; if at all, their parents speak for them. Even associations of adult persons with autism seem to be few and far between[63]. In this context, it is important that people with autism are seen as individuals with individual needs (and, I would add, individual rights) instead of just in need of a diagnosis, as important as a diagnosis is[64].

49. I was also struck by the fact that the views of how well the state is providing for persons with autism and supporting their families varies considerably, depending on whether you ask this question of associations of persons with autism and their families, NGOs, governments, parliaments, or other organisations (such as international organisations, professional organisations, etc.). Thus, for example, in the Slovak Republic – like in most countries – organisations of parents and the non-governmental sector have repeatedly voiced dissatisfaction with the role and support from the state. While the legislation currently discussed in the Slovakian parliament reflects some of these concerns, it is felt that not all of them are being addressed.

50. The petition "For the Resolution of everyday problems of people with autism" with more than 12,000 signatures (which was addressed to the Prime Minister, the Ministry of Education as well as the Ministry of Social Affairs and Family of the Slovak Republic in June 2019) is emblematic in this respect. It included eight requests for improvements which, I believe, could have come from every other state, as well: concerning early

---

[60] https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf, p. 28.

[61] In the UK, according to the judgment of the parliamentary Joint Committee on Human Rights, unlawful blanket bans on visits were put in place, routine inspections were suspended, and there was increased use of restraint and solitary confinement, creating "a severe crisis". See the summary of findings by the National Autistic Society: https://www.autism.org.uk/what-we-do/news/coronavirus-new-parliamentary-report-highlights.

[62] Ibid, p. 46.

[63] In the Netherlands, there exists and an independent interest group, "People from the Autism Spectrum", PAS for short, that puts the perspective of the person with autism first, as the members are autistic and view the world from the autism spectrum. https://www.pasnederland.nl/

[64] I was impressed by the way Finland has based its provision of services on this requirement, supporting independent living in the community and strengthening the "functional capacities" of the person, and designing a service plan for each individual person based on an evaluation of his/her needs.

diagnosis of autism; state co-ordinated care from childhood to adulthood; better integration into the education system; available experts on autism within the educational system; education of parents, teachers and assistants; change of educational programs to include the topic of autism; improvement of legal and financial conditions for providers of social care to people with autism; improvement of available capacities of providers of social services; improved availability of social services for people with autism and their families (including respite care for family carers)[65].

51. While I have been in a position to highlight several examples of good practice in this report, it has to be acknowledged that problems – of different severity – do remain in most member states, and these need to be recognised and addressed. I have based my recommendations to member states on the examples of good practice, as these clearly show that, where there is a will, there is a way to properly support people with autism and their families. The good practice example of the UK has convinced me that taking a "whole government", holistic approach, which brings together all stakeholders (including people with autism and their families) is crucial to success.

52. I would also underline the importance of the involvement of parliaments, which can adopt legislation as necessary – in line with the CPRD – and allocate the necessary budgetary resources, but can also promote the adoption by governments of appropriate national strategies and action plans, and hold them to account when it comes to their effective implementation – as well as, of course, contribute to awareness-raising and even research efforts[66].

53. One statistic which struck a particular chord with me was that research shows that autistic people are seven times more likely to suffer from loneliness than other people.[67] Often, they fear that if they go out, they will be judged. This is something which we can all influence: we do not need to wait for legislation to be adopted, or governments to devise national strategies and action plans, to go out ourselves and get ourselves educated to understand autism better, and make our world more "autism-friendly", one person at a time.

---

[65] The text of the petition (in the Slovak language) is available here: http://www.changenet.sk/?section=kampane&x=1037402&fbclid=IwAR0uf5JU5eXcB1Bj0jAqKR7eKojH20go9gD7q0wPPKH-oP0NnISfh-sXIVI

[66] The Grand National Assembly of Turkey took the innovative step, in May 2019, of establishing a parliamentary research committee to determine the prevalence of people with autism, those with down syndrome and other developmental disorders, and to specify the measures to be taken to resolve their problem and those of their families. A conference on "Autism in Lithuania" was held at the Seimas on the occasion of World Autism Day in April 2019.

[67] Research cited by Ms Georgia Harper, of Autistica (UK).