

Autism-Europe's response to the European Observatory on Health Systems and Policies' survey on health priorities for the EU ahead of the new European Commission

Consultation feedback – March 2024

Question 1 – Enhancing health security

What is it about? Ensuring protection of people's health through prevention of, detection of, and response against threats or events that could harm it, including (re-) emerging infectious diseases, bioterrorism and natural disasters.

The Covid-19 pandemic exposed numerous problems in how healthcare systems manage crises. This is particularly relevant for persons with disabilities, including persons on the autism spectrum. Learning from Autism-Europe's report on the impact of Covid 19 on autistic people, we have the following recommendations:

1. Ensure access to information on healthcare services and related issues (prevention, detection, response) in Easy-to-read format.
2. Ensure effective non-discrimination measures are in place across the healthcare system, including in intensive care and triage.
3. Ensure training of staff and the creation of specialist units targeted towards people on the autism spectrum. This will better equip medical personnel to assist autistic people.
4. Ensure that any public strategy for managing a healthcare crisis is inclusive of persons with disabilities and is informed by their perspective.
5. Provide clear guidance on how people can access reasonable accommodations in health care situations.
6. Ensure that response protocols to healthcare crises include provisions that continue mental health services for people with disabilities, including autistic people.

As [indicated by Mental Health Europe](#) (MHE), mental health should be an integral part of health security preparedness. 62% of EU citizens think that recent world events (the Covid-19 pandemic, the Russian aggression against Ukraine, the climate crisis, unemployment, and the food and energy costs) 'somewhat' or 'greatly' affected their mental health. Mental health should be an integral part of the future health security plans of the EU.

Question 2 - Addressing the determinants of health through Health in All Policies and Health for All Policies

What is it about? Adopting systematic approaches that direct policies towards health and maximise efforts to promote (or at least) avoid damaging health (Health in All Policies), as well as highlighting ways, in which health can contribute to other agendas (Health for All Policies)

Policies in different areas can impact positively on mental health by strengthening protective factors and mitigating risk factors. The consideration for health should be a primary focus across sectors. Accessibility should remain a key priority for policies across Europe that regard not only healthcare, but also social services, education, employment, travel, leisure, etc. Universal design should inform how spaces cater to the needs of society as a whole, considering how to minimise or avoid health risks in all environments. In this regard, proxemics and processes in all settings should be designed with accessibility in mind. Similarly, measures that promote inclusion and accommodations for people with disabilities in education, employment, travel, leisure, etc. should be implemented, as they impact directly and indirectly on the mental and physical health of the population. All of these measures should be implemented in line with the UN Convention on the Rights of People with Disabilities, ratified by all EU member States and the EU itself.

Question 3 - Supporting health system transformation

What is it about? Transforming health systems to meet new challenges and rising demands, which may require implementing different types of innovations. This process can be facilitated by supportive framework conditions, including targeted resources, political commitment, and sustained investment.

Research has shown that the prevalence of autism is between 1-2%¹ and it has currently increased in recent years due to better awareness and changes in diagnostic criteria. All over Europe, there are lengthy delays to receive an autism diagnosis, which is necessary in order to access specialist services. Additionally, recent European, American, and British research (such as the 2023 UK study in *The Lancet Regional Health – Europe*) confirms that autistic people have a lower life expectancy than the general population. This can be due in part to a lack of accessibility in healthcare services (such as a lack of accommodations for the sensory and communication needs of autistic people), which can result in conditions being undiagnosed or misdiagnosed. Research has also shown that over 70% of autistic people have a co-occurring mental health condition, such as depression, anxiety, ADHD, etc.²

Healthcare systems should therefore:

- Provide systematic and comprehensive training to healthcare professionals on autism.

¹ Autism Research Centre, University of Cambridge

² Meng-Chuan Lai et al., "Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis," *The Lancet Psychiatry* 6, no. 10 (2019)

- Ensure the development, availability, affordability, and quality of specialist services for autistic people with sustained and earmarked funding in order to respond to the specific diagnostic and support needs of the autistic population, including comprehensive mental health support.
- Implement and monitor safeguarding measures to ensure that autistic people are protected from abuse, mistreatment, and discrimination in all healthcare services.
- Implement a rights-based and person-centred approach to prevention and care services.
- Develop accessibility protocols for all healthcare settings that include accommodations for autistic people, including for communication (use of AAC tools, personal assistance, etc.), sensory sensitivities as well as materials in Easy-to-Read format. Healthcare services should indeed adopt an accessibility framework that takes into consideration the needs of autistic people in order to provide equitable access to healthcare. The Autistic SPACE framework, addressing five core autistic needs (sensory needs, predictability, acceptance, communication, and empathy) was developed for this purpose.³

Question 4 - Enhancing the labour market for health and care workers

What is it about? Enhancing the working and framework conditions for health and care workers to counteract health worker shortages, medical deserts, attrition, and skill gaps, which are issues most countries are currently dealing with, and which will likely be exacerbated by an ageing health workforce.

Any support/care provision should be individualised and in line with the UN Convention on the Rights of People with Disabilities. There is currently a widespread shortage of support and specialist services such as occupational therapists, psychologists, and mental health specialists to enable autistic people to live in the community.

Despite recent policy developments addressing the need for accessible, available, and affordable care services, such as principle 18 of the European Pillar of Social Rights, the European Care Strategy, and the 2022 Council Recommendation on Long-term Care, a lack of significant investment in this sector is resulting in labour shortages, a lack of professionalisation of the care sector and insufficient community-based services, among others.

We call on Member States to:

- Implement measures to address staff shortages, provide support to informal carers and improve wages and working conditions.
- Professionals should receive training on autism that has been co-produced or at least informed by autistic-lived experience.
- Provide training for care professionals, including on the right-based approach to disability.
- Implement safeguarding measures.
- Provide robust funding for community-based services.

³ Doherty, Mary et al. "Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings." *British journal of hospital medicine* (London, England : 2005) vol. 84, 4 (2023): 1-9.

- Work alongside civil society to ensure national strategies uphold human rights with a person-centred approach.

We call on the European Commission to:

- Provide a monitoring and evaluation framework to the European Care Strategy, focusing on accessible, affordable, and lifelong quality services.

Question 5 - Achieving universal health coverage

What is it about? Ensuring people have access to quality healthcare without facing financial hardship. Much progress has been made in European countries, but gaps in coverage and access still exist in many settings.

Universal health coverage must be truly universal for persons with disabilities. This means that mainstream healthcare services must be adequately trained on how to assist persons with disabilities, including how to recognise and address possible co-occurring conditions. It also means that specific services dealing with the needs of individual disabilities, such as autism, should be adequately resourced, so the needs of the targeted group are met. Addressing the specific care needs of each individual person needs to be prioritised. Furthermore, recognising and addressing regional disparities in healthcare provision is important, and additional resources should be deployed to address these disparities. The provision of healthcare services must be person-centred, provide clear information to the service user, and actively engage with persons with disabilities about their healthcare needs. Achieving universal health coverage would not be complete without the inclusion of mental health services.

Challenges faced by autistic people:

- Lack of adequate screening programmes.
- Very long waiting times due to lack of capacity of diagnostic services delaying access to necessary support.
- Lack of harmonised diagnosis guidelines across the EU.
- Lack of qualified professionals able to make screening and diagnosis.
- Lack of mutual recognition of diagnosis across Europe, hindering freedom of movement.

Recommendations for actions at the EU-level

- Promote the adoption of common EU standards for screening, early detection, diagnosis and interventions for autism across all EU Member States, based on the most successful models available.

- Promote training of professionals in autism at various levels – through the development of basic training and specialisation curricula. This training should be co-produced or at least informed by autistic-lived experience.
- Tackle inequalities related to intra-EU mobility by addressing issues related to mutual recognition of disability status that give access to the provision of benefits, reasonable accommodation support, and services tailored to individual needs, education, and habilitation programmes.

Question 6 - Implementing digital solutions and AI

What is it about? Maximising positive health outcomes and gains for healthcare delivery from using digital health solutions and artificial intelligence, while successfully mitigating risks and ensuring their safe use

Digital solutions offer opportunities to improve healthcare service provision for persons on the autism spectrum. Innovations such as online digital appointments can help autistic people manage sensory sensitivities and anxieties around attending routine medical appointments such as going to their general practitioner. Furthermore, digital tools, such as emails and text messages to remind service users of their appointments may be particularly helpful for all patients. Other tools that could be considered are virtual hospital tours to help familiarise patients with the layout of the hospital, and what to expect during the appointment. These actions can be helpful in mitigating anxiety and confusion.

Despite their potential benefits to autistic people any framework designed to implement digital solutions must be adapted to ensure:

1. Easy-to-Read language is used across the healthcare system and in any digital tools deployed to assist patients.
2. Digital tools should be accessible by design and be developed to enable their use of all persons particularly those with disabilities.
3. Any tools developed to assist people with disabilities should be designed with the input of their targeted group.
4. Informed consent around the data that has been collected from use of digital tools.
5. Safeguards are designed and implemented to protect against abuse and the exploitation of patients.
6. Appropriate data protection policies are implemented, monitored, and published by every organisation collecting data for any use.

Question 7 - Improving the performance and resilience of health systems

What is it about? Strengthening the resilience and performance of health systems to maximise health outcomes and ensure health systems can rapidly adapt and meet their goals, including quality, access, equity, responsiveness, health improvement, people-centredness and financial protection.

There is no mention of mental health or psychosocial risks in this briefing note. This omission is concerning given the commitment taken by the EU to put mental health on par with physical health and adopt a mental health in all policies approach.

Challenges faced by autistic people in the health sector:

- Lack of availability of evidence-based and rights-based interventions.
- Ineffective (and sometimes potentially harmful) interventions for autism are available in certain countries.
- Lengthy delays for diagnosis, support, and healthcare services.
- Lack of accessibility in health services.

EU Member States

- Issues related to the inadequate use of drugs for children and adults on the autism spectrum.
- General healthcare needs of autistic people (both physical and mental) are not satisfactorily met.

Recommendations for actions at the EU-level:

- Support the development of EU guidelines on evidence-based, rights-based interventions for autism, based on existing guidelines at national and international levels to be followed by Member States.
- Foster access to adequate assistive technology.
- Foster accessibility and reasonable accommodation of all mainstream healthcare services (including mental health, dental care, emergency and preventive services)
- Promote the inclusion of compulsory training on specific and evidence-based habilitation strategies for autism, as well as on ethical issues in the curricula of all the habilitation professionals.
- Promote training in autism and accessible communication/accommodation in the curricula of all healthcare professionals and other relevant staff. This training should be co-produced or at least informed by autistic-lived experience.

Question 8 - Addressing long-term challenges, such as population ageing or climate change

What is it about? Understanding the stakes of long-term challenges such as population ageing and climate change for European health systems and building resilience to adequately detect, prepare for and act on challenges, ideally before they manifest as crises.

Autism is a lifelong condition, and autistic people will have changing support needs throughout their lifetime. As many autistic adults remain undiagnosed, their support needs continue to be unmet in their adulthood, which can have a devastating impact on their quality of life. As autistic people age, their families – who continue to be in many European countries their primary systems of support and caregivers – age also, which results in their inability to continue supporting their autistic relative. This lack of support and healthcare provision results in many ageing autistic people facing poverty and homelessness. Without coordinated support services addressing the need of the ageing autistic

population, social exclusion, poverty, and homelessness will continue to increase among the autistic population.

Additionally, European health systems should consider and address the regional specificities of support services, as many autistic people living in rural areas or lower-income regions do not have sufficient access to health and care services.

Question 9 - Which topic outside of the discussion framework should the EU prioritise and why? Which related actions should the EU pursue to add value at EU level and to support EU Member States? (maximum 1000 characters)

Regarding the provision of healthcare for autistic people, the EU and its Member States should prioritise providing specialist services for autistic people, as autism requires specific support services, including for mental health. Additionally, healthcare systems should implement safeguarding measures that protect autistic people against dangerous care practices and victimisation. In fact, research shows that 44% of autistic people have been victims of some sort of violence.⁴ In order to achieve this goal, the EU and its Member States should provide robust funding for care services, while monitoring that it is not allocated to services that institutionalise, segregate, or abuse people with disabilities.

As noted by Mental Health Europe, according to the last Eurobarometer, 89% of Europeans believe mental health deserves the same attention as physical health.⁵ Mental health should now be taken forward with the publication and funding of a long-term EU Mental Health commitment with clear targets, deadlines, and indicators. This action should be developed in consultation with relevant stakeholders and monitored according to clear standards. The long-term plan should adopt the psychosocial approach to mental health, which should also be strengthened in all policies.

⁴ Grace Trundle et al., “Prevalence of Victimisation in Autistic Individuals: A Systematic Review and Meta-Analysis,” *Trauma, violence & abuse* 24, no. 4 (2023).

⁵ Eurobarometer <https://europa.eu/eurobarometer/surveys/detail/3032>