



AOTI
Association of Occupational
Therapists of Ireland

Opening Statement: Services and supports provided by the State for autistic people

28th February 2023

Introduction

Thank you for inviting the Association of Occupational Therapists of Ireland (AOTI) to this meeting of the Joint Committee on Autism to discuss services and supports provided by the State for autistic people. This is a very important matter and AOTI welcomes your in-depth consideration of it. This statement is informed by Occupational Therapists working in different practice areas with autistic individuals across the lifespan, as well as Occupational Therapists working in education and research.

The centrality of the need for a society that accepts and affirms autism and neurodiversity is an overarching principal that AOTI advocates. This is reflected in our call today for societal level change, collaborative thinking and new practices so that Irish society becomes more inclusive of autistic people.

Occupational Therapists believe that a just society is one where individuals, families and communities have the capabilities and the freedoms to choose to participate in the everyday activities that they need and want to do in the different environments of their life. These everyday activities that are important to us are what Occupational Therapists call occupations, hence Occupational Therapy. Occupational Therapists are experts in supporting and enabling everyday living and can therefore play a key role at both societal and individual levels to help autistic people thrive.

Occupational Therapists focus on the person, the environments where they live their life (like home, school, the community and the workplace) and the occupations they want to participate in to help them live life how they want. Supporting people to engage in occupations and facilitating their full participation in community life, at both an individual and a societal level, is the bread and butter of our profession. Our professional perspective provides a unique framework to guide positive change for autistic people in the areas of health, education and work, and across the lifespan.

An Overarching Perspective

AOTI recognises and upholds the following values and principles which we believe must be central to the analysis of services and supports provided by the State for autistic people:

- **Participatory democracy:** we welcome the collaborative consultation with all stakeholders being undertaken by the Committee as it examines the services and supports provided by the State for autistic people. Community participation and co-design are a central pillar in contemporary democratic society and in the design, delivery and review of public services. Autistic people need to be central to this and empowered to participate in our communities and in Irish society.
- **Language use:** The stated preferences of autistic advocacy groups and the autistic community is that of identity-first language. This must be incorporated into all actions that emanate from the Committee's work and into services and supports provided by the State for autistic people. We should be guided by autistic people to ensure we are using the correct language and frameworks when developing and delivering services.
- **Human rights:** A human rights approach to the development and delivery of public services is imperative. This will align with the increasing recognition of neurodiversity and a shift from awareness to acceptance, as a means of realising autistic people's human rights and potential. A human rights approach means Ireland must ratify the UNCRPD Optional protocol. A thorough review of the Disability Act and EPSEN Act is also required. We welcome the Department of Education's current consultation process on the review of the EPSEN Act and call again for a review of the Disability Act.
- **Diversity:** Autistic people are not a homogenous group and the diversity of experience of autistic citizens across the many different contexts of their lives must be acknowledged and accepted. It is also important to recognise the convergence of intersectional barriers for autistic citizens and the diverse challenges these can create.
- **Collaboration:** Cross-departmental and cross-sectoral working is essential in order to ensure the rights of autistic citizens are met and to deliver services and supports provided by the State that are inclusive of and meeting the needs of autistic people.

What is Occupational Therapy?

Occupational Therapy affirms diverse ways of being and doing, while also recognising that individuals face barriers to participation in everyday activities and roles due to personal, environmental and societal factors. Occupational Therapists can support and advance the life goals and occupations of autistic and other neurodivergent children, youth, and adults.

Occupational Therapists are traditionally employed within the health and education services in Ireland and their work has therefore often reflected these service models. However, Occupational Therapists are well suited to supporting autistic citizens outside of these traditional models and approaches, which can sometimes limit Occupational Therapy's potential. A neuroaffirmative framework is advocated to enable the development of Occupational Therapy services which best meet the needs and requirements of autistic citizens.

There are many reasons why an autistic person may seek the support of Occupational Therapy, which helps them participate in their meaningful occupations and activities of daily life. Having an autistic neurology can often be disabling in a neurotypical world as there are many sensory, motor, psychosocial and environmental challenges that an autistic person faces. Occupational Therapy can assist autistic people with addressing these challenges. To provide optimal services and supports, we need to ensure that autistic people have the right to timely and thorough interdisciplinary team assessment carried out by suitably qualified and experienced professionals, including Occupational Therapists.

AOTI Framework for Positive Change

AOTI proposes the following framework for achieving change in how services and supports provided by the State for autistic people are delivered:

1. Equality
2. Mainstreaming
3. Neuroaffirmative approaches
4. A lifespan perspective

1. Equality

The autistic community should have equal access to all aspects of health services in the same way that neurotypical people do. Barriers to accessing services based on a diagnosis of autism need to be removed. It is not uncommon for a service to refuse a referral because a person has a diagnosis of autism. This contravenes the principle of equality in the provision of services and supports by the State.

There is a wealth of evidence showing that autistic people can have other health needs for which they seek to access services. The current practice of excluding citizens on the basis of an autistic diagnosis is discriminatory and hard to justify within a human rights context.

2. Mainstreaming

Currently, most health services are built and delivered with a neurotypical person in mind. Neurotypical describes individuals who display typical intellectual and cognitive development. Individuals who are neurotypical develop skills, such as social or organisational skills, at around the same rate as others their age and in their culture. Neurodivergent describes people whose brain differences affect how their brain works and includes autistic people and others such as those with ADHD, dyslexia and dyspraxia.

Our health services (and indeed all public services) need to be re-oriented so they become inclusive of the needs of neurodivergent people. AOTI advocates for this mainstreaming approach whereby all health services become autism-friendly and inclusive of autistic and other neurodivergent people. An example of mainstreaming in action is the town of Clonakilty which has become an autism-friendly town. Staff in businesses, shops and public services are trained to be accepting of autism and deliver their services in a way that caters for autistic people.

An example in our health services where mainstreaming would make a real difference is in acute services and emergency departments. The way emergency departments currently operate means that they are highly challenging environments for autistic people to be in at a time when they need those services most. Current overcrowding and other service pressures further exacerbate this problem. An example of where the health services have taken a mainstreaming approach that works for a particular group of people is dementia-friendly emergency services. From the point of access to an emergency department the service is tailored to the specific needs of someone with dementia and therefore provides for better health outcomes and a much better experience of using the service.

Occupational Therapy is at the forefront of developing and delivering dementia-friendly services. With this experience, and collaborating with the autistic community, the Occupational Therapy profession is well positioned to assist the State in delivering health and other public services in an autistic-friendly way.

3. Neuroaffirmative Approaches

The medical model focuses on finding a cure for diseases and disorders. This approach assumes that a person is broken in some way that needs to be fixed. The aim is to improve functioning so doctors focus on making someone more “whole” or giving them a “normal” life. The medical model has historically shaped the way health services were designed and delivered in Ireland as well as the way we understand human nature itself.

Using a neuroaffirmative approach means that we do not view autism as something that is “wrong” with a person, or that something is “broken” or needs fixing. Instead, autism is accepted as a different neurotype (the way your brain works) that is a part of human diversity. AOTI advocates for a neuroaffirmative approach to the design and delivery of all health and public services in Ireland. A neuroaffirmative approach to health and disability services works on the assumption that autistic people have an innate potential and identity that can best be actualised by providing person-centred, neuroaffirmative services and supports.

The world is designed for neurotypical people which in turn disables autistic and other neurodivergent people. A neuroaffirmative approach requires us to reorient how we design and deliver public services and restructure our communities, so they enable rather than disable autistic people and support their full participation in everyday community life.

4. Lifespan Perspective

Cradle to Grave Health Services

Early intervention and assessment is essential in order for autistic children and their families to get the supports and intervention that will best enable the autistic child to reach their potential. Occupational Therapy is one of essential services delivered at this crucial stage. Autistic people may continue to benefit from Occupational Therapy and other health and social care professional services throughout the lifespan and these essential support services must be provided but the State.

Play and Leisure

Play is an essential component of childhood and child development. Occupational Therapists understand the importance of play and leisure participation in peoples’ lives. It is a priority for the Occupational Therapy profession that autistic citizens have equal access to play and leisure opportunities. Play for autistic children can look different from neurotypical children’s play and we need to move to accepting and supporting this. Autistic children can be excluded and marginalised in mainstream leisure and play facilities and clubs through lack of acceptance, poor infrastructure and availability of supports and services.

Given the importance of play, we need a recognition of the right to play in the home, in the community and in school. We need to develop inclusive play and leisure spaces so autistic children and young people are not excluded in our communities. At an individual level supporting autistic sensory processing and regulation can be a key factor to enable participation and engagement, and this is something Occupational Therapists are experts at. AOTI also calls for an urgent review of Ready, Steady, Play, the national play policy, as this policy was published in 2004.

Education

Supporting autistic students in education to ensure they reach their potential and thrive within the educational system is a key role for Occupational Therapists. A lack of supports within the education system poses significant challenges for autistic students. They often experience environmental barriers to social participation in education, such as lack of acceptance and negative attitudes among peers and staff. In addition, inadequate support across the school system, as well as support in managing educational transitions, (such as from primary to secondary) further limit the educational potential of autistic students.

Progress is being achieved by the National Council for Special Education (NCSE). We know the Committee is aware of the NCSE and its work. Being able to expand and further develop the NCSE's supports in schools is essential so that autistic students can benefit from Occupational Therapy intervention as well as other HSCP services. This will help create a more inclusive and enabling school environments for autistic children. An expansion of the Occupational Therapy role is advocated to address educational environments, especially the social, physical, and policy aspects, to promote social participation and inclusion of autistic students. Occupational Therapy can help reduce the segregation of autistic students throughout their educational journey.

Occupational Therapy is now recognised as a key support service for students in higher education and many Irish universities now directly employ Occupational Therapists on campus to deliver services when needed by students including autistic and other neurodivergent students as well as those with physical and sensory disabilities and mental health difficulties.

Work

Work and employment are very important parts of autistic people's lives and Occupational Therapists work with both autistic individuals and employers to support active participation in the workplace. On an individual level, autistic people may benefit from support with managing disclosure, accessing reasonable accommodations and developing strategies to manage their worker role and responsibilities. Workplaces can benefit from a universal design approach to support participation for autistic employees.

Occupational Therapists are skilled in universal and inclusive design and are at the forefront of driving efforts to reorient work environments, including physical and virtual spaces, so they accommodate the needs to autistic employees. Occupational Therapists use adaptive strategies, tools and technologies across the lifespan to help autistic people enter and remain in the workplace. Our workforce can be greatly enhanced through the inclusion of autistic people in workplaces.

Health Management

Occupational Therapists play an essential role in supporting autistic individuals to manage their health and wellbeing across the lifespan. As dual trained health professionals, Occupational Therapists can also help autistic people with the psychosocial and mental health impacts of living with autism. Occupational Therapy can help autistic adults meet their long-term mental and physical health needs, maintain a good quality of life and achieve a state of wellbeing and satisfaction with everyday life.

Conclusion

In conclusion, our statement was informed by Occupational Therapists working in different practice areas with autistic individuals across the lifespan, as well as Occupational Therapists working in education and research.

We have set out some of the key values and principles that AOTI believes must be central to the analysis of services and supports provided by the state for autistic people. We have also set out a framework we believe is necessary to achieve change in how services and supports provided by the State are delivered to autistic people. This framework focuses on:

- Equality in all service delivery
- Re-orienting mainstream services so they become inclusive of the needs of autistic and neurodivergent people
- Taking a neuroaffirmative approach in the provision of health services and other public services
- Taking a lifespan perspective

We thank the Committee for the opportunity to meet with you today and value your detailed consideration of this very important matter for Irish society. We look forward to discussing this further with you today and welcome any questions you may have.



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