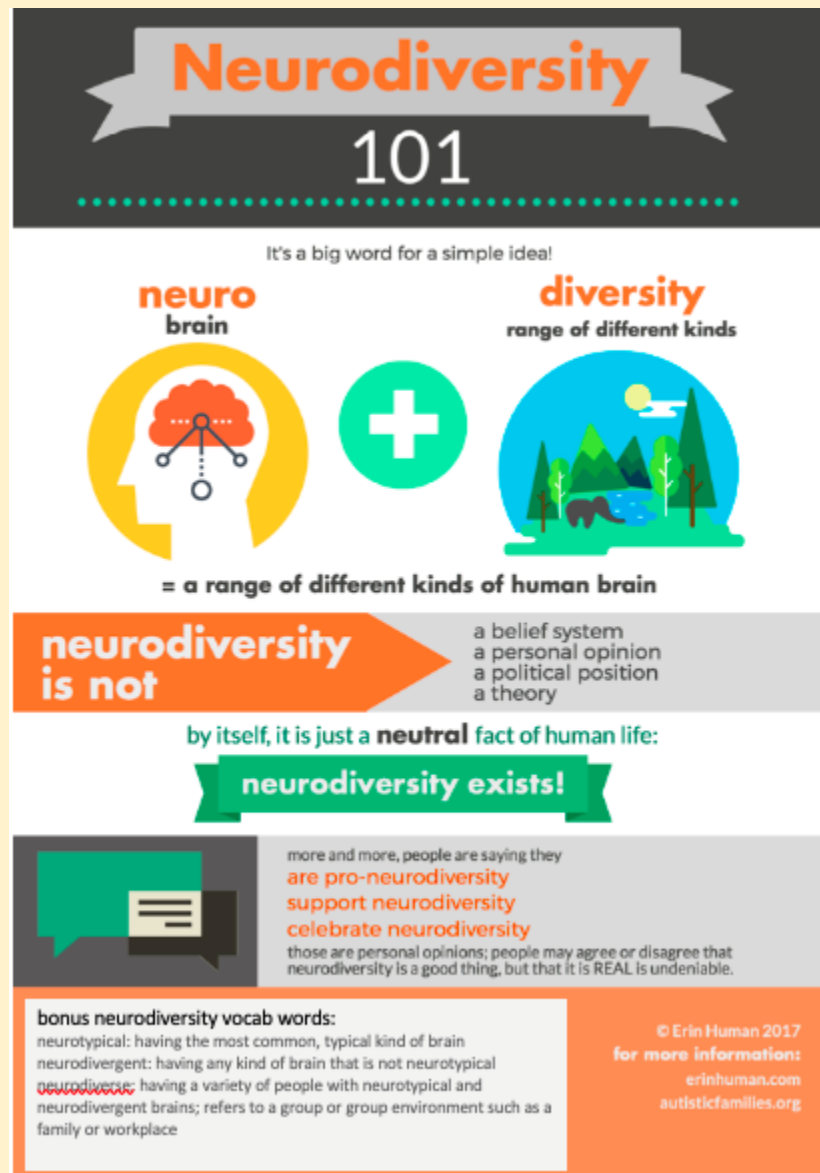


# Autism Innovation Strategy

## Joint submission

This submission is on behalf of the **Irish Association of Speech and Language Therapists** and the **Psychological Society of Ireland**.

The strategy should be for all Neurodivergence, inclusivity at all levels across all services and practices and lifespan.



## Topic 1 – The key ideas

### Question 1 - Innovation

**Do you have examples of new and different ways of working that we could use in Ireland?**

**Would this make it easier for people with autism to use services and support?**

**What we recommend:**

- Develop and adapt pre-diagnostic supports using a NeuroAffirmative model  
<https://www.bom.org.uk/wp-content/uploads/2022/03/Am-I-Autistic.pdf> (example of pre-diagnostic supports for adults)
- Acknowledge contemporary thinking may not have published research yet. There is a need for examples of innovative co-produced and participatory research in order to inform policies and strategies. This presents an opportunity for co-production of research by neurotypical and Neurodivergent researchers.  
<https://matthewshub.org/advice/news/139/pre-diagnosis-workshops-for-those-waiting-for-an-autism-assessment> (example of pre-diagnostic workshops for parents of children awaiting autism assessment)  
<https://www.karger.com/Article/FullText/523723> (See link for information on neurodiversity approach and how it can align with scientific research).
- Family approach - Communication options / styles- supporting families in providing education around authentic Autistic communication styles, reassurance that authentic Autistic forms of communication are valid and do not need to be altered to appear more neurotypical. Providing accessible information and training on Autistic theories of autism (e.g. Milton's Double Empathy Problem Theory, Dinah Murray's Monotropism Theory, Autistic Sensory Perception)

# MONOTROPISM

Implications for practice: "The biggest practical thing to take away from this is the importance of meeting the child, or adult, where they are."



~ Fergus Murray  
<https://thepsychologist.bps.org.uk/volume-32/august-2019/me-and-monotropism-unified-theory-autism>

## monotropic interest system

Monotropism also suggests a reason for the sensory integration difficulties found in the accounts of autistic people, as they suggest there is a 'hyper-awareness' of phenomena within the attentional tunnel, but hypo-sensitivity to phenomena outside of it. Also, that an interest in the social world may not occur in the early years of life.

Milton, Damian (2012) So what exactly is autism? - Autism Education Trust, 15 pp. Online article. (KAR id 62698)

## What is monotropism?

Atypical strategies for the allocation of attention including social interactions, the use of language, and the shifting of the object of attention – a central core Autistic feature.

Murray, Dinah & Lesser, Mike & Lawson, Wendy. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism: the international journal of research and practice*, 9, 139-56. 10.1177/1362363305051395



## A DIFFERENT COGNITIVE STYLE

"In a nutshell, monotropism is the tendency for our interests to pull us in more strongly than most people. It rests on a model of the mind as an 'interest system': we are all interested in many things, and our interests help direct our attention. Different interests are salient at different times. In a monotropic mind, fewer interests tend to be aroused at any time, and they attract more of our processing resources, making it harder to deal with things outside of our current attention tunnel."

~ Fergus Murray (2018)  
<https://thepsychologist.bps.org.uk/volume-32/august-2019/me-and-monotropism-unified-theory-autism>

## GOOD THERAPY PRACTICES

- Work *with* interests and passions
- Avoid the ableist practice of pathologizing a person's focused interests; intense focus is indispensable in various fields such as science, math, technology, music
- Understand that it's extremely difficult, anxiety-producing, and even frustrating for a monotropic brain to shift focus when the person is in a flow state
- *Become part of* attention tunnels, rather than focused on pulling the person out of their flow states
- Help maintain a sense of safety, stability, and routine

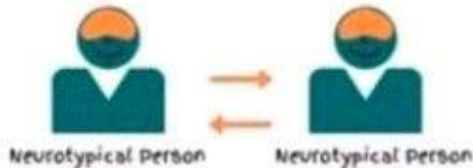
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## BOTH AUTISTIC & NEUROTYPICAL PEOPLE NEED TO LEARN HOW TO SOCIALISE WITH EACH OTHER

Research tells us **both** Autistic people and Neurotypical people demonstrate effective social skills when interacting with their **own** neurotype.

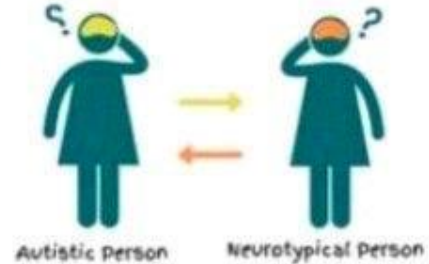


How language is used is understood, emotional expression through face and body movement is understood, social interactions are successful.



How language is used is understood, emotional expression through face and body movement is understood, social interactions are successful.

Research tells us social interactions are often less successful for both Autistic and Neurotypical people when interacting with a **different** neurotype.



Autistic people can and often do learn to interpret neurotypical use of language and neurotypical facial expression and body language. They often use these learnings to bridge interactions with neurotypical people, including through mimicking and masking.

Current research suggests Neurotypical people find it difficult to interpret Autistic expression and that there is a general absence in Neurotypical people learning to interpret Autistic social expression.

**Social interactions are bidirectional - a two way interaction between individuals. Each group has equal responsibility to learn how the other uses and understands language, and how each uses facial expression and body movement as part of their emotional expression. Each group has equal responsibility for successful social interactions.**

<https://Autistic-village.com/2021/08/05/building-super-highways-why-monotropism-works-for-Autistics/>

- Adopting how we can address the suitability of environments, Conduct sensory Audits of Spaces by Autistic Consultants. And employ Autistic consultants to review accessibility



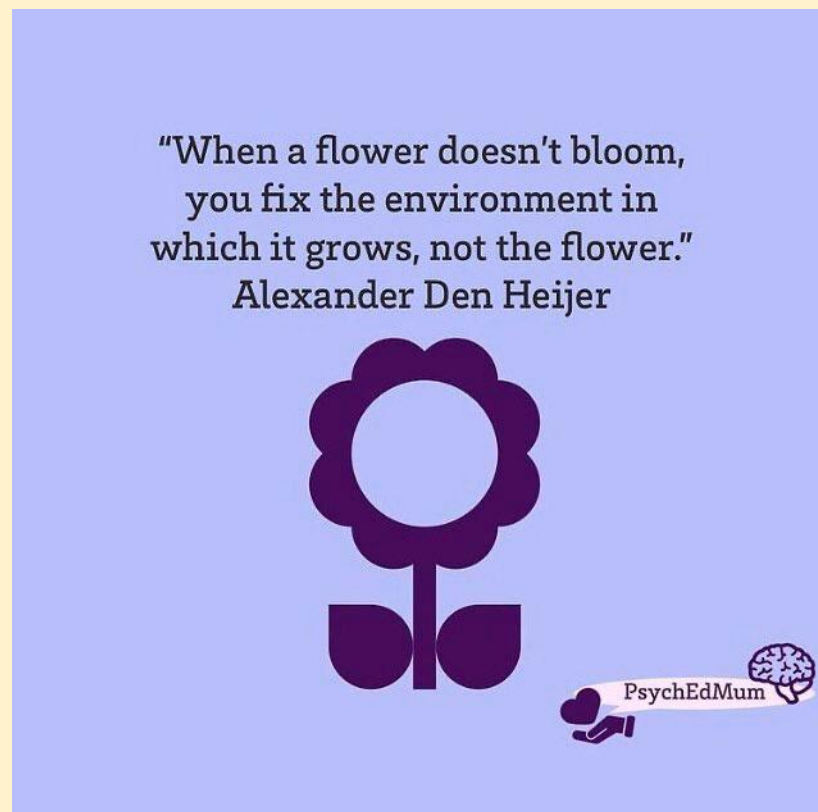
of spaces. See below references for examples of existing initiatives that target suitability of environments:

<https://www.neurodiversityhub.org/enabling-spaces>

- Innovative work from **National Development Team for Inclusion (NDTi)** in the U.K. using Autistic consultants to review and advise on hospital environments/ wards and CAMHS inpatient units:

<https://www.ndti.org.uk/assets/files/Sensory-Friendly-Ward-Principlesv2.pdf>

<https://www.ndti.org.uk/assets/files/Its-not-rocket-science-V5.pdf>



- Addressing barriers to mental health and well-being

<https://link.springer.com/article/10.1007/s40489-020-00226-7>

- Acknowledging intersectionality of autism and gender identity- need for models of shared care / joint work:

<https://journals.sagepub.com/doi/full/10.1177/095935352210748>

## **Question 2 - Empowerment**

**Do you have examples of good ways to support people with autism to make their own choices, have a say, and have control over their lives?**

**Could these be used in Ireland and be part of the Strategy?**

**What we recommend:**

- **Autistic Representation**

Having Autistic representatives is crucial when discussing anything to do with autism. The group writing this submission are incredibly fortunate to have had input from Autistic clinicians, representing psychology and speech and language therapy, when discussing and writing this feedback. A key component of writing any policy for disabled people is including the actual people the policy is about - this is what is meant by “nothing about us without us”.

It is essential that any Autistic representation comes from multiple sources to ensure that many Autistic viewpoints and voices are heard and considered. A variety of stakeholder groups should be consulted regarding anything to do with autism. Suggested groups include - Neuro Pride Ireland, Autistic Social Group Ireland, and by using callouts on social media channels. Ireland has many Autistic professionals including teachers, psychologists, speech and language therapists, social workers, occupational therapists and healthcare professionals who can and should be recruited to devise and deliver any training which comes from this strategy. Autistic researchers should be given the opportunity to be involved in production and co-production of any research on the topic of the Autistic experience in this country.

- **Rebalance of Power**

Be empowering by sharing power, dissolving power, speaking to many, involve many, there is so much diversity in the Autistic population as the non-autistic population and to make change nationally good practice needs to be inclusive and accessible to that diversity. Foster collaboration. Consult different people, don't rely on the same group of Autistic people all the time, Consult groups you never talked to before from different backgrounds, different races, different occupations, different ethnicities, different societal groups, different ages etc. Celebrate difference and disagreement, we can all (all humans) grow from balanced uncertainty which is

supported and not threatening. Accept that things that are most worth doing are often somewhat hard to do, but in that challenge there is so much adventure and opportunities for growth and positive human development. Be open to thinking about things differently, accepting the range of different perceptions that exist even the ones we cannot access ourselves or understand, don't reject the unknown on the basis of fear and uncertainty but be open to explore new ways. and being unsure and explore the unknown that exists. Build societies where Autistic and non-autistic people can support each other in the unknown to create a society that is new for both but works for both. Adopt a neurodiversity paradigm and be NeuroAffirmative in all practice at all levels (not just when interacting with the Autistic community). Build a foundation of strong NeuroAffirmative practice and values, with respect for the difference but validity of both non-autistic, Autistic and otherwise Neurodivergent ways of being. Respect neurodiversity as we do biodiversity Ensure practices/supports are not ableist, provide training on what ableism is and how we can often engage in it without realising but how it can have devastating effects. Make sure all practices are informed by a neurodiversity paradigm and all the neurodiverse human ways of being, perceiving and ways of communicating and interacting in life add so much to life and human society. This is likely to require NeuroAffirmative training from those with a solid understanding of Neurodiversity and how it applies to all people, not just Neurodivergent people. Foster Autistic autonomy and Abolish neuro normative practice used against Autistic people

- **Autistic Housing for the diversity of changing Autistic needs and across the lifespan.**

Practical example of support, As seen in the uk, provision for PA assistance with executive functioning tasks life skills, maybe something like felicity house but with more emphasis of Autistic peer support and NeuroAffirmative practice that fosters and embovers Autistic developmental trajectory, learning styles and communication. <https://www.vox.com/the-highlight/2019/6/11/18659912/autism-women-felicity-house-social-club>

Another option could be Autistic housing communities for the diversity of the Autistic population and changing states of all people, like retirement homes where they can get more services when needed and then when not but their autonomy is respected at all times as they move through life. Spaces which are adaptable and respecting autonomy and rights. based not on social skills training or fitting into neurotypical expectations but fostering positive Autistic identity,



community and culture, across the lifespan for changing needs and option and be open to people on HAP as well for those who can access it in other ways.

-

Development of Autistic communities / villages, housing, that are integrated and part of all of the rest of society but which difference is respected and celebrated and the emphasis is on empowerment and respect for Autistic neurology, communication, cognition, perception and supports and fosters Autistic developmental trajectory throughout the lifespan from childhood to elder age. This could work well through a structure similar to Vygotsky scaffolding, similar to democratic schools see <https://wicklowsudburyschool.com/>, Autistic communities and culture could be designed in a similar way, where Autistic development trajectory can be supported and foster throughout the lifespan and for the diversity of the Autistic population.

Autistic community housing could work across the lifespan and include Autistic peer mentoring and advocacy, enabling spaces open to the Autistic and Autism community (non-autistic parents with Autistic children) and Autistic peer support learning and growth that is Neuroaffirmative to Autistic neurology but not segregated from the rest of society, but is collaborative and respectful of all neurodiversity. Creating a range of adaptable spaces within society for all people.

- **Reverse design, universal design from the start,**

Reverse design and universal design from the start. Design of spaces and services from Autistic and otherwise Neurodivergent sensory perceptions from the start and not add in only in the end or only in a certain part of society. service with communication choice at each step, phone, text, email etc. but have communication options all the way through to have access to moving on to other services.

Design for the minority first. As often what is essential for accessibility for Autistic people is also very useful for non-autistic people too. But if you leave it till the end to consider Autistic and otherwise Neurodivergent accessibility needs, then it can be too late or it can get forgotten, or only remembered as an afterthought and only for one type of Autistic experience..

Use the design principles of universal design from the start and that does not mean every space is designed the same but that spaces are designed to be adaptable with a variety of spaces within one area to suit the diversity that exists across all human society.

Don't make one day or one week or one month "autism month". Changes need to be made for everyday, for example you would never consider putting in a wheelchair ramp for an hour one

evening every week and then removing it at other times. That would be highly unethical. Instead the ramp is always there. Similarly, Autistic accessibility needs to be built into everyday society all the time, not just for a select time. But to be a part of everything. Strategies like "autism hour" in supermarkets can be problematic if they are not continually growing and adaptable because there is so much diversity with the Autistic population that "autism hour" is really only design for one type of Autistic person, and it doesn't take into account that humans change, and Autistic people or any people are not stagnant, rather, people change, needs change, states fluctuate. Design for neurodiversity, which means designing a collection of environments and space that suit the diversity of humans that exist and are adaptable and there are a variety of different types each given the same amount of resources and then society can be accessible for all neurodiversity.

It doesn't work to be accessible by designing more segregation. All public spaces and services need to be designed for all human neurodiversity including Autistic people and otherwise Neurodivergent people as well as neurotypical people. The world needs to be accessible at all times for all and further separation won't help that. We can acknowledge and embrace different neurology while collaborating to build a society that is accessible to all.

Consider sensory perception and sensory design in everything that is done, for all people and all places not just specific "autistic spaces" but all spaces because all spaces should be accessible for Autistic people, because there are Autistic people in every part of society, Sensory design and building awareness of the diversity of sensory perceptions can be really beneficial to non Autistic people too. If we are thinking of some public environments as being "autistic spaces" and others not, that should indicate to us a problem. As all public environments should be spaces for everyone.

Set up /adapt supports and services to be universally designed with the least amount of steps without losing the richness and details that are important to Autistic people. Have a collection of different Autistic people be involved in the design of supports and services and trial out services such as communication pathways before they go live. And give open and clear ways that feedback can be given. Be open to services evolving over time. Particular attention should be paid so that design has choice is communication including video/visual, in person, written, text and phone, don't just have one method and never assume that all Autistic people prefer one

way (ie written text, often we come to be aware of this preference only from people who write through text about their preference which means we are missing the people that don't find written and text accessible) of communication or that communication preferences will stay the same across time for individuals. a variety of adaptable communication methods need to be available for the diversity that exist but also for the change within individuals e.g. those that are sometimes NonSpeaking.

- **Research**

Autistic researchers should be involved in co-production of research that directly affects policy changes in this country.

### **Question 3 - Raise Awareness**

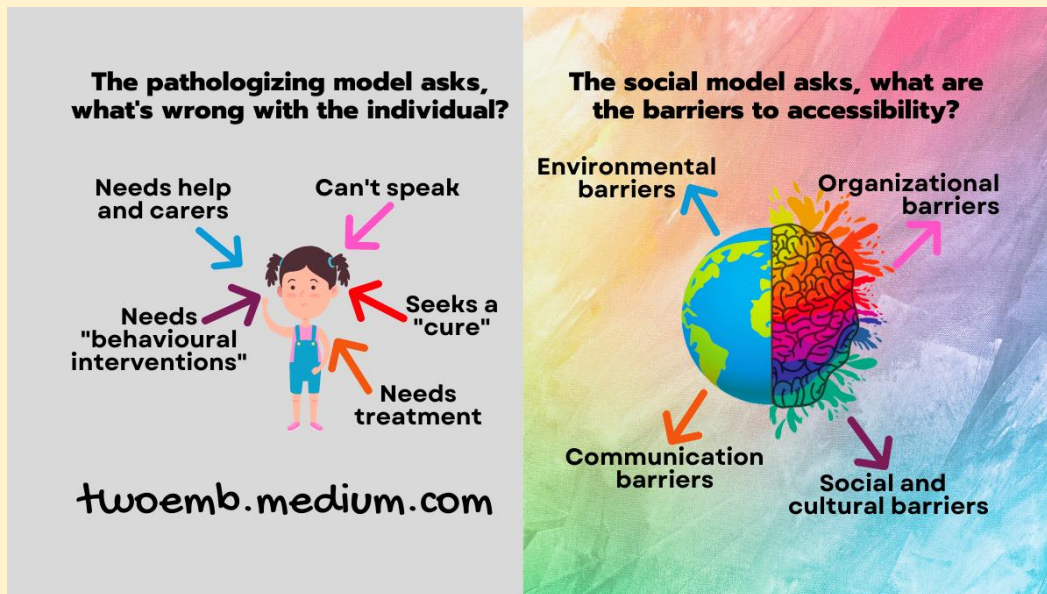
**Do you have examples of good ways to raise awareness? Could these be part of the Strategy and used in Ireland?**

#### **What we recommend:**

- All schools should have lessons on Neurodiversity and Autistic communication styles. This would promote awareness of autism and other neurotypes across all pupils in Ireland. This curriculum is being released for free in June 2022 so all schools will have access to it.
- It is important that neuro-affirmative post diagnostic sessions are offered to parents of Autistic children, Autistic children, and Autistic adults. These should take place as part of the diagnostic assessment where completed by the HSE and voluntary organisations.
- Education, Healthcare, and all government staff should get training from Autistic people regularly on issues which are important to the Autistic community (while individual differences exist the general consensus of Autistic people should be taken into account as a default place to start from).

This is partially in line with what the United Kingdom are starting to do as part of their autism Innovation Strategy by providing training to British MPs by Autistic people [George Stanbury on the first Understanding autism session for MPs](#)

- **Autism Acceptance:**



Language is important, and awareness and acceptance come from vastly different mindsets. Awareness focuses on highlighting how different autism is from the neuro-norm. It educates on clusters of “deficits”, and suggests that anything objectionable about an individual is their autism. Awareness (often unintentionally) reinforces stigma. Awareness is also easy. It’s an unrepeatable thing (you’re either aware or you are not), and doesn’t require a whole lot of thinking. It’s rooted in ableism, and fails to hold society to account for exacerbating challenges and for failing to embrace true inclusion. Acceptance is about acknowledging and valuing difference in our society rather than about tolerance. It is about shifting the onus of change from the Autistic individual to society as a whole. Acceptance involves challenging perceptions in order to overcome prejudice and change society which may appear at the outset like a daunting task. It is important to consider however, the way in which a society benefits completely through embracing human neurodiversity, similar to the strength biodiversity brings to our natural planet .

Include links to practical examples of Acceptance campaigns, some documentary or shorts of Autistic people in different professions doing well in a world that has been adapted for them and how they do that. also Autistic people not living independently being happy and adding to others happiness and life in a world adapted for them.

Being Autistic is a valid neurotype and an Autistic person should not have to hide or change their true self (masking/camouflaging) to “fit in” with non-Autistic people. Currently in Ireland, both the Department of Education and the Health Service Executive (HSE) operate from a deficit-focused model which can appear reductionist to Autistic people and the autism community, noting that it is also not beneficial to the families of Autistic people. This is evident in the usage of person-first language, such as “person with autism”, suggesting an individual can be separated from their neurotype. We see this from the recommendations of “social skills” groups/training run in schools, disability services, primary care and secondary mental health, to encouragement of whole body listening, and stimming suppression. We see it in how autism can be framed as *challenging behaviour*, as Autistic individuals ‘*suffering because of autism*’, or as parents *struggling*, while environmental and societal factors which are seen to drive suffering for Autistic people and their families are overlooked. We see it too in how public money is spent on initiatives aimed at intervention at the individual level as opposed to intervention at a societal level. Individual approaches taken that are seen to attempt to fundamentally change or hide Autistic experience are not considered to be neurodiversity affirmative. We see the consequences of this approach in secondary mental health services at both child and adult level, where there are disproportionate numbers of Autistic service users compared to the non-Autistic population. There is a missed opportunity for embracing interventions at the individual level that are neurodiversity affirming (for example interventions focused on building self-awareness, creating sensory profiles etc) in conjunction with intervention at the societal level.

Healthcare and education providers should promote autism acceptance through rejection of practices/approaches which can be considered to be in direct conflict with acceptance of neurodiversity. This would involve transparent and open discussions with service users and their families throughout the journey from pre-diagnosis, during diagnosis and post-diagnosis and also moving throughout the lifespan, supporting the Autistic individual and their authenticity and providing education to those around the Autistic individual at the macro and meso levels and not solely at the micro level

With this in mind, autism acceptance should be promoted by the HSE through specific training on the neurodiversity affirmative paradigm shift and model for practice, to be delivered to all tiers of healthcare. Similarly, the Department of Education and National Council for Special Education (NSCE) should provide specific training on the topic of neurodiversity affirmative practice, the “Double Empathy Problem” (Milton) and the Diversity in Social Interaction research. This training should be delivered to all tiers of education and all public health services. All tiers should include management level with respect to both healthcare and education. These trainings should be delivered by Autistic people and on a recurring basis to account for staff turnover. Co-production and co-delivery of training can also be viewed as viable options (Eg. autism Level Up). Current government (and voluntary organisation) policy documents should also be reviewed with the social model of disability in mind. For example, the HSE’s current ‘Dignity at Work’ policy states “The intention of the person engaging in the unwelcome behaviour is irrelevant – the effect of the behaviour on the employee concerned is what is important.” In this example, the policy should be rewritten to include recognition of intent of the Autistic person, and that communication breakdown can be the responsibility of both parties, and not just the Autistic person.

- **Retraining for those in Education and Health Services**



# Diverse ways of being in the world



Dyspraxia/  
DCD



Dyslexia



ADHD



Autism

Our planet has a neurodiverse population because every single human has a unique mind.

Neurodiversity is NOT a characteristic of an individual within a population – a person cannot be labelled as neurodiverse or having neurodiversity.

Neurodiversity refers to all of us!



Much of what was taught about autism at university level is now known to be incorrect, outdated, and ableist, yet many therapists and teachers, and those working with Autistic people, have not been given updated training on this. This training should come from Autistic therapists and teachers themselves who are seconded to teams to provide this training. This training should not come from a variety of sources in order to ensure a balanced view of the Autistic lived experience. The view of this group is that there is a need also perhaps for universities to review teaching content/sources to ensure that they are inclusive of Autistic voices and Neurodivergent-affirmative practices.

Neurodivergent clubs or groups should be set up for Autistic people - the goal of these is not to “teach” the Autistic person social skills, but it would be

- Creation of a space for Autistic people to meet each other if they wished
- Opportunity to nurture their Autistic identity with support from their community.
- Ways to support the Autistic person in learning how to adapt the world to suit their neurology rather than fundamentally change themselves to suit the world.
- These clubs should be available for all age groups.
- Autistic people should also have access to peer support from other Autistic people.

## Cultivating A Positive Autistic Identity

- Recognise & Increase Strengths
- Provide Opportunities for Flow States
- Appreciate Own Developmental Trajectory
- Value Internal Drives (stimming)
- Value Own Communication Preferences
- Value Own Play Preferences
- Value Own Learning Preferences
- Promote Autonomy & Self-Advocacy
- Connect with Autistic Peers & Community
- Appreciate Social Model Of Disability
- Develop Personal Perspective on Components of a Good Life

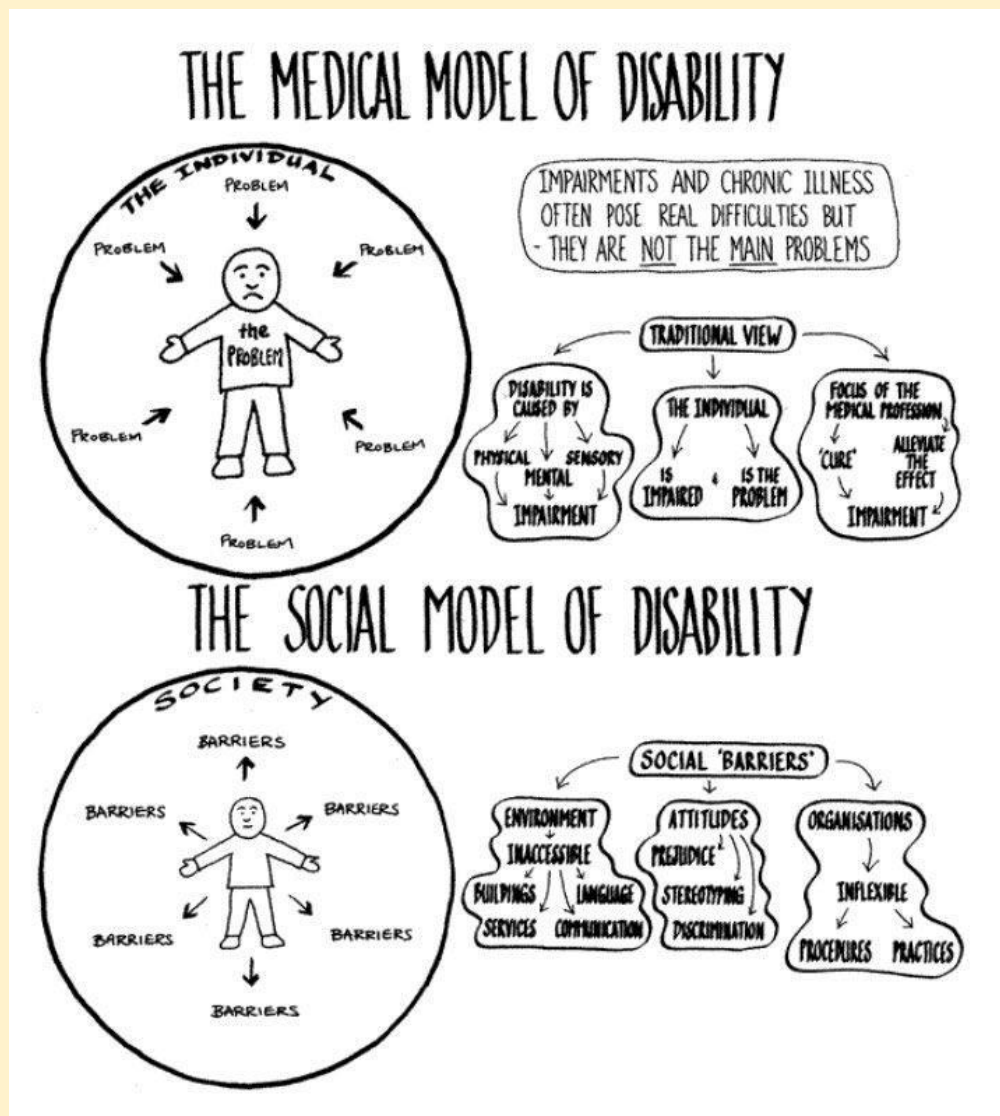
## Topic 2 – Writing the Strategy

### Question 4

What are the main challenges and barriers that the Strategy should focus on for the next 12 to 18 months?

What we recommend:

- Permanent shift from medical model to social model of disability and rights based framework in line with UNCRPD and towards acceptance of Neurodivergent people in an important part of society. This will avoid perpetuating stigmatisation and marginalisation of Autistic people in Ireland.



- Permanent shift in terms of language use incorporating language/terminology changes recommended in this submission.
- Creation and actualisation of autism services that support Autistic people across the lifespan. Such services should be equitable and accessible to all within the public service. We welcome the news of preliminary discussions regarding a national autism pathway and include our own vision regarding autism Across the Lifespan.

- **Vision Across the Lifespan:**

Autism assessment and intervention in the public sector in Ireland is predominantly focused on children, when available. Autistic children and adolescents are likely to require access to various public services during childhood due to complex shifting needs and (unfortunately) mental health concerns including; the community disability network team, primary care services, and child and adolescent mental health services. Unfortunately, waitlists for these services vary and there is little communication and shared care between them. Some Autistic children fall between services, not meeting acceptance criteria for any and left without support. For those who do receive supports from one or more services, they run the risk of missed diagnosis, mis-diagnosis or inappropriate care/intervention because of stigmatised views of autism, ignorance of neurodiversity affirmative practice, and/or lack of knowledge on how to adapt service provision for an Autistic individual.

Where a private autism assessment has taken place for people under 18 years they should be referred to their local primary care or disability team for this intervention. Post-diagnostic sessions are already offered in some disability teams, however it is important that any outdated information contained within these is revised to be updated in line with current research and using a neuro-affirmative framework. It is equally important that a clear post-diagnostic pathway be rolled out nationally to ensure equity of access across all disability teams in this country.

For Autistic children who are experiencing mental health challenges in this country, an observed lack of shared care or linking between CAMHS, primary care and disability services increases risk of avoidable negative outcomes for Autistic children and adolescents. National policies are needed that are explicit in stating how Autistic children and adolescents in Ireland can be supported with their mental health and these policies must be honoured consistently nationwide. All Autistic children who are experiencing mental health challenges should be supported

accordingly. These policies should be trauma-informed and co-produced by Autistic mental healthcare experts who have unique insight into the Autistic experience of mental health.

Laxman et al found that services reduced with each year of secondary school, and that students experienced a post high school services cliff (Laxman, 2019). Song, Salzer, Nonnemacher, *et al* (2022) found that “Young adults (22–30 years) were more likely to report unmet needs than both adolescents and transition-age adult groups” as compared with younger cohorts. This is particularly the case in Ireland, where there are no autism specific services for Autistic adults without intellectual disability. It is the opinion of this group too that adult disability services available for Autistic adults fall short of meeting their needs.

There is currently no publicly funded autism assessment or intervention for adults who are questioning their neurodivergence. Anyone who can afford to is paying private clinicians for this service. This creates a system where those who can pay can get a diagnosis and therefore access to (for example) reasonable accommodations in the workplace, whereas those who cannot pay are discriminated against in this regard. This raises issues of equity of access to service, and is a breach of human rights.

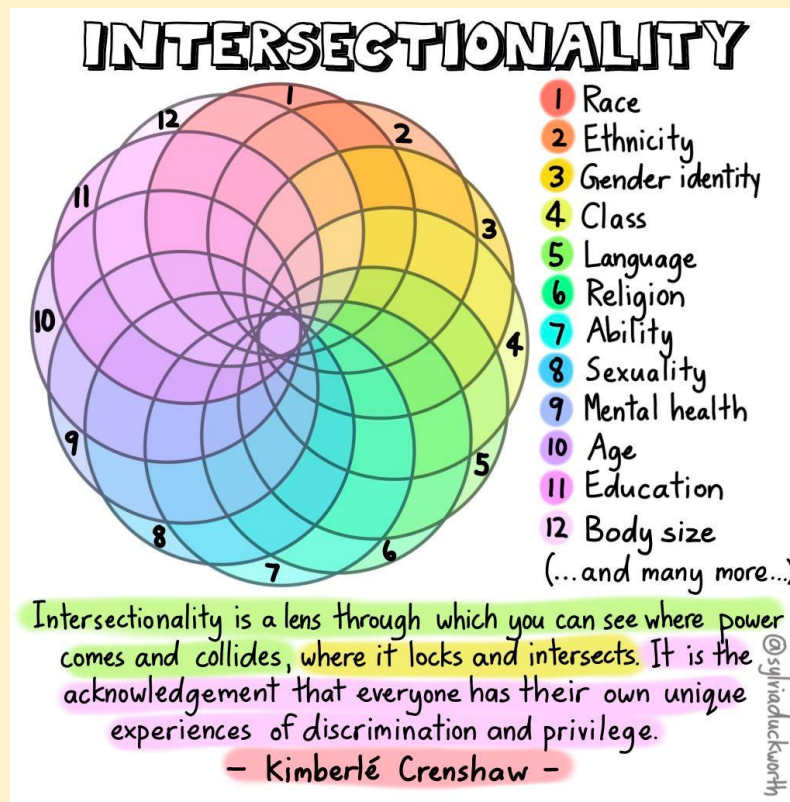
We strongly feel that centres of excellence for neurodivergence are lacking in Ireland and we welcome news that a national autism pathway is already under discussion and development through a separate national working group. An integrated lifespan service (like those being piloted in the UK), would combine professionals with the most advantageous experience into one service. This would reduce the likelihood that families and service users will be under the care of someone who doesn't have any expertise in the area. This would also help to reduce the unreasonable waiting times for childhood diagnosis, and actually provide a diagnostic and intervention service for adults.

Most of the difficulties in securing services in Ireland for children and adults appear to arise from lack of joined up services, and gaps in area, expertise and funding. Having patchy services also opens up questions of equality of access to service, and breaches of human rights. There is an unknown number of children and adults who have yet to be diagnosed, and a recent study, Eberhard, Billstedt, and Gillberg (2022) showed that about 63% of people seeking services in a general psychiatric ward met the criteria for ADHD or autism or both, and that these diagnoses



are missed in children, particularly women. autism will be seen in 100% of health settings, and so as stated above, training on autism and other Neurodivergent neurologies is essential for primary, secondary and tertiary clinicians in every setting.

Such training should also incorporate intersectionality within the Autistic experience. Weir, Allison, & Baron-Cohen (2021) found that “both Autistic males and females may express a wider range of sexual orientations in different sex-specific patterns than general population peers” suggesting that those working with the Autistic population need continuing professional development in LGBT affirming practice. The HSE “rainbow badge initiative” should be rolled out across such healthcare settings as a minimum, with further specialist training also needed. Lim, Sigafoos et al (2021) also found that families within minority communities experience barriers when accessing services for their Autistic children.



#### Question 5

Do you have ideas for actions in the Strategy to deal with these challenges and barriers?

What we recommend:

- Creating positive experiences rather than dealing with problems.



- An immediate change to neuro-affirmative and identity first language across all health, education and state literature.
- Mandatory retraining for all staff in education, health, and state departments on autism through a neurodiversity-affirmative lens, as well as Autistic led workshops on how to make changes to a neuro-affirmative framework

### **Topic 3 – Working with other policies**

#### **Question 6**

**Think about the challenges or barriers that people with autism face in Ireland?**

**How can the policies we have now be stronger at dealing with these?**

**What we Recommend:**

- Address the suitability of all existing policies that directly impact Autistic people, and review by a diverse range of Autistic consultants in line with participatory approaches (. processes are relational and negotiated acknowledging differing perspectives), making adjustments based on any recommendations from said consultants and approaches..

- Phase out Ableist Approaches that are in Conflict with autism Acceptance:

Currently compliance-based interventions are being offered throughout Ireland's health and education services. This is incongruent to the Autistic community's view on such services. Such compliance-based practices which attempt to fundamentally change the Autistic individual to look or perform more like a neurotypical person or hide their authentic Autistic selves to make them appear less Autistic to the external world have been shown to be harmful to Autistic people (Herlinda Sandoval-Norton, & Shkedy, 2019), and lead to strengthening behaviours, such as masking (acting the role of a neurotypical person) or camouflaging (hiding external Autistic features to blend in and appear less Autistic). An increasing amount of research is emerging that shows that both masking and camouflaging are factors in many negative outcomes such as being a barrier to authentic connection and self awareness, low self esteem, loneliness, misdiagnosis, reduced mental wellbeing, fatigue, burnout, (Pearson & Rose, 2021) depression and suicidality (Cassidy, Gould, Townsend, Peloton, Robertson & Rodgers, 2020).

The view of this group is that such Compliance based practices and interventions should be phased out and eventually stopped in Ireland as no approach which has been shown

to have minimal therapeutic value while also causing significant harm should be funded by the state.

### **Question 7**

#### **What new actions would build on the work of the National Disability Inclusion Strategy and the Comprehensive Employment Strategy for People with Disabilities?**

The National Disability Inclusion Strategy (NDIS) (2017-2021) is a whole of government approach to improving the lives of persons with disabilities. It provides a framework which can support progress in delivering on the obligations in the United Nations Convention on the Rights of Persons with Disabilities UNCRPD. The Comprehensive Employment Strategy for People with Disabilities (CESPD) (2015-2024) is a cross-government approach that brings together actions by different departments and state agencies in a concerted effort to address barriers and challenges that impact on employment of people with disabilities.

#### **Actions that would build on the work of the NDIS and no:**

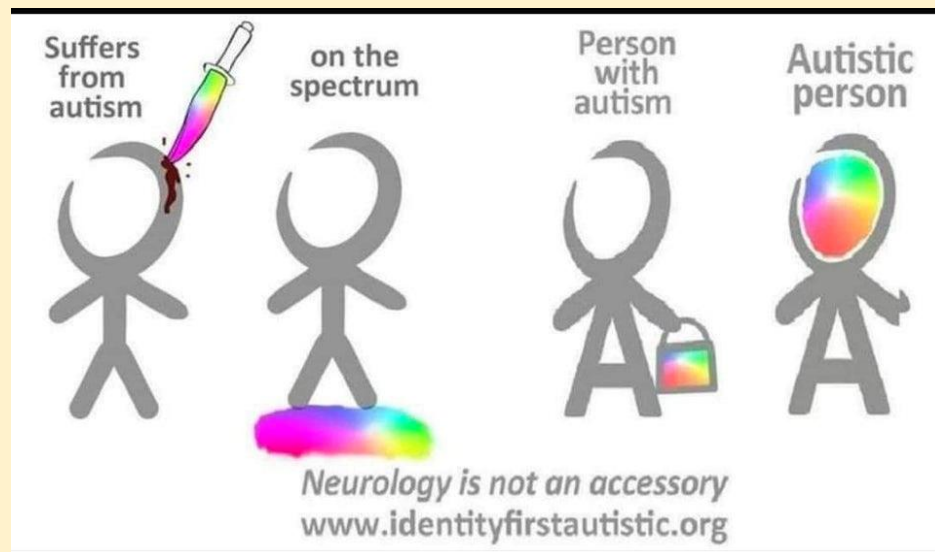
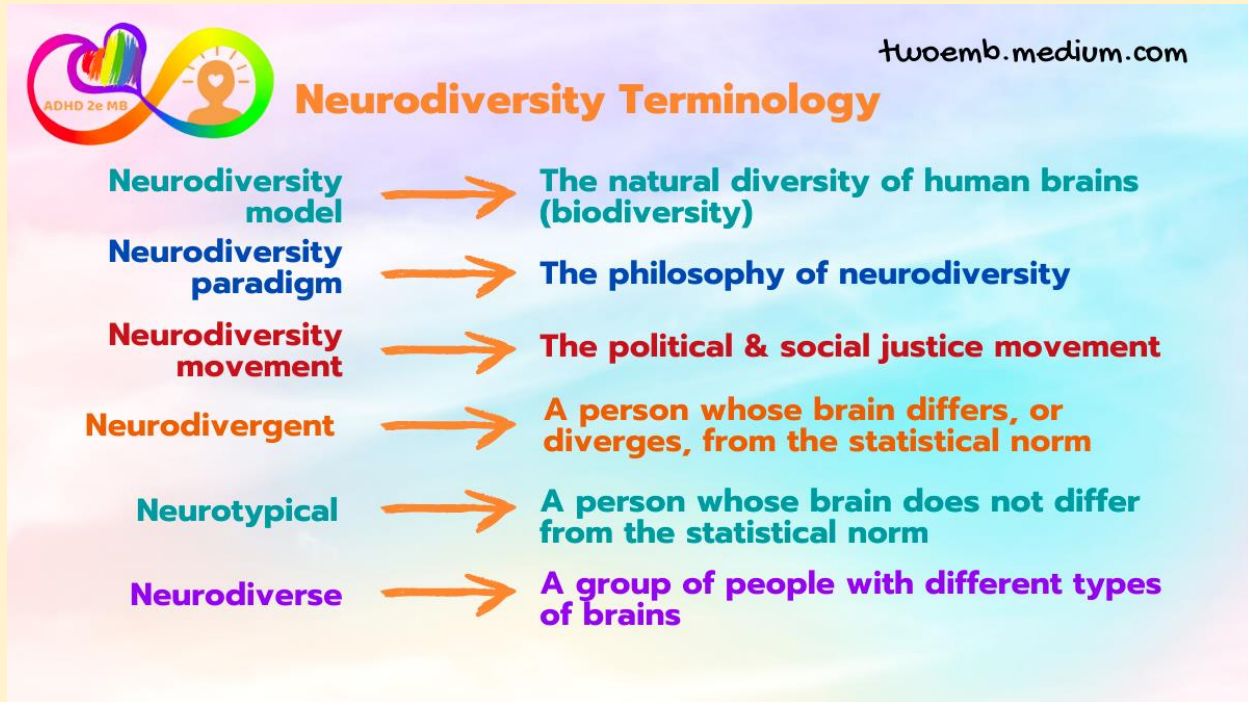
- Encouraging TDs and policymakers to increase their awareness and understanding of neurodiversity and the diversity of the autism community. Consider provision of autism awareness sessions such as is the case in the U.K.

<https://www.autism.org.uk/what-we-do/news/george-stanbury-understanding-autism-mp>

- Mandatory training on autism awareness for all public service staff, starting with the health service. The Health and Care Act 2022 in the U.K. has passed into law that from July 1st all NHS staff will receive training in learning disability and autism. This training has been co-produced and is co-delivered by Autistic and learning disabled trainers.
- Ensuring that, in line with UNCRC and UNCRPD, all children have a right to an inclusive education and that all schools have autism-inclusive cultures.

- Develop programmes targeted at preventing and addressing stigma, bullying and discrimination against Autistic people.
- Ensure that recruitment campaigns and interview processes are adapted to meet the needs of Autistic adults.

## Topic 4 – The words we use



Question 8

## **What words should be used in the autism Innovation Strategy to talk about autism and people with autism?**

- **Language/Terminology:**

Language is a powerful tool for shaping how society views autism and the Autistic experience. Through avoiding ableist language when describing the Autistic experience, non-Autistic service providers, educators, and Irish society at large can be more understanding, accepting and inclusive of Autistic people. Consistency of language use is paramount.

### **We recommend:**

- Honouring the widely expressed preference amongst Autistic people of identity-first language. This is in line with recent updates from the National Institute for Health and Care Excellence (NICE). This means using “Autistic individual/person/child/adult” in place of “individual with autism” and doing so consistently throughout all government documents, communication, public fora and social media posts. Inconsistency contributes to confusion in Irish society and can perpetuate stigma and misunderstanding.
- While we acknowledge that the diagnostic classification systems continue to require use of Autism Spectrum Disorder (ASD), we recommend use of “Autism” in line with NICE guidelines.
- Avoiding use of terms “high-functioning”, “low-functioning”, “mild/moderate/severe” when describing the Autistic experience. This can wrongly imply that some Autistic individuals do not require support at certain time points in their lives or in certain settings. The use of this language is also firmly rooted in the medical model of disability. It is deficit-based language which we need to move away from and towards a more inclusive social model of disability. Instead, describe the Autistic individual’s strengths and specific needs with acknowledgement that these needs can be context-specific and not across all domains.
- Instead of describing the individual as being “at risk of ASD”, describing instead an “increased likelihood that the individual is Autistic”.
- Instead of describing “autism symptoms or traits”, use instead “Autistic features”.



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