



neuro-affirming
community
of practice
scotland



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Scottish Government
Riaghaltas na h-Alba



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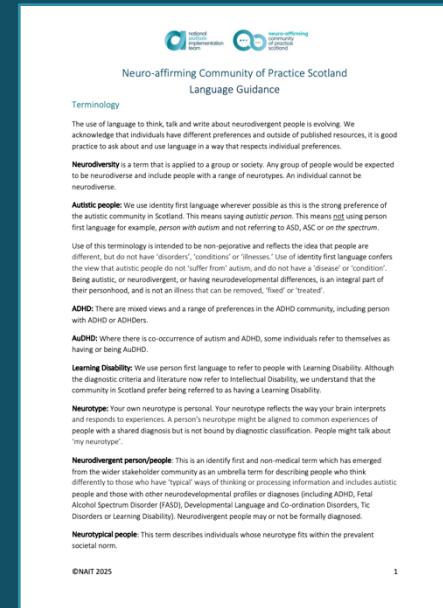
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Terminology

- Most autistic adults prefer **identity first language**. This means using terms like ‘autistic person’
- Some neurodivergent groups prefer **person first language**, like person with learning disability
- Neurodiversity refers to a group or society
- An individual cannot be neurodiverse



Plan

- Developing a Neuro-affirming Community of Practice in Scotland
- Aims, Vision and Values
- Key Messages
- Thinking Differently
- Community Action
- Resources

Developing a Neuro-affirming Community of Practice in Scotland

What is a community of practice?

“...groups of people who share a concern, a set of problems, or a passion about a topic and who deepen their knowledge and expertise in this area by interacting on an ongoing basis.”

Wenger et al (2002)



“There is no cavalry - we are the cavalry”

- Peer support and discussion
- Learning and keeping up to date
- Multi-disciplinary perspectives
- Sharing knowledge and practice
- Raising issues
- Developing resources together
- Radical acceptance

Vision and values

Our Vision

A public sector in Scotland where professionals work together guided by neuro-affirming principles, to ensure neurodivergent individuals are supported, respected, and empowered at every stage of life.



Our Values





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Nothing about us without us





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Difference not deficit





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Support to be my authentic self





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Listen without judgment





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Universal neuro-affirming practice



Diagnosis matters



Membership



64 - 76%
neurotypical



9 - 35%
neurodivergent



9 - 73% part of a
neurodivergent
family

Participant reflections

“We need to change practice, but we have to do it together.”

“Small things make a big difference.”

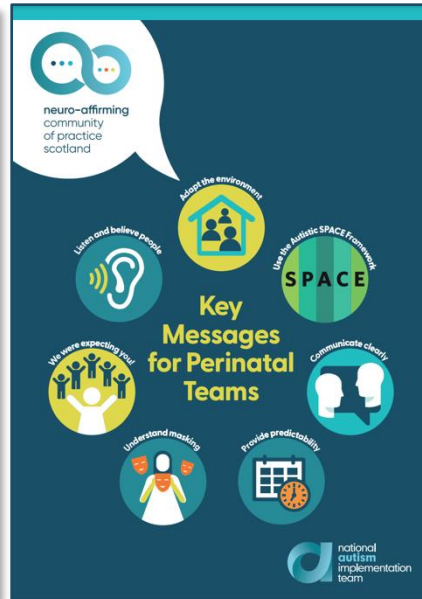
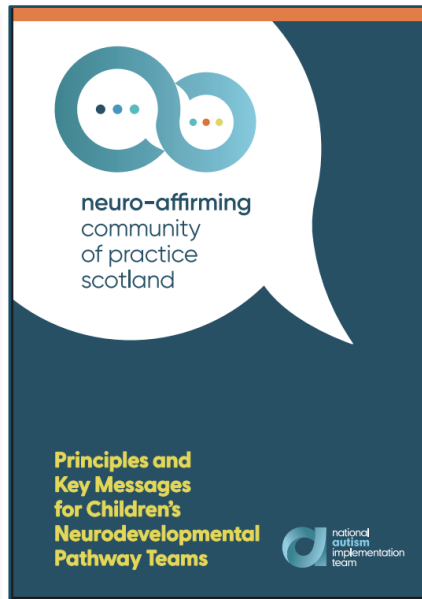
“We have to spread the message far and wide that it’s our responsibility to create spaces where people can be confidently autistic and be confident allies.”

“There’s a whole community of people wanting to make these changes – we are not on our own!”

“These events are lifelines to clinicians surfing against the tide of the tsunami of work ahead.”

Key Messages

Key Messages



Community Actions

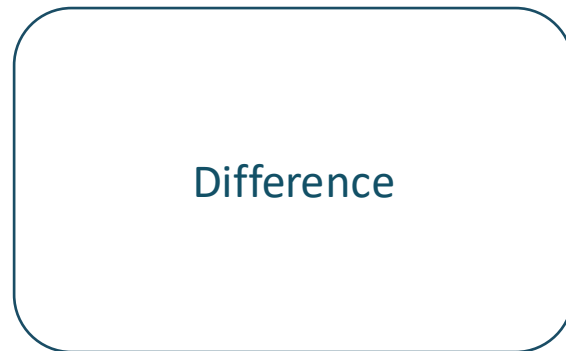
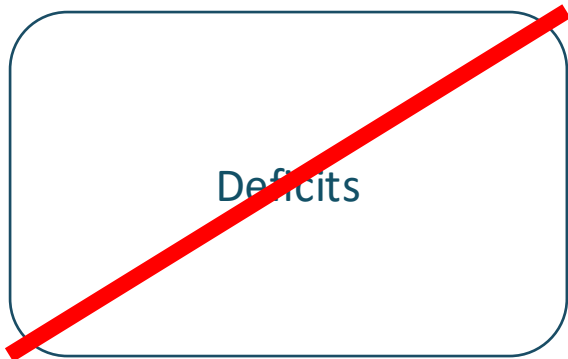
A neuro-affirming approach

- Using language of difference not deficit
- Having expectations matched to individual neurotype
- Affirming neurodivergent identity
- Supporting individuals to become their authentic self
- Being mindful of masking
- Learning from neurodivergent people

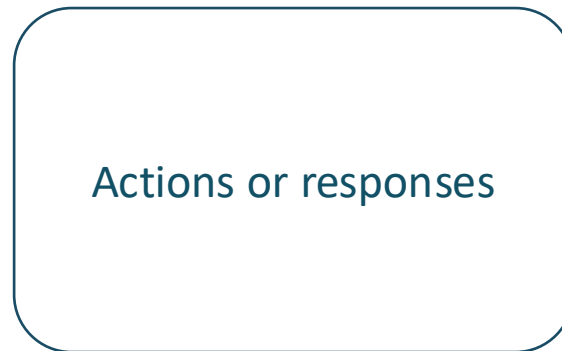
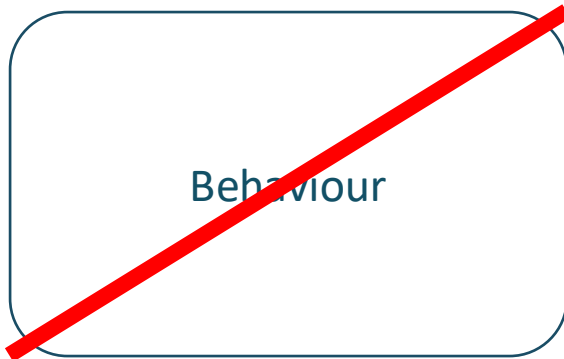


Thinking Differently

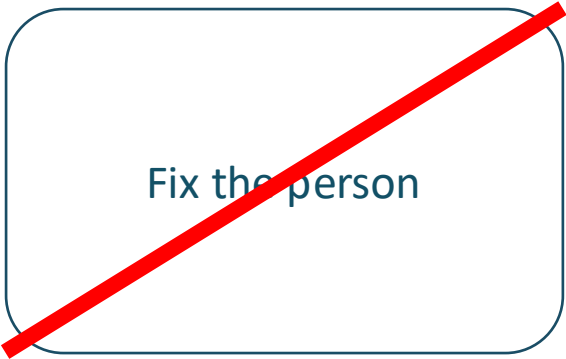
Changing language



Changing language



Changing thinking



Fix the person

Adapt the environment

Changing thinking

~~Earning rewards~~

Good things just happen

Changing thinking

~~Teaching neurotypical
social skills~~

Honouring individual
communication styles

Changing thinking

~~Demand for services~~

Need

How can the community help?

- Co-production guidance – how can we do ‘nothing about us without us’ in our context
- Guidance on language and terminology
- An evidence informed definition of neuro-affirming
- Collaborating
- Practical guides and tools
- A place to share achievements
- Training resources for local teams to use



Members asked us... The community acted

...how do we put the principle of 'nothing about us' into practice?



NAIT guide to co-production with neurodivergent communities

What is co-production?

"Real co-production means that people are truly involved in planning and designing services from the very beginning."

Table 1 Ladder of Co-production

Co-producing	Work includes service users and other organisations at each stage. Decisions are shared.
Co-designing	Service users and other organisations are involved in the design of services or products. They influence decisions but aren't involved in seeing it through.
Engaging	Service users and organisations are given opportunities to express their views and can influence some of the decisions.
Consulting	The views and preferences of service users and organisations are sought and considered.
Informing	People receive information about services and how they work.
Educating	People are educated about the benefits and rationale of services. This may include trying to persuade them to act differently.
Coercing	Requiring people to do something without considering their needs and preferences.

Co-production works towards maximising acceptability, participant adherence and satisfaction. Consideration must be applied to ensure that everyone is able to contribute to the process on an equal footing. Successful co-production requires project coordinators to address issues relating to shared decision making, power hierarchies, tokenism and ensure meaningful partnership with consumers.

Incorrectly defining a project as co-production when it only includes aspects of co-production may cause participants to feel frustration and mistrust the project coordinators (Nicolaidis et al., 2019). Be clear from the beginning about how community members will be involved in the project and how decisions will be made. If organisational structures, policies, time pressures or lack of resources are likely to obstruct aspects of co-production, try to be open about these limitations with participants to increase trust and temper expectations.

If it is not possible to fully co-produce a project, there is still value in including neurodivergent people in other ways. It is important that practitioners continue to reflect and move from coercing and educating practices up the ladder towards co-production (see Table 1).

There are many publications which described co-production processes and we have provided links to some resources which may be helpful.

These projects are examples of projects which include aspects of co-production.

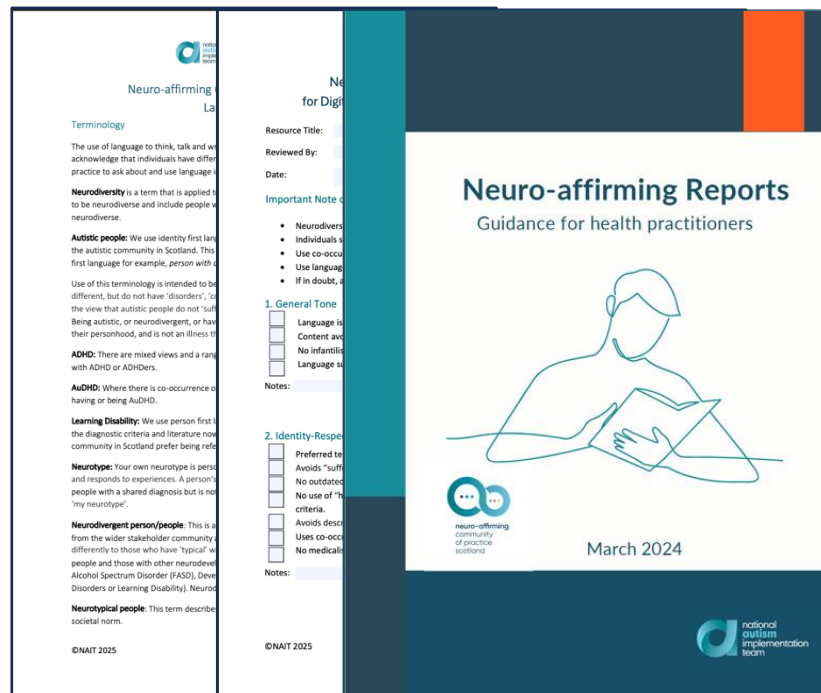
- <https://www.hiengage.scot/sharing-practice/case-studies/neurodevelopmental-differences/>
- <https://www.scid.org.uk/learning-disability-lived-experience-board-an-update/>
- <https://scottishtransitions.org.uk/divergent-influencers/>
- <https://wisp.capability.scot/about/co-production/>
- <https://www.autismcentral.org.uk/co-production>

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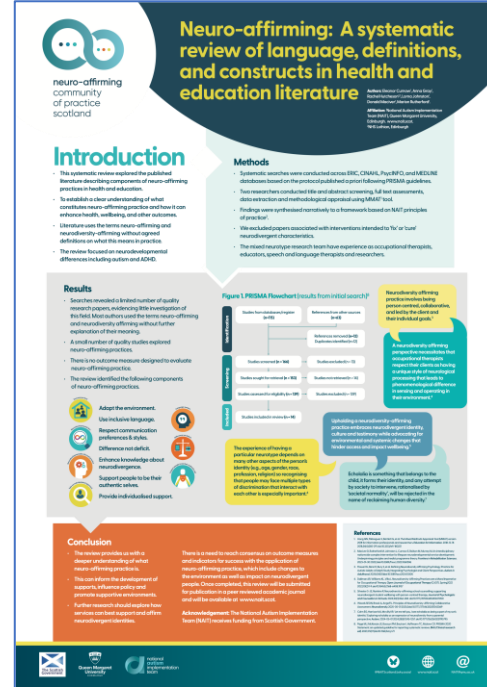
Members asked us...

The community acted

...how do we use
neuro-affirming
language?



...what is the definition of neuro-affirming practice?



Members asked us... The community acted

...how can we
get involved?



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Working groups 2024-25

We are extending an invitation to the community of practice, to express interest in being part of a working group. The community identified priority areas of interest and need. The following working groups are planned for the 2024-25 session.

-  1. Neuro-affirming support for parents and carers
-  2. Neuro-affirming approaches to AAC
-  3. Neuro-affirming plans and reports in education settings
-  4. Resources to support adults to develop understanding of being neurodivergent, that are neuro-affirming and up to date

To express interest in being part of a working group, contact
NAIT@qmu.ac.uk



national
autism
implementation
team

Members asked us... The community acted

...can we have
some practical
guides and
tools?



Members asked us...

...how can we
better support
neurodivergent
colleagues and
employees?

The community acted



Members asked us...

The community acted

... is there a tool for considering neuro-affirming health environments?



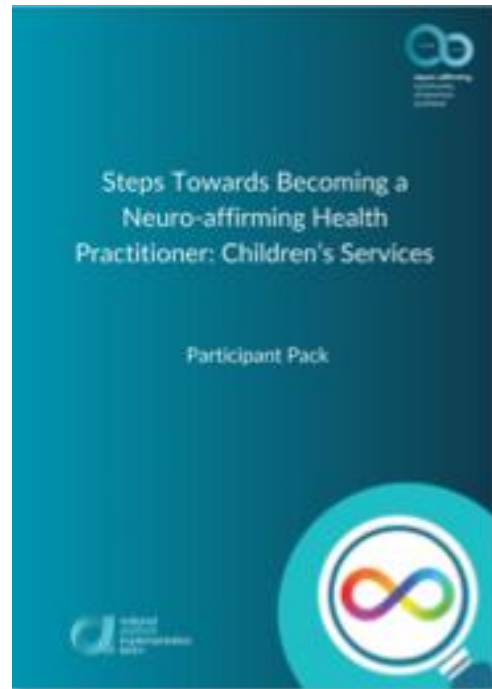
Members asked us... The community acted

...how can we
share our
achievements?



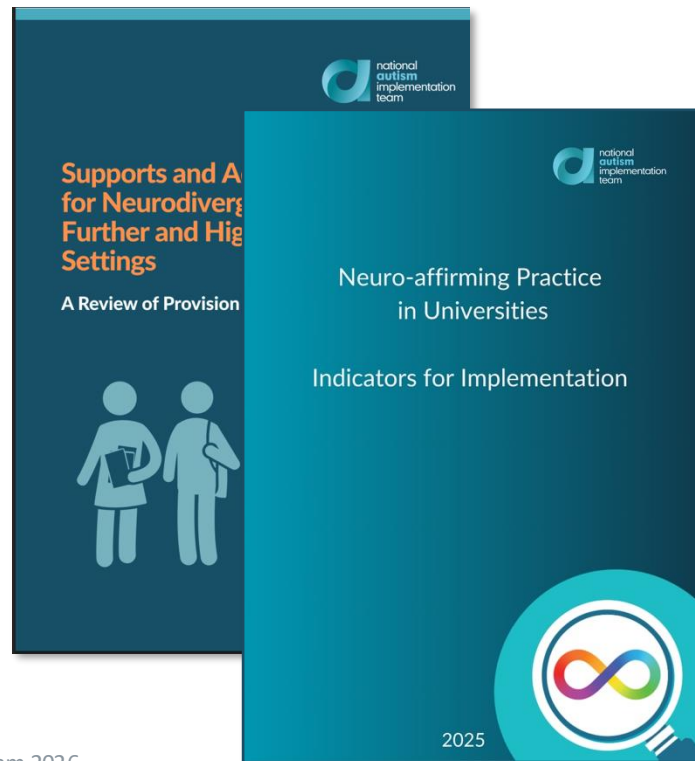
Members asked us... The community acted

...how can we train
our local teams
about neuro-
affirming practice?



Members asked us... The community acted

...what about
universities and
colleges?



Resources

NAIT masking resources



NAIT Guide to Autistic Masking

Introduction

The following is a short summary about autistic masking, written in partnership with autistic people, for professionals to increase awareness of this phenomenon and to signpost to further reading for those who wish to know more. It can be helpful for people involved in diagnostic assessment and those around autistic people day to day, to understand why it happens, how tiring it can be, and to create environments which are accepting of differences in a way that individuals can feel safer being themselves.

In the undiagnosed, masking can lead to the possibility that diagnosis is missed. Even if the need for diagnostic assessment is recognised, masking means that professionals need to look beyond the words people say or initial impressions.

What is autistic masking?

- Autistic masking involves covering up or suppressing natural and actual internal feelings, preferences, and reactions to sensory, communication and social experiences, also referred to as 'autistic traits'.
- It is a coping strategy for many individuals.
- Sometimes this is a deliberate decision but often, particularly in younger people, it is unconscious or not deliberate.
- It can serve a necessary purpose but is also immensely tiring and comes at a cost to mental health and wellbeing.
- This is a particular phenomenon in autistic people because they live in a world where they don't have the 'predominant neurotype', and which is not always accepting of diversity and difference.
- Masking can help individuals avoid feeling as though they stand out and they might adopt behaviours and responses observed in the 'neuromajority'.
- Nearly 75% of autistic people (male and female) surveyed, report masking all or some of the time to avoid being perceived as visibly autistic.

Why does autistic masking happen?

Masking tends to happen as a coping or self-preservation strategy, and as a kind of 'stigma management' individuals use to avoid being judged negatively for being themselves, and to prevent discrimination and harassment.

What might we notice if someone is masking?

The conversation partner or observer is often unaware that someone is masking. It is possible that individuals mask most or all of the time in some contexts and you may only know them with this demeanour.

When we know someone well, they might tell us about things they do, or we might notice them using a range of strategies, tactics, and processes:

- A rehearsed repertoire of social responses, to greetings, questions, conversations, or overtures others make

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Talking to your child's school about... Autistic masking



Who is this guide for?

If your child is autistic or has related support needs and you answer yes to any of the following questions, this guide might be helpful.

Do you...

- notice differences between the ways that you and your child's school describe your child?
- sometimes feel like you and the school team are describing different children?
- wonder if your child might be masking or covering up how they really feel?
- worry that masking might lead to their support needs not being recognised and met?

This guide has been produced in partnership with the **National Autism Implementation Team**. NAIT is a cross sector partnership working to support the delivery of Scottish Government priorities for people with neurodevelopmental differences.

Understanding autistic masking

Autistic masking involves a person covering up natural feelings, preferences, and reactions to the world around them. Masking can be useful but is also hugely tiring and can affect mental health and wellbeing. Often autistic children are working much harder than everyone else just to get through the day. Not all autistic children will be aware they are masking.

Why does masking happen?

Masking can feel like a way for the child or young person to:

- Avoid negative attention, stigma, bullying or discrimination
- Feel accepted or included in a friendship group
- Succeed in social settings of school and in their community

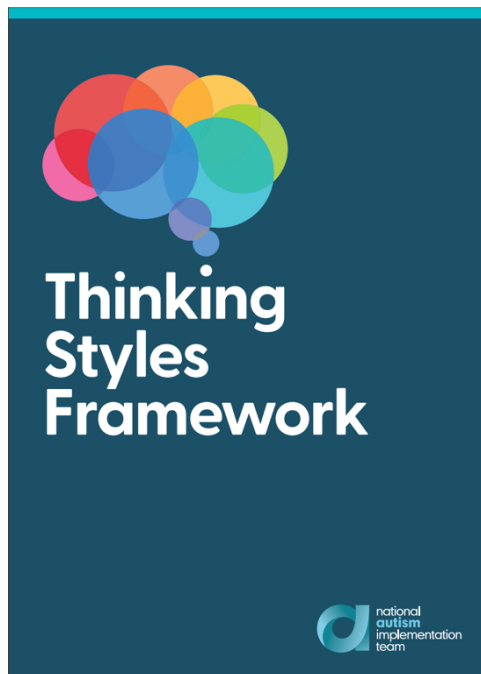
For more detailed info:
NAIT Understanding Autistic Masking:
A Guide for Parents and Carers



NAIT masking resources



Thinking Styles




Thinking Styles Framework

Practitioners can use this neuro-affirming framework when making observations, to better understand individual thinking styles and to support neurodivergent learners. Through understanding different ways that individuals process their inner and outer world, we can take a non-judgmental approach to actions and responses that we observe. We can understand what we see as natural ways of being, that may be different to some of the learners in school, but are definitely not wrong.

- 

1. Processing the environment
We all have our own individual processing style, preferences, actions and responses in relation to the information around us in the sensory and communication environment. Some things support participation, other things make it harder.
- 

2. Predictive & sequential thinking
Individuals have ways of processing information which affect how they prioritise, plan, organise and sequence thoughts and actions. Each person has different capacities to control impulses at different ages and in different contexts.
- 

3. Drawing meaning from context
There are different ways to process and take meaning from context. Some learners might focus on detail and miss what is obvious to others. Alternatively, individuals might use multiple sources of information from visual, auditory, historical and social contexts to try to make sense of experiences in the moment. Some may find it hard to pick out which are the relevant and salient bits of information.
- 

4. Attention priorities
People naturally use particular attention styles in social and non social activities. We might notice what captures attention best, how we prioritise and process all the things competing for attention and how easily individuals can shift or share attention. Some individuals can really focus on something for a long time when passionate about the topic or activity.
- 

5. Perspective taking
We pick up and send dynamic signals about thoughts, feelings, beliefs and experiences with or without words, in more or less direct ways and with more or less intention. This is true of our own perspective and how we pick up direct or indirect signals from other people about their thoughts, feelings, beliefs and experiences.
- 

6. Making connections
People find ways to understand other's intentions, motivations and communication styles. We identify good connections with some people more than others. We have different preferences for how much time we spend making connections and the way we do this.

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Newsletters and Bulletins





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- **a listening and learning community**
- **connecting professionals across sectors**
- **building alliances with neurodivergent people**
- **evolving evidence and practice**

