

National Neurodivergence Team Engagement and Participation Strategy, 2023-25



Purpose:

The purpose of the National ND Team is to help improve the lives of neuro divergent people and their families in Wales.

The strategy clearly outlines the ethos and practice of the team in working **with** neuro divergent people, their families, and professionals to achieve our purpose.

Background:

The first engagement and participation strategy produced by the team was implemented in 2019. That strategy, produced in partnership with autistic people and other partners, established the principles that informed the work, direction and outcomes for the team. That strategy ended in 2022. However, in reviewing the current strategy it was evident that those underlying principles remain unchanged. Therefore, this strategy will build upon the firm foundations already established. (see appendix 1). The initial strategy focused on autism and the updated version has a wider ND focus.

Progress to date:

- The development of a series of resources – videos, training packs and eLearning modules developed with autistic people.
- The development of a project management approach to resources development. This has included the development of autism advisory groups that are comprised of a range of autistic people, working groups that has a mix of stakeholders including autistic people, parent carers and professionals. (see appendix 3 for good practice case studies).
- The delivery of jointly planned and facilitated events including an employment conference, and a wellbeing conference.
- The development of clear participation packs for members of advisory groups (see appendix 2)
- Partners, including autistic people, have been part of our recruitment process for any vacant posts in the team. This has also helped to inform the whole process making it more inclusive for both candidates and panel members.
- Our website was co-produced partners.

- We have worked closely with Tourette's Action to help them establish effective links with local authorities and health boards across Wales.
- Held a series of community of practice webinars on range of topics including gender dysphoria, family dynamics and autism, ADHD in women and girls, FASD, ND in the classroom. These events have been delivered to a diverse membership and routinely includes the voice of ND people in the delivery – often as the keynote speaker.

Future developments:

- The establishment of ADHD advisory and working group
- The development of a mental health advisory group comprised of ND people with experience of secondary and primary mental health services.
- The expansion of the mental health working group
- The development of ND resources
- The development of a parent carer advisory group, a ND parents advisory group and a Family Support working group.
- The development of specific communities of practice for education professionals
- The development of a specific community of practice for parent carers
- The establishment of a working group to oversee the expansion of the website.
- The further development of information and resources for autistic and ND adults
- The further development of information and resources for parent carers
- The development of information and resources for children, especially teenagers.

Appendix 1

Engagement and Participation Strategy 2019-2022

Working together for the best possible outcomes for autistic people and their families and carers.

The National ASD Development Team was set up to assist the Welsh Government in rolling out its Autism Strategy across Wales. In this role the team has produced a range of free resources that autistic people, their families and carers, professionals and the wider community can use. The resources, training and guidance aims to increase the wider understanding of autism whilst offering practical tools, training and advice for autistic people and their families and carers. The overall aim of the team is to help improve the lives of autistic people so that they have the same life chances as neuro typical people. To better reflect this the team is now called the National Autism Team.

1. Background

Throughout the lifetime of the team there has been informal and ad-hoc arrangements in place to gain the views of autistic people and parents and carers. Their views helped inform the development and roll out of resources and training. However, it is apparent that going forward that this arrangement must be more formalised and the Team actively engage with a much wider range of people from the autistic community on a regular and ongoing basis. The participation and engagement process will underpin the work of the team. This strategy is aimed at autistic people, their families and carers, professionals, organisations and the wider community.

There are numerous benefits of meaningful engagement and participation including:

1. Autistic people are given a voice
2. Parent and carers of autistic people are given a voice
3. People feel valued and listened to
4. Services are more responsive to need and fit for purpose
5. Autistic people (and their families/carers) are involved in the development of new resources and in assisting in rolling out current
6. People who use the service are viewed as assets with skills
7. Breaks down barriers between service users and professionals
8. Build upon capabilities
9. Mutual respect
10. Work with peers and personal support networks and professional network
11. It improves the quality of research and service delivery.
12. Partners from the statutory and 3rd sector are actively involved.
13. Best practice - working with people more productively and effectively ensures that individuals achieve the best outcomes. 'Nothing about us without us.'
14. It raises the profile. Autism is widely promoted and there is a greater understanding and acceptance within the community.

2. Defining engagement and participation

Participation Cymru promote the use of the following definitions:

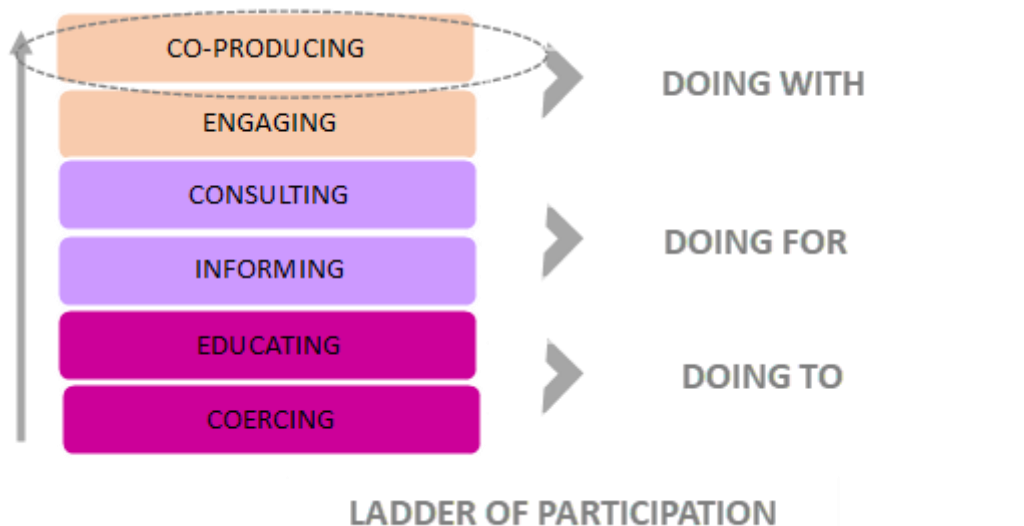
1. **Engagement** is 'an active participative process by which people can influence and shape policy and services that includes a wide range of different methods and techniques.'

2. **Consultation** is 'a formal process by which policy makers and service providers ask for the views of interested groups and individuals.'
3. **Participation** is 'People being actively involved with policy makers and service planners from an early stage of policy and service planning and review.'
4. **Co-production**. SCIE defines co-production as 'A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities'. (National Co-Production Critical Friends group) and 'a fully co-produced approach will stress the value of meaningful engagement with people at all stages, through design, delivery and evaluation, rather than simply as 'feedback.'

3. Levels of engagement

'Whole system approach.'

- Participation becomes part of daily practice
- Organisation must adopt the change at every level
- Different levels – many ways to involve people.



4. Methods of engagement

To ensure that people have the opportunity to engage at the most appropriate level for them and via their preferred method a range of methods will be used including:

- Face to face
- Network meetings
- Workshops
- Representation on a management group
- Robust links with existing groups, forums, steering groups etc.
- Media
- Website
- Email
- Text
- Telephone
- Surveys
- Events

For these activities to be meaningful they must be effectively planned, organised and coordinated. The National Autism team are committed to ensuring that this process works and reaches out to as many people as possible across the age range, levels of ability and the country. Therefore, to ensure that this happens we will work with partners to develop a 3-year work plan that will inform the development of any new resources, evaluating and updating of existing resources, roll out of training and resources, awareness and understanding activities and campaigns, and inform our work with Welsh Government and other agencies.

5. Putting it into action

We will launch a draft strategy at the 2019 Going Gold Event and encourage autistic people, parent, carers and organisations to be involved in the development of this work. In partnership we want to undertake the following actions to inform, develop and implement an engagement and participation work plan. We will set up a working group to:

1. Identified stakeholders
 - autistic people
 - Parents and carers
 - Communities
 - Organisations
 - Other partners as appropriate to the subject e.g. housing providers if related to housing
2. Identify the what we want to do
3. Identify why we want to do it
4. How and where we want to do it
5. Develop and oversee the progress of the work plan that will incorporate the engagement objectives below.

Engagement objectives			
Why	1	Activity	What is the purpose of the activity?
Who?	2	Stakeholders	Who are your key stakeholders?
How?	3	Level of engagement	What level is required?
	4	Proposed method of engagement	Outline how you are going to undertake the process
When	5	Timing	When do you want this process to happen – intervals, process etc.
What	6	Resources	What will we need to undertake the process
Who	7	Responsibility	Who has responsibility for each aspect
How	8	Communication	How are we going to communicate throughout the process

6. Next Steps

1. Launch the draft strategy at the Going Gold event in April 2019
2. Establish the working group, which will include autistic adults and parents and carers, to oversee the work
3. Develop work plan and networking template to incorporate Participation Cymru's principles of participation checklist (Appendix 1)

4. Via a range of methods gain views and establish work plan areas for the next 3 years.
5. Develop processes to facilitate engagement and participation.
6. Produce work plan with stakeholders.
7. Implement work plan to include more detailed plans around each identified work area e.g. updating the parent carer guides, updating the adult's guides.
8. Each work area will have an engagement plan to ensure that as wide a range of views can be gained as possible.
9. The working group will meet regularly to review progress and amend work plan as appropriate.

7. What do you have to do if you want to be involved?

Contact the National Autism Team at www.ASDinfoWales.co.uk / ASDinfo@WLGA.GOV.UK and they can tell you how to get involved.

Principles into practice



a checklist for implementation

This checklist, based on the **National Principles for Public Engagement in Wales** and the **National Children and Young People's Participation Standards in Wales** is to enable those designing engagement to plan effectively for success. As part of your planning process work through each principle / standard, asking yourselves the following questions.

1 Engagement is effectively designed to make a difference

Respect - Your opinion will be taken seriously - CYP standard 4

- Will it make a difference?
If yes, are you clear about the purpose and outcome of the engagement activity?
If unsure, then spend more time to gain clarity on the purpose and outcome.
If no, then don't do it or challenge those who are expecting you to do it.
- Are you clear as to what can and can't be changed or what is and isn't up for discussion or decision making?
- How will you measure what difference the engagement has made?

2 Encourage and enable everyone affected to be involved, if they so choose

It's Your Choice - enough information and time to make an informed choice - CYP standard 2

- Who needs to be involved?
- Who wants to be involved?
- How do you reach these people?

3 Engagement is planned and delivered in a timely and appropriate way

- How long are you allowing for the planning stages of engagement? (it ALWAYS takes longer than you think)

- Are you clear about the level/ s of engagement needed?
- What variety of mechanisms are you going to use?

4 Work with relevant partner organisations

- Who are you currently working with?
- Who else do you need to work with?
- Are you able to shared existing engagement information?
- Are you working with the third sector to access groups?

5 The information provided will be jargon free, appropriate and understandable

Information - which is easy for children and young people to understand - CYP standard 1

- Is the information free of jargon?
- Is the information relevant to the engagement?
- Is it accurate and up to date?
- Does it give people everything they need to know to engage?
- Have you tested it out with a user group?
- Are there different formats available e.g. children and young people's version, easy to read, audio, large print, bilingual

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Appendix 2

Advisory group case studies

Below are some case studies from members of our advisory groups, reflecting on their experience of being part of a project advisory group.

Case Study 1:

Please could you give an overview of your experience as a member of the advisory group? i.e. Which projects have you worked on? What tasks have you done as part of the group?

I have been a member of the Autism Advisory group for a couple of years, helping create updated website content and e-learning modules.

How have you found the experience of being part of the advisory group? I.e., has it been positive or negative? What impact has it had on you?

As a late in life self-realised and later diagnosed autistic woman I have found it to be a deeply positive experience. Having my voice heard, meeting other autistic people and being able to play a leading role in raising awareness and dispelling myths are just some of the positive outcomes of my involvement.

If your experience has been positive, what do you think works well about the advisory group format/approach?

The frequency of the meetings work well: not too often to become unmanageable, but frequent enough to feel progress is being made. Each advisory group member can contribute in a way that suits them. Also all members of the team are approachable and really listen. It matters that there are neurodivergent team members too - it aids communication.

Case Study 2:

Please could you give an overview of your experience as a member of the advisory group? i.e. Which projects have you worked on? What tasks have you done as part of the group?

Information sheets for autistic people.

How have you found the experience of being part of the advisory group? I.e., has it been positive or negative? What impact has it had on you?

Mostly positive, it has helped my confidence to be able to have a voice in the decision making processes affecting neurodivergent people.

If your experience has been positive, what do you think works well about the advisory group format/approach?

It's a good way to connect with people with lived experience who can bring their experience to the decision-making process. It has been good to think about the issues and best approaches to information sharing for autistic people.

Case Study 2:

Please could you give an overview of your experience as a member of the advisory group? i.e. Which projects have you worked on? What tasks have you done as part of the group?

I've been involved for about a year to 2 years.

How have you found the experience of being part of the advisory group? I.e., has it been positive or negative? What impact has it had on you?

It's been hugely positive for me to engage on issues that matter in a largely safe space. Only once have I come away from this and felt that it was a bad experience, due to the behaviours/attitudes of other attendees.

If your experience has been positive, what do you think works well about the advisory group format/approach?

It brings people together with lived experiences to share those and help shape our future.