



# **National Neurodivergence Team Engagement and Participation Strategy, 2025-27**



## **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 their 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 and was reviewed and updated in 2023 and again in 2025. 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.

Coproduction is a key principle underpinning the work of the National Neurodivergence Team. It was decided to add a Coproduction Checklist to this updated version of the Engagement & Participation Strategy (see appendix 3), as well as include the Participation Information (see appendix 4)

## **Progress to date:**

- The creation of a series of resources – videos, training packs and e-learning modules developed with neurodivergent people.
- The development of a project management approach to resources development. This has included the development of various advisory groups, comprised of a range of neurodivergent people, working groups that has a mix of stakeholders including neurodivergent people, parents & carers, neurodivergent parents & carers and professionals. (see appendix 2 for good practice case studies).
- The delivery of jointly planned and facilitated events including an employment conference, a wellbeing conference and relaunch event.

- The development of clear participation packs for members of advisory groups (see appendix 4 for an example ) Partners, including neurodivergent 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.
- The expansion of our website, moving from AutismWales.org to NeurodivergenceWales.org and the establishment of working groups reviewing content and usability.
- Working closely with Tourette's Action to help them establish effective links with local authorities and health boards across Wales.
- The expansion of Community of Practice webinars on a range of topics. These events have been delivered to a diverse membership of professionals and routinely include the voice of ND people in the delivery – often as the keynote speaker.
- The establishment of an ADHD advisory and working group and creation of an ADHD information Film and e-learning module.
- The establishment of Parent & Carer Advisory Groups including a Neurodivergent Parent & Carer Advisory Group.
- The creation, development and delivery of a series of virtual information & advice sessions for parents and carers on a range of topics and delivered by neurodivergent speakers.
- The creation and development of audio information sessions by and for neurodivergent parents.
- The creation of resources for parents & carers including Hints & Tips sheets
- The development and delivery of a suite of communities of practice for education professionals.
- The creation of advice sheets for neurodivergent people.

## Future developments:

- The further development of information & resources for neurodivergent adults.
- The further development of resources for parents and carers and neurodivergent parents & carers.
- The development of information & resources for children and teenagers.
- Reviewing & updating the Learning About Autism scheme to a Whole School Approach to ND programme.
- Developing resources for family facing professionals.

# 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 3<sup>rd</sup> 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:

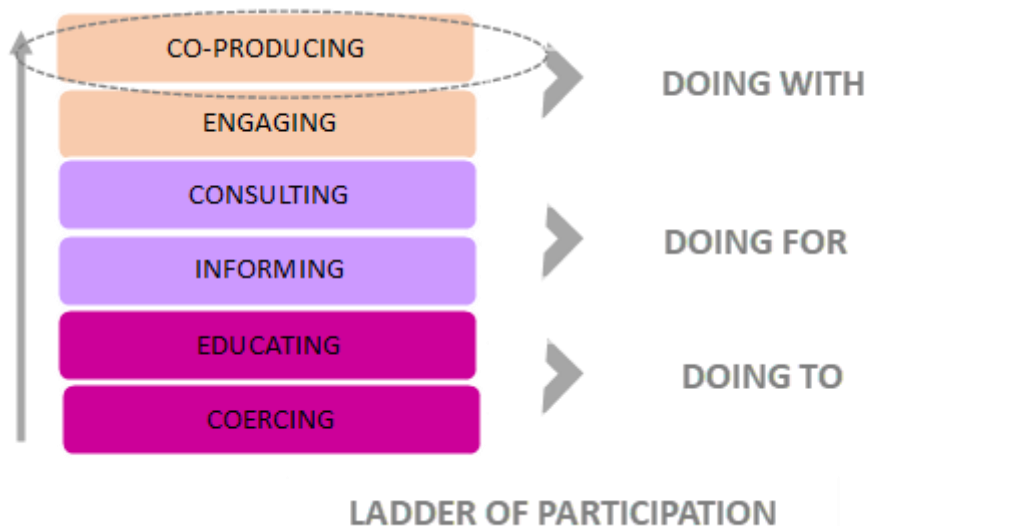
1. **Engagement** is 'an active participative process by which people can influence and shape policy and services that includes a wide range of different methods and techniques.'

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 |   |                               |   |
|-----------------------|---|-------------------------------|---|
| <b>Why</b>            | 1 | Activity                      | What is the purpose of the activity?                              |
| <b>Who?</b>           | 2 | Stakeholders                  | Who are your key stakeholders?                                    |
| <b>How?</b>           | 3 | Level of engagement           | What level is required?   |
|                       | 4 | Proposed method of engagement | Outline how you are going to undertake the process                |
| <b>When</b>           | 5 | Timing                        | When do you want this process to happen – intervals, process etc. |
| <b>What</b>           | 6 | Resources                     | What will we need to undertake the process                        |
| <b>Who</b>            | 7 | Responsibility                | Who has responsibility for each aspect                            |
| <b>How</b>            | 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](http://www.ASDinfoWales.co.uk) / [ASDinfo@WLGA.GOV.UK](mailto: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

**Participation**  
**Cymru**



## 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.

### Appendix 3 - Coproduction checklist

|   |  |  |
|---|--|--|
| 1 | <p><b>Is everyone an equal partner?</b></p> <p>All parties recognise that everyone involved has something valuable to contribute and with the opportunities to do so. The team should actively explore and identify opportunities for Co-production, working in a collaborative way to involve skilled and experienced people in shaping and influencing the work of the team.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"><li>• Are decisions made by all group members in partnership?</li><li>• Are all parties (including the ND community and professionals) equally represented in the group?</li><li>• Do all partners understand their roles and responsibilities?</li></ul>  |  |
| 2 | <p><b>Does everyone have opportunities to participate in all stages of the process?</b></p> <p>Co-production can happen at all stages of work, from inception to completion. Co-production itself should be reviewed, with everyone taking an active role. Where possible, all parties should be offered opportunities to get involved at all stages.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"><li>• What opportunities have been identified for Co-assessment?</li><li>• What opportunities have been identified for Co-design?</li><li>• What opportunities have been identified for Co-delivery?</li><li>• What opportunities have been identified for evaluation and reflection of the work of the team and Co-production processes?</li></ul> |  |

|   |   |  |
|---|---|--|
| 3 | <p><b>Are everyone's views and experiences represented?</b><br/>Efforts are made to seek views and experiences from a diverse range of people.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"> <li>• Have partners from a broad cross section of intersectionality been identified? How was this achieved?</li> <li>• Have partners from a diverse range of backgrounds / professions etc. been engaged? How was this achieved?</li> <li>• Have first language Welsh speakers been given equal opportunity to participate?</li> <li>• If not successful then what are next steps?</li> </ul>  |  |
| 4 | <p><b>Is there a commitment to try new approaches and to work in different ways to achieve desired outcomes?</b><br/>Co-production activity often requires the investment of time, money and resources, and these requirements should be met by those leading the work. Everyone should be able to recognise the impact of their contributions, for example through the use of 'You said...we did' responses or other feedback mechanisms.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"> <li>• What engagement methods have been used? How successful were they?</li> <li>• Has a Co-production Plan been developed to support the work? Is this being used?</li> <li>• Have all partners helped to inform on how best to engage a diverse range of people in this work?</li> </ul> |  |

|   |  |  |
|---|--|--|
| 5 | <p><b>Has clear, concise participant information been developed and shared?</b></p> <p>Decisions and information will be clearly communicated, to agreed timescales, with details and terminology clearly explained and agreed. Communication preferences will be respected.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"> <li>• Have preferred methods of contact been agreed with all partners?</li> <li>• Is all information accessible to all in different formats or languages where needed?</li> <li>• Have timescales and methods for distributing information / meeting minutes etc. been agreed?</li> <li>• Does everyone know who to contact if they need further information or clarification?</li> </ul> |  |
| 6 | <p><b>Is everyone able to actively participate in meetings and other events?</b></p> <p>Meetings, activities and events should be held at mutually convenient times and venues where possible.</p> <p>Everyone should be involved in the decision-making process, with a range of opportunities to fully participate.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"> <li>• Have you discussed preferred meeting times with all parties?</li> <li>• Are meetings held at venues that are suitable for / local to the majority of attendees?</li> </ul> <p>Have alternatives to formal meetings been considered?</p>  |  |

|   |  |  |
|---|--|--|
| 7 | <p><b>Is everyone's contribution recognised and valued?</b></p> <p>Everyone's contributions are respected and valued. Everyone should feel they are able to make a difference and be confident that they can have an impact on the outcome of the activity.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"> <li>• How are partners able to see how their contributions have been used to inform the work?</li> <li>• Is a feedback process in place to follow Co-production activity? How effective has this been?</li> </ul>  |  |
| 8 | <p><b>Is everyone supported to actively and meaningfully participate in and / or facilitate Co-production activity?</b></p> <p>The team should consider innovative ways to engage under-represented groups, and dedicated efforts should be made to empower people and communities to Co-produce.</p> <p><b>Things to Consider</b></p> <ul style="list-style-type: none"> <li>• Is a budget available to reimburse partners of any out-of-pocket expenses?</li> <li>• Are documents available electronically and in paper form so they can be accessed by all?</li> </ul> <p>Gift vouchers given as an acknowledgement of people's time and commitment</p> |  |

### **Practical tips**

Co-production needs to be embedded in everything we do throughout the process.

### **Review**

Identify and acknowledge everyone's input

Get feedback from all parties on process and outcomes of co-production activity

**Co-production may not always be easy, accept that power should be shared and take risks!**

This checklist is based on the Trafford Directory Co-production checklist

<https://www.trafforddirectory.co.uk/kb5/trafford/fsd/advice.page>



## **Appendix 4 – Example Participant Information Sheet**

### **(ND Parents & Carers Advisory Group)**

#### **What is the aim and purpose of this advisory group?**

The National Neurodivergence Team are developing a set of resources for neurodivergent (ND) parents and carers. These will cover some commonly-experienced issues, and suggest strategies that other ND parents have used, that have worked for them. The aim of these resources is to help them to navigate the world of parenting, from a specifically ND perspective.

As well as this, we hope to create a separate set of resources aimed at professionals who work with ND parents. The aim of this set of resources would be to help professionals to understand how neurodivergence might affect a parent, suggesting ways in which they might be able to adapt their working practices to best support the ND parents that they are working with.

It is important that this work is co-produced with the ND community, so that we can collaboratively create resources that are as beneficial as possible.

The aim of the advisory group is to inform the focus and content of these resources.

#### **What do I have to do?**

The advisory group will take part as online meetings held via Microsoft Teams (if you are not familiar with MS Teams, we will include a guide on how to use this platform).

The meetings will be facilitated by the National Neurodivergence Team, but be chaired by an ND parent or carer, who will be chosen by others within the group. We will consult with participants and ask for volunteers to take on this role before the start of each meeting. Participants can then vote for the chairperson via e-mail consultation.

The online advisory groups will be a series of semi-structured discussions. The National Neurodivergence Team will create some suggested agenda points before the meeting. It is important that these discussions are led by ND parents & carers. However, we will need an agenda as a guide so we can structure the meeting and keep to timing, as well as allowing participants to prepare.

These discussions will focus on what resources and information would be of most benefit to ND parents and carers. This may involve talking about your personal experiences of parenting, if you feel comfortable doing so. The advisory group will be a safe space and everything that's discussed in the group will be confidential and treated sensitively. Having said this, if you don't feel comfortable speaking in the actual meeting, there will be other opportunities to contribute to the discussion both during and afterwards, using either the chat function of Teams or Jamboard/Miro (an online digital whiteboard).

We will provide an outline of some guidelines that participants will be expected to adhere to during the meeting.

With participants' permission, we can make a recording of the advisory group meeting available to those that request it. This would enable participants who cannot make the meeting times to access these discussions and provide feedback should they want to.

### **How much time will it take?**

There will be one meeting held every month, with each meeting lasting for two hours.

The dates and times of the meetings are to be confirmed. But it is anticipated that there will be about 6 meetings in total held between January 2024 and June 2024. You can attend as many or as few as you would like to or are able to.

### **How will I be thanked for my work?**

All attendees will be thanked for their participation with a Love2Shop voucher for every meeting attended. These vouchers can be used at a specified list of high street stores and will be sent to participants via email.

### **How do I tell you I would like to take part?**

#### **What will happen next?**

If you would like to be part of this advisory group, please contact [name] at [email].

You will then be contacted with a calendar invite, a link to the advisory group meeting and an agenda at least two weeks in advance of the date of the advisory group meeting.