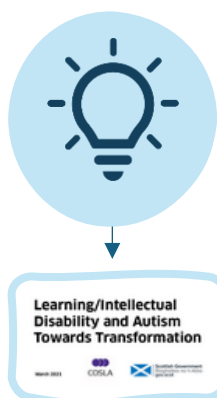


Towards Transformation Leadership Framework summary of the stages involved

1. Understand and define (2021)

Conception



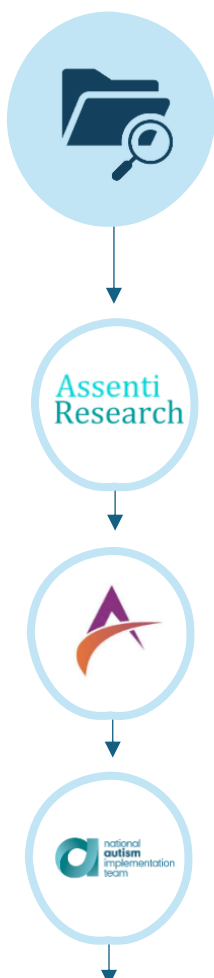
Conception of the approach through the Towards Transformation Plan policy conversations.

The Scottish Government, Inspiring Scotland, The Assembly, and others worked with people with lived experience to establish a new process that put the voices and experiences of autistic people and people with learning disabilities at its heart.

Created new roles ***Drivers, Allies and Engineers.***

Governance arrangements established to explain roles, clarify expectations and lines of accountability.

Research



Research commissioned on accessing mental health services with autistic people, people with learning disabilities, and parents and carers.

An **autism research survey topic guide** was developed with 10 members of the Inspiring Scotland Autism Advisory Forum, Autistic People-led Organisations, national autism charities and Scottish Government.

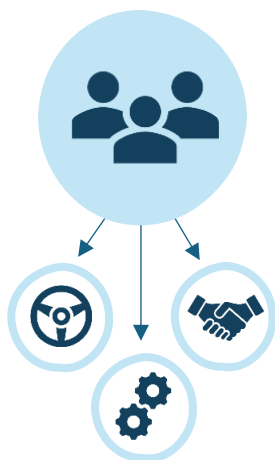
Assenti Research commissioned to do two pieces of primary research into autistic adults, and parents and carers of autistic adults and adults with learning disabilities experience of accessing mental health services.

The **Assembly Programme Manager** completed one to ones with a range of Assembly members with a learning disability and/or autism. Focus groups held with adults with learning disabilities through the Assembly to find out main issues on accessing mental health support and services.

The National Autistic Implementation Team (NAIT) commissioned to undertake a Rapid Review of Mental Health in Autistic Adults, focusing on 'Prevalence, Interventions and Outcomes.' Autistic Drivers produced a list of primary studies, theoretical papers and other literature.



Recruitment



The Scottish Learning Disabilities Observatory

commissioned to produce a review of evidence of 'Mental ill health and behaviours that challenge in adults with learning/intellectual disabilities'.

Drivers recruited. The Driver role was advertised through The Assembly and the Autism Advisory Forum.

Engineers recruited. Engineers invited by Scottish Government policy team for their potential to influence and progress agreed actions and reflect a wide range of sectors and services.

Allies recruited. Allies invited based on existing and long-standing engagement and working relationships with people with learning disabilities and autistic people.

Towards Transformation Leadership Framework summary of the stages involved

2. Prioritise (2022)



Drivers, Allies and Engineers discussed priorities based on the research findings.

Learning disability priorities



1. Access to face-to-face community mental health support
2. Accessible information about accessing mental health support and services
3. Training for GPs and health care professionals
4. Education about mental wellbeing and mental ill health

Autism priorities



1. Delays and navigating the system for mental health services
2. Training, understanding and experience among health professionals
3. Post diagnostic support and ongoing lifelong support
4. Autism informed services and flexibility



Scottish Government assessed short, medium and longer terms actions to address and presented to Drivers.

The Scottish Government team advised some of the 'long list' of suggestions needed further clarification before they could be categorised, and recommended that others needed to be withdrawn because they were either beyond the remit of the policy team, or not feasible and could not be funded.

Towards Transformation Leadership Framework summary of the stages involved

Process evaluation (2022)¹



Animate Consulting were commissioned to undertake a process evaluation of the Leadership Framework.

A series of one-to-one conversations with a sample of 18 participants across the diversity of the leadership and engagement process (autistic Drivers, Allies, Engineers and the Scottish Government team). Focus group with six learning disability Drivers and support workers.

Highlighted a range of ongoing tensions around speed, depth and convenience built into the co-production approach, including:



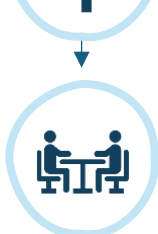
- The need to move quickly on issues which affect the day to day lives and human rights of people with learning disabilities and autistic people and the importance of slowing down enough that everyone can get on board and understand the information which is presented to them



- The need to provide everyone with enough information without swamping them with too much



- The need to involve everyone with a stake in the process, from the outset but also at a time when they can make a genuine and meaningful contribution



- The need to make meetings accessible by working online whilst acknowledging the benefit of in person workshops to develop relationships and improve communication.

Recommendations made and agreed by the Scottish Government team:



- Hearing from a wider range of voices from across the autistic and learning disability communities including younger people (18- 25 years), Black and Minority Ethnic people, and those with more severe communication needs

¹ <https://inspiringscotland.org.uk/wp-content/uploads/2023/11/Animate-Leadership-Process-Evaluation-Final-Report.pdf>



- Ensuring all participants receive the same information in accessible formats in sufficient time to prepare for meetings, and travel support to attend



- Increasing the frequency of meetings and pre-meeting preparatory and linking sessions with the autistic Drivers to aid flow and continuity



- More opportunities to meet together as Engineers, Allies and Drivers in separate groups as well as collectively to develop trust, working relationships and a shared understanding of the process, scope and limitations



- Developing a working agreement that is based on the PANEL principles, capturing what each party needs to collaborate and work well together



- Exploring the possibility of engaging an autistic facilitator to co-facilitating meetings



- The Scottish Government and COSLA continuing to engage and bring in public sector Allies and Engineers with decision making powers and leverage to enable and accelerate change.

Animate undertook a rapid review of 'Good practice in participatory approaches to working with autistic people and people with learning disabilities²'. It concluded that the participatory approach being pursued and further developed by the Scottish Government team was in line with good practice in Scotland and elsewhere.

² Good practice in participatory approaches to working with autistic people and people with learning disabilities – Animate Consulting, January 2023

Towards Transformation Leadership Framework summary of the stages involved

3. Design (2023)

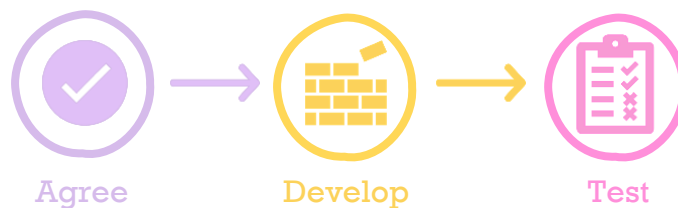
Creating working groups

3

Three working groups were formed.

Working groups took first priority area and co-produced outputs and activity to address it.

Learning disability Drivers working group



Agree, develop and test resources needed to raise awareness and improve general understanding of what it is like to live with a learning disability and more explicitly how people's mental health is impacted and the challenges and barriers faced in accessing mental health services and supports.

Autistic Drivers - GP and other practice staff working group



To develop training materials and resources to make GP services more accessible to autistic people and support improved mental health.

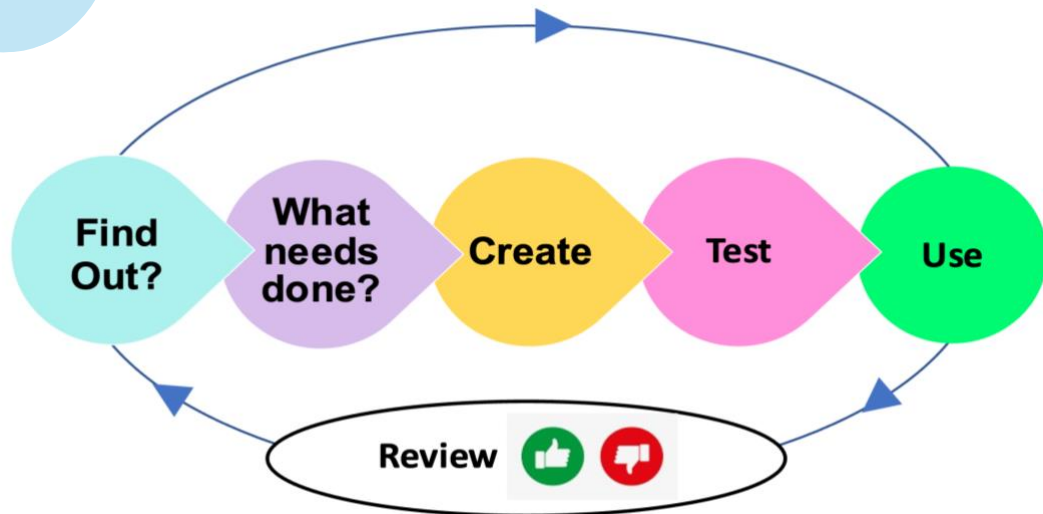
Autistic Drivers - Autism Informed Services working group



To develop co-produced informed level professional learning resources for all NHS professionals working in adult services or with adults. This includes mental health services.



The groups agreed an accessible planning and evaluation model to use. See below.



An autistic facilitator was recruited.



Relevant Allies and Engineers were involved in the working groups.

Towards Transformation Leadership Framework summary of the stages involved

Summary of learning disability working group

Find out



Group considered what GP, NHS 24 and Scottish Ambulance Service staff training is currently in place
Group talked about who to target in these settings
Drivers shared personal experiences

What needs done?



Group came up with top 10 tips for health professionals

Group asked the wider Assembly membership about the top 10 tips and what they would prioritise

People said all 10 were important

Drivers identified how these top 10 tips could be applied by health professionals

The top 10 tips are:

- | | | | |
|----------|---|-----------|--|
| 1 | Listen to me | 6 | Give me the time I need |
| 2 | Believe me | 7 | Speak to me first |
| 3 | Value me | 8 | Explain to me and show me what you are going to do |
| 4 | Give me accessible information | 9 | Use simple words |
| 5 | Create an environment that works for me | 10 | Check if I understand |

Create



Scoping work with potential test sites (and Engineers), building relationships and agreeing to work together with the sites.

Short term working group established with NHS 24.

The group created a suite of resources:

- Film with top 10 tips
- Film on behind the scenes making the film
- 3 things card
- Booklet on top 10 tips
- Poster on top 10 tips

The resources will use dynamic QR codes, which means:

- They can be easily updated
- They can be interfaced with AI
- It is accessible for people with learning disabilities
- They provide good data for evaluation.

Test



Test the **Learning Disability top 10 tips** in 4 GP surgeries across Inverclyde, NHS 24 staff, Scottish Ambulance Service and NHS Fife in 2024.

The working group developed a questionnaire with baseline questions based on the experience and learning of implementing mandatory learning disability training in England (the Oliver McGowan training).

Towards Transformation Leadership Framework summary of the stages involved

Summary of autism GP and other practice staff working group

Find out



Took the research findings from the Assenti Research report relevant to GPs and mental health support, including:

"Autism informed training for all frontline staff but especially GPs to improve Autism understanding and the relationship with mental health. The vast majority of respondents had approached their GP for help with mental health issues, and it is essential for them to have a much better understanding."

- Drivers shared their personal experiences of seeing GPs and the things that make a difference
- Drivers shared their experience of developing and delivering autistic led training for GPs

What needs done?



- The group came up with an idea for a film to cover things identified in the research that make a difference when making an appointment and seeing your GP (recognising that materials already exist but more autistic perspective and experience is needed)
- The group felt posters for GP surgeries could pull out the key messages in the film

Create



- A workshop with Drivers was held to develop the framework for the film script
- Working group meetings then developed the film script and poster content
- Members of the group shared GP contacts. Connections were made with GPs to ask for comment on the draft film

script. Comments were provided from two GPs (one autistic GP) on the draft film script.

- A test outline was shared with all Allies and Engineers with a request to highlight any gaps identified or similar work to be aware of.

The group resources:

- A film sharing and depicting the experiences of making an appointment and seeing a GP. This was created by Ability Academy, an autistic led film company.
- Two posters for GP surgeries with key messages highlighted from film. The poster visuals were created by an autistic illustrator.

Test



The aim is to test the difference in GP and practice staff understanding of autism and their practice with autistic patients after watching the film.

The working group used a questionnaire with baseline questions based on the experience and learning of implementing mandatory autism and learning disability training in England (the Oliver McGowan training).

The testing to take place in 2024 in two GP practices.

If the tests work well, it is intended that the resources will be launched nationally. The group has agreed with NHS Education Scotland (NES) that they will go on the Turas learning platform which is part of NES. This might include a specific recorded learning session for practitioners.

Towards Transformation Leadership Framework summary of the stages involved

Summary of Autism Informed Services working group

Find out



Using conclusions and recommendations of the Assenti Research report around autism informed services, namely:

"Enable autistic people to communicate in their preferred way, e.g. offering digital appointments, allowing people to bring written notes, communicating in writing during the appointment. If appointments are running late keep the autistic person informed.

Keep questions specific and offer examples of the type of answer they might give.

Make allowances for difficulties with executive functioning, e.g. missing appointments – offer reminders."

- The National Autism Implementation Team (NAIT) mapped existing training material
- Drivers were asked what key messages should be included in all training material and shared suggestions about what training could include
- Examples of good practice recorded

What needs done?



- Group decided which NHS Education Scotland level this work will focus on - agreed on 'informed'
- Group discussed the improvements needed to services
- Agreed key messages and then topics under a communication theme to focus on in resources

Create



Heard from two mental health practitioners about training and what makes the most impact.

The group created:

- Short films on key themes under communication strand
- An ebook training support resource

The group feel that in person and autistic led training is very important.

Test



The aim is to test the resources developed by the working group in 2024. Preparatory work included:

- Asked NHS Education Scotland for advice on content, presentation and hosting
- Asked Autistic Doctors International for advice and input
- The working group used a questionnaire with baseline questions based on the experience and learning of implementing mandatory autism and learning disability training in England (the Oliver McGowan training).

If the tests work well, it is intended that the resources will be launched nationally. The group has agreed with NES that they will go on the Turas learning platform which is part of NES. This might include a specific recorded learning session for practitioners.