

Background to the Inclusive Governance Project

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Positionality Statement

- Practice background: Support worker in various roles with autistic people and people with learning disabilities since 1990s
- Researcher, Social Anthropologist, with Scottish Autism since 2013
- Recently stepped up to Director level
- Non-autistic professional

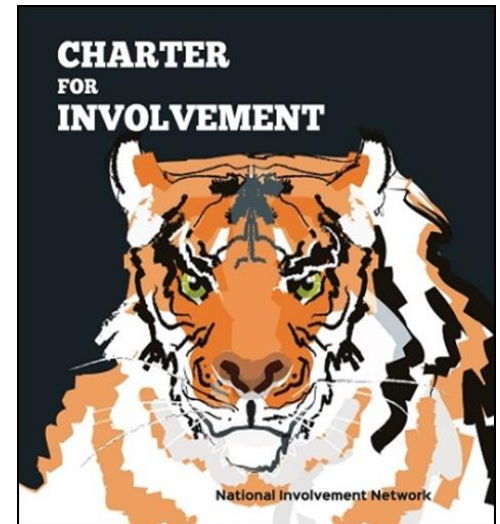
Foundations of Inclusive Governance at Scottish Autism

2011 Public Service Improvement Framework identifies 'User Participation' as an organisational priority for Scottish Autism.

Various practice initiatives underway by 2013 including Service Forums, more inclusive review processes.

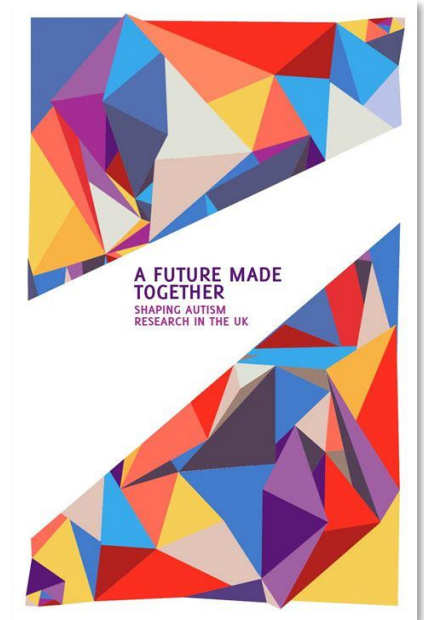
Practice Research projects set out to capture and share innovations in involvement and inclusive practice.

2015 Scottish Autism signed "Charter for Involvement".



Context (early 2010s)

- Greater emphasis on 'user participation' in health and social care services, growing talk of co-production.
- A growing autistic self-advocacy movement leading critical engagement with practice models and research. Emphasis on neurodiversity paradigm, social models of disability, human rights.
- Critical questions appearing in research context intersect with practice and service provision.

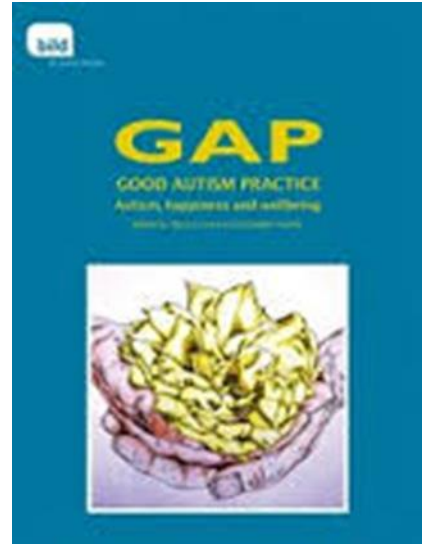


The Voice and Participation project

Practitioner research model with participatory ethos.

Capturing practice innovations:

- Service Forums
- School assembly
- Creative Projects
- Individual Review processes
- Day-to-day decision-making
- Use of technology for choice-making and recording



Long et al. *Good Autism Practice* November 2017

The Voice and Participation project

“Recognising, validating and *acting upon* an individual’s unique way of communicating is to recognise their ‘*voice*’ whether that is in the literal sense – through spoken communication – or through non-verbal means”

“Participation and Involvement mean supported individuals taking a role in making decisions about their lives and the support that they receive”



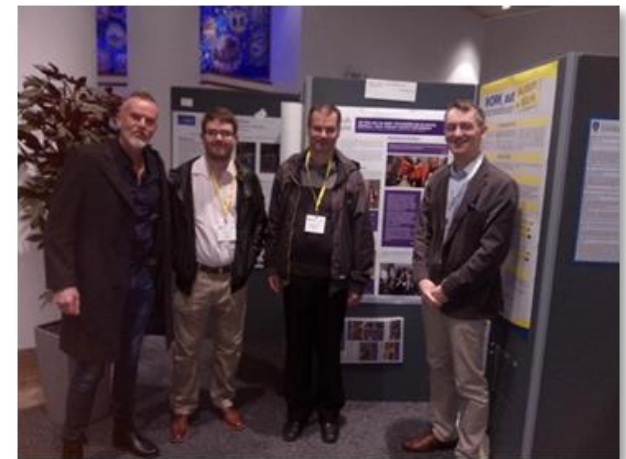
Key themes

Individual Involvement

- Preserving authenticity of voice
- Harnessing interests and media meaningful to the person
- Ownership of process
- Providing a concrete output
- Family involvement and shared understanding

Collective involvement

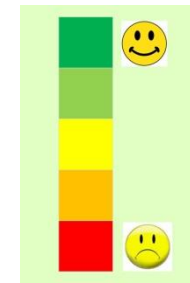
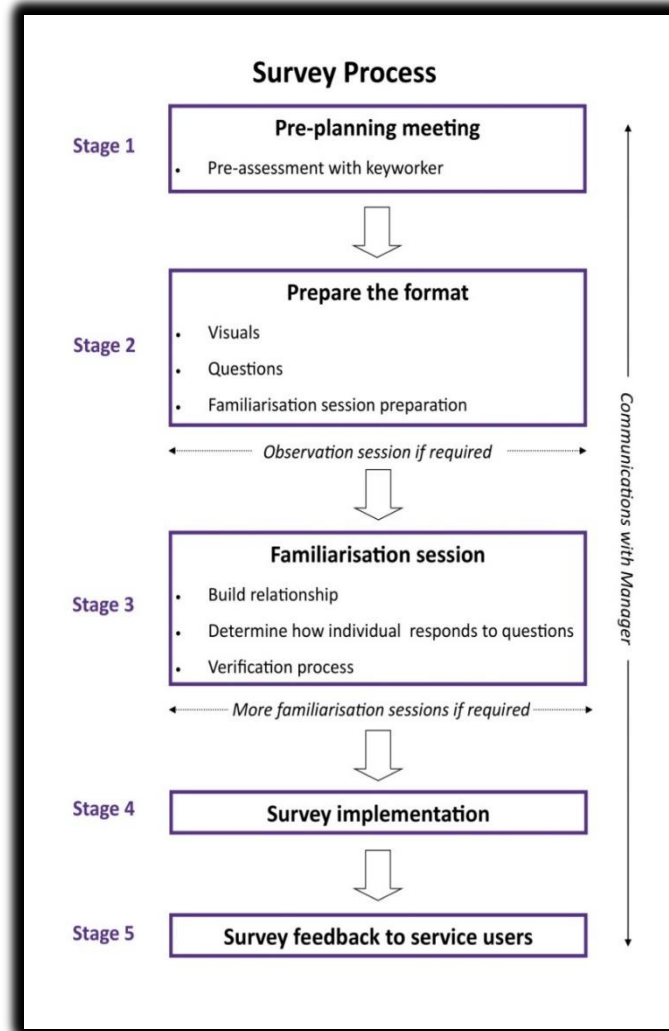
- Recognising and validating individual voice
- Structuring space and format
- Turn-taking and active listening
- Autonomy and responsibility






From communication to “voice”

Understanding
communication
enables us to
listen to an
individual
person’s voice
and choice.

The Service Experience Survey



The individualised survey workspace

<p>Let's talk about the resource room at Rowans</p> 	<p>How does Steven feel in the resource room?</p> 	<p>In the resource room Steven feels ..</p> 
<p>What is it about this room that makes Steven feel this way?</p>		

Individualisation in Practice



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What things make you happy about your work?

What things make you unhappy about your work?

My work makes me feel ..

Happy

Ok

Unhappy

computer

people carrier

shop

board game

lunch out

lunch

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Further Research Developments

- Collaborative PhD Studentship on Autistic Communication preferences, empathy and double-empathy in practice settings

(Holly Sutherland, University of Edinburgh)

- Collaborative PhD Studentship on autistic community and space and the inclusion of those supported in social care settings

(George Watts, University of Stirling)

2020: The next steps to greater inclusion

- Shared our work in practice resources, articles and practitioner workshops, informed our practice model
- 2020 Staff conference posed the question “Where is the voice and participation at service and organisational level?”
- Board agreed to a competitive tender for a comprehensive project to advise on inclusive governance
- Won by consortium of National Autistic Taskforce, AMASE and ARGH.