Inclusive Governance: What did the project do and how?

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The Inclusive Governance Team

Who we are

AMASE is an Autistic People's Organisation based in Edinburgh. It aims to represent its autistic members, as well as the broader autistic community, in issues that affect autistics.

ARGH is a group run by and for autistic adults; the ARGH committee and full voting members are all autistic. ARGH is a collective advocacy, lobbying and campaigning group of autistic adults living in the Highlands and beyond, which promotes self advocacy for all Autistic people.

NAT is a UK-wide autistic-led organization which seeks to draw on the collective knowledge and experience of autistic adults to inform and improve care and support, especially for autistic people whose own voices are rarely heard.

How this project came about

- In March 2021, Scottish Autism issued an invitation to tender explicitly seeking "creative and collaborative tenders from autistic consultants and autistic led organisations/consortiums" to support them "to develop and deliver a change programme" resulting in "an inclusive governance approach at Board and operational level."

- A group of individuals from NAT, ARGH and AMASE came together and agreed to collaborate across the 3 organisations to submit a tender. The group prepared a detailed, professional tender including a GANTT chart, costings and detailed project plan. This tender was accepted by Scottish Autism and a contract for the work was signed.

Overview of the project

Project stage	Content	Timing
Stage 1a	• Exploratory meetings with Board and senior leadership • Broad desk research – initial survey of 100+ organisations (worldwide and across sectors), summary information on approx. 30 organisations	June 2021 – November 2021
Stage 1b	• Preliminary work towards wider stakeholder engagement (particularly with Supported Individuals) • Narrow desk research – In-depth case studies of 7 organisations and 5 thematic case studies	December 2021 - June 2022
Stage 2	• Stakeholder engagement and co-production • Development and working up of specific options in detail	July 2022 – May 2023

Exploratory Meetings

- Met with SA Board, SLT and WLT

- Asked:

    - How would you define 'inclusive'? What would be 'inclusive'?

    - What wouldn't be inclusive?

    - What barriers can you identify?

    - How inclusive do you think SA's governance is currently?

    - What would you like to see change?

Broad desk research

- Review of SA's policies and internal documentation

- Brief scan of academic literature on IG

- Broad scoping review of potentially relevant organisations worldwide (over 100):
  - Autism, but also LD, Mental Health, other disabilities, Deaf
  - Non-disability groups e.g. Care experienced, tenants

- Summary information on 30 organisations including:

  - Description of organisation
  - Who governs or sets the strategic direction of the organisation and how
  - What forms of inclusion do they use

Desk research – case studies

- 7 organisations in depth:
  - British Deaf Association
  - Glasgow Disability Alliance
  - Glasgow Centre for Inclusive Living
  - Learning Disability England
  - Mencap
  - People First Scotland
  - Vox Scotland
  - Who Cares? Scotland

- 5 thematic case studies:
  - Governance and leadership training programmes
  - Approaches to supporting communication
  - Approaches to supporting decision making
  - Service-level models of governance and recruitment
  - Intersectionality

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Stakeholder engagement – what did we do?

- Survey – targeted at staff, wider autistic community (WAC), Supported Individuals (SIs) and families of SIs

- Focus groups (largely virtual):
  - Some publicised through SA – targeted as above
  - ARGH-AMASE focus group – targeting WAC
  - Autscape focus group (in person) – targeting WAC

- Bespoke interviews (in person):
  - For SIs for whom above methods inaccessible

Stakeholder engagement – how did we make it accessible

- Project explanation materials available in Easy Read and video, as well as Text version

- Survey questions reviewed by multiple autistic people for accessibility

- Online form asked about accessibility adjustments needed

- Focus groups offered autistic accessibility adjustments routinely e.g. use of text-based chat as alternative to speech
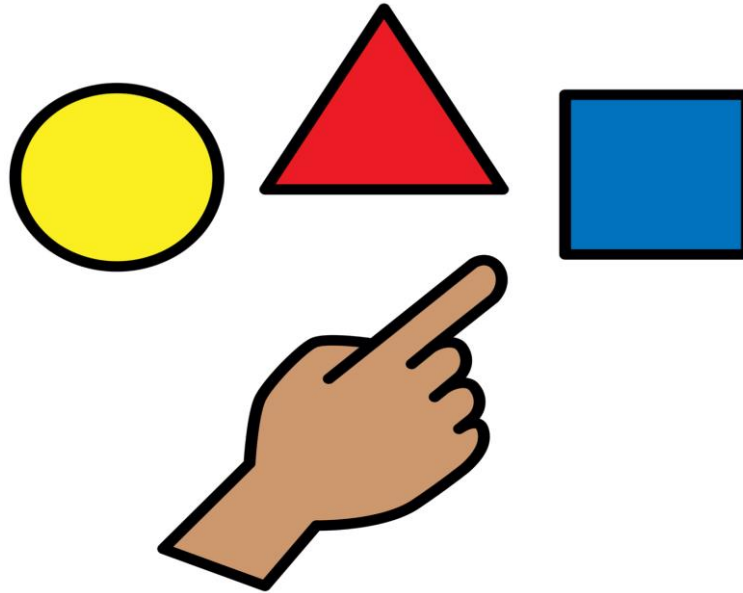
What is this about?

This is a project about how Scottish Autism makes decisions.

Scottish Autism's decisions affect things
they do for staff and people they support.

Scottish Autism want to get better at including people they support in their decisions.

Who are we?

We are all autistic.

Stakeholder engagement – bespoke interviews

- Each interview involved prior discussion with staff working with each individual and family members (parents in all cases) to gather information about communication needs and concrete information for adapting questions

- Used Boardmaker (used within SA) to create visual materials for use in interviews

- Data gathering included observation and use of autistic empathy, in addition to direct interaction

- Limited time and opportunity to develop relationships

Who did we consult across the project as a whole?

Consultees by stakeholder group membership

- Senior Staff and Board — 39%
- Staff — 13%
- Supported Individuals — 19%
- Family Members — 6%
- Wider Autistic Community — 23%