Inclusive governance and decision-making workshop

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How did we include autistic people with high support needs in the project?

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

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

What is this about?
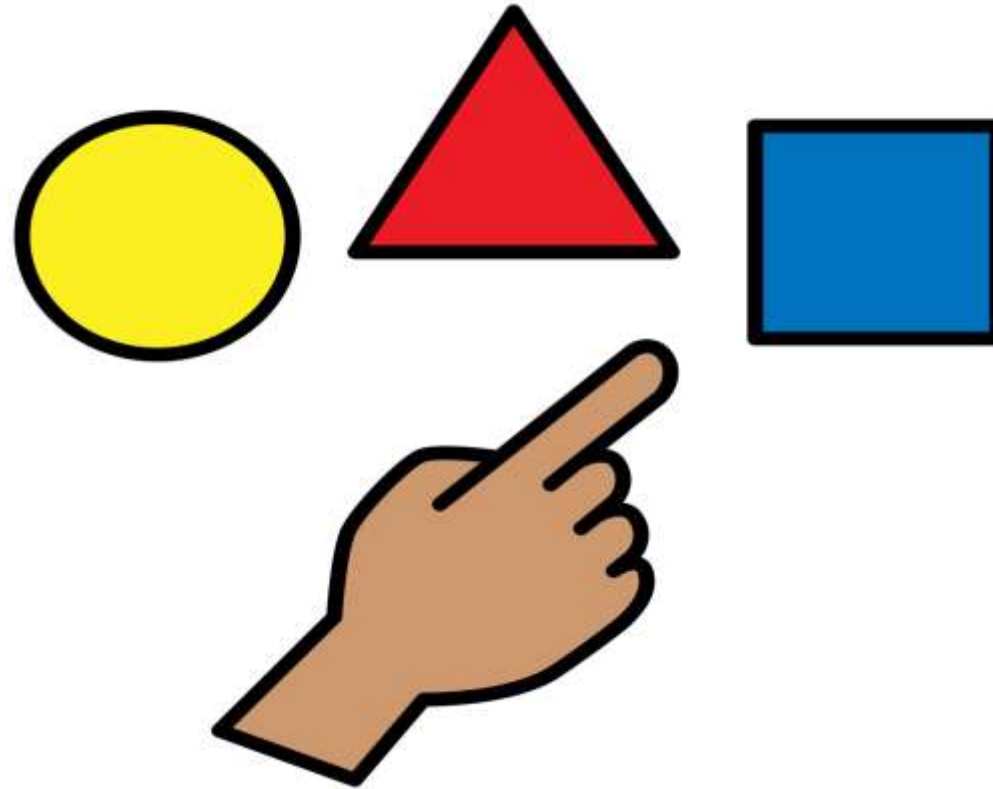
This is a project about how Scottish Autism makes decisions.

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.

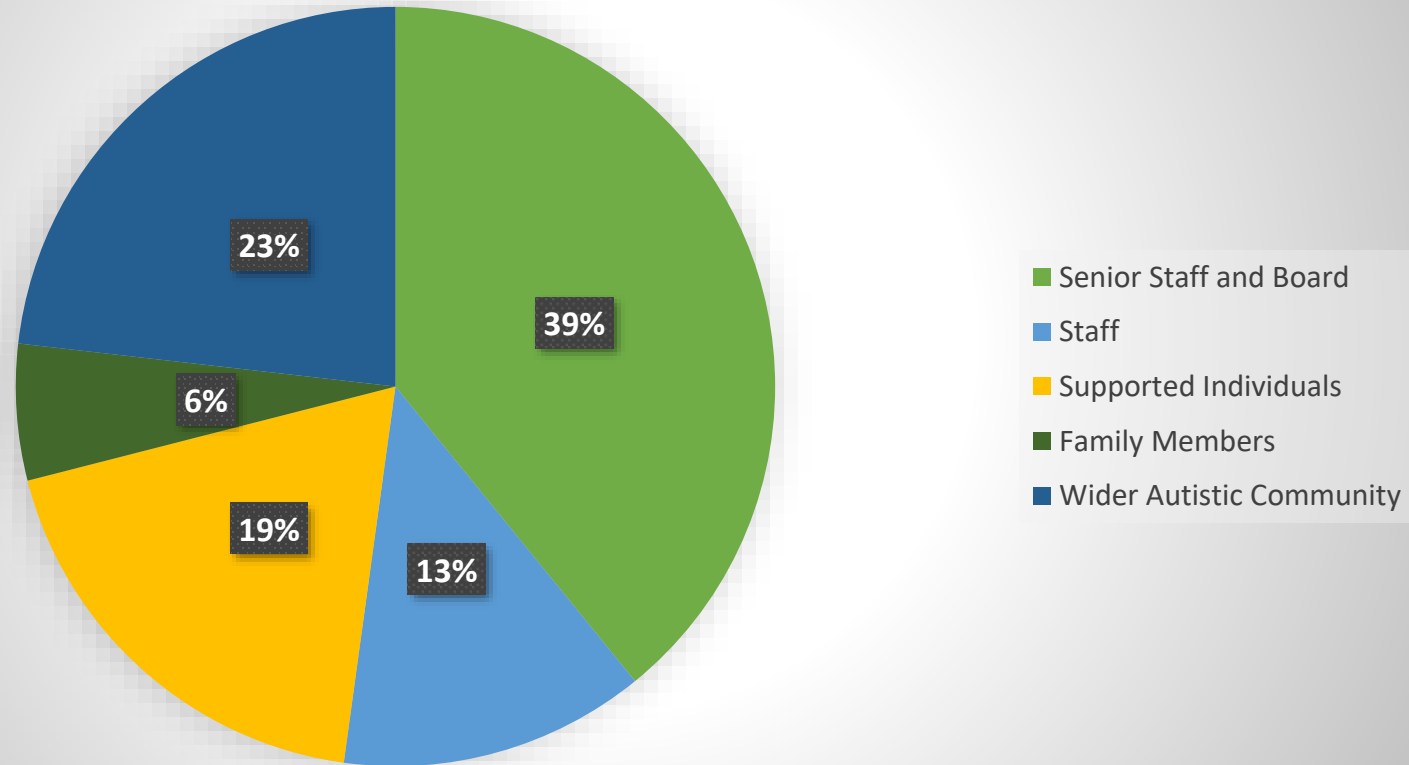# How could you make materials and resources more accessible?

Things to consider:

- Simple, clear language

- Pictures or symbols

- What about people who can't read – video/audio?

- Signing

- Any other considerations?

Who did we consult?

Consultees by stakeholder group membership

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

What did we try to recruit autistic people with high support needs?

- Easy Read and Video versions of project information

- Had to rely largely on staff to:
  - Put individuals forward
  - provide us with information about communication needs
  - Seek consent on our behalf, sharing project materials

- Found it useful to get direct contact details for family members (parents in all cases) and seek consent and background information directly from them

Stakeholder engagement – bespoke interviews

- For those for whom surveys and focus groups were inaccessible

- 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 and to supplement direct interaction

- 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

Challenges and barriers

- Organisational Inertia
  - Covid
  - Social Care recruitment crisis
  - Difficulty transmitting concept clearly

- Consent – organisational confusion and inertia in identifying and constructing a process

- Data sharing and confidentiality

- Consent – Guardianship

- → compressed time frame → limited scope to develop relationships and communication

Our first visit to a residential care service

- One of two participants not there!

- The disaster of NT mediated interaction:
  - Being 'introduced' NT-style e.g. "Kevin say hello"
  - Performing seals e.g. staff prompting Supported Individual to tell us about book in classic NT fashion

Autistic empathy

- Two of us spent time at a residential care service, simply observing and being present with Supported Individuals

- Sensory nightmare!
  - squeaky floors and doors
  - multiple TVs
  - cupboard doors banging
  - people coming and going
  - leaving doors open

- Supported Individual had blanket over head most of the time, but it took us highlighting issues to staff

Autistic-autistic engagement and communication

- Severely limited by time constraints

- Abstract concepts → concrete contexts

- Used Boardmaker, because used within the organisation and familiar

- Informal communication mostly more effective than formal, due to limited time and need for work to support agency and decision making

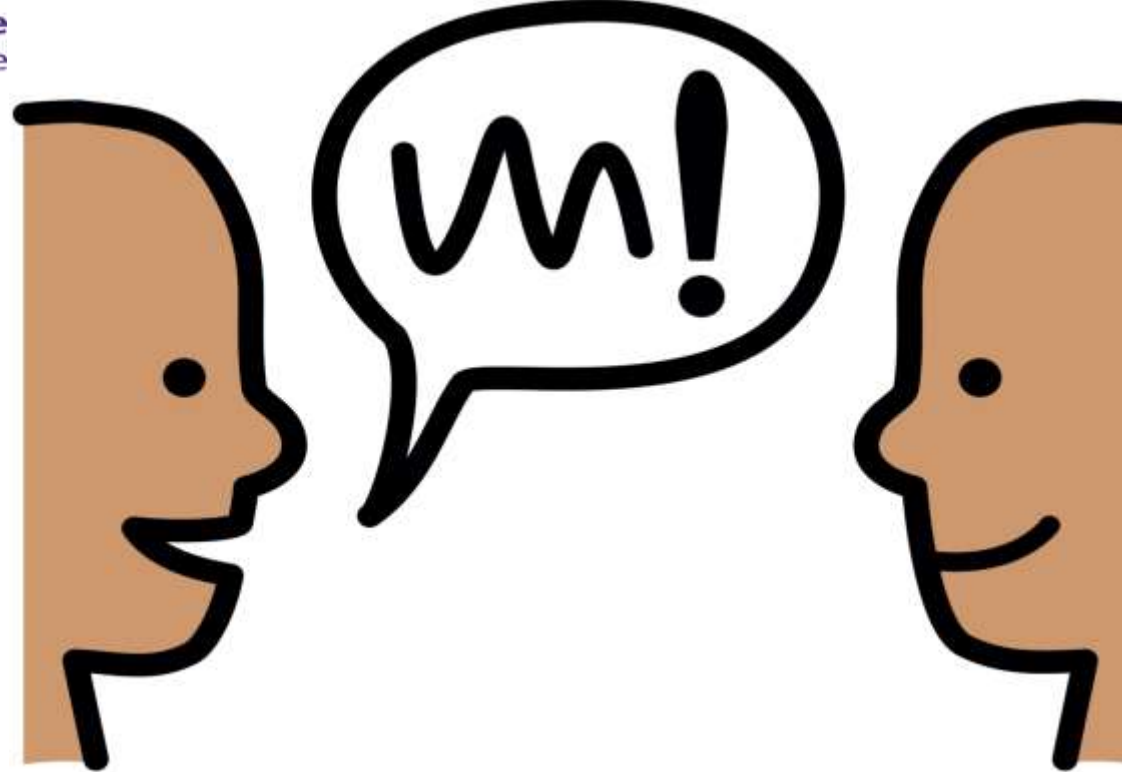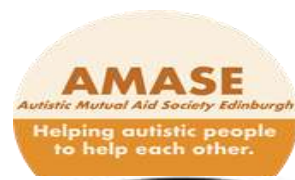- Organisational/attitude barriers e.g. the email address
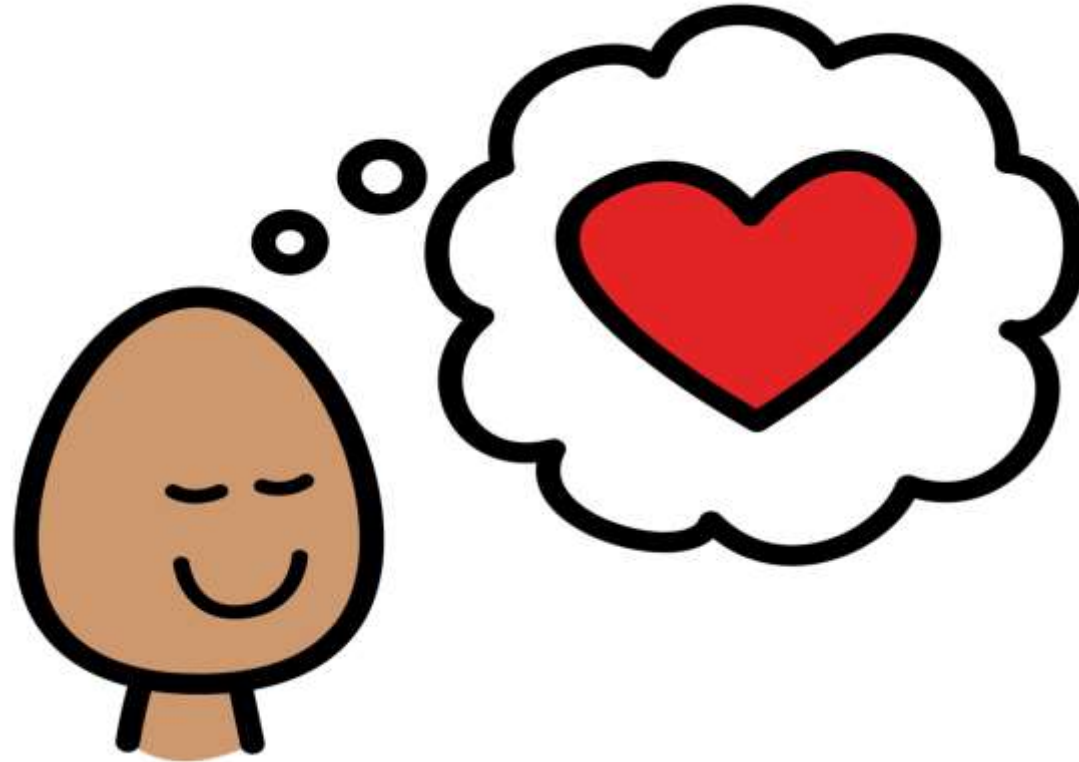
We want to know what you think
Scottish Autism should do.

You can tell us in many ways.

You can talk.
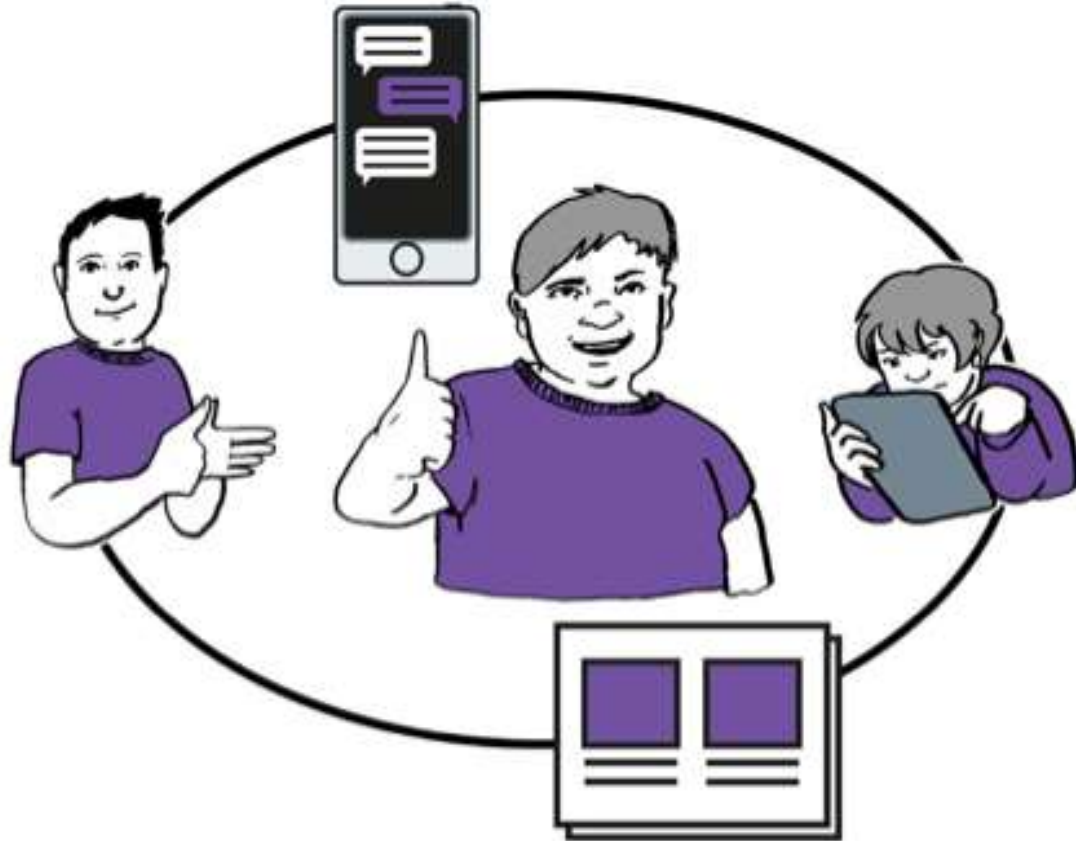
You can write or type.

You can use signs.

You can use pictures.

You can use another way.

We will ask you some questions like:

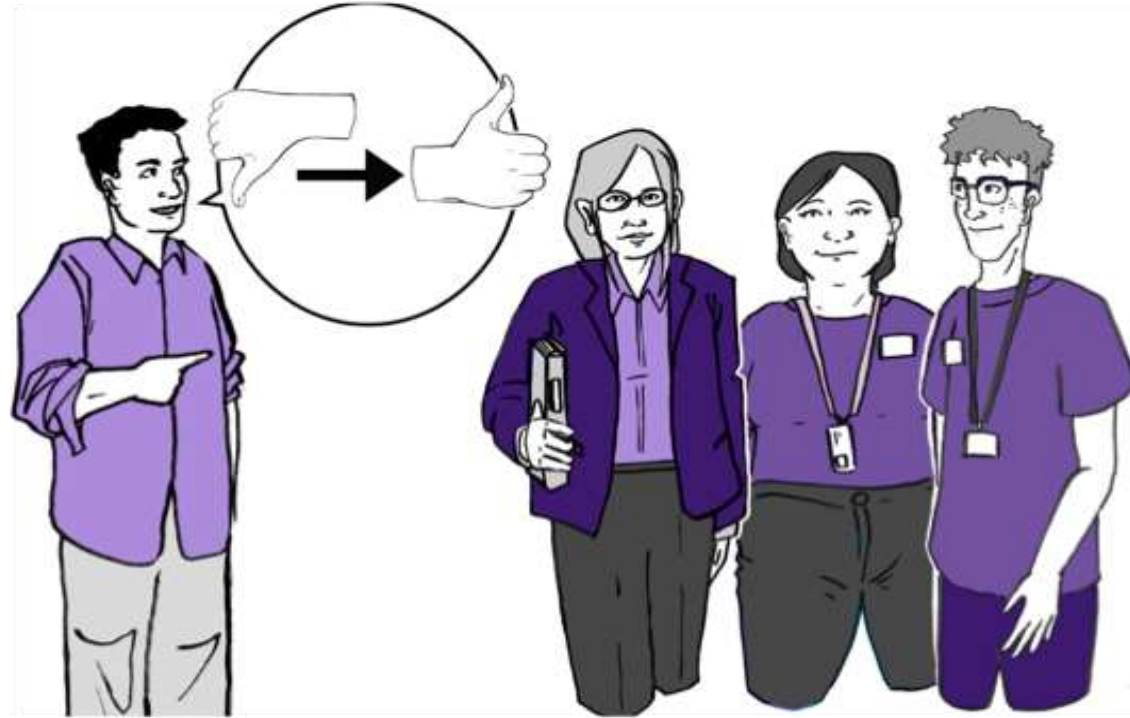Do you choose how to spend your time?
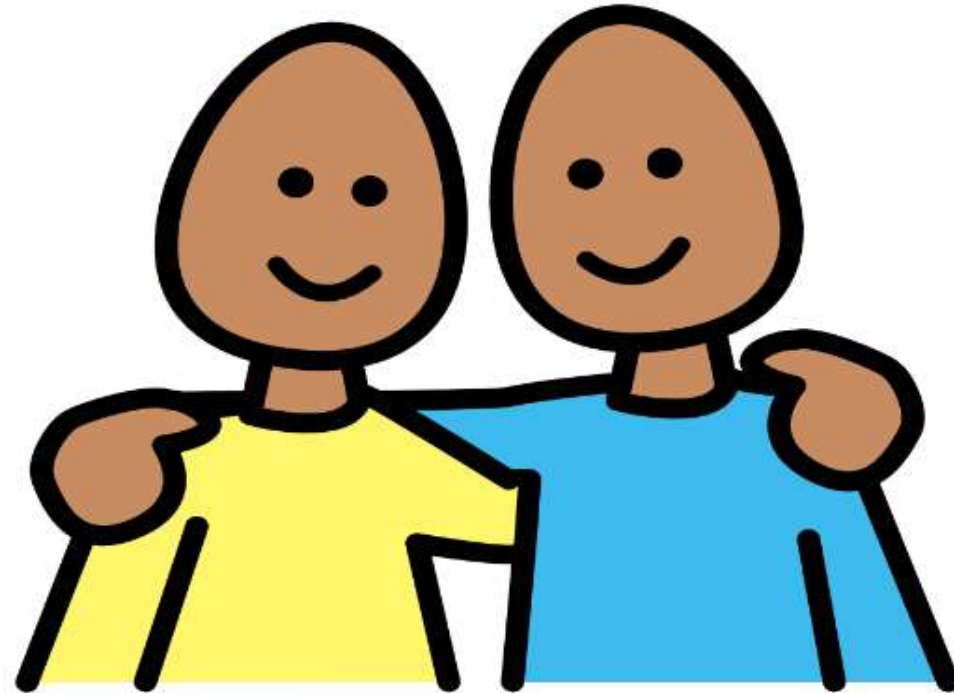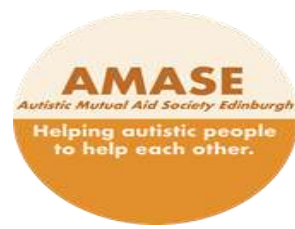
Do you choose who to be with?

Do you choose who helps you?

Practical resources

- AAC resources

- Supported decision making toolkit – simplifying language

- Long and Clarkson (2017) *Towards meaningful participation in research and support practice: effective change in autism services*. In Autism and Intellectual Disability in Adults, volume 2

- NAT's paper on supported decision-making may be relevant in some ways

- The NAT Independent Guide to Quality Care for Autistic People

How could you include more autistic people with high support needs in your projects and activities?

Things to consider:

- Recruitment
- Consent and finding out about communication needs
- Avoiding NTs mediating the interaction
- Using autistic empathy
- Communication

What would need to change in your organisation or environment to better enable autistic people with high support needs to participate in advocacy?

Things to consider:

- How representative is your organisation of the autistic community as a whole? What needs to change?

- How can autistic people with high support needs be supported to develop their agency and leadership skills?

- To what extent are autistic people with high support needs actually in control of their lives and support?

- How are support services accountable to those who need support? What needs to change?

Full report available on request from:

general@nationalautistictaskforce.org.uk