

# The Inclusive Governance Project: Shaping practice to support inclusion of autistic people in decision-making



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National Autistic Taskforce

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Scottish  
autism  
WHERE AUTISTIC PEOPLE  
ARE VALUED

# Structure

1. Introduction to the project
2. What did the desk research tell us about including people with high support needs in governance?
3. What do our recommendations have to offer for autistic people with high support needs having increased involvement in governance?



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# 1. Introduction to the project



## 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.

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# How this project came about

- Scottish Autism are a large parent-professional-led charity and company. They are Scotland's largest provider of autism-specific services, as well as a campaigning and advice charity.
- 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 undertake the project.

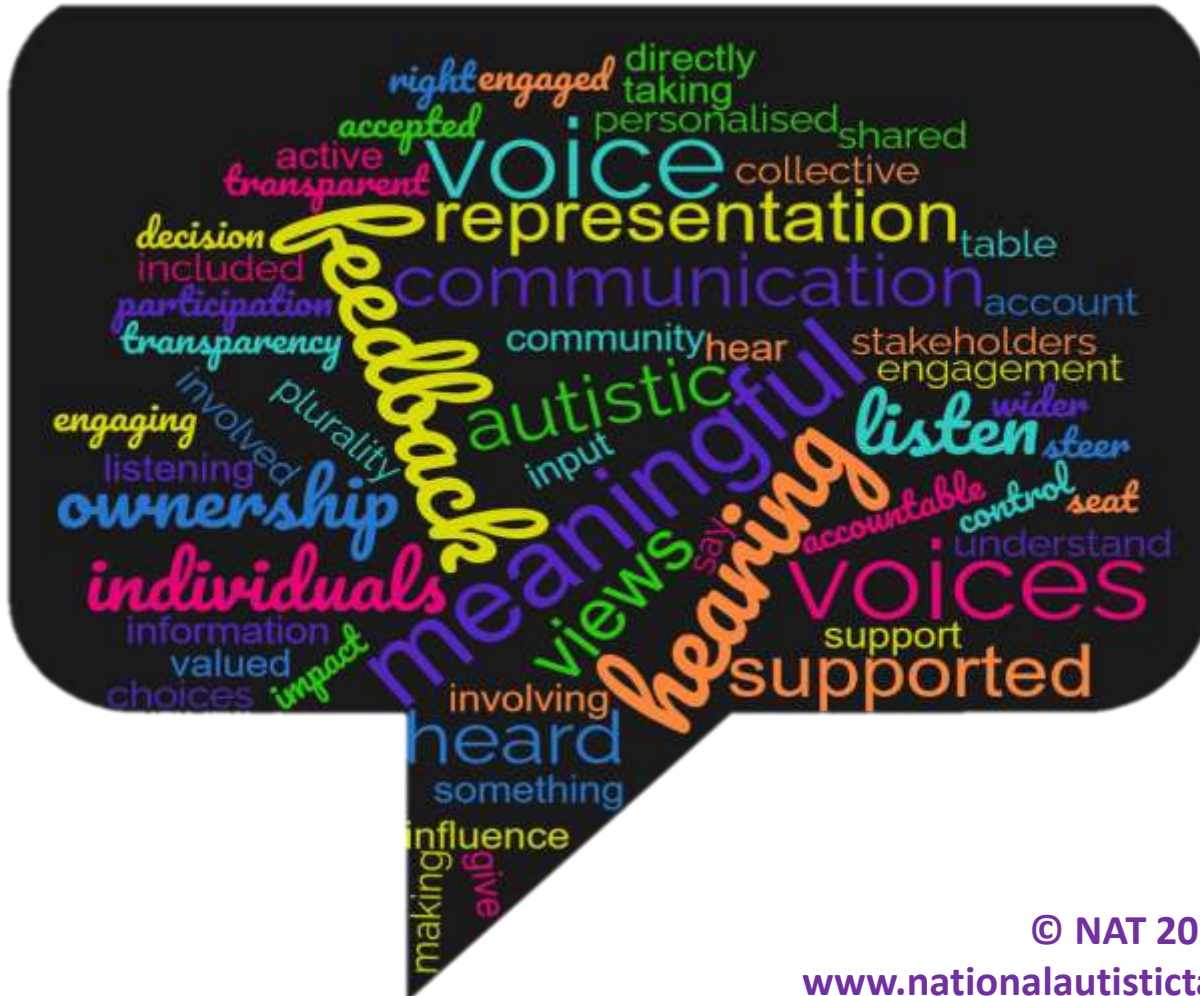
# Overview of the project

Project stage	Content	Timing
Stage 1a	<ul style="list-style-type: none"> <li>• Exploratory meetings with Board and senior leadership</li> <li>• Broad desk research – initial survey of 100+ organisations (worldwide and across sectors), summary information on approx. 30 organisations</li> </ul>	June 2021 – November 2021
Stage 1b	<ul style="list-style-type: none"> <li>• Preliminary work towards wider stakeholder engagement (particularly with Supported Individuals – those with high support needs)</li> <li>• Narrow desk research – In-depth case studies of 7 organisations and 5 thematic case studies</li> </ul>	December 2021 - June 2022
Stage 2	<ul style="list-style-type: none"> <li>• Stakeholder engagement and co-production</li> <li>• Development and working up of specific options in detail</li> </ul>	July 2022 – May 2023

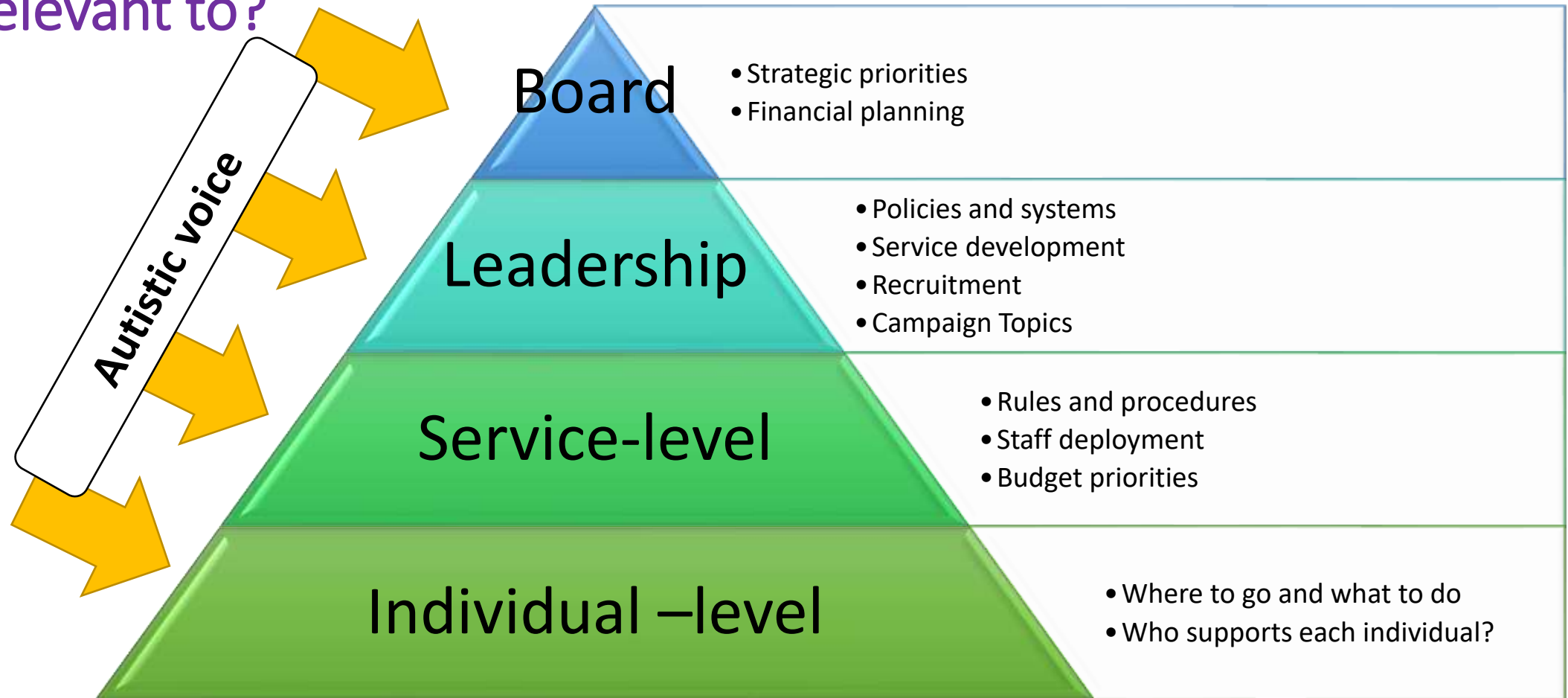
# What is 'inclusive governance'?

Colenbrander *et al.* (2017) identify three important elements of inclusive governance:

- (i) capital (e.g. share ownership or membership);
- (ii) binding and non-binding influence on the decision-making process (e.g. voting or consultation rights); and
- (iii) accountability (e.g. information and monitoring rights)



# What parts of the organisation did we think 'inclusive governance' was relevant to?





## 2. What did the desk research tell us about including people with high support needs in governance?



# Building on past work: Principles of Inclusive Practice

- Principle 1: Preserving authenticity of voice – validating preferred means of communication
- Principle 2: Harnessing interests and media meaningful to the person
- Principle 3: Ownership of process – being actively involved in the process, not just one-off consultation
- Principle 4: Providing a concrete output
- Principle 5: Family involvement and shared understanding between families and care services
- Service user forum and newsletter project

*Joe Long (2017)*

# What did the desk research tell us about including people with high support needs in governance?

- **Asking key questions** – *The Arc* (US parent initiated charity, now has IDD-representation at Board level)
- **Different approaches to care services** – *Small Supports, Care co-operatives, Direct Payments/Self-Directed Support*
- **Leadership development programmes and Supported Decision Making** – *Disability Rights UK, Sylvia Rodgers Aus, South Australia SDM project*
- **Reasonable adjustments in leadership** – *Learning Disability England, Communication First and Deaf Action*
- **The concept of 'Autistic Space'** – *Autscape and various autistic community organisations*

# Asking key questions

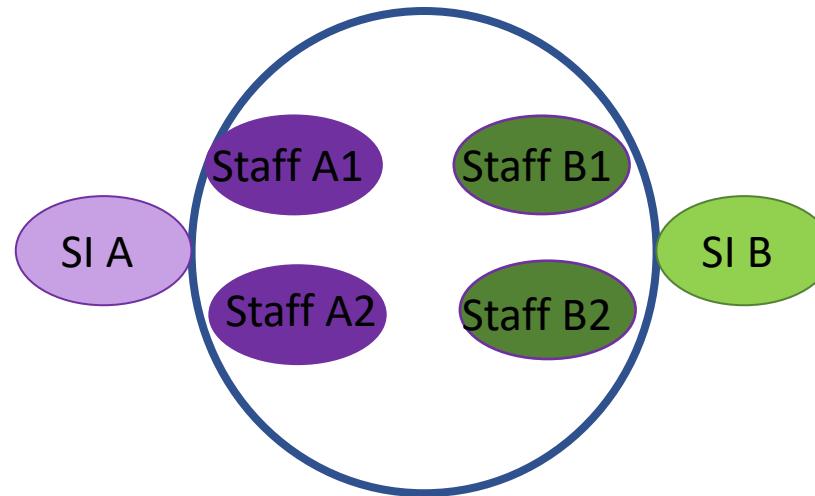
- *Diversity* – who is in the room?
- *Access* - Can everyone get inside the room or even the building?
- *Equity* - Who built the room? Who received an invitation?
- *Inclusion* - Does everyone in the room feel welcome?



## Autistic norms

# Different approaches to care services

- Support recipient as support director
- Small, bespoke services
- No 'one size fits all'
- Consistent staffing
- Service termination built out
- Positive risk taking built in



# Leadership development programmes and Supported Decision Making



- People with high support needs often grow up in a ‘prison of protection’
- Need to explicitly teach agency and decision making
- Need to provide opportunities for practise and culture of promoting autonomy
- Need to develop confidence and skills to participate in advocacy
  - Representing others
  - Speaking in front of groups
  - ‘Soft’ skills

# Reasonable adjustments in leadership

- Change on both sides!
- Challenging assumptions
- Easy-read
- Visuals
- Autistic-friendly communication (information based)
- Changes in meeting formats



# Autistic Space

Autistic space is any virtual or real-world space that is:

- Shared by several autistic people
- Designed or adapted for autistic processing; values autistic ways of functioning
- Designed and controlled by autistic people
- By and for autistic people where autistic needs and culture take priority
- Being and acting autistic is acceptable and accepted

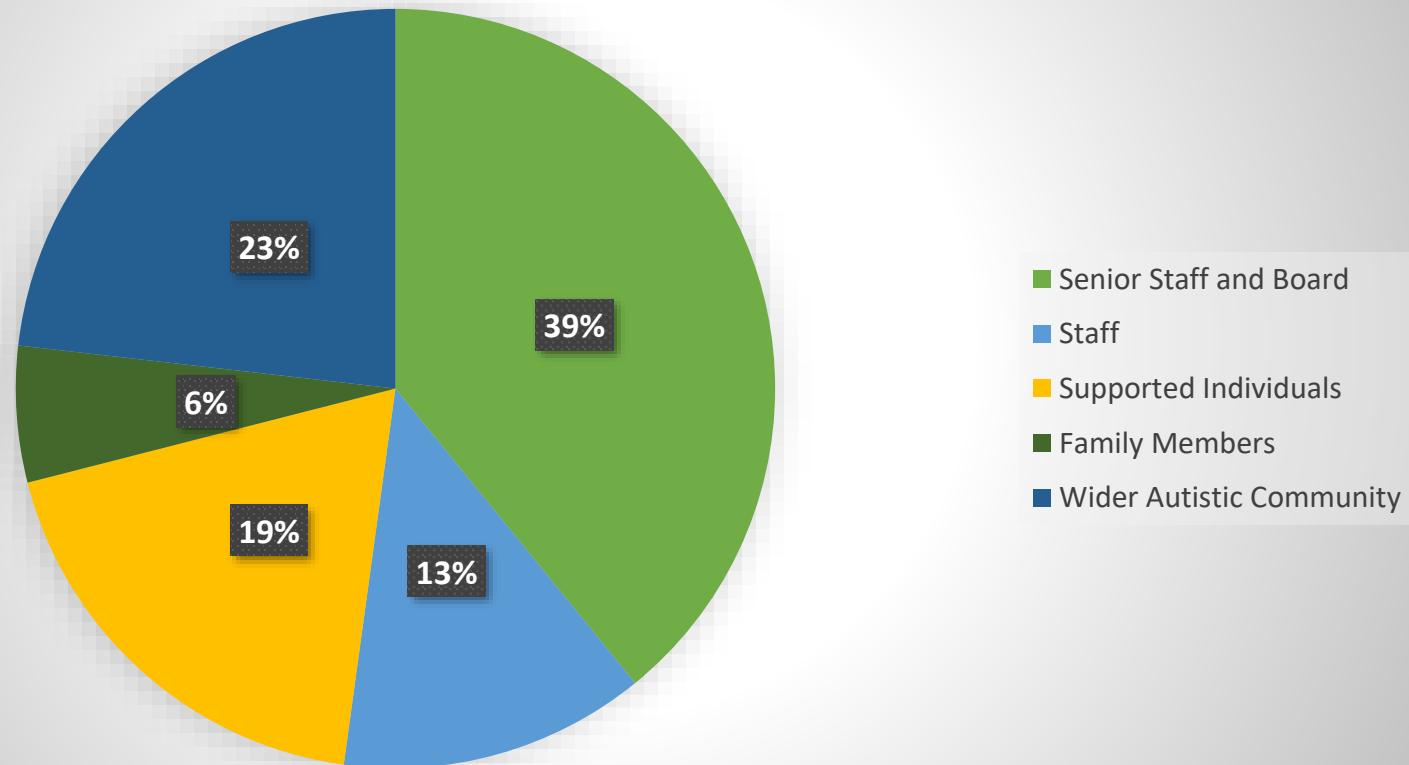
Common features which often arise in autistic space include:

- Non-spoken forms of communication are respected and used at least as commonly as speech
- Sensory sensitivities are respected
- Choices not to communicate or not to interact are respected and participants valued whether or not they choose to interact
- There is lower pressure towards conformity
- Communication contains greater informational content
- Participants are valued for their knowledge and contribution, rather than social status
- Social and communication errors and missteps are more likely to be explained and blame avoided, particularly on the first occasion



# Who did we consult?

Consultees by stakeholder group membership





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3. What do our recommendations have to offer for autistic people with high support needs having increased involvement in governance?



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# Four recommendations

1. Representation in governance
2. Developing agency and leadership
3. Values and recruitment
4. Service autonomy and accountability

# 1. Representation in governance recommendations include:

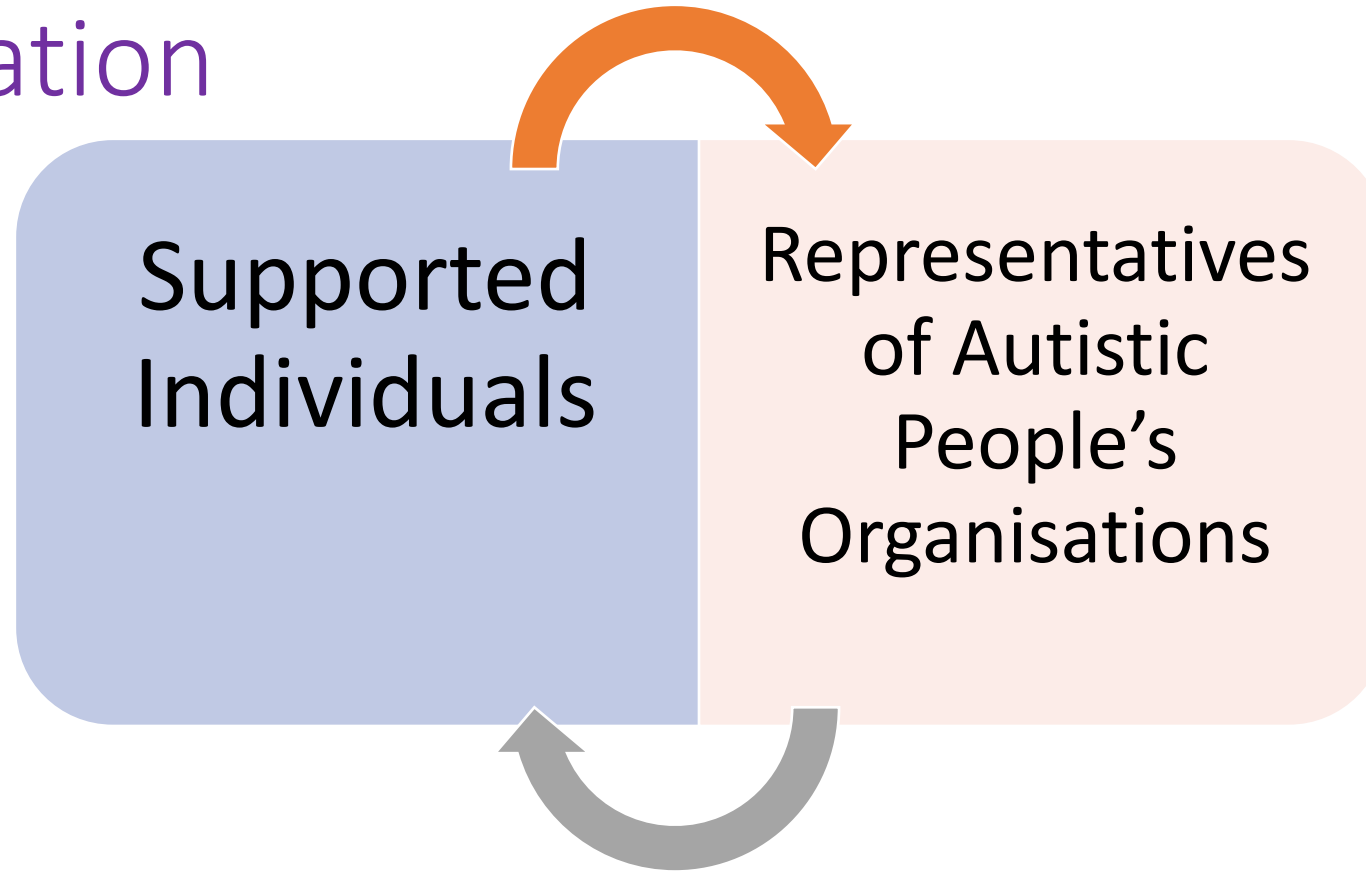
- Board representation:
  - Data on intersectionality
  - Minimum level of representation and target number
  - Accessible working practices e.g. meeting modification, buddy system, accessible papers
- Autistic advisory panel (AAP): Representative Supported Individual from each service + Autistic DPO representatives
  - Mandate to oversee service quality
  - Review nominations to the board
  - Input into job descriptions/person specifications
- Inclusive strategic priority setting process
- Diversity taskforce

# 1. Representation in governance recommendations include:

- Board representation:
  - Data on intersectionality
  - Minimum level of representation and target number
  - Accessible working practices e.g. meeting modification, buddy system, accessible papers
- Shared Leadership – 2 autistic paid co-chairs (at least 1 a Supported Individual) to work alongside the CEO at minimum in campaigning and representation activities

- Autistic advisory panel: Representative Supported Individual from each service + Autistic DPO representatives
  - Mandate to oversee service quality
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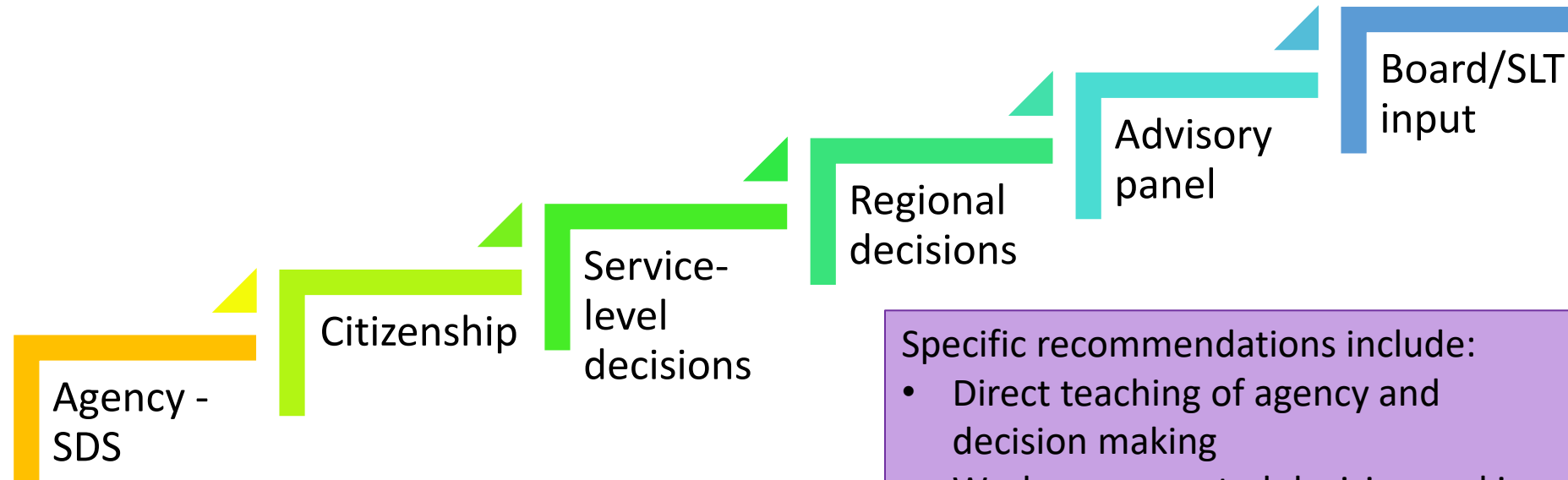
# Progressing representation through collaboration



*“It is the systems – they are very stiff. Minutes are all written, debate at Board is inaccessible. Finances are inaccessible. You need to have a certain level of skill to understand how the money is spent. None of the people we support would be able to interrogate that in its present form.” (SA senior staff)*



## 2. Developing agency and leadership



- Specific recommendations include:
- Direct teaching of agency and decision making
  - Work on supported decision making
  - Leadership development programme for Supported Individuals



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*“it's important to ensure that the program is tailored to the specific needs and goals of the participants”  
(Supported Individual)*

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## 3. Values and Recruitment

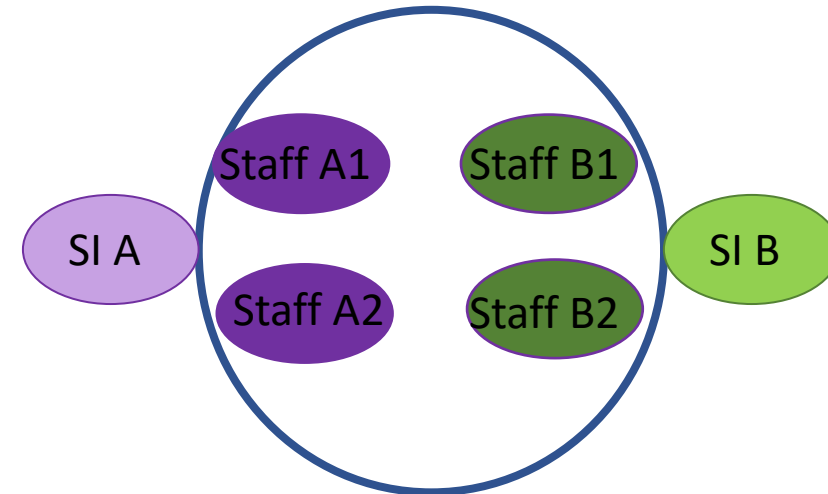
- Recommendations include:
  - Shift to staff seeing themselves as primarily working **for**, and accountable to, Supported Individuals
  - Prioritise autistic needs (e.g. consistency) over organisational or other priorities
  - Recruit from neurodivergent talent pool
  - Pilot project – Fully autonomous support



## 3. Values and Recruitment

Also includes:

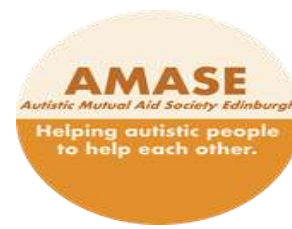
- Creation of Staff/Supported Individual 'bubbles', where staff cover within bubble and SIs know all staff in bubble



Challenge: feasibility in  
current recruitment crisis?



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*“I dislike uncertainty and would struggle with staff around me changing. This is a great idea.” (wider autistic community)*

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## 4. Service autonomy and accountability



Services connected to and rooted in their local communities



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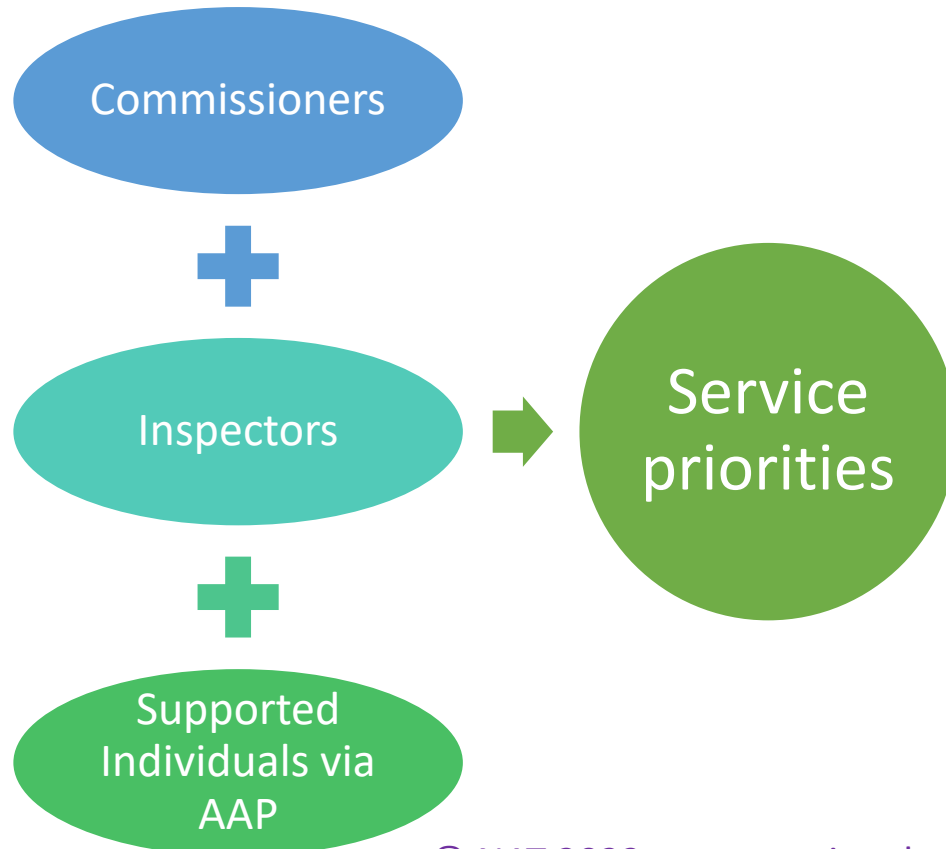


*“I feel like a lot of the time, decisions are made by management that aren’t in the best interests of the individuals.” (SA staff)*

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## Recommendations include:

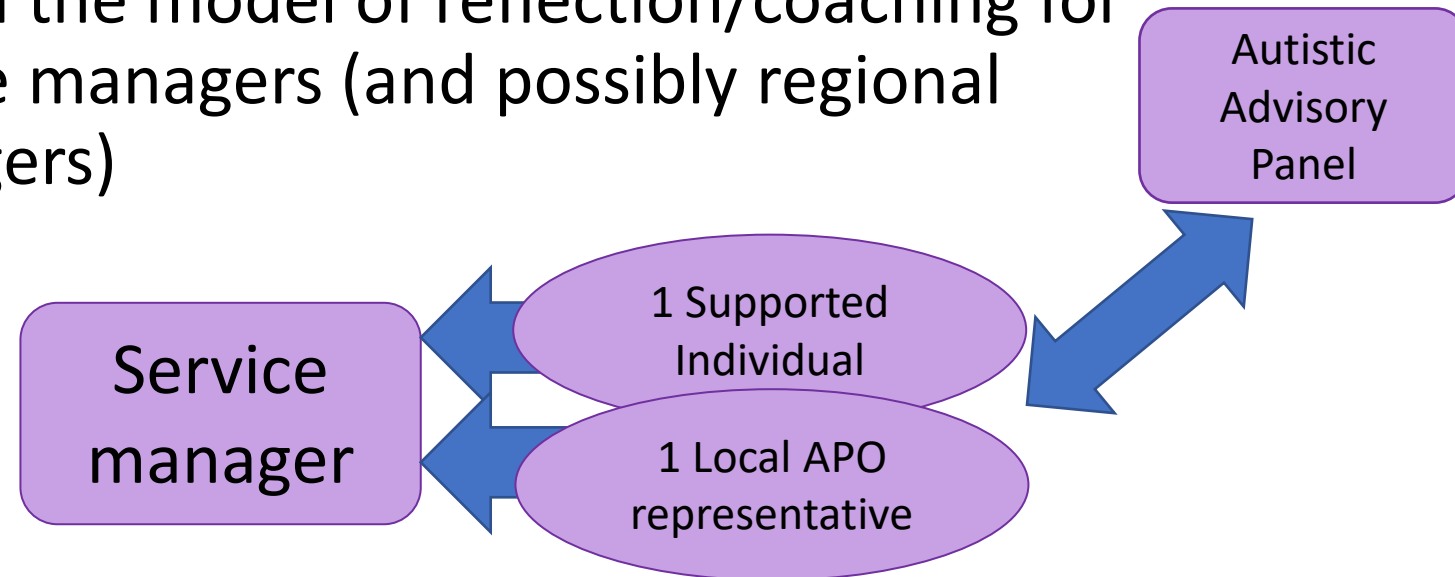


- Service quality accountability to AAP
- Increase the autistic influence on service-level decision-making
- Supported Individual having significant input into support plans



## Recommendations include:

- Shift in the model of reflection/coaching for service managers (and possibly regional managers)



## What now?

- Scottish Autism are now considering our recommendations, engaging with their stakeholders, scoping out what they need to do and producing a programme of work looking at what they will implement in the short, medium and long term.
- Once this has been produced, Scottish Autism will make this available to the public on their website.
- Scottish Autism will also be hosting a webinar on Wednesday 15<sup>th</sup> November 2023 where they will discuss what they have learned from this ground-breaking project.

Full report available on request from:  
[general@nationalautistictaskforce.org.uk](mailto:general@nationalautistictaskforce.org.uk)



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