

Scottish Autism Inclusive Governance Project

Final Report – Summary Version



This document is a summary version of the report on Inclusive Governance at Scottish Autism by the National Autistic Taskforce, Autism Rights Group, Highland, and Autistic Mutual Aid Society Edinburgh.

Readers seeking references to the wider literature that was reviewed, a more detailed breakdown of consultation findings, and appendices may wish to consult the full report:

www.scottishautism.org/inclusive-governance-project

Introduction

This summary report outlines the recommendations of the final report on the Inclusive Governance Project undertaken for Scottish Autism by the National Autistic Taskforce, Autism Rights Group Highland, and Autistic Mutual Aid Society, Edinburgh.

The project team undertook a thorough review of literature on inclusive governance and looked at a range of examples of inclusive governance in practice in order to learn about what worked well and learn lessons from challenges that others had experienced.

The project consulted a range of stakeholders about what inclusive governance at Scottish Autism means. These included supported autistic people; family members; the wider autistic community; Senior staff and board members; and Scottish Autism staff. The team identified three themes that were common to stakeholder responses:

- 1) Meaningful means having an impact
- 2) Plural and collective voices, not just individuals
- 3) The need for innovative approaches, proactive and accessible

Drawing on this consultation and the literature review, the project team were clear that the transformation required was not just about having autistic voices heard, but also valued, respected and acted upon in a context where autistic people are important and empowered.

In considering how to create this real shift in power at Scottish Autism, the project team considered carefully how to balance the inclusion of autistic people supported by Scottish Autism with perspectives of the wider autistic community to ensure that a range of voices are represented.

The team also determined that alongside formal representation in governance structures, transformation requires greater 'soft power' for autistic people – through ensuring that consultation with autistic people and explicit requirements to engage with advice from autistic representatives are built into key decision-making processes at all levels within the organisation.

Autistic Space

The project team propose that the concept of “autistic space” will be crucial to creating contexts in which autistic stakeholders can be truly empowered and in control. Autistic space is defined as any virtual or real-world space that is:

- Shared by several autistic people
- Designed or adapted for autistic processing; and 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.

Four recommendations In this report, the project team set out detailed and specific recommendations for change in four areas:

1. Representation in Governance
2. Developing Agency and Leadership
3. Values and recruitment
4. Service Autonomy and Accountability

The recommended changes will ensure that the voices of autistic people supported by Scottish Autism, and those of autistic people in communities across Scotland, have a meaningful impact on Scottish Autism's strategy and service delivery.

1: Representation in Governance

1.1 Data collection to monitor diversity

Scottish Autism should routinely collect and publish data monitoring the diversity of the board and senior leadership, across a range of characteristics including neurodiversity, or being a family member of an autistic person. This would increase transparency over who is involved in governance; provide accountability to those that Scottish autism seeks to represent; and encourage progress towards increasing diversity.

1.2. Direct representation of autistic people (and others) on the Board

The board should set a target for a proportion of the board to be autistic over the short to medium term, and for some of these to be autistic people directly supported by Scottish Autism in the longer term. This allows time for the development of leadership and agency among supported autistic people as envisaged by the broader project. This change will require a shift in culture for the Board to ensure that working practices, materials, and terminology are accessible and inclusive to all. This means breaking down current hierarchies of knowledge to ensure lived experience knowledge is as valued as professional skills. The project team did not recommend an outright autistic majority on the board, to ensure space for smaller, autistic-led organisations to thrive and provide a voice for the autistic community in wider society.

1.3. Establishment of an Autistic Advisory Panel (AAP)

The establishment of an entirely autistic advisory panel would create autistic space in which autistic people supported by Scottish Autism can be empowered through collaboration with representatives of autistic-led Disabled Persons Organisations from the wider autistic community to establish their own ways of working. The coming together of these groups would support the development of autistic advocacy and leadership among autistic people supported by Scottish Autism. The panel should have significant input into key decisions, including Board appointments; campaigning priorities; job descriptions; Scottish Autism's practice framework; definitions of service 'quality'; and leadership development. Participants should be remunerated for their contributions to the panel. This panel should not become a tokenistic exercise but hold real power and influence in the work of the organisation. To achieve this, the panel should have explicit powers, and the Board should publicly explain decisions which are contrary to the advice or input of the panel.

1.4. Creation of a diversity taskforce

The team recommends that Scottish Autism establish a diversity taskforce comprising staff from across the organization to improve diversity in the governance and representation of Scottish Autism's work. The Diversity Taskforce would support greater inclusion of people from different under-represented backgrounds at all levels of Scottish Autism. The group should build partnerships with organisations representing under-represented groups to proactively support

recruitment, including for senior roles. The group should also screen organisational communications and event programmes/speakers for diversity; develop accessibility including autistic accessibility; promote events run by autistic people who are also members of other marginalised groups; and ensure that autism information reaches marginalised communities. The group should work with the board to develop strategy for increasing diversity within the organisation.

1.5. Shared leadership – co-chairs alongside the CEO

Drawing on Shared Leadership models developed elsewhere, the project team recommends the appointment of two autistic co-chairs to work alongside the CEO, at least one of whom should be a person supported by Scottish Autism. The co-chairs should work collaboratively with the CEO as joint post-holder – at minimum on issues around campaigning and representation, and potentially also in relation to strategic and operational decision-making. This would ensure that, particularly in campaigning and representation activity, Scottish Autism actually has a majority autistic ‘voice’ in situations where the organisation can be seen as ‘speaking for’ autistic people. This input should be valued and remunerated appropriately.

1.6. Inclusive strategic priority setting process

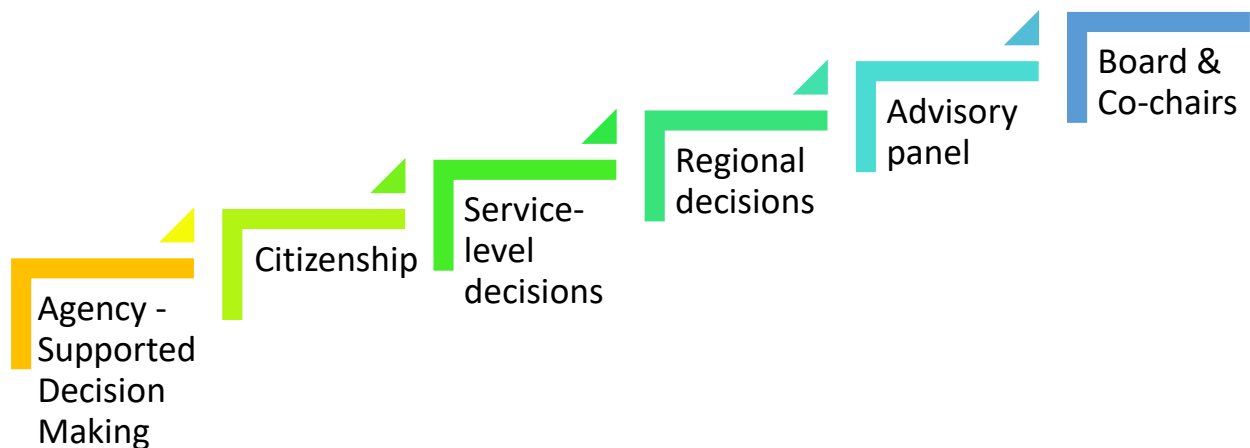
Scottish Autism should pilot an inclusive process for setting strategic priorities periodically. A list of options should be developed with the Autistic Advisory Panel. Supported autistic people would be supported to rank potential priorities and dedicated workshops run for wider stakeholders, including the wider autistic community, to also have input into setting the priorities. If the Board depart from the priorities set through this exercise, they will need to be clear and transparent about the reasons why.

1.7. Transparency in decision-making processes

Scottish Autism’s organisational structure and decision-making processes should be made clear to all in accessible formats. The Diversity Taskforce and Autistic Advisory Panel should screen and check these materials for accessibility. Managers should also be transparent about the rationale for their decisions and explain these routinely.

2: Developing agency and leadership

Inclusive decision-making at all levels starts with an individual's autonomy over all aspects of their life, as outlined in international human rights frameworks. This entails a move from substituted decision making (made on a person's behalf) to supported decision-making. This day-to-day control of decision-making and sense of agency must be developed as a basis for empowering supported autistic people to become active citizens and, if they wish, become involved in service and organisation-level decision-making. This envisages a stepped approach to developing leadership and agency for supported people.



2.1. Development of supported decision-making for all Supported Individuals

Scottish Autism should provide an individualised programme for all supported people to increase their level of involvement in decisions about their own lives. This would involve supporting individuals to develop their communication skills, confidence and understanding of their own agency and identity. This should be formally laid out in Supported Decision-Making agreements between supported people and their guardians. A specialist Communication Support Worker role should be developed to establish the most appropriate communication systems for individuals, with a particular focus on decision-making. The principles of autonomy and supported decision making should be embedded in the work of all frontline staff.

2.2. Involvement of Supported Individuals in 'life admin'

Supported people should be encouraged to be involved in the 'life admin' associated with their day-to-day lives including carrying identity documents; having control of their own support plan and the format it takes; and being involved in processes such as voter registration, benefits applications, or census returns.

2.3. Universal high quality internet access in all services

Communication with family and friends; accessing online communities and social groups (including the wider autistic community) and many aspects of citizenship require the use of effective digital technology, which can be used independently of support staff supervision. It is therefore essential that the infrastructure for fast and reliable connection is available in all Scottish Autism services. Connection speeds should be monitored regularly by the organisation. Supported individuals should be encouraged and supported to communicate with family, friends, and the wider autistic community in private and supervision of communication should be seen as a restrictive practice and steps taken to minimize and seek to eliminate such supervision.

2.4. Modifying SA documentation to require inclusion of views of Supported Individuals

Scottish Autism documents – from support plans through to daily logs and notes – should be reviewed to ensure that there are prompts that require staff to seek, record and engage with the views of Supported Individuals in order to complete routine documentation processes. Support plan documentation should be modified to ensure an explicit focus on developing autonomy, agency, and decision-making, including positive risk-taking, making mistakes and wider citizenship.

2.5. Participation of Supported Individuals in their communities

It is recommended that Scottish Autism proactively encourage supported individuals to participate in their communities and be active citizens. This would include support to vote; support to access information about elections, parties and political processes; support to learn about campaigns and activism around topics and issues of interest; to participate in community organisations and, if they wish, stand for election to community councils; and to learn about and access volunteering options in a local area. It is recommended that an Advocacy Officer be employed to facilitate greater inclusion of supported people in community activities and to support individuals to overcome any discrimination or barriers to community participation.

2.6. Participation of Supported Individuals in the wider autistic community

The report recommends that supported individuals are proactively encouraged and supported to participate in the wider autistic community, locally, nationally, and internationally. This includes encouragement and support to join an autistic-led Disabled Persons Organisation in their local area and Scottish Autism supporting the development of autistic DPOs in areas where none yet exist. This would further the representativeness of autistic DPOs and enable access to autistic space for a larger number of supported individuals.

2.7. Leadership Development Programme

In the medium term, the team recommend that Scottish Autism create an autistic leadership development programme, empowering individuals who wish to do so to develop the self-advocacy skills and confidence to influence services at local or regional level, to represent others on the Autistic Advisory Panel, or to serve as co-chairs or Board members. The programme should be designed and overseen by the Autistic Advisory Panel with support from the diversity taskforce and the team at Scottish Autism's Centre for Practice Innovation.

3: Values and recruitment

In their engagement with a range of stakeholders, the project team identified the importance of supported individuals being supported by staff who are well matched with the individual and by a consistent staff team. They also identified the need to ensure that autistic staff also experience an inclusive and empowering environment for autistic people.

3.1. Review of Scottish Autism's values

Scottish Autism's organisational values should be reviewed and revised to reflect the changed prioritisation of the inclusion agenda and should include supported individuals and the wider autistic community in agreeing those values. Values that should be considered for adoption include equity, justice, diversity, rights, and autonomy.

3.2. Language use policy

The organisation should adopt a language use policy that would improve the extent to which all autistic people feel welcome and like they truly belong. The Autistic Advisory Panel should be asked to draft a proposed language use policy, and this should be reviewed and screened by the diversity taskforce to ensure that all organisational communications reflect autistic community preferences and consider diversity in all its forms.

3.3. Reorientation towards viewing staff as working for supported individuals

A key recommendation is for a further shift in the orientation of employment and working practices to staff seeing themselves as working for and accountable to the individuals they support.

This would include supported individuals routinely being present on interview panels, including those with the highest support needs. This requires a shift in culture to see the presence of supported people as essential in the same way that management or HR professionals might be presently. In the medium term the team recommends that supported individuals lead the recruitment process with HR and Managers being seen as advisory.

Interview questions and formats should also be reviewed and modified to ensure that they do not disadvantage autistic candidates. This might include undertaking an activity with a supported person, or job trials rather than a traditional interview.

3.4. Prioritising autistic needs over organisational needs

A further shift is recommended in the orientation of working practices to prioritise autistic needs (such as consistency) over other pressures and demands (such as the redeployment of staff from an individual's support team elsewhere).

To support this aim, it is recommended that 'bubbles' of staff are created around small numbers of supported people to promote consistency and familiarity. This would allow some

flexibility where staff sickness or annual leave create gaps but would maintain consistency within the bubble.

This approach values relationships between practitioners and supported people and acknowledges their importance to supported people. The bubble system may also serve to improve the cohesiveness of teams and, consequently, staff recruitment and retention.

3.5. Diversity and neurodiversity in recruitment

We recommend that Scottish Autism seek to improve diversity and the inclusion of under-represented groups at all levels of staff within Scottish Autism. The organisation should proactively diversify the talent pool it draws on, particularly in the inclusion of neurodivergent talent.

Prioritising neurodivergent traits in recruitment – such as directness and clarity of communication, attention to detail, and consistency - over traditional ‘caring’ attributes will further the synergies between support staff and supported individuals.

3.6. Strategies to enable raising staff pay

Supporting individuals to develop decision-making skills, communication and autonomy requires staff who have the skills to do that in ways that do not include restrictive practices. Such a level of skill, and demonstration of the right values, require a commensurate rate of pay.

The project team recommend considering whether reducing staff ratios in some instances might allow for a better rate of pay for a smaller number of staff hours. Such a rate would attract more skilled practitioners. For example, where the need for 2:1 support, or 24-hour cover is often assumed to be necessary, these factors may, in fact, increase anxiety or distress and place a brake on the development of autonomy, privacy and agency. The project team recommend Scottish Autism seek to influence commissioners towards such re-envisioned support packages.

3.7. Pilot of a self-directed support model

Self-directed Support (“Option 1”) in Scotland provides a model through which an autistic adult can directly employ support staff and control their own support. Scottish Autism should explore the possibilities of moving towards a service model facilitating greater take up of SDS Option 1 and the development of care co-operatives among autistic people with support needs. Scottish Autism provision would therefore be in the form of ‘Case managers/support brokers’ to facilitate recruitment and HR support and would not take the form of a hierarchical management structure. This arrangement could be piloted, perhaps in an area where Scottish Autism does not currently have services.

4: Service Autonomy and Accountability

4.1. Services connected to, working with and offering services needed by their local autistic communities, including autistic DPOs

We recommend that Scottish Autism services should be rooted in and connected to their local communities. This should include engagement with the wider autistic community beyond those supported in commissioned services, and engagement with local autistic Disabled People's Organisations as representatives of the local autistic community. This will leave Scottish Autism better placed to respond to the needs of the local autistic community, including developing a support offer to the local autistic community, fostering the development of new autistic Disabled People's Organisations where they do not exist and the active encouragement and facilitation of supported people to join and be involved in the work of local DPOs.

4.2. Increasing the autonomy of services rooted in their local communities

The report recommends that greater autonomy for Scottish Autism's local services could facilitate better networking with local communities, and greater community participation for supported people. This would allow for more localised service offerings to develop and re-cast central functions (such as HR and IT) as supporting local services rather than directing them.

4.3. Ensuring autistic influence on service quality

Currently what is seen as service quality is influenced significantly by commissioners and inspectors. At the same time the influence of health professionals and, sometimes, guardians, often driven by misperceptions of legal requirements, can lead to risk averse practice. Autistic people should have greater input into what is defined as quality autism support. Consequently, we recommend that the Autistic Advisory Panel should have significant input into Scottish Autism's 'Autism Practice Improvement Framework'.

4.4. Ensuring autistic influence in the inspection and appraisal of services

It is recommended that members of the Autistic Advisory Panel should participate on an equal basis with existing compliance or quality staff within Scottish Autism in service inspections, visits, and in quality review processes. We also recommend the creation of a clear and accessible route to the AAP for supported individuals, staff, and family members to raise concerns, or for 'whistle blowing'. This would not replace existing channels or processes but add an additional safeguard for those that seek an autistic-controlled forum for raising issues. The APP would then be empowered to speak up at a senior level and, if necessary, externally about serious concerns.

4.5. Manager reflection and coaching carried out by Supported Individuals and members of the wider autistic community

Under this recommendation, reflection, coaching and appraisal sessions for managers should be undertaken by supported individuals, aided by representatives of autistic DPOs or the wider autistic community. Training through the leadership development programme would facilitate this process and those involved would be overseen by the AAP. The purpose of this recommendation is to increase the degree of autistic influence over decision-making and to counterbalance the influence of commissioners, inspectors and other influences over the thinking and priorities of managers.

4.6. Enhanced vertical communication between frontline staff and senior leadership

Communication directly between frontline staff and senior leadership should be enhanced, ensuring that these voices are heard by senior leadership, and making clear routes for raising concerns or whistleblowing. The Autistic Employee forum and the Autistic Advisory Panel should develop close links, so that the voices of all autistic stakeholders can be represented collectively to senior leadership and Board by the AAP.

4.7. Locating Inclusive Governance staff in the Centre for Practice Innovation as a knowledge distribution hub

The project team recommend an enhanced role for Scottish Autism's Centre for Practice Innovation to support and further the Inclusive Governance agenda. Specialist Inclusive Governance staff and the Advocacy Officer should sit within the Centre and care will be required to ensure sufficient separation of potentially conflicting interests from marketing and income generation activities with those of practice improvement and inclusive governance. Working in partnership with services, the Centre's role as a knowledge exchange hub will serve to amplify autistic voices and distribute knowledge externally and internally.

Conclusions

The concept of 'inclusive governance' was not rigidly defined at the beginning of the project, and Scottish Autism permitted the project the freedom to develop the idea as it progressed. In the end, we arrived at a very broad conception reaching all areas of SA, from day-to-day decisions in a supported individual's life to broad strategic decisions made at board level.

Scottish Autism exists, in very large part, to meet the needs of supported individuals in the contexts of social care, education and wider society. In those contexts, it is increasingly being recognised that support for disabled people needs to better empower and represent disabled people ourselves, through concepts such as inclusion, self-determination and autonomy. Supported individuals must be supported to take the lead in what happens in the services they use, to the extent that they are able and wish to do so.

Scottish Autism is not just an inward-facing organisation, it also has a role in regional and national social policy relevant to the lives of autistic people. To be 'inclusive' in its decision making in these outward-facing areas it was clear SA needed to make connections with the wider autistic population, including autistic DPOs who collectively represent the views of their autistic members.

Our knowledge of the wider autistic community and the importance for the development of agency and increased autonomy of exposure to autistic space and culture, led directly to recommendations to promote links between supported individuals and the wider autistic community outside of Scottish Autism. Our proposal that the Autistic Advisory Panel would in part be comprised of autistic people from the wider community, will create connections between supported individuals and autistic people outside Scottish Autism, and create a vital pocket of autistic space within Scottish Autism.

Governance starts with control over an adult's day-to-day life and decisions. These recommendations involve significant shifts of power into the hands of supported individuals. For autistic people who depend on paid staff for care and support, governance of those staff is a vital element of control over our own lives. Seeking to increase the consistency, retention, compatibility, and autistic empathy of those staff and maximise the inclusion of supported individuals in the selection and deployment of those staff are essential elements of inclusive governance.

None of the recommendations in this report exists in a vacuum. The recommendations are necessarily interdependent. If Scottish Autism wishes to effect change capable of having the 'meaningful impact' identified in the exploratory discussions, it is by adopting the totality of our recommendations that this can be realised.