Scottish Autism Inclusive Governance Project – Final Report

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Appendices

Note on the attribution of quotes

Throughout the report we have included anonymised quotes from exploratory conversations, formal and informal interviews and co-production workshops undertaken throughout the project. In order to protect the anonymity of participants whilst also providing insight into the perspectives of different stakeholder groups, throughout the report quotes are attributed via the following categories:

Senior Staff (SS): Present and former Board members, members of the Senior Leadership Team (SLT) and members of the Wider Leadership Team (WLT).

Scottish Autism Staff (SAS): All Scottish Autism staff apart from Senior Staff (SS).

Supported individual[1] **(SI):** Former or current user of Scottish Autism's services, except the advice line.

Family member (FM): Parents, carers, family members and guardians of Scottish Autism's supported individuals.

Wider Autistic Community (WA): Autistic people[2] who are not former or current users of Scottish Autism's services or have only used the Advice Line or, in some cases, a One Stop Shop.

Unidentified (U): In a few cases it has not been possible to identify the group membership of the individual quoted.

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[1] Throughout the report, we use the Scottish Autism term 'supported individual' to refer to autistic people who use Scottish Autism's services, primarily those who are provided with formal care and support services by Scottish Autism

[2] Self-identified

Executive Summary

As an organisation, Scottish Autism wished to ensure that the voices of the people they support and those of autistic people in communities across Scotland shape Scottish Autism's strategy and service delivery. This project was commissioned to support Scottish Autism to develop and deliver a change programme that will result in inclusive governance at Board and operational level.

In this report, we set out our recommendations for change in four areas:

- Representation in Governance
- Developing agency and leadership
- Values and recruitment
- Service Autonomy and Accountability

In each of these areas, we identify specific innovative and creative recommendations for change. We set out proposals which 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.

Taken together, these recommendations offer a comprehensive and challenging programme of change throughout the organisation. They provide an opportunity for Scottish Autism to show leadership by ensuring that governance at all levels is meaningfully inclusive of the autistic people they support and the wider autistic community across Scotland. Making Scottish Autism's governance inclusive has the potential to empower autistic people to take control of our own lives and futures.

Introduction

This is the final report of the Scottish Autism Inclusive Governance project. The project has been undertaken by a consortium of three autistic-led organisations:

- Autistic Mutual Aid Edinburgh (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.
- Autism Rights Group Highland (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.
- National Autistic Taskforce (NAT) is a UK-wide autistic-led organisation 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.

Representatives from each of these organisations formed the all-autistic Inclusive Governance Team who undertook the project and preparation of this report.

Background and project structure

As with all projects, the Inclusive Governance Project developed and changed as it progressed. There were two core strands to the project, (i) desk research and (ii) stakeholder engagement.

(i) Desk Research

Initially, this involved a very broad survey encompassing a literature review which included Scottish Autism's (SA) previous service user surveys, policy and other documents, consideration of 100+ organisations (worldwide and across sectors) and creating summary information on approximately 30 organisations. Following that, the team undertook in-depth case studies of 8 organisations (Table 1) and 5 thematic case studies (Table 2). In some cases this included speaking directly to organisations to gather information beyond that publicly available. The full organisational case studies can be found in Appendix A, the thematic case studies are detailed in Appendix B, and an extended thematic case study of Supported Decision Making is found in Appendix C.

Table 1: Organisational case studies

Organisation
British Deaf Association
Glasgow Disability Alliance
Glasgow Centre for Inclusive Living
Learning Disability England
Mencap
People First Scotland
Vox Scotland
Who Cares? Scotland

Table 2: Thematic Case Studies

Approach	Organisations/material considered
Governance and leadership training programmes	Sylvia Rodger Academy at Autism CRC, Australia Disability Rights UK
Approaches to supporting communication	Communication First, US Deaf Action
Approaches to supporting decision making	Mental Welfare Commission South Australia SDM project People First Scotland Scottish Autism participation and involvement research and supported individual survey Essex Autonomy Project summer school
Service-level models of governance and recruitment	Edinburgh Development Group Care Co-operatives Enable North-West Care co-operative Peace of Mind Small Supports Glasgow Centre for Inclusive Living
Intersectionality	The Arc, US A2ndVoice CIC

(ii) Stakeholder engagement

The stakeholder engagement process started with a series of exploratory meetings with members of the Board, Senior Leadership Team (SLT) and Wider Leadership Team (WLT). A consultation event for the wider autistic community was held at Autscape[3] and a further co-production workshop online targeted primarily at Autism Rights Group Highland (ARGH) and Autistic Mutual Aid Society Edinburgh (AMASE) members. The project team created and worked with SA's comms team to distribute materials about the project in a range of formats, including Easy Read and video, to supported individuals, families and staff across the organisation. Those communications led to survey responses from 55 individuals from a range of stakeholder groups, bespoke interviews and observation, primarily with supported individuals, and, at a later stage, further interviews with a range of stakeholders and co-production workshops. Not including the survey, these stakeholder engagement events included 69 people in total: supported individuals, parents/guardians/family members, staff (other than WLT members), autistic people who are not supported individuals, and a few members of the wider community (mostly representatives of pan-disability groups). The breakdown is set out in Figure 1. Members of the Inclusive Governance team who produced this report also attended the WLT event at Largs in August 2022, provided an interim report at a Board meeting in January 2023 and met with members of the SLT throughout, including

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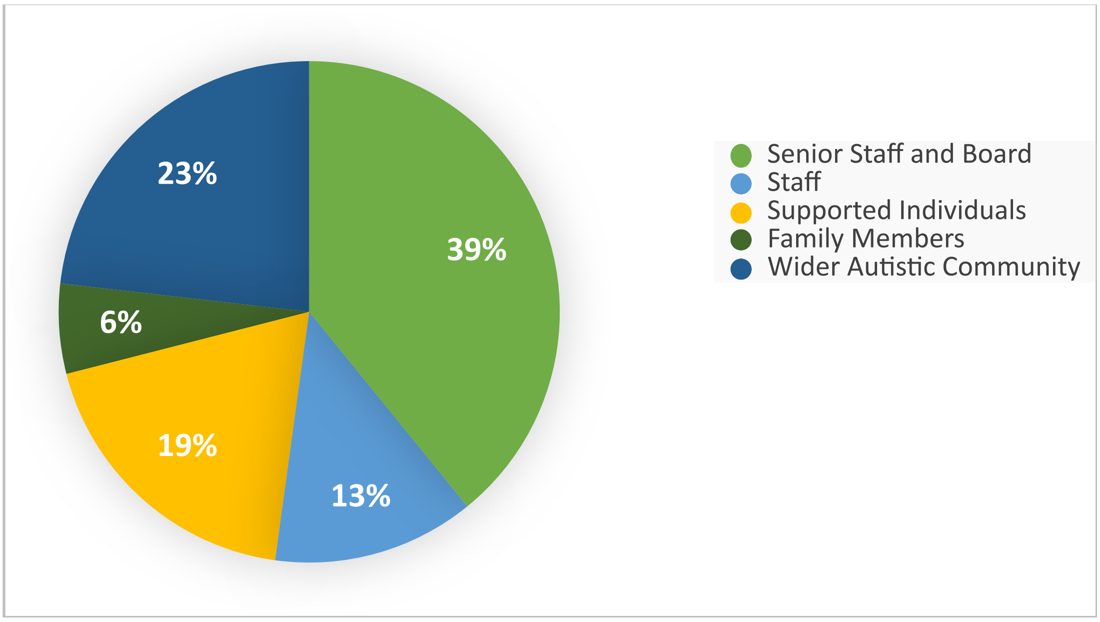
[3] Autscape is an annual residential event by and for autistic people. www.autscape.org

regular meetings between Yo Dunn (as project lead) and Dorry McLaughlin (on behalf of Scottish Autism) in the final phase of the project.

Figure 1: Consultees by stakeholder group membership



What is inclusive governance?

The literature

The literature on inclusive governance highlights the potential benefits:

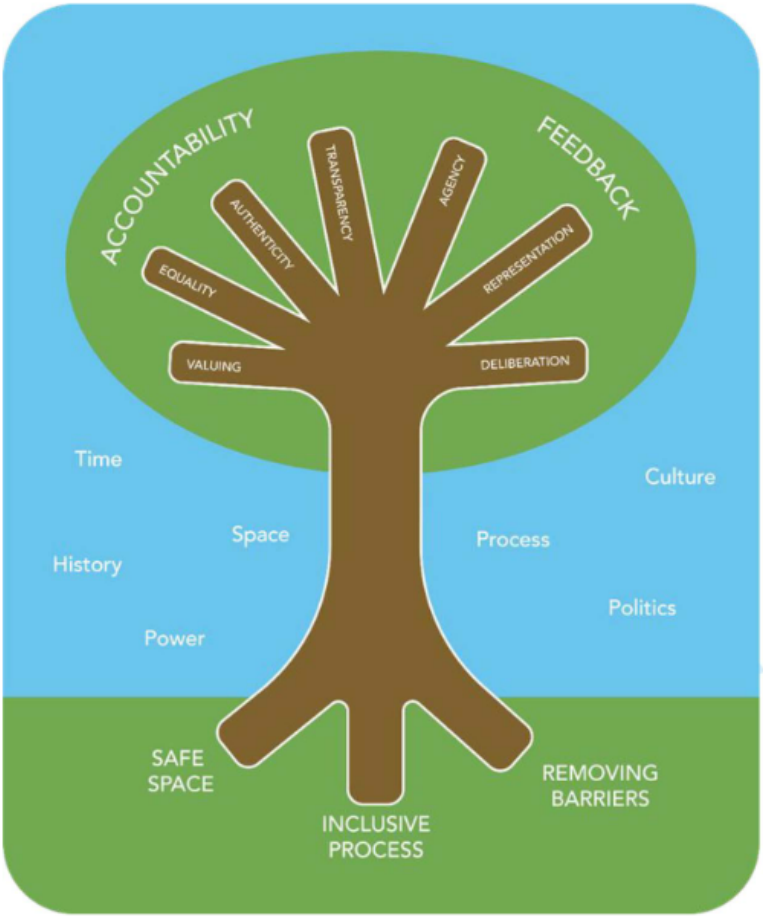
> *"An inclusionary outlook has the potential to broaden the design of community-care services and facilities. An inclusive ethics would radically open up policy design to a range of other service options that account for the complexities of place, policy context, and the needs of key interest groups, such as service users, workers, relatives/advocates, and local communities."* (Gleeson & Kearns, 2001, p. 61)

We have considered throughout a range of factors identified in The Tree of Participation model (Bell & Reed, 2021; Figure 2) as likely to influence the effectiveness and functioning of our recommendations. These are (Reed et al., 2017, p. 1):

- Socioeconomic, cultural and institutional contextual factors; for instance, the existence of a participatory culture, former experiences of engagement and available resources.
- Process design factors (such as transparent, structured opportunities to engage).
- Power dynamics, the values of participants and their epistemologies; that is, the way they construct knowledge and which types of knowledge they consider valid.

- Temporal scales, such as early engagement and match to the temporal and spatial jurisdiction of the decisions and interests of stakeholders.

Figure 2: The Tree of Participation (Bell & Reed, 2021)



We have also been strongly influenced by Colenbrander et al. (2017), who 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).

Stakeholder views

Participants in the exploratory meetings (Board, SLT, WLT) and in the survey (family members, supported individuals, wider autistic community) were asked what 'Inclusive Governance' meant to them. Three themes emerged: (i) meaningful means having an impact, (ii) plural and collective voices, not just individuals, and (iii) need for innovative approaches, proactive and accessible. Illustrative quotes for each of these are given below, and figure 3 illustrates the comments of stakeholders.

Themes from stakeholder engagement

(i) Meaningful means having an impact

"Real influence at strategic level. A form of steer." SS

"Highest levels of participation in governance as possible when outcome impacts the person." WA

"Active participation. If people are asked their opinion that leads to their voice being heard and having impact." SS

"Those making decisions need to listen to autistic people and behave in accordance with their wishes." WA & SAS

> *"Listening and doing something with it. Meaningful." SS*
>
> *"Ownership in decision making." SS*

(ii) Plural and collective voices, not just individuals

> *"All interested parties are able to feel included in process and outcomes, how decisions are made and who benefits from them. End users in particular should be included." SI*
>
> *"Collective not just individual." SS*
>
> *"Plurality of voices." SS*
>
> *"Being open and listening/involving everyone in a way that ensures needs are met." WA*
>
> *"Expanding sphere of engagement [to include] the wider autistic community and stakeholders." SS*

Figure 3: **Word cloud illustrating the words used to describe inclusive governance in the exploratory meetings.**

Note: The word cloud illustrates the range and frequency of words used by stakeholders, generated from transcripts of the meetings. Larger words were used more frequently.

> *“People with personal experience is both good and bad because those with personal experience tend to focus on their own.” SS*

> *“Inclusive governance is inclusive of lots of different voices.” SS*

> *“I find it difficult to speak for other people (and we all do). I am representing something sometimes, but ultimately, I am kind of giving my perspective. I try to represent as best I can, but it’s a challenge when we are trying to hear voices, and I would be keen for the plurality of voices.” SS*

> *“We need to be careful. There isn’t necessarily a perspective – there is a range of perspectives amongst the community we service. This is part of the diversity.” SS*

(iii) Need for innovative approaches, proactive and accessible

> *“Broadening our idea about what representation looks like, and wonder if we are stuck in a normative view about that.” SS*

> *“Taking reasonable steps to consider and accommodate the needs of everyone, ideally by default and proactively. Including representatives from all interested groups in all governance decision making.” SI*

> *“Including people is giving them opportunities to participate in society, in a proactive / active way, rather than as passive recipients.” WA*

> *“Also not just about presenting people an option, its about trying to actually get that involvement at an early stage and what we all want it to look like at an early stage. Often we end up presenting choices, rather than going ‘what would you like to do?’” SS*

> *“Involving everyone, regardless of their capabilities, with adaptations to make up for capabilities they might be missing.” FM*

> *“Are we asking the right questions?” SS*

> *“Difference is accepted and celebrated. Accommodations are matter of fact autistic Representation at all ages and stages.” WA*

How these perspectives have influenced our approach

Inclusivity is not just about having a say, it's about feeling like you are an essential and important person in whatever your role is in the organisation. Relationships, respect, and feeling important are all important (Hindberg, 2016).

> *“It is not just about having the space to say things but also that what is said is taken seriously and considered to be of high value.” (Bell & Reed, 2021, p. 7)*

We have focussed throughout on seeking to ensure our recommendations are capable of providing a real shift in power and ensuring that those voices which are included have a meaningful impact on decision making.

We have also been aware of potential concerns arising from some approaches to inclusion. Some forms of democracy can risk reinforcing existing power imbalances in society and require extensive outreach to include marginalised groups (Bell & Reed, 2021). As identified in the exploratory discussions, if there is to be a layer of governance that is controlled by a particular stakeholder group and meant to be representative, there is a risk that this is likely to attract a certain kind of person that may not be representative and this can lead to problems and possible breakdown (Ottmann et al., 2008). We have been mindful of this danger, particularly with regard to the inclusion of autistic people, throughout our proposals. We have given a great deal of thought to the advantages and disadvantages (Richter, 2018) of both internal inclusivity of supported individuals and to including the wider autistic community. Throughout our recommendations, we have sought to balance these in ways which harness the value of greater engagement with and participation of the wider autistic community, whilst also ensuring that the voices of supported individuals are enhanced, rather than drowned out, by the involvement of autistic people external to Scottish Autism. We have sought to ensure our recommendations enable collective and plural voices to be heard.

We have explored a wide range of potential approaches to inclusive governance, but they all fall broadly within two categories: direct representation and 'soft' power. Direct representation can involve mechanisms such as categorizing the interests of stakeholders into various classes and deliberately attributing to each class a similar influence in the organisation, regardless of its substantive size. 'Soft' power approaches include issue by issue consultation or the creation of advisory bodies comprising stakeholders and/or their representatives with the power to advise on, or even veto, certain material decisions (Colenbrander et al., 2017). Mindful of the need for innovative, proactive and accessible approaches, we have recommended the adoption of multiple approaches to inclusion across the organisation, encompassing both direct representation and 'soft' power.

Throughout we have taken a broad view of inclusive governance, considering decision making at all levels throughout the organisation (Figure 4).

The concept of 'Autistic Space'[4]

A number of our recommendations draw on the concept of 'autistic space', a concept that developed in the autistic community over time. 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

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[4] See this presentation by Martijn Dekker at Autscape 2015 for a history of early autistic space, the core ideas of the definition given here and more depth about the concept: http://www.autscape.org/2015/programme/handouts/early-autistic-space.pdf (Dekker, 2015)

Figure 4: Inclusive governance through all levels of the organisation

- By and for autistic people where autistic needs and culture take priority
- Being and acting autistic is acceptable and accepted

In autistic space there is an increased probability of autistic people meeting similar and/or compatible people. Non-autistic people can feel socially disabled, disorientated and, even, out of place in autistic space. It is important to note, however, that autistic space does not magically remove all difficulties: autistic people are not just different from non-autistic people but also different from each other, and there will still be incompatibilities. Nevertheless, time spent in autistic space can:

- be empowering
- be relaxing
- provide a sense of community and belonging
- enable the sharing of rare or less common experiences and interests
- allow for experiences of feeling less disabled than in non-autistic space.

A number of specific differences are observable between autistic space and non-autistic space. Common features which often arise in autistic space include:

- Non-spoken forms of communication are respected and used at least as commonly as speech and there is parity of esteem between different forms of communication.
- Sensory sensitivities are respected and the space is more likely to be lower in sensory stimuli, e.g. less bright, quieter, less movement.
- Choices not to communicate or not to interact are respected and participants are 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 being accorded on the basis of aspects of presentation.
- Social and communication errors and missteps are more likely to be explained and blame avoided, particularly on the first occasion.
- Aspects of ‘nerd culture’ such as science fiction, video games, and comics are considered ‘normal’ cultural knowledge by many (though not all), and having no idea who a celebrity is would be perfectly normal.
- Spilling food down your clothes and tripping over your own feet does not draw unwanted attention, or often any attention at all.
- It is normal to forewarn others about all changes, do exactly what you say you are going to do and provide detailed information about expectations.
- It is socially acceptable to ask direct questions such as ‘Why?’, ‘What’s the point?’, ‘Can I join your group?’ or ‘Do you want to be friends?’ and expect an honest, direct answer.
- It is considered unreasonable to expect someone else to know what you think or how you feel without telling them.

Recommendation 1: Representation in Governance

What are we proposing?

A range of strategies to increase the representation of autistic people, particularly supported individuals, in the governance of Scottish Autism. The scope of this recommendation also includes consideration of the diversity of Scottish Autism's governance more broadly. In developing this recommendation, we drew on a series of questions originally developed by The Arc[5], a US-based organisation advocating for and with people with intellectual and developmental disabilities:

Diversity — Who is in the room?

Accessibility — Can everyone get inside the room? Can everyone participate?

Equity — Who built the room? Who has the power?

Inclusion[6] — Does everyone in the room feel welcome? Like they truly belong?

1.1. Data collection to monitor diversity

We propose that Scottish Autism set up processes to routinely collect and publish data on the diversity of, initially, the Board and also, over time, the Senior Leadership Team and Wider Leadership Team. We also recommend that Scottish Autism consider extending this data collection to all staff over time.

The data collected should cover a wide range of identities including:

- Autistic/otherwise neurodivergent/neurotypical[7]
- Family member or carer of autistic person
- Ethnicity
- Age
- Lived experience of disability broadly
- Family member or carer experience of disability broadly
- Gender (including non-binary)[8]
- Religious or philosophical belief
- Sexual orientation (LGBTQI+)

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[5] https://thearc.org/about-us/access-equity-inclusion/

[6] Inclusion means people feel supported to bring their authentic selves into a space, knowing their differences will be embraced.

[7] Self-identified

[8] Self-identified

- Socio-economic status[9]
- and possibly further identities[10]

The publication of such data should be undertaken in a way which balances the advantages of transparency against the right to privacy of individuals involved in governance. For example, by publishing figures on the proportions of various identities represented amongst various groups, such as the Board, as a whole.

Data collection and publication is an essential underpinning for several inclusive outcomes. It would:

- Provide baseline information about the current diversity of Scottish Autism's governance.
- Provide transparency around diversity in order to increase Scottish Autism's accountability to those it seeks to represent.
- Encourage progress towards increasing diversity.

Monitoring and information rights are essential to stakeholder participation so that stakeholders can formulate informed opinions and ensure accountability, but this only works if these are linked to access to an adequate remedial mechanism (such as Board elections) to ensure accountability (Colenbrander et al., 2017).

The importance of ensuring a wide range of voices are meaningfully included in governance was raised throughout the project:

> *"Voices that don't always agree and say different things. There might be subtle tension and I want to hear all of that so we can come to a rounded view, rather than a filtered view. The full breadth." SS*

It is possible that, if the data shows a lack of diversity in some respects, publication of these data could attract negative publicity. However, if presented with care, publication could be used as an opportunity to make a public commitment to increasing diversity, challenging barriers to autistic participation and representation. This has the potential to enable Scottish Autism to be seen as progressive in terms of transparency, accountability and progress towards diversity and to contribute to implementation of Article 31 of the United Nations Convention on the Rights of People with a Disability (UNCRPD) (United Nations, 2006). We have assumed no additional cost attached to this recommendation, as the process could be integrated with existing induction, data collection and publication processes. Data collection and

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[9] It is likely to be most useful to base this on the National Statistics Socio-economic classification (NS-SEC) 5-group structure. However, it will be particularly important to include the additional 'Never worked and long-term unemployed' category, given the likelihood of significant autistic membership of that category.

[10] Equality Act 2010 protected characteristics: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation.

storage will need to be compliant with UK GDPR, or applicable legislation at the time; however, this is likely to involve only minor changes to existing data policies and processes.

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

We propose that Scottish Autism commit to the direct representation[11] on the board of autistic people and that this commitment should be made explicit in the governing document. We recommend setting a target number or proportion of autistic board members[12] and work towards achieving this in the short to medium term. We also recommend considering setting a separate target number or proportion of family members/carers/friends of autistic people on the board. This target should be separate from and additional to that for autistic board members, however it should allow for overlap and multiple identities (i.e. family members of autistic people who may also be autistic themselves)[13].

This is an obvious, but important mechanism to move governance towards greater inclusion:

> *"An important way in which inclusive governance can be given shape is through multi-stakeholder ownership and direct representation in the decision-making processes." (Colenbrander et al., 2017, p. 549)*

This recommendation attracted widespread support from all stakeholder groups:

> *"Autistic people should be leading the organisation." WA*

> *"The control and ownership are shared meaningfully." SS*

> *"Another thing that might help, as well, is parents of autistic people on the board." FM*

We propose additionally specifying that a target number or proportion of those board members should be supported individuals with direct experience of receiving significant services (more than merely advice line) from Scottish Autism.

> *"Including and accountable to the people we support." SS*

It is likely that this additional requirement may need to be implemented over a longer time period, in order to allow time for the development work needed (see *Recommendation 2:*

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[11] It should be noted that the use of 'representation' here does **not** imply that those Board members would be democratically representative of autistic people or taken as speaking for all autistic people.

[12] This does not include non-autistic family members/carers of autistic people.

[13] Although it is probably beyond the remit of this report, we suggest that Scottish Autism also consider a target number of at least one current or former frontline care worker on the Board. *"But I think a lot of the time at the top, it's not people that have really worked in care, it's people with a business mind that can run Scottish Autism as a business, whereas they've not really got any experience in care, whereas I think it should be somebody from the bottom that works their way up." SAS*

Developing agency and leadership). However, the time period set should be ambitious and seek to make this recommendation a reality within the medium term.

We are not recommending that Scottish Autism should seek, at least not in the medium term, to increase the representation of autistic people on the board to comprise an outright majority. This is because, as a large well-established organisation with a secure financial position, if Scottish Autism met the same definitions as small, grassroots, autistic-founded and led organisations (referred to in this report as autistic Disabled People's Organisations[14] (DPOs)), there would be a significant risk that Scottish Autism would become a competitor to such organisations in opportunities to represent and advocate for the needs of autistic people in public policy contexts. This would risk a counter-productive impact on the wider representation of autistic people on our own terms in Scottish society. No one organisation should present itself or allow itself to be seen as representing all autistic people.

We are not recommending a specific number or proportion of autistic people on the Board. However, we note that, at present, it appears that this proportion is approximately one sixth (1/6) of the Board. If Scottish Autism seeks to represent all stakeholders across the wider communities of autism (autistic people, family members, professionals), then setting a proportion closer to one third (1/3) might be considered appropriate.

In addition to supporting the personal development of individuals discussed in Recommendation 2, implementation of this recommendation, particularly the direct representation of supported individuals, will require significant changes to Board working practices and culture. Our desk research included at least three organisations (The Arc, Learning Disability England and People First Scotland) which have successfully developed the direct representation of people with learning disabilities at Board level. Learning from their experiences indicates that there are two essential changes required to make this a reality.

The first essential change is 'building in' accessibility, so that documents, processes and procedures are automatically accessible to all. As a result, Board members with additional needs do not have to request special adaptations. A genuinely inclusive approach will include disabled people as part of a broad approach to governance, not as a special or exclusive case (Ryan, 2007).

'Building in' accessibility is likely to involve modifying the format of meetings to include more workshop style elements, such as the discussion of issues in pairs or small groups prior to discussion across the Board as whole. A 'buddy' system which pairs Board members either with a peer or a partner from another subgroup of Board members (there are advantages to both models) could be an effective way to support Board members to prepare for

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[14] General comment no. 7 UNCRPD describes DPOs as "Representative organisations" which "can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves.". For further discussion of the term see https://www.linkedin.com/pulse/what-disabled-peoples-organization-dpo-jibon-william-gomes/

meetings, discuss issues and develop their skills and understanding of Scottish Autism[15]. These changes could be implemented fairly quickly and at little or no cost. One consequence could be that Board meetings and associated preparation may take a little more time than with existing working practices; however, the benefits for accessibility and inclusion are significant. Additionally, changes of this nature may well prove to bring additional benefits which enhance the quality of discussion and decision making generally.

'Building in' accessibility also requires the creation of accessible materials[16] and the provision of support for Board members who require support to undertake their role due to their disabilities. There is no question that these two changes would be relatively expensive. Some support needs can be met via procedural changes or the provision of technology (such as screen readers), but creating accessible documents and the majority of support needs require the provision of staff with the needed skills and dedicated time to achieve.

We project that this recommendation, in combination with several others, will require at least 2 FTE posts for Inclusive Governance Officers. This is projected to cost £42,000 pa x 2 = £97,000 pa including all employment costs, plus required investment in IT for 2 x new employees, a further £2,000 total. Start-up costs will be higher than ongoing costs as there will be an upfront workload to create accessible versions of existing and current documents, assess support needs and trial options. Much of this work will be possible within the costed posts, but we would recommend some additional support via the creation of a temporary additional role for the first six months, to focus specifically on making documents accessible, projected to cost £14,300 total.

> *"Taking reasonable steps to consider and accommodate the needs of everyone, ideally by default and proactively. Including representatives from all interested groups in all governance decision making." SI*
>
> *"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." SS*
>
> *"The people involved in creating the accessible materials and actually developing what those working practices would be. So I think there is an enormous amount of work that would need to be done in order to make this happen." WA*

The second element needed to achieve this change is a conscious, ongoing and reflective process of deconstructing the hierarchy of knowledge. The literature is clear that meaningful inclusion requires "Equal recognition of all types of knowledge from local, lay, informal, implicit, contextual 'know-how' to scientific, expert, formal, explicit, universal 'know-why'' (Bell

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[15] See People First and Learning Disability England case studies for examples

[16] See Appendix D for an example of Accessible Accounts kindly provided by People First Scotland

& Reed, 2021). The importance of establishing parity of esteem between different types of knowledge was also reinforced in several case studies[17] (Appendices 1 and 2). To do this, several attitude shifts are needed:

- Accepting that autistic people, including those with intellectual disabilities are potentially capable Board members. This requires acceptance that Board members need to understand 'big picture' information, but don't necessarily need to understand all the fine detail. For example, understanding that 'if we do this, we can't afford to do that as well,' but not necessarily being able to follow all the figures. To use an analogy, Board members need to be capable of steering the ship, but can rely on someone else to fix the engines.
- Routinely providing contextual information and not expecting people to know.
- Parity of esteem for lived experience knowledge – recognising that supported individuals contribute a different, but equally valid, type of knowledge to those with qualifications and experience which are seen as 'professional'[18].
- Slowing things down and checking in to ensure everyone is able to contribute.
- Real honesty about who can or should do what – transparency is vital to build trust.

Changing ingrained attitudes which are prevalent in wider society is not easy and will take time. We encountered indications of the challenges involved, but also the willingness to reflect, during the stakeholder engagement:

> *"It's just the likes of places like where [supported individual] is at [SA service], there's nobody able to do that, because obviously, they're so severely autistic." FM*
>
> *"A challenge is to have people on the board people with domain knowledge (i.e. autism) and people with some other kind." SS*
>
> *"My son, he's severely autistic, and he's not got the mental capacity to be on a board, or anything like that. But again, there are other people who, I'm sure, have got the understanding and have got the capabilities to be on something like that." FM*

This cultural change has no cost implications and implementation could start immediately. Sustaining real cultural change is challenging and requires significant ongoing commitment from a sufficiently large majority of existing Board members and senior staff to be successful. It also requires a degree of confidence, willing to recognise and be transparent about one's own unconscious biases and openness to challenge.

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[17] See People First, Learning Disability England and Intersectionality case studies

[18] LD England provided the example of their 'Stay out late' campaign. They described how there was a discussion in which people were talking about how people with LD should have the right to ask support people to let them stay out late. A self-advocate representative said 'Why should they have to ask', which was enormously valuable in helping representatives without lived experience empathise with the perspective of those supported and significantly influenced the development of the campaign.

> *"Challenging to get people to accept no correlation between ability to talk and ability to know what they want in their life." SS*
>
> *"Broadening our idea about what representation looks like, and wonder if we are stuck in a normative view about that." SS*
>
> *"I think, with accessible, particularly papers, and that sort of thing, it is often an excuse to make things opaque. Even when people don't necessarily know themselves that they're actually doing… Like they'll tend to use words which aren't really the right ones… 'jargon'… Also, I think, timeliness… one of the things I've realised that I've always struggled with, was papers coming out for meetings at the last minute… I appreciate that pulling together the papers can often take time, but often, it's a bit of an indicator that actually it's not taken seriously … people tend to downplay it, because they don't understand how it affects everyone. So actually trying to build that in, it just makes the whole process better… constantly reviewing, are we actually reaching the right people in the right way? Because I think another very human thing is that we get complacent." WA*

Openness and confidence can be difficult in a wider political and social context in which unconscious biases are deeply embedded. However, the principles which underlie this recommendation are in line with the demands of Articles 5, 12, 21 & 29 of the UNCRPD. A significant challenge, but one with the potential for really significant gains in the inclusivity of governance. Nevertheless, we are clear that **mere representation on the Board is insufficient to achieve inclusive governance**.

1.3. Establishment of an Autistic Advisory Panel

We propose the creation of an Autistic Advisory Panel (AAP). We recommend that the membership should consist entirely of autistic people. One key purpose of creating a body with exclusively autistic membership would be to create *autistic space* (see p. 12), empowering supported individuals by affording them the opportunity to experience autistic space and interact directly with members of the wider autistic community.

The creation of an AAP would also provide more opportunity for the direct involvement of the wider autistic community in Scottish Autism's governance, alongside the inclusion of supported individuals. There are advantages to both internal (staff, service users) inclusivity and to including the wider community (Richter, 2018).

We recommend a broadly representative model across Scottish Autism's services. There are various approaches that could be taken including: one supported individual being nominated by each service, or proportionately to the total numbers of individuals supported across the organisation. Attention should be paid to ensuring representation which spans geographical regions and service types. Scottish Autism should work towards nominations to the AAP being made on a democratic basis by supported individuals. We additionally propose that the AAP should also include members of the wider autistic community, particularly representatives of autistic DPOs. Overall, the AAP should maintain a majority of supported individuals, but include significant representation from the wider autistic community – perhaps in the region of one-third.

> *"I see a vast range of abilities to represent the individual need and voice, from highly articulate to non-verbal. So my concern is how to we capture the range, and a balance in how we're responding and understanding need and voice and how we respond to it." SS*
>
> *"Inclusive governance also includes advisory lines, training, etc. not just supported individuals. More added value things to educate generally. Need to include wider community to make sure it's what those in the community need and want. Need to make sure this is in the strategy." SS*

The creation of the AAP would not be an alternative to the direct representation in *recommendation 1.2*, but, rather, additional to that representation. One of the many functions of the AAP could be to operate as a step on the ladder (described in *Recommendation 2*) enabling supported individuals and members of the wider autistic community to develop their skills and confidence in representing others towards becoming Board members.

As mentioned above, a key element of the functioning of the AAP would be to create autistic space. This means that the norms, methods, rules and processes within the AAP must be controlled and establish by the AAP and that any non-autistic support staff who are needed to attend meetings in a support capacity must respect both confidentiality and the norms of autistic space.

The role of the individual members of the AAP who are not SA supported individuals would be to both represent the wider autistic community and to provide peer support[19] to develop the confidence and self-advocacy skills of all members, including supported individuals.

We envisage the role of the AAP as an internal, but largely autonomous group with a specific remit to:

- review all nominations to the Board and make recommendations[20];
- have an influential role in identifying priorities for campaigning activity (see *recommendation 1.6*);
- have significant input into the development of and to review job descriptions and person specifications for all levels of staff (see recommendations 3.4 and 3.5);

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[19] This does **not** mean, however, that non-SI members should be expected to provide support in place of paid support for individuals requiring paid support to meet their needs.

[20] Recommendations would probably need to be non-binding, but the Board should commit to publishing reasons for diverging from the AAP's recommendations.

- have significant input into the Autism Practice Improvement Framework[21];
- review and make recommendations regarding any other mechanisms which influence what is viewed as 'quality' in services;
- design and oversee the Leadership Development Programme (recommendation 2.7) jointly with the diversity taskforce (*recommendation 1.4*).

We believe this recommendation has the potential to contribute significantly to furthering the inclusivity and equity of Scottish Autism's governance by shifting the balance of power. By creating a body which is autistic-led and which works in ways which create autistic space, the AAP would create an environment in which autistic people are in control, truly belong, and have real power and influence over key elements of Scottish Autism's decision making.

We foresee two significant threats to successful implementation of this proposal. Recruitment for the AAP will take time, the development of individuals, and connections between Scottish Autism and autistic DPOs across Scotland. Implementation of recommendation 2 is an essential pre-requisite to the realistic recruitment of sufficient individuals with the confidence and skills to contribute meaningfully to the AAP. Consequently, we anticipate that it may be most realistic to seek to implement this recommendation in stages over the medium to long term. Maintenance and refreshment of AAP membership will depend on Scottish Autism sustaining an ongoing commitment to both this recommendation and those under *recommendation 2*.

The second barrier is, again, cost. Giving people real power requires meaningful support in similar ways to those relevant to direct representation on the Board – making documents accessible and providing direct support to the AAP as a whole and to individual members and potential members of the AAP. We project that this recommendation will contribute substantially to the requirement for the Inclusive Governance Officers discussed under the previous recommendation.

It is important that AAP members are remunerated at a level appropriate to their expertise, as defined by the deconstructed hierarchy of knowledge identified above, and the time demands of the role. We recommend that those participating in the AAP should be paid an honorarium of £200pa (a total cost for 25 people of £5,000pa). The honorarium would recognise the time and commitment required to attend and prepare for meetings[22] (assumed to be 4 x 4-hour meetings per year).

All members of the AAP should be paid the honorarium at the same rate; however, some individual AAP members are likely to volunteer or be asked to take on additional tasks within the ambit of the AAP, such as participating in an inspection, reviewing and proposing detailed amendments to a document. Tasks of this nature, which require an additional time

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[21] https://www.scottishautism.org/about-us/commitment-quality

[22] With whatever support, accessibility adaptations and prompting they required to do so.

commitment over and above that expected of all AAP members, should be paid on an hourly basis for the work undertaken. We recommend a rate of £20 per hour on a self-employed basis and the provision of a capped 'pot' to fund such work from AAP members, which should assume a significantly higher workload in the first year, as the AAP focusses on the initial workload of reviewing job descriptions and providing detailed input on both the Autism Practice Improvement Framework (see *recommendation 1.3*) and the leadership development programme (see *recommendation 2*). We propose that the 'pot' to fund this work should be set at £5,500 in the first year and then £3,000pa[23].

It will be important for full accessibility that provision for the payment of AAP members takes account of the challenges of the benefits system, to which many autistic people are subject. Options should be routinely available for individuals to request payments to be spread over a period of time, to simplify administration for benefits purposes, and for all or part of their payments to be made to an organisation, e.g. a charity or DPO of their choice, rather than to themselves personally.

It will be important to ensure that the AAP develops and sustains a culture of parity of esteem for all contributions to the decision making functions of the body as a whole, rather than attributing greater weight to the contributions of those who undertake task-focussed work. This is a common feature of autistic space, but will need to be explicitly emphasised in the AAP's terms of reference.

Implementation of this proposal will also pose an even greater challenge in terms of cultural change. Handing over power and control is a scary thing to do. We believe that the creation of the AAP and handing over real power to influence key decision making has the potential to engage all three of Colenbrander et al.'s (2017) elements of inclusive governance:

(i) Capital – by offering a real stake in Scottish Autism's decision making to both supported individuals and the wider Autistic Community

(ii) Binding and non-binding influence on the decision-making process – by offering influence around key decisions on Board membership, recruitment, campaigning policy and service quality; and

(iii) Accountability – by providing direct access for supported individuals to external autistic self-advocates, enhancing the accountability of Scottish Autism to both its supported individuals and the wider autistic community.

Colenbrander identifies such 'soft power' mechanisms as including:

> *"The creation of advisory/consultation bodies/committee comprising stakeholders and/or their representatives with the power to advice on, or even veto, certain material decisions (usually listed in bylaws or similar)." (Colenbrander et al, 2017)*

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[23] This assumes approx. 23 hours per month for the first year and 12.5 hours per month thereafter.

It is vital, therefore, that the AAP does not become a tokenistic talking shop[24] with no real power or influence.

> *"I like the idea of an autistic advisory panel, definitely. But very much it does need to be beyond consultation, some kind of decision-making process, some kind of accountability." WA*

Challenging as it is for those who have a stake in existing power structures, we are clear that meaningful inclusive governance requires letting go of some control and power.

> *"Real influence at strategic level. A form of steer." SS*

> *"But in our experience, there's been a lot of tokenistic drive for [supported individuals] to have their voice heard. I don't feel that's anything more than a surface-level lip service." FM*

> *"I can't help but feel that this is just another tokenistic- they're not actually going to take any of it onboard. Nothing's going to change." WA*

To achieve meaningful influence, it will be essential for the AAP to have explicit powers, which, at the very least, must include requiring the Board to publicly explain decisions which are contrary to the advice or input of the AAP, to ensure meaningful accountability. This is likely to require some constitutional change.

1.4. Creation of a diversity taskforce

We recommend that Scottish Autism create a Diversity taskforce comprising staff from across the organisation, with mandate to improve diversity. Research has identified having a specific committee or taskforce on diversity as an effective factor in improving inclusivity (Brown, 2000). This could be done by seeking volunteer 'diversity champions' from amongst existing staff in a range of departments and levels of the organisation, creating a digital network for them to collaborate, and providing them with a small amount of protected time for meetings and to further their diversity work. The remit of the diversity taskforce[25] would be:

- Assist the AAP to design and oversee the Leadership Development Programme (recommendation 2) with support from the IGOs.
- Proactive recruitment (for Board, senior roles and staff generally, as identified by the diversity data in Recommendation 1.1: Data collection to monitor diversity) from underrepresented communities through fostering links with grass-roots organisations in those communities (including autistic DPOs), including explicitly talking to individuals

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[24] Our case studies provided several examples, such as Mencap's 'Voices Council', which we recommend specifically against emulating

[25] These recommendations for remit draw on the Intersectionality case study

connected to people from under-represented backgrounds such as those with high support needs, particular ethnic, religious or age groups

- Encouraging the formation of formal and informal partnerships and relationships with other organisations representing diverse groups in their teams and normal roles.
- Screening comms, structures and processes for diversity (ie representation of diverse identities), accessibility (eg Easy Read, non-English languages) and inclusion (especially autistic inclusion[26]), including website and events.
- Consult with AAP about what other 'autistic norms' SA should be routinely including to 'build in accessibility' throughout the organisation (as in *recommendation 1.2*).
- Screening selection and proactively recruiting keynote speakers at Scottish Autism events and conferences with more diverse identities, including consideration of the overall proportion of speakers who are autistic (whilst always focussing on speaker skill and expertise in relevant area).
- Creating and/or promoting events run or delivered by autistic people who are also members of other marginalised groups and support autistic people and family members from marginalised communities to lead groups and activities.
- Targeting autism information, support, outreach to communities who are marginalised in other ways and tailor resources to the needs of those groups.

The diversity taskforce could also support the Board to draw up a Strategic Action plan to improve inclusion and diversity, setting out specific actions and targets. This could include consideration of partnership and supporting campaigns on non-autism diversity or equity issues and building pan-disability/pan-marginalised group solidarity, including challenging other social justice groups to be more inclusive of disability generally and autistic people specifically.

> *"Our board currently lacks diversity so it's a good thing to tackle." SS*

The influence of the diversity taskforce would be a form of 'soft power' which would not be prescriptive or formalised. We are mindful that:

> *"Cultural change cannot easily be wrought from the top down by simple exhortation. Successful strategies need to take into account the needs, fears, and motivations of staff at all levels." (Davies et al., 2000)*

Creating diversity champions from amongst existing staff has no direct cost implications, but would likely require increasing the staff 'pool' slightly to create the protected time needed. Based on Senior Autism Practitioner (SAP) salary band[27] and a time commitment of 3 hours per week across each of ten regions, this is projected to cost £32,000pa.

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[26] For example, ensuring that all Scottish Autism services and events provide autistic-friendly communication options, such as text and email, in addition to phone.

[27] As an average. Diversity champions should be drawn from all levels of the organisation.

1.5. Shared leadership: Co-chairs alongside the CEO

We recommend Shared Leadership, a concept that we have adopted from the Learning Disability England case study (Appendix A.3), which illustrates the model and which has similarities to models of 'reverse mentorship' already in use in many organisations. In the medium to long-term, we recommend that Scottish Autism seek to appoint 2 autistic co-chairs (of whom at least one must be a supported individual) to work collaboratively with the CEO[28] as joint postholders, at minimum in relation to campaigning and representation activities, potentially also with regard to strategic and, possibly, operational decision making (depending on feasibility). In making this recommendation, we have been aware of the need to incorporate methods of inclusion which go beyond one-off or time-limited mechanisms:

> *"Was impressed by survey but it was expensive and resource heavy and took a year. Lots of great evidence, but not practical." SS*
>
> *"Challenge is how do you have an ongoing program rather than a 4 yearly survey." SS*
>
> *"Something about lengthening the time spans of things if we want to make sure we are doing them properly. Getting the voice into the work can extend the projects. It's a pragmatic consideration." SS*
>
> *"How could we hear from everyone? Survey showed it was so hard to get information from some people with significant communication needs. Too much resource. Rather have processes day to day that captures it." SS*

Staff stakeholders particularly identified a number of challenges which this recommendation would need to overcome:

> *"Even though I personally really like the idea of shared leadership, I think it's, probably at that stage, a really nice-to-have, but at this particular stage, there's a lot more work that probably needs to be done, to get it up to scratch, from what I understand of it." SAS*
>
> *"I don't understand how it would work, given the level of business knowledge you have to have." SAS*
>
> *"Because of the fact that a council needs to give them a service, they have to have quite a selection of needs that maybe makes them not suitable for these kinds of roles." SAS*
>
> *"It is a good idea, if the individuals have the support they need for the roles. I also think it is important that these two individuals have an advisory panel to feed into, ensuring there is a wider autistic voice." SAS*

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[28] It is important to note that this recommendation does **not** imply that Scottish Autism's CEO should necessarily not be autistic themselves, merely that the CEO must be employed on the basis of their skills, experience and suitability for the role and may or may not be autistic.

> *"Unfortunately, many of the individuals that we support do have other, mainly anxiety-led, issues, that would probably prevent that high level of involvement."* SAS

Wider autistic community stakeholders were largely positive about this proposal, but recognised the likehood of significant barriers and threats to realising it:

> *"I think also we're actually talking about a role where considerable pushback can happen, for lots of different reasons. And I think that's a good start, in terms of trying to build in a mechanism to prevent that. But it's complex."* WA

Clearly, this proposal would need clarity about the boundaries and relationships between the roles:

> *"This would be about really understanding what a CEO's role is and how a co-chair would work in that space. I think that's something that really would need to be nutted out and really agreed with, and understood by all parties concerned."* WA

This is why we have differentiated above between campaigning and representation activities on the one hand and strategic and operational decision making on the other. If we recognise that, in campaigning and representation activities, Scottish Autism is largely seen as 'speaking for' autistic people, then there is a strong argument for that being done by an autistic majority leadership group. This would ensure that autistic people are speaking for ourselves, in line with the principles of the UNCRPD.

However, we also recognise, as the Learning Disability England case study demonstrates, that the model of shared leadership has disadvantages and challenges, particularly around slowing down decision-making processes. There may be some strategic and, probably, many operational decisions required of the CEO, where this drawback could be a serious impediment to the effective functioning of the organisation. This is why our recommendation is more open about the extent to which these decisions should be included within the shared leadership model.

A further concern around this proposal is the risk of co-chairs being exploited and insufficient value being accorded to their lived experience knowledge and the work they contribute. Avoiding this pitfall will require careful design and embedding of the parity of esteem principle identified above. It also requires the roles to be appropriately remunerated as part-time roles at a level which recognises the skills required and level of responsibility involved. Assuming 1 day per week at a salary level of £30,000pa, this recommendation would cost £14,000pa for two co-chairs[29].

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[29] This assumes co-chair roles encompassing campaigning and representation only. If strategic responsibilities were included, this would need increased time and also a salary level closer to that of the existing CEO. If operational were also included, then this should become a full split post and all 3 roles (that of the CEO and the 2 'co-chairs', who would become joint CEOs) should be paid at an equivalent level.

Decisions around remuneration for those undertaking shared leadership roles will also need to take account of the implications for individuals in receipt of benefits, as above for *recommendation 1.3*.

1.6: Inclusive strategic priority setting process

We recommend Scottish Autism pilot an inclusive strategic priority setting process[30], which would take place periodically (every 1-3 years). This would involve using the advice line, the Autistic Advisory Panel[31] and other sources to develop a 'long list' of potential priorities. It may be that, at this stage, a few priorities need to be 'locked in' as clearly essential. Then supported individuals would be provided with opportunities to rank all other potential priorities within each service; one or more workshops would also be run and advertised to supported individuals, autistic DPOs, families/carers of SA supported individuals, SA autistic staff and the wider autistic community, at which there would be the opportunity to rank and provide other comments/feedback on the potential priorities. Assuming two workshops, we project a total cost of £1,500 per iteration of the process[32]. An online survey option should also be provided to facilitate the widest possible access to the process, which would incur no tangible cost. The final priorities list would then consist of those 'locked in' priorities plus the highest ranked priorities.

This would provide for wider community input into SA decision making:

> *"Ask us what we think!!!" SI*
>
> *"Include me in its decisions. Currently it doesn't." WA*
>
> *"I would like them to interact with me at all - which they haven't done before this project!" FM*
>
> *"Invite [supported individuals and other autistic people] to the table, ensure autistic people can feed into what they want to happen and ensure their priorities are met." WA*
>
> *"How they campaign being more influenced by me and other autistic people in Scotland's views." WA*

It would also help to address a risk inherent to the forms of inclusive governance discussed so far. One risk of mechanisms such as representation on the board and the AAP is that there is a risk that this is likely to attract a certain kind of person who may not be representative and this can lead to problems and possible breakdown (Ottmann et al., 2008). Con-

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[30] In developing this recommendation, we drew on the 'Who Cares? Scotland' case study

[31] In this process, members of the AAP should be encouraged to consult with others known to them in the autistic community as widely as possible.

[32] In the overall costings, we have assumed a frequency of once every 2 years

sequently, we feel it is important to include a broader consultative process as one way of addressing this risk.

This recommendation has implications for Board responsibility for setting of strategic priorities. It is likely to be necessary for the resulting priorities to be advisory, but we recommend that the Board should commit to publishing a statement of reasons in any instance where the Board does not follow the recommendations of this process.

1.7. Transparency in decision-making processes

We recommend greater transparency about how Scottish Autism works and, particularly, about decision-making processes. The need for this was apparent during the stakeholder engagement:

> *"I have such a, it feels like a very blinkered view that I have of my small input." SAS*
>
> *"I have very little idea or practically no idea of how Scottish Autism works." WA*
>
> *"What I would like to see is a map of the whole of Scotland with Scottish Autism and to know where the supported individuals are, how many people work for Scottish Autism, are there 20 people in Lewis who are supported individuals? How many people are working for Scottish Autism on that island? To divide Scotland up into its areas and to know how it's spread." SAS*

We recommend that clearer information is provided, at minimum on Scottish Autism's website and at Scottish Autism services, about organisational structure and decision-making processes. This should be written in Plain English[33] and an Easy Read version should also be widely available. This information should include answers to Frequently Asked Questions expressed clearly and directly such as 'What actually happens when you ask for stuff?'.

We recommend that the AAP be asked to suggest questions for the FAQs from an autistic perspective and also to draw on the perspective of those external to Scottish Autism. We propose that the diversity taskforce and the AAP be asked to help with screening and checking these materials to ensure the widest possible accessibility.

We also recommend that induction and coaching for managers, including regional managers, should include the importance of transparency and openness in decision making and that managers should routinely explain the full rationale for their decisions. We believe this would help to address comments such as:

> *"I would agree that the management style at [SA service], and probably throughout Scottish Autism, is very top-down." SAS*

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[33] https://www.plainenglish.co.uk/

> *"And I feel myself, personally, I don't feel that our management always listens to what the staff are saying. Because what our job is, is to advocate for those individuals, and have their needs and wants met." SAS*
>
> *"More effective communication and interaction within higher authorities." SAS*
>
> *"Why did somebody make that decision to [Scottish Autism decision]? I would imagine it's purely financial." FM*
>
> *"And the decisions that are taken at [Scottish Autism service] are mainly to do with just the way the managers want things run." SAS*
>
> *"I think in the private sector perhaps you get more of an idea of the hierarchical structure, and you know who is the boss of who. And generally, you would know more or less why the decisions are made." WA*
>
> *"In my own experience, I would go to management and say, like, "So and so needs this.", or whatever. But I think there's just a lot of politics and things as well." SAS*
>
> *"I feel like a lot of the decisions made by Scottish Autism are often, like, the staff and individuals that we support are not consulted a lot of the time. So, they will put out these, kind of, surveys online, and things like that. But they're usually quite basic, in that the questions that are asked are quite simplistic, or geared towards what their decision would be anyway. And a lot of the time we feel that a lot of the decisions made are already made before the surveys come out." SAS*

This recommendation has no tangible cost implications.

Conclusions

Taken together, the recommendations above offer a comprehensive approach to representation and inclusion within the governance of Scottish Autism. These recommendations provide an approach balance between:

- Direct representation and soft power;
- The inclusion of supported individuals and of the wider autistic community;
- The voices of diverse stakeholder groups, including families and staff; and
- Short and long-term progress.

Recommendation 2: Developing agency and leadership

Why is this needed?

The final report of the Scottish Mental Health Law Review (2022) highlights the need to move away from substituted and towards supported decision making in order to give effect to Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):

> *“Supported decision making starts from the premise that everyone, including those who may have decision making challenges, has a right to make decisions for themselves. The decision maker should be at the centre of the process, with respect given for their autonomy.” (United Nations, 2006, p. 114)*

The overall direction of travel of the recommendations is clear:

> *“If the Scottish Government is truly committed to developing a human rights-based system placing a person’s rights at the centre then resource is needed to develop Supported decision making and embed it fully in mental health, capacity and adult support and protection law and practice.” (United Nations, 2006, p. 117)*

The review goes on to recommend changes to the Adults with Incapacity (Scotland) Act 2000 to give greater priority to the will and preferences of the adult, in order to move Scots law further in this direction.

The political and legal contexts are moving away from current concepts of guardianship and substituted decision making focusing on welfare towards rights-based supported decision making approaches which respect the autonomy of disabled people, including those with the most severe and profound disabilities[34]. This context provides Scottish Autism with an opportunity to innovate and lead change.

The need to support structural changes in the direction of inclusive governance by also providing training and support to enable individuals to develop the skills, knowledge and confidence to participate emerged as an issue during the early exploratory discussions:

> *“Supposed to have experience to be on board, but how do you get the experience? Induction to board can be difficult. Would be good to get younger people and understand what the board is and what they do.” SS*

> *“How to overcome the communication barriers? Sometimes wishes of guardian can conflict and then there is a balancing act.” SS*

> *“Some don’t have capacity to participate in that way, some things in policy and strategic will struggle to understand and participate. Tokenistic if don’t understand. Want*

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[34] We note also the imminent commencement of the Assisted Decision Making (Capacity) Act 2015 in Ireland.

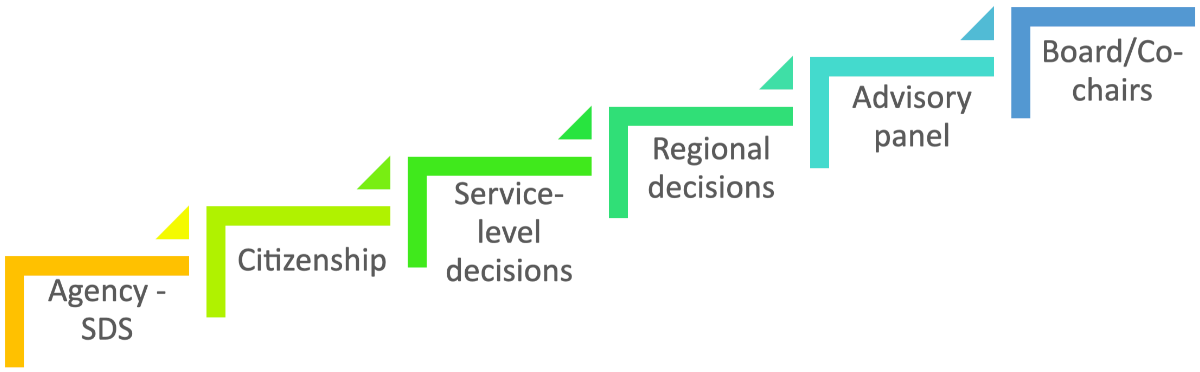
> *people to be able to communicate their desires to us, how to do in practice? Lots of people with institutional backgrounds don't know how to be heard." SS*
>
> *"Just an observation around inclusiveness, I am hearing investment is really needed in terms of educating people and laying solid foundations for that participation and inclusivity in governance that it would be very easy to leap into what the structure is and assume the structure would just work. It needs all of it." SS*

Our desk research included key learning from the Future Visions[35] programme, which was designed to help address the relatively low uptake of self-directed support amongst disabled people. The programme is analogous in that it identified that people needed to boost their confidence and skills in order to understand that they might have choices and begin to take ownership of their support. This highlights the need to provide a programme to develop skills, confidence and offer practice at decision making and autonomy, recognising that many of the autistic people SA support may never have even learned the concept that they can make decisions for themselves (agency). This is likely to require a combination of learning, capacity building, peer support and role models.

What are we proposing?

A structured and explicit development programme for supported individuals (with the possibility to expand to include autistic staff and the wider autistic community to also have access). The programme would take a stepped approach to developing decision making, autonomy, self- and collective-advocacy skills, as illustrated in Figure 5. This 'development ladder' would lead from supporting individuals to understand and develop their agency in decision making about their own lives all the way to board/leadership roles, with individuals beginning wherever they are, and participating and progressing up levels to the extent desired by them and compatible with their own quality of life, not on the basis of the expectations or assumptions of others about their capacity, ability, desires or limitations.

Figure 5: Leadership development programme



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[35] delivered by Glasgow Disability Alliance (GDA) and funded by the Scottish Government

The overall programme would be designed and overseen by the AAP with support from the diversity taskforce and the Centre for Practice Innovation. In developing this recommendation, we drew on the thematic case studies on supported decision making, supporting communication and governance and leadership development programmes (Appendix B.1). We also consulted closely with Joe Long in order to build on previous relevant work (e.g. Long et al., 2017; Scottish Autism, 2017a, 2017b).

2.1 Development of supported decision making for all supported individuals

We recommend that Scottish Autism develop supported decision making for all supported individuals. We recommend encouraging, challenging and supporting guardians to draw up Supported Decision Making (SDM) agreements with supported individuals to increase their level of involvement in decisions about their own lives. We recommend that Scottish Autism provide an individualised programme for every supported individual, to assist supported individuals to develop their communication skills, confidence, understanding of their own agency and identity, and decision making skills to support SDM agreements. To support this work, we recommend the development of a specialist Communication Support Worker (CSW) role. The CSW would be responsible for exploration based on observations and trials to find and develop the most appropriate communication systems for individuals. This would include liaison with Speech and Language Therapy[36], continuous assessment and review of each services user's preferred form(s) of communication, including the development of functional communication (the ability to communicate needs) and consideration of the introduction of assistive technology. This would also include advising and supporting other staff to implement and sustain good quality communication support, including to initiate and maintain communication with the supported individual's family and friends, and, if desired, the wider autistic community and health professionals. This communication support would particularly focus on support to develop decision making skills and autonomy by, for example, introducing new concepts and vocabulary such as 'Don't know', 'Leave me alone', 'No', 'I want' and other concepts relevant to autonomy. This programme would also support staff to develop and maintain skills in modifying communication to support decision making, in line with good practice[37].

This recommendation builds on Scottish Autism's previous work around voice, participation and involvement, which adopted the principle that "participation and involvement mean supported people taking a role in making decisions about their lives and the support that they receive." (Scottish Autism, 2017b, p. 4)

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[36] If they are already involved. However, this should also include advocacy and professional challenge to seek Speech and Language Therapy (SALT) involvement where SALT input would benefit the individual but is not currently being provided to them.

[37] For example the Supported Decision-Making Toolkit. See the Supported Decision Making case study (Appendix C) for further resources.

Ultimately, we would like to see at least one specialist CSW in each Scottish Autism service (National Autistic Taskforce, 2019). However, in the short to medium term, we recommend recruiting one CSW per region, from amongst autism practitioners who are particularly enthusiastic and progressive in their attitudes towards supporting the communication of supported individuals. The role would be paid at a level between Autism Practitioner (AP) and Senior Autism Practitioner (SAP) for 0.2 fte (costing £66,000pa). The role of CSWs would be distinct from those of SAPs in that there would be no management or supervisory responsibilities involved. Rather, the CSW role would have a brief to progress the communication of individual SIs, probably starting with the SI the CSW normally works with and then moving on, one at a time, through other SIs in the region. Support and oversight for CSWs would come from practice advisers and from SALT.

We also recommend Scottish Autism invest additional resources in further embedding and developing the key principles identified by previous work in day-to-day practice within services:

Principle 1: Preserving authenticity of voice – Validating the individual's own preferred means of communication, including the use of photos, film or pictures.

Principle 2: Harnessing interests and media meaningful to the person – Encouraging and developing passionate interests and harnessing these as a means of engaging supported individuals in expressing preferences and making choices.

Principle 3: Ownership of process – Ensuring that the preferences and choices of supported individuals actually impact on the day-to-day decisions taken about their lives and supporting them to increase their participation in each stage of that decision-making process.

Principle 4: Providing a concrete output – Ensuring that supported individuals can see and control the materials which result – visual timetables, support plans etc. Reinforcing their ownership of decisions about their support.

Principle 5: Family involvement and shared understanding – This needs to be developed to become bi-directional. Family members can help to elucidate the communication preferences and special interests held by supported individuals; however, they may also need both support and, on occasion, challenge around respect for the autonomy of supported individuals. Both family members and staff may also need support throughout the process of seeing through the choices and decisions made, particularly when these conflict with the family or staff view of what should happen.

We further recommend that this embedding also support staff to routinely apply 4 tips on simplifying language (Atkinson et al., 2023):

1. Choose familiar, high frequency words e.g. home rather than accommodation.

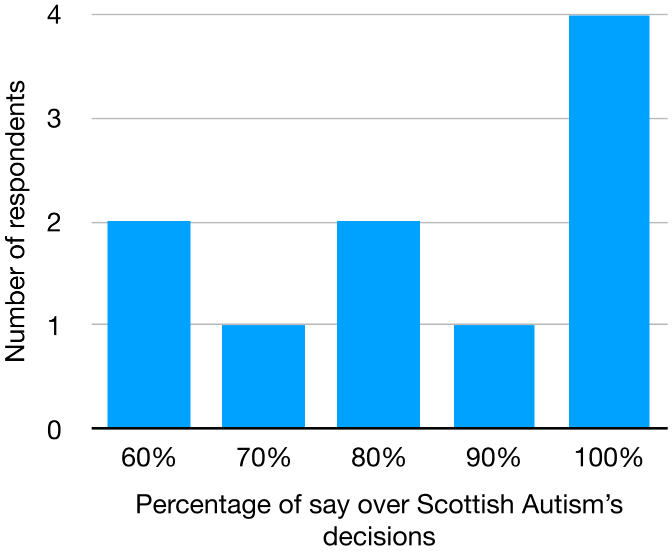
2. Use active sentences instead of passive sentences e.g. "The doctor will check your heart." Rather than "Your heart will be checked by the doctor."
3. Reduce the use of pronouns such as 'he', 'she', 'they', 'us', 'this', 'that'. E.g. "The heart doctors will scan your heart. Then the heart doctors will tell your GP your results." Rather than "They will scan your heart. Then they will tell us your results."
4. Avoid sentences with multiple parts (clauses). Try to make one point per sentence.

This proposal attracted significant support across stakeholder groups. Survey respondents were asked how much say they thought different stakeholder groups should have in the decisions Scottish Autism makes. Out of the 10 respondents who answered this question, almost all felt that supported individuals should have the largest say, with the percentage of influence they thought supported individuals should have ranging from 60-100% (Figure 6).

This enthusiasm was reflected in comments across the range of stakeholder groups:

> *"I totally agree. It's ambitious, but I like it, yes. My son is at the lower one, as well you know. He's got a mind of his own and he can't talk, but he can certainly show what he wants." FM*
>
> *"I think it is promoting diversity and inclusion." WA*
>
> *"Part of support plan being to help the person build the ability to share their views and influence. E.g. many have never been taught the language or communication expression and understanding systems needed to do this. Build cultures where it is standard for people they support to be asked, to be connected with and aware of wider oppor-*

Figure 6: Percentage of say supported individuals should have



> *tunities for them to advocate for themselves and influence. Do more than just find out if they are happy or sad with the service they get." WA & former SAS*

There should be further work done with frontline staff, via practice advisers, to embed the principles in day-to-day practice in all services and in induction of new staff. This should include input, potentially from the Inclusive Governance project team, via practice advisers, to extend this work beyond the scope of the existing work on Voice, Participation and Involvement into supporting staff to explicitly teach agency and decision making skills. This would be beyond the life of the current project, so input from the Inclusive Governance would incur a further one-off cost, projected to be £2,500[38]. We also recommend that these skills in supporting decision making should be explicitly included in the Autism Practice Improvement Framework.

Developing a culture of supported decision making will, necessarily, require challenging some preconceptions and cultures:

> *"Guardians and external professionals want to control what a person should be doing. Staff can be dismissive and may have a journey to go on re. tension around people being assumed to be unable." SS*
>
> *"I don't see how that would work, given the individuals that I know. And that's the only reason that I'm going on, is the people that I support, I don't see anybody reaching those skills even." SAS*
>
> *(In answer to the question 'If Scottish Autism were fully inclusive what would be different?') "I wouldn't feel anxious/scared about raising concerns / asking questions." SI*
>
> *"People from other organisations who have been trained to think that people can't make good decisions about their lives need a culture shift to see their role to support people to live their lives." SS*

As highlighted above, this recommendation is also in line with the political and legislative climate around implementation of the UNCRPD in Scotland. Article 12 requires that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." And to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (United Nations, 2006). Whilst the legislative framework to fully support Article 12 is not yet in place in Scotland, Scottish Autism has the opportunity to be at the forefront of this shift.

2.2. Involvement of supported individuals in 'life admin'

We recommend that Scottish Autism routinely involve supported individuals in their own 'life admin', and encourage and support guardians to do so, in anticipation of developments in the legal framework around incapacity and guardianship. This includes:

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[38] This assumes 2 x 6-hour face to face workshop sessions with practice advisors and includes travel costs.

- Supporting individuals to apply for and keep on their person at least one form of identity document (e.g. passport, citizen card, provisional driving licence).
- Supporting individuals to have control of their own support plan, where and in what format(s) it is kept, and who has access to it.
- Involving individuals in filling out forms about themselves for real life purposes e.g. voter registration, benefit applications, census returns.

> *"Actually, what we're really talking about, when we're talking about leadership, is all almost taking leadership of our own lives, in a sense." WA*

This recommendation has no projected cost implications.

2.3. Universal high quality internet access in all services

We recommend that Scottish Autism create the infrastructure necessary to enable supported individuals to communicate with and participate more effectively in their communities by ensuring that all services have reliable, fast internet access available to supported individuals. Many aspects of citizenship these days require reliable and sufficiently fast internet access, as does participation in social groups and communities, including the autistic community. The importance and potential of technology to empower meaningful inclusion was being highlighted by the late Dinah Murray as long ago as 2006 (Murray & Aspinall, 2006), so it is past time for this to be effectively addressed as routine, essential service provision across Scottish Autism services.

We also recommend that the communication of supported individuals with their families and friends should be better supported and that the default assumption should be that there be as much communication as the supported individual wants (to the extent that is consistent with the consent of the family member or friend) and that communication via more modern methods should routinely be supported. This could include the use of AutNav[39] and/or video calling, WhatsApp groups and more, depending on the preferences of the supported individual after a range of methods have been trialled. The development of the use of these forms of communication could be supported by the Communication Support Workers called for in *recommendation 2.1*.

We further recommend that supported individuals be supported and encouraged to communicate with family, friends and the wider autistic community in private (potentially using AutNav) and that supervision of such communication by staff should be seen as a restrictive practice and only take place as often and to the extent absolutely necessary on the basis of evidence. Steps should be taken to move towards reducing and eliminating such supervision.

> *During visits with supported individuals, members of the Inclusive Governance team observed interest and engagement from 3 different non-speaking supported individu-*

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[39] https://www.scottishautism.org/services-support/autnav

als in interacting with IG team members (who were all autistic), despite those team members being unfamiliar to the SI and only meeting them on one occasion.

We recommend setting a reasonable minimum acceptable level of service for internet connectivity for supported individuals in services where that provision is controlled by Scottish Autism[40]. This level should be reviewed at reasonable intervals, perhaps every two years, in consultation with the AAP, in order to ensure it keeps pace with technological developments. What is needed to meet this standard may vary from service to service. When assessing whether the standard is being met, the most onerous conditions of usage should be assumed[41]. As resolution of streaming services increase, so does the bandwidth needed to access them[42]. We understand that there are factors beyond the control of Scottish Autism that may place a limit on speeds; however, we recommend SA be creative and proactive in meeting the minimum acceptable level of service, and continue to monitor the situation when there are limiting external circumstances which cannot be mitigated.

Given the communication challenges faced by most supported individuals, and the importance of internet access to most autistic people, we do not consider that reliance on services to report problems is sufficient. In order to meet the minimum acceptable standard in as many services as possible, it will be necessary to periodically collect relevant data about internet speeds and reliability in all services, when under maximum likely loading, whether they are controlled by Scottish Autism or not. We suggest a period of perhaps two years between surveys is reasonable.

We have assumed no additional costs for these recommendations, since it should be possible to integrate them into the major IT update due November 2023.

2.4. Modifying SA documentation to include views of supported individuals

We also recommend that Scottish Autism review its processes and documentation to consider the degree to which the voices of supported individuals are supported in documents

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[40] We recognise that Scottish Autism are not responsible for internet access in some services. Where Scottish Autism do not control the internet provision in a service, we recommend proactively engaging with parents or guardians (or whomever is responsible) and suggesting reasonable improvements where needed.

[41] Consider, for example, a service with five supported individuals when all five of the supported individuals are simultaneously on video calls, watching streaming video, downloading data or playing an online game, between 7pm and 11pm. The internet service should be robust enough to ensure that all of the service users have a reliably acceptable experience.

[42] We are not experts on internet services, but it seems, in 2023, a download speed of perhaps 20mbps is likely to meet most individuals' needs at present. The factors affecting the speed any individual experiences are complex and beyond our expertise to analyse in detail. However, consideration should be given to relevant factors such as the number of users sharing a WiFi connection; the age, quality and settings of the router; router firmware updates; physical barriers and the need for repeaters; the price/value of the service paid for; use of ethernet on stationary PCs (to save on WiFi sharing) and so on.

and where they are substituted (Scottish Autism, 2017b, p. 12). Encouraging supported individuals to express their wishes and preferences cannot achieve meaningful inclusion unless those voices actually influence decisions.

Stakeholders with direct experience of SA often mentioned obstacles which had led to the wishes and views of stakeholders, particularly supported individuals, being overridden by other priorities:

> *"I think, sometimes, what he wants control over, or he's trying to express himself, it's a double-edged sword, you know, with the staff. I think, being in a care home environment, there is a lot of red tape and things that curtails things, to a certain extent. So, I think, it's kind of difficult, sometimes, for them, with the environment that my son is in at the minute, with it being classed as a care home, it comes with its own kind of restrictions." FM*
>
> *"Listening or pretending to listen but not acting on the information given, not allowing autistic people to speak or be heard." WA & SAS*
>
> *"Overall I think Scottish autism really truly listen and to try to listen, but I don't think there are enough processes to input into governance and that they aren't very accessible and/or not including all the groups they should. Some parts of SA and people are better at listening with an open mind than others." WAC & former SAS*

We recommend that Scottish Autism documentation, ranging from support plans to day-to-day records and logs, are 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. This review should be led by the AAP with input from the diversity taskforce and support from the CPI.

This review could include, for example, inclusion of supported decision making as an explicit element under the 'Life Skills' section and in the Autism Profiling tool and requiring explicit consultation with the supported individual themselves about their experiences of restrictive practices in the Personalised Support Plan section.

This is projected to cost £17,000[43] as a one-off cost. Proposals for revisions should be reviewed by the AAP and those undertaking the review should work with the AAP to address issues they raise.

As discussed earlier, this shift is in line with the developing legislative and political climate. However, this recommendation can be fully implemented under the current law. Although culture change can be slow, the wider leadership team shared with us their awareness that

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[43] based on 0.5fte @ £30,000 for a one-year project

thinking in health and safety is slowly moving to manage risk rather than denying rights. Similarly, despite tensions, work in safeguarding adults is increasingly recognising the importance of liberty and autonomy, promoting the supported individual's decision making and rights.

2.5. Participation of supported individuals in their communities

We recommend that Scottish Autism proactively encourage and support supported individuals to participate in their communities and as citizens. The following is a non-exhaustive list of examples:

- Registering to vote (this should be opt-out rather than opt-in, i.e. unless the individual explicitly objects).
- Being supported to access accessible information about elections, potential parties and candidates and to form political opinions.
- Being supported to vote in local and national elections.
- Being supported to learn about and participate in campaigns and activism around topics of interest to them (e.g. the environment, animal rights, housing, signing petitions, starting petitions, participating in consultations, attending 'pride' events, campaigning about closing a local amenity, participating in demonstrations).
- Participating in community organisations including potentially standing for election to their Community Council.
- Being supported to find out about volunteering options in the local area.
- Being supported to volunteer/participate on a voluntary basis in community projects/services of interest to them (e.g. heritage railway, food bank, local hospital, dog walking etc.).

The political and legislative context developed by the Community Empowerment (Scotland) Act 2015 supports increasing the involvement, inclusion and participation of all members of society. This is in line with Article 29 UNCRPD which includes the requirements: "To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected" and "To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties" (United Nations, 2006).

Other aspects of this recommendation move towards fulfilment of Article 19 around preventing "isolation or segregation from the community" and provides the challenge to ensure that “community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

This wider understanding of what is required for ‘inclusive governance’ also drew on stakeholder comments such as:

> *“Including people is giving them opportunities to participate in society, in a proactive / active way, rather than as passive recipients.” WA*
>
> *“To be supported by SA to influence decision makers in the community, i.e. the IJB.” WA*
>
> *“Direct support staff to create opportunities for people they support to share their views, to ask more, to support them in learning how to share their views and advocate for themselves. Support staff to connect people they support with wider opportunities to share their views and advocate for themselves.” WA and former SAS*

The participation we are describing goes significantly beyond current practice. For example, we are proposing that a supported individual who is interested in steam engines should be supported (if they might like to do so) to volunteer on a heritage railway or participate in a model railway club. Similarly, a supported individual who is interested in local issues in their neighbourhood should be supported (if they might like to do so) to stand for election to their Community Council. Our experience as disabled adults and as family and friends of disabled adults makes us aware that one of the main reasons such participation rarely occurs at present is the likelihood of encountering significant resistance and discrimination when individuals, particularly those with more obvious disabilities and differences, attempt to participate in mainstream community activities. Consequently, we recommend the creation of a new role of Advocacy Officer, to sit within the CPI structure. The remit of this role would be to support staff with issues of access and discrimination they encounter and to actively advocate for full inclusion of supported individuals in their communities on an individual level and an issue by issue basis. This would provide the necessary support for supported individuals to challenge and overcome these barriers. The role of Advocacy Officer is projected to cost £40,000pa.

The Inclusive Governance Officers (see *Recommendation 1.2: Direct representation on the Board*) should source or create materials for supported individuals providing accessible information about discrimination, the Equality Act and their rights.

2.6. Participation of supported individuals in the wider autistic community

We recommend that Scottish Autism proactively encourage and support supported individuals to participate in the wider autistic community locally, nationally and internationally. Specifically, we recommend that Scottish Autism encourages and supports supported individuals to join and participate in an autistic DPO in their area. In areas where no autistic DPO yet exists, we recommend that Scottish Autism supports and fosters the development of new autistic DPOs, at a projected cost of £5,000 pa.

This would include supported individuals being supported to:

- Access information about local autistic DPOs
- Undertake the process for joining a local autistic DPO
- Find out about and attend local, national and international autistic community events (e.g. Autistic Pride days, autistic DPO meetings, Autscape[44])

Participation in local events and groups can be accommodated within current service provision. Support for events requiring overnight stays, for a small proportion of supported individuals, is projected to cost £7,000pa[45]. However, it may be possible to recoup some or all of this cost from service commissioners on the basis of necessary support for activities the supported individual wishes to undertake.

This recommendation is also in line with UNCRPD Article 29 (United Nations, 2006) around participation in political and public life. Further, we consider this recommendation extremely important in both furthering the representativeness of autistic DPOs and in enabling access to autistic space for larger numbers of supported individuals, not merely those who become members of the AAP.

2.7. Leadership Development Programme

In the medium term, we recommend that Scottish Autism create an autistic leadership development programme[46] supporting a limited number of individuals who wish to do so to enable them to become leaders in all contexts, ranging from individual agency and self-advocacy, leadership at service or regional level and fostering the skills and confidence amongst those who aspire to do so to represent others through the AAP, serving as co-chairs or becoming Board members.

The programme would seek to develop skills, confidence and offer practice at:

- Personal decision making and autonomy
- Self- and collective-advocacy skills
- Representation
- Challenging limiting beliefs, real and perceived barriers
- Developing leadership skills

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[44] www.autscape.org

[45] Based on 4 days additional support per year for 20 supported individuals (5% of the total)

[46] See Leadership Training programmes case study for further information about the origins of this recommendation.

The design of the programme would need to actively consider and promote the wellbeing of those participating, ensuring that individuals are supported, encouraged and build up confidence, but do not feel under pressure to take on more demands than they are able to sustain.

> *"I'm only talking about that one individual, who would like to be more and do more, but you've got to balance what he's capable of and where his anxieties lie." SAS*

The programme should be designed and overseen by the AAP, supported by the diversity taskforce, and with input from Centre for Practice Innovation. The programme would be open initially to supported individuals, but could ultimately be widened to be additionally open to autistic staff and potentially to the wider autistic community. The programme would include a coaching/mentoring approach, in addition to other forms of learning and could also include funding individuals to participate in pre-existing leadership development programmes provided by external organisations (options include Disability Rights UK and Partners in Policymaking, amongst others).

The programme, once it is up and running, is projected to cost £25,000pa for 10 participants per year. Startup costs would be covered by existing expenditure (e.g. CPI) and the provision already made under other recommendations (e.g. AAP and diversity taskforce).

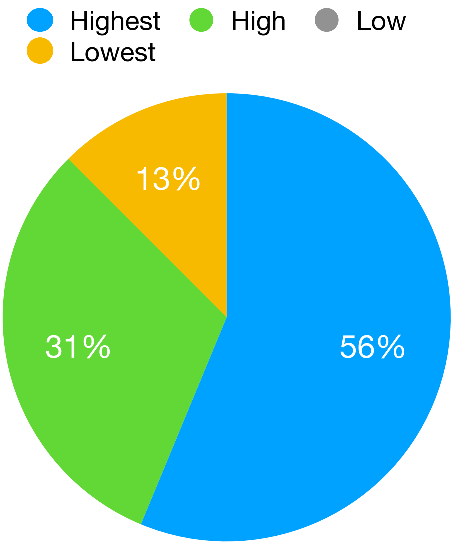
There was wide support for this proposal from the stakeholders consulted:

> *"Give autistic individuals training and knowledge to lead." WA*

> *"It's important for individuals with autism to feel comfortable and supported in the program, and for facilitators to be able to effectively connect with and understand the participants. This can help create a positive and effective learning environment." WA*

Amongst participants at the largest focus group (16 participants), 14 rated this proposal a high or the highest priority (Figure 7).

Figure 7: Leadership development as a priority recommendation



Recommendation 3: Values and Recruitment

Why is this needed?

A range of points relevant to this recommendation emerged throughout the stakeholder engagement. They came from all stakeholder groups, although perspectives and emphases varied across roles.

Both staff and the wider autistic community highlighted the importance of predictability and consistency in the staff team supporting each individual:

> *"I dislike uncertainty and would struggle with staff around me changing. This is a great idea." WA*
>
> *"[supported individual] went through a spell, and it turned out that it was the large number of staff that were coming and going from his team. It wasn't a settled core team. It was a kind of mix of everybody, whereas [supported individual] benefits from people he knows, a settled core team, and people he can trust, and we've got back onto that, he's now gone back to his core team: people he knows, people he can trust, and he seems to have come out of the other side of this wee spell that he was going through. So, it is important." SAS*

Many highlighted the importance of supported individuals having greater influence over the choice of staff recruited and deployed to work with them:

> *"So [supported individuals] need to have the better say than HR saying this should be." SAS*
>
> *"It's getting staff, while still being selective. You can't just take somebody because they're a warm body. And we do try and match people, where possible, with people where we think their skills will suit." SAS*

And of a diverse and inclusive staff group having the right values and being compatible with autistic needs, including staff having neurodivergent traits themselves:

> *"Recruiting and retaining talent, and we shouldn't underestimate an inclusive approach being part of this too." SS*
>
> *"When talking about inclusivity it can't just happen at board level. It needs to be wider engagement." SS*
>
> *"That would come down to training for management to be able to… pick up on these sorts of things. [One person might] be good in an interview, but [a different person] might have good person-to-person skills and might be able to understand the individual a bit better." SAS*
>
> *"This is what I think and some people might not agree with me, but I think it takes one to know one. As autistic people, we kind of tend to understand each other better, be-*

> *cause of the double empathy thing. So, I think probably we could do good support to other autistic people." WA*

Autistic staff, former staff and potential staff commented on the need for further progress towards ensuring that autistic staff are well supported and experience an inclusive environment within Scottish Autism in order for this to work well:

> *"I think this is a good idea because I started a job with Scottish Autism and told the service manager (or the manager of the place) [that I'm autistic] and she seemed surprised and I felt insecure after that." WA & former SAS*

> *"I wouldn't have to fight for reasonable adjustments and to get the organisation to behave in a way that is not offensive to the autistic community. My opinion would be valued and changes would happen more easily. Everyone would respect each other. All managers would be trained in supporting autistic employees." SAS*

> *"We need more breadth in age, background, ethnicities in order to be more representative." SS*

> *"From personal experience of looking at the job specs, you know, to support other autistic individuals, I know it would take a lot out of me to support someone, for example, someone who has problems sleeping or that kind of thing. So, we would need to consider the possibility that if you're recruiting neurodivergent people, then you might have to support them in order for them to be able to support the supported individuals." WA*

What are we proposing?

A range of strategies to promote inclusivity and diversity across the organisation and increase the direct and indirect influence of supported individuals and autistic people more broadly over the recruitment, retention, distribution, priorities and values of staff.

At first glance, this area may seem outside the scope of inclusive governance; however, we believe it to be fundamental. The Feeley report (Scottish Government, 2021) highlighted the impossibility of influencing practice in adult social care from the outside saying:

> *"You cannot inspect quality into a product; instead you have to reduce the need for inspection on a mass basis by building quality into the product in the first place." (Scottish Government, 2021, Chapter 7)*

Staff are SA's biggest area of expenditure and the behaviour, attitudes and practices of staff exert significant influence over the lives of supported individuals.

> *"A lot of our individuals are non-verbal, so they rely on the staff that know them really well to be able to advocate for them." SAS*

> *"It's knowing your service user and your staff getting to know your service user, and building up a relationship and understanding, and I suppose, to a certain extent, being a bit of an interpreter for them." FM*
>
> *"And the other problem you've got at [SA service] is the huge turnover of staff as well." SAS*

Consequently, this area of recommendations was rated as a high priority for inclusive governance by a majority of participants who completed the survey or a poll in a focus group.

3.1. Review of Scottish Autism's values

We recommend that Scottish Autism consider changes to the current organisational values of: Collaboration, Compassion, Change Makers, and Contribution. If inclusive governance is to achieve fundamental change, then that change needs to be reflected in the organisation's values. This reconsideration should include discussion of the existing values in terms of the questions discussed under Recommendation 1: Representation in Governance.

- Diversity – Who is in the room?
- Accessibility – Can everyone get inside the room? Can everyone participate?
- Equity – Who built the room? Who has the power?
- Inclusion - Does everyone in the room feel welcome? Like they truly belong?

Values that should be considered for adoption include: equity[47], justice, diversity, rights, and autonomy.

We project a cost of £2,500 for workshops around these changes. However, it will be important that any consultation is not merely a consultation of those who are able to attend and participate in workshops, but draws on other mechanisms recommended here to ensure that, particularly, the views of supported individuals and the wider autistic community are broadly and diversely represented.

3.2. Language use policy

We recommend that Scottish Autism adopt a language use policy throughout the organisation. This would help to improve the extent to which all autistic people feel welcome and like they truly belong. The policy should include:

- Respecting individual choice of identification terminology
- Using identity-first language (i.e. autistic person) as the default other than when respecting individual choice

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[47] See Appendix E for illustration from The George Washington University (2020) which helps explain the choice of equity and justice over equality or inclusion

- Using the term ‘non-speaking’ rather than ‘non-verbal’
- Avoidance of ‘functioning’ labels (such as ‘high functioning’, ‘low functioning’, ‘savant’) which encourage assumptions about abilities and deficits
- Using the term ‘distressed behaviour’ rather than ‘challenging behaviour’
- Avoidance of the term ‘high arousal’ as a synonym for ‘challenging behaviour’
- Avoidance of the use of the word ‘complex’ to describe individuals or their behaviour. This should be substituted by a specific description of the particular support needs an individual has. In broader use, having ‘high support needs’ would be an acceptable alternative.

The AAP should be asked to draft a proposed language use policy, taking account of views across the autistic community. Following this, we project a cost of £3,500 for workshops to support with transmission of the new policy throughout the organisation.

This is good practice broadly and reflects comments such as:

> *“Helping the organisation to work in a way that is not offensive to autistic people eg by not using inappropriate language." WA*

Part of the remit of the diversity taskforce should be to review, screen and challenge representations and the use of language across all organisational communication (internal and external), seeking advice and guidance from the AAP on autistic community preferences, as well as considering diversity in all its forms. This would require consideration of intersectional diversity issues, such as routine identification of pronouns, checking position statements/training etc. to ensure inclusion of the full range of diversity.

3.3. Reorientation towards viewing staff as working for supported individuals

We recommend a further shift in orientation of employment and working practices towards staff seeing themselves as primarily working for, and accountable to, supported individuals, as illustrated in Figure 8.

To work towards realising this aim we recommend that supported individuals and, possibly, family members should routinely be present on interview panels. This is achievable in the short term. Stakeholders discussed with us instances in the past where this had occurred but widely commented that the pandemic had disrupted or ended this (see below).

We further recommend that interview questions are reviewed and modified if needed to ensure they avoid disadvantage to autistic candidates (Maras et al., 2020) and that interview formats are modified to include, whenever possible, interviewees doing an activity with a supported individual they might support (if the supported individual is willing). Job trial elements, as an alternative to the traditional interview, are likely to increase equity for autistic candidates (Employment Autism, 2023):

> *"If an organisation claims to value diversity and inclusion, but its recruitment practices do not reflect this and its employees do not feel included or valued, this can lead to a lack of trust and engagement." SAS*

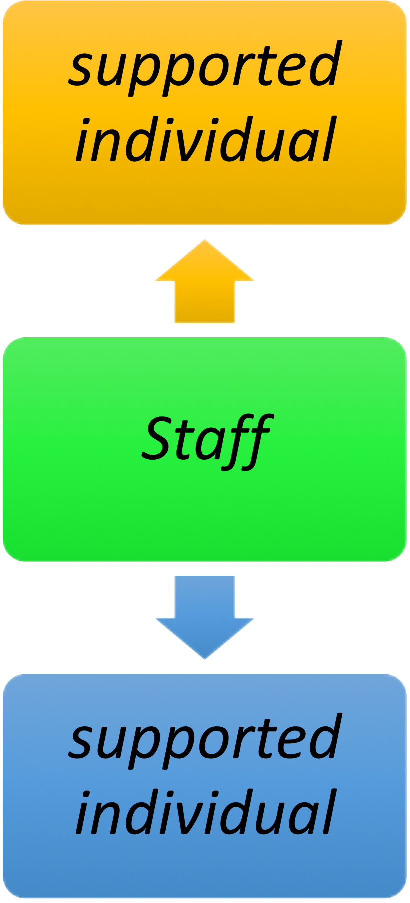
We are aware that some of these things have been done in the past; however, we believe that there is an important shift which still needs to happen from these approaches being seen as a 'nice to have' to being seen as an essential requirement for all recruitment.

> *"We are in a bit of a staffing crisis at the minute, so it tends to be the higher-up service and regional managers that are doing the majority of the interviews just now." SAS*

As we discussed in the definition of inclusive governance:

> *"It is not just about having the space to say things but also that what is said is taken seriously and considered to be of high value." (Bell & Reed, 2021, p. 7)*

If we recognise that inclusivity is not just about having a say, but requires autistic people (and particularly supported individuals) being seen as essential and important people in the organisation, then this requires a change of culture to ensure that the presence of supported individuals on interview panels is considered just as important as the presence of HR and managers.

Figure 8: Accountability to supported individuals

Note: Visualisation of the concept of staff working for as well as with supported individuals.

It is also important that a range of supported individuals participate in these processes, including those with the highest support needs:

> *"We have already had service, supported individual-led recruitment days. But it' quite often- it's the verbal individuals that get selected. You know, the more sociable, verbal individuals that get selected to go to these recruitment days, welcome applicants for the jobs." SAS*

We recommend that the diversity and representativeness of supported individuals selected to participate in recruitment processes is monitored and steps taken to ensure diversity and representativeness are maximised.

In the medium term, we recommend working towards supported individuals leading recruitment for their own support staff with the role of HR and managers being seen as advisory, rather than leading the process.

This recommendation has no cost implications.

3.4. Prioritising autistic needs over organisational needs

We recommend a further shift in the orientation of employment and working practices to prioritise autistic needs (such as consistency) over organisational or other priorities. Some stakeholders highlighted good practice in this area:

> *"We do try and match people, where possible, with people where we think their skills will suit." SAS*

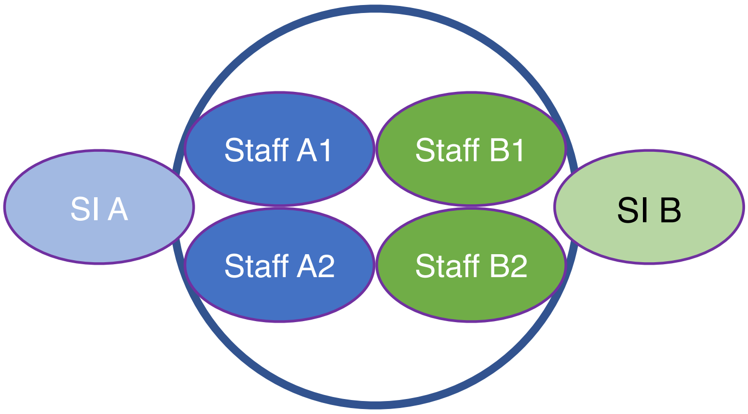
However, it was also clear that these aims tended to fall away when in competition with other organisational priorities:

> *"In the past, as I say, we did have, for the supported people that I work with, a kind of questionnaire that we supported people to fill out. And if they couldn't fill it out themselves, we went with what type of people, what kinds of interests they should have, if it was male or female, young or old." SAS*
>
> *"Because [supported individual's] staff is changing on a regular basis. He's supposed to have a team, and because whatever the reason is, his team keeps getting deployed, elsewhere, and probably because they've got a bit more experience than some of the younger ones. Anyway, it's not really helping him." FM*

To drive this shift, we recommend that the AAP have significant input into the job descriptions, person specifications, interview questions and activities for staff at all levels, and that this should begin with input on these for frontline support staff.

The most important mechanism we propose for the implementation of this recommendation is the creation of 'bubbles' surrounding small numbers of supported individuals and the staff who work with them. This is illustrated in Figure 9.

Figure 9: Staff bubbles



Note: Visualisation of a 'bubble' of staff linked to a small number of specific supported individuals to increase familiarity and consistency.

Our thematic case study on service-level models of governance and recruitment included several models of care and support which were based, not only on significant involvement and influence of supported individuals in the recruitment of support staff specifically to work with each individual, but also on the deployment of those staff within small groups of supported individuals, forming a ‘bubble’. Within that bubble, supported individuals would know and have familiarity with all the staff and all the staff would know and have familiarity with all of the supported individuals. This allows gaps in staffing due to sickness, leave etc. to be covered by staff from within the bubble, leading to significantly increased consistency of support and minimising disruption for supported individuals.

The services analysed in this case study were all relatively small and there are clearly challenges in scaling up this model to function effectively within a large organisation such as Scottish Autism.

Stakeholder comments were largely supportive of this concept and clearly recognised the importance of stability for autistic people.

> *“I’m quite passionate about the staff, supported individuals’ bubbles. Because I really do feel that, you know, somebody being supported should have familiar people, it shouldn’t just be, like, they have six different people introduced to them, like, within a few weeks.” SAS*

> *“It's recruitment that now seems to be an issue. It's the shortages of staff. And [supported individual] is well within his right to say, ‘Well, I don't really like this member of staff,’ so they maybe need to… that he’s more suited for somebody else, so it’s getting back to getting the core teams in place, people settled, and, as I say, I have seen a difference in [supported individual} since we’ve got back to that.” SAS*

> *“As I say, my experience with care [not at Scottish Autism] was quite horrendous. And I understand that things can happen, but when, seven days a week, seven different people walk in, when you're told at the start it will only be two or three different staff… And I believe that happens all over the place… The one thing that I can’t stand, and many people can’t stand, is the change, the constant change. I can’t cope with that constant change, I need to know who is coming, who is there, a very small group.” WA*

A concern was raised that this approach:

> *“Creates dependency on certain staff members." SS.*

This is an important issue to address. We recognise that this approach it may create some dependency on certain staff members. However, we do not see this as necessarily negative. Some degree of dependence on others is an inevitable consequence of an adult having needs for care and support. For many disabled people, dependence is a necessity, but autonomy can still be exercised in choosing who we are dependent on and in what ways.

All adults, disabled and non-disabled, are dependent on others to some extent and this is often a good thing. For example, most of us depend on garages to fix our cars. It would be a significant additional demand for most of us to learn to be independent at fixing our cars, so we choose to be dependent on garages. We all make choices about what to be independent at and what to depend on others for. We should afford the same autonomy to supported individuals.

The choice is, therefore, not between creating dependence and not creating it, rather the choice is between being dependent on a more random, larger group of support staff, which autistic people mostly find unpredictable and stressful, or being dependent on a smaller consistent group of support staff that the supported individual is familiar with and can communicate with. Our view, drawing on the lived experience of autistic people who are dependent on care and support, is that autonomy is more important than independence. Generally, autistic people are likely to be better able to live the lives they choose when they have support they are familiar with and can have their needs and wishes understood and respected.

If the concern is that a supported individual will get emotionally attached to a particular support worker, we suggest to be relaxed about that. A life is enriched by close, valuable relationships. Sometimes those relationships end, but that does not diminish their value. This applies to disabled people as much as it does to anyone. The reality of autism and learning disabilities is that often support staff are supported individuals' only friends and are the source of vital emotional connections. That is a fact that should be recognised and accepted, even with the complications and issues that may come with it (Williams, 2021). Boundaries can be important for the prevention of abuse, but there is no reason legally why policies and conventions designed to prevent abuse need to be taken to such extremes that they prohibit healthy and positive human relationships[48]. Joe Long (2020) has highlighted the importance of friendship between support staff and supported individuals at Scottish Autism (emphasis added):

> *"Both the staff focus groups and talking groups with supported people found that questions around friendship and affective attachment did not just pertain to relations between supported people but often centred on relations between practitioners and those they supported. These insights led us to consider social care as a form of* ***relational support*** *in which interactions and relations with practitioners are central to the lived experience of supported autistic people."*

See the case study on supported decision making (Appendix C) for further discussion.

There are also obvious challenges in the current context of a sector-wide staffing crisis, which were voiced by stakeholders, particularly staff:

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[48] See A (fact-finding) [2019] EWCOP 58

> *“The idea of the staff bubbles breaks down when there isn't the staff to cover it.” SAS*
>
> *“I can see difficulties surrounding this at the present moment in our services but something which should be achieved for supported individuals.” SAS*

However, rather than concluding that Scottish Autism should wait for a better climate in which to introduce this model of working, we believe the model itself has potential to improve both recruitment and retention of staff. A notable feature of our stakeholder engagement with both current and former staff at the autism practitioner level was the frequency of feedback which highlighted the pleasure and job satisfaction staff achieved from their direct work with supported individuals.

> *“I do what I do because I love what I do “ SAS*
>
> *“When employees are happy with their work environment, they’ll be more likely to stick around—meaning higher retention and improved employee satisfaction." U*
>
> *“There’s four staff that have been here the longest within the team that are very, very passionate about what we do.” SAS*

By contrast, the same current and former staff expressed varied views on the extent to which they felt listened to, including some discontent and feelings of being disconnected from management.

> *“I think my voice is definitely heard within my close team to give everyone the best we can … 90% is because we’ve got an excellent manager. … Our manager is somebody that manages us in a way that we all feel on the same level as her. She manages it and we know she’s our manager but she doesn’t expect anything of us that she wouldn’t do herself. So, she’s never forgotten that she has also been in our shoes so she nurtures us and she encourages us and then with doing that, she brings us together.” SAS*
>
> *“Good staff only leave because undervalued by top.” SI*
>
> *“As a member of staff I did feel truly listened to the vast majority of the time. The times I didn’t were when it was with those individuals or small groups who don’t listen with an open mind as much. In comparison to other organisations in the sector I think Scottish autism listen loads and allow people to influence things a lot.” Former SAS*

We recognise the challenges of implementing the ‘bubbles’ approach during a sector-wide recruitment crisis. However, enabling staff to work within consistent, cohesive teams, with and for specific supported individuals is likely to improve staff retention and, in the medium term, recruitment:

> *“Good idea for positive work environment and improved staff morale.” U*

This effect is in addition to the significant advantages from the perspective of autistic supported individuals and autistic staff.

Creating the staff/SI 'bubbles', as recommended, here may be cost neutral overall, if it succeeds in improving retention. It is very difficult to cost this recommendation in isolation, and it is closely related to the other recommendations in this section. Therefore, we have considered recommendations 3.3 to 3.6 holistically in the costings set out at the end of recommendation 3.6 below, and recommendations 3.3 to 3.7 holistically in the costing set out at the end of recommendation 3.7 below.

3.5. Diversity and neurodiversity in recruitment

We recommend that Scottish Autism seek to increase diversity and representation (particularly but not exclusively of autistic people) at all levels of staff within Scottish Autism.

> *"Overall I think Scottish autism really truly listen and to try to listen, but I don't think there are enough processes to input into governance and that they aren't very accessible and/or not including all the groups they should. … [I would like to see] broadening governance input to include people from minority intersectionalities where at least one of their personal characteristics makes them a stakeholder E.g. having input on policies from LGBTQ+ staff, parents of autistic children from minority ethnicities, autistic people who do not receive support from SA, etc.." WA & former SAS*

We propose that Scottish Autism seek to deliberately diversify the talent pool it draws on in recruiting (in all senses from frontline roles to senior leadership, from Board recruitment to selection of conference speakers) by proactive recruitment from under-represented groups, including specifically neurodivergent talent[49].

> *"From experience in previous organisations, I think it's also making sure that people recognise the fact that diversity refers to a wider population. And it actually affects everybody, as opposed to just that group over there or that individual over there." WA*

> *"This approach can be beneficial because it allows for a more diverse range of perspectives and experiences to be considered in decision making, which can lead to better decision quality." WA*

The thematic case study on intersectionality identified similar strategies which had been undertaken by several different organisations. These should include:

- Deliberate targeting of autism information and advice at locations and for communities which are marginalised in other ways, tailoring resources to the needs of those groups
- Supporting autistic people and family members from marginalised communities to create and lead groups and activities

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[49] This recommendation is strongly connected with recommendation 1.1, since collecting and monitoring data on intersectional identities would aid in both encouraging and evaluating implementation of this recommendation.

- Partnering with in projects and supporting campaigns on non-autism diversity and equity issues and building pan-disability and pan-marginalised group solidarity – this can include challenging other social justice groups to be more inclusive of disability-generally and autistic people specifically
- Partnering with small, independent organisations representing a range of marginalised groups to disseminate recruitment materials and advertising in publications, locations and through organisations where marginalised communities are
- Prioritising diversity in consideration of candidates, considering overall representation of diverse characteristics at all levels within Scottish Autism
- Explicitly talking to existing staff or others connected to Scottish Autism who have connections to individuals from under-represented groups to encourage and solicit applications.

We also propose that Scottish Autism consider prioritising neurodivergent traits in recruitment of staff, such as directness and clarity of communication, attention to detail and consistency/reliability over more traditional 'caring' attributes such as neurotypical expression of empathy, team working and social communication skills. We recognise that there are challenges that would need to be examined to ensure that any changes were in line with the requirements of both employment and equalities law. Nevertheless, there are significant advantages to seeking to further the synergies between autistic and otherwise neurodivergent staff and autistic supported individuals and this recommendation was strongly supported amongst autistic Stakeholder groups:

> *"I like the neurodivergent talent pool idea a lot." WA*
>
> *"Neurodivergent individuals can bring unique strengths and perspectives to the workplace." SI*

When visiting a service supporting non-speaking individuals, members of the IG team communicated our autistic experience of the sensory challenges of that environment to staff and managers, who had previously had limited awareness of the issues we raised. This illustrates one of the benefits of increasing the presence of autistic people within SA services.

This recommendation has no cost implications beyond those already discussed in relation to other recommendations.

3.6. Strategies to enable raising staff pay

Recruiting and retaining staff who have the skills and values which supported individuals need to thrive and be fully included requires a rate of pay which reflects those skills and communicates to staff their value and the value of those they support. Low pay has long been an issue across the social care sector and we fully understand that there are external factors which limit the degree of flexibility within Scottish Autism's control, particularly the rates commissioning bodies are able and willing to pay for care and support. However, we recommend that Scottish Autism seek to increase rates of pay for frontline care and support staff.

We recommend consideration is given to each of the following:

- Seeking to reduce staffing levels with any individual currently receiving multi-staff support (e.g. 2:1 and above). The primary driver of higher staff numbers is the possibility of using restraint and other restrictive practices. We also believe that there is a risk of a vicious circle, in that, saying that an individual requires a certain level of staffing, may provoke anxiety and expectation of 'challenging' behaviour amongst staff, which is then likely to cause staff to behave in ways which may cause or trigger further distress. We believe that risk can be managed more effectively and ethically (in the vast majority of cases) by, instead, ensuring a small number of more highly skilled and consistent staff, who are able to effectively implement strategies (such as those outlined in NAT (2019); also see Dunn (2020), and NAT (forthcoming)) to reduce stress and distress and prevent the need for restraint and restrictive practices. It seems to us that the key exchange is to use the funding currently expended on increasing staff numbers instead to increase staff quality and skills
- For supported individuals who have 24-hour support at all times, revisiting the necessity of this for each individual and, where appropriate, undertaking trials to explore whether, with highly skilled staff capable of creating systems (such as checklists) and supporting learning by experience (including making mistakes), some individuals may be able to move towards a more intermittent package of support[50]. Whilst we accept that, for some individuals, 24-hour support is a genuine necessity, in our experience, 24-hour support is often a blanket assumption made about a significant proportion of autistic people with learning disabilities from an early age, without full exploration of whether this is really necessary or meaningful attempts being undertaken to develop alternative forms of background support (such as setting up systems) and provision of opportunities to develop agency and learn from experience. The benefits of moving to intermittent support for privacy and control over one's own life are significant. For autistic people who find interaction and communication demanding and tiring, periods of time without the presence of support staff can also be in the interests of improving quality of life.
- Seeking to influence and challenge commissioners around funding rates to encourage commissioning which supports a higher level of pay (including as an alternative approach in cases where the commissioner is requesting staffing beyond 1:1 or requesting 24hr care when there is a lack of clear evidence that it is actually necessary) – highlighting the impact on human rights, equity and the value society ascribes to individuals with needs for care and support. The focus of commissioners on numbers of incidents and staff numbers were highlighted to our team:

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[50] This might, for example, start by the person spending short periods unsupported whilst doing a familiar activity such as playing a computer game (e.g. By creating a half hour gap between support shifts). It could involve the use of assistive technology, such as door sensors, if absolutely necessary, to maintain safety.

> *"It's a tightrope. The business relationship is paramount. We have to engage with commissioners. From a policy perspective, commissioners are directly out of step with what we are trying to do. This creates a lot of tension to maintain the professional and personal relationships. Its more about spot purchase now so we have more of an in-road. But when its tenders there's a lot less flexibility." SS*

Nevertheless, we consider that furthering such challenge at a strategic level is in the interests of supported individuals.

We recognise that some will feel that such a recommendation goes well beyond our remit of inclusive governance. However, the issue of pay was spontaneously raised several times, mainly, but not exclusively, by staff stakeholder groups. Whilst staff were clear that pay is not their primary motivation:

> *"I don't look at it for pay, I don't do this job for pay." SAS*

they were also clear that pay is directly relevant to the recruitment and retention of staff with the values and skills supported individuals need.

We agree. Supported individuals cannot be meaningfully supported to develop decision making skills, communication and autonomy, without ensuring that they are supported by consistent groups of staff who have the skills to do that and in ways which do not include restrictive practices.

Moving to this modified model of care is not projected to have any significant cost implications for Scottish Autism. Projected costing per annum **for commissioners** for this modified model of care and support proposed in recommendations 3.4-3.6.

Table 3: Cost for commissioners of modified model of care

Type of package (for 1 supported individual)	Now	Pay increase (to £15 per hour) Support hours as now	Pay increase (to £15 per hour) Support hours reduced
Core 1:1 with sleepover	£173,000[a]	£199,000[b]	£173,000[c]
Core 2:1 with Wakened Night Shift 1:1	£303,000[d]	£365,000[e]	£303,000[f]

Note: Estimated annual costs of adjusting support towards a lower number of more highly skilled staff per supported individual.

[a] Assumes 112hrs + 56hrs sleepover (per week) at current pay rates and staffing as at present.

[b] Assumes 112hrs + 56hrs sleepover (per week) at £15ph, less supervisory/manager interventions

[c] Assumes 93hrs + 56hrs sleepover (per week) at £15ph, less supervisory/manager interventions

[d] Assumes 224hrs + 56hrs nights (per week) at current pay rates and staffing as at present

[e] Assumes 224hrs + 56hrs nights (per week) at £15ph, less supervisory/manager interventions

[f] Assumes 175hrs + 63hrs extra support (per week) at £15ph, less supervisory/manager interventions

3.7. Pilot of a self-directed support model

The highest possible level of involvement and control over care and support that can be achieved for autistic adults with support needs is a model in which the autistic adult directly employs and controls their own support. This 'inverted' model (compared to traditional forms of care) already exists and the framework for it is already available in Scots law in the form of Self-Directed Support (SDS) option 1[51].

In the long term, therefore, we recommend that Scottish Autism explore the possibilities of moving towards a service model based on facilitating the takeup of SDS Option 1 and the development of care co-operatives[52] amongst autistic people with needs for care and support. This would provide the ultimate model for 'inclusive governance', empowering autistic people to direct and control our own support.

Each individual would require the support of a 'case manager/support broker'[53] to work on their behalf to write job descriptions (which would be bespoke to that individual's needs and preferences), recruit and provide HR support for their support staff. Such a model would involve removing managers and seniority amongst support staff, creating a largely autonomous and collaborative group of well-paid and skilled support staff working together directly for the individual they support. Creating a 'flat' model without a hierarchy amongst support staff is essential to ensuring that support staff see themselves as working for the supported individual and turning to them for direction, rather than to a manager or 'senior'.

Movement in this direction would be possible by starting with a pilot project, perhaps in a region or area Scottish Autism doesn't currently offer services in[54]. A pilot would involve:

- Promoting the model to care commissioners
- Support and training from CPI for autistic people with support needs to understand the degree of autonomy and options which are possible via SDS Option 1[55]
- Training individuals to work as 'case managers' to recruit and manage support packages on behalf of autistic individuals with support needs whilst keeping the suppor-

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[51] As set out in Section 4 of the Social Care (Self-directed Support) (Scotland) Act 2013

[52] See service-level models case study (Appendix B.3) for more detail on various care co-operative models

[53] Each case managers could potentially fulfil the role for more than one supported individual, depending on the size of their care package

[54] In order to avoid the potential conflict of interest in competing with an existing Scottish Autism service and to enable a 'fresh start' pilot, rather than seeking to evolve a fundamentally different model from an existing service model.

[55] We have assumed no cost for the first two elements as these can readily be accommodated within SA core functions

ted individual in control of their support and promoting their autonomy in all aspects of their lives[56]

- Employing 2-3 case managers for 3 months prior to the first packages starting[57]
- Providing administrative and other logistical support to facilitate the development of care co-operatives amongst the individuals receiving support and their staff teams[58].

We project that the start-up cost to Scottish Autism of piloting this model would be £20,000, with an additional £5,000pa as ongoing costs for the support to facilitate the formation of care co-operatives.

Projected costing per annum **for commissioners** for this 'inverted' model of care and support proposed in recommendation 3.7 (Table 4).

Table 4: Estimated costs for commissioners of an inverted model of care and support (recommendation 3.7)

Type of package (for 1 supported individual)	Now	Inverted model with case manager and pay increase Support hours as now	Inverted model with case manager and pay increase Support hours reduced to 80 hours per week + sleepover
Core 1:1 with sleepover	£173,000[a]	£214,000[b]	£173,000[c]

[a] Assumes 112hrs + 56hrs sleepover (per week) at current pay rates and staffing as at present.
[b] Assumes 112hrs + 56hrs sleepover (per week) at £15ph, a case manager – 0.5fte @ £38k, no service manager, no SAP time, reduced admin and clerical time
[c] Assumes 80hrs + 56hrs sleepover (per week) at £15ph, a case manager – 0.5fte @ £38k, no service manager, no SAP time, reduced admin and clerical time

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[56] This assumes a cost of £7,500 for training 2-3 case managers and £2,500 in consultancy fees for members of the IG team to provide support to CPI to develop their understanding of the model, the case manager role and training for autistic people on the benefits

[57] This assumes a cost of £10,000 for 2-3 case managers to be employed for 3 months prior to start of funded packages

[58] An ongoing cost of £5,000 pa to provide administrative and other logistical support to the individuals receiving support and their staff teams to facilitate the development of care co-operatives

Recommendation 4: Service autonomy and accountability

Why is this needed?

The above recommendations include greater inclusion of supported individuals in their local communities and the involvement of both supported individuals and the wider autistic community, including through autistic DPOs, in the governance of Scottish Autism. Those processes can only succeed and be sustained if Scottish Autism's services are more strongly connected to their local communities and also more accountable to their communities, including both supported individuals and the wider autistic community. This was highlighted in the stakeholder engagement:

> *"It can help improve the quality of the services being provided, as the people responsible for them have more control over their operations and are accountable for their successes and failures." WA*
>
> *"I think this is only a good idea if the services are held accountable for their standards." WA*

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

We recommend that Scottish Autism services should be rooted in and connected to their local communities. The role of regional managers should be enhanced[59] to include wider community engagement, alongside responsibility for commissioned services. Wider community engagement should include engagement with the local autistic community, particularly any existing autistic DPOs and, if none exist, fostering and supporting the development of new autistic DPOs. As discussed in *recommendation 2.6* above, this must include active encouragement and facilitation to enable supported individuals to join and participate in local autistic DPOs. It should also include developing a support offer to the local autistic community, for example through existing advice line and One Stop Shop services, but also listening to and collaborating with the local community to develop new services relevant to and needed by that community.

The need for increased engagement between Scottish Autism and local autistic communities around Scotland was widely highlighted by stakeholders, particularly from the wider autistic community:

> *"More support and engagement opportunities in my local area." WA*

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[59] Enhancing the role of regional managers is projected to cost £36,000pa (based on extra £7,500 pa for 4 RMgrs). However, this change should be seen as part of wider shifts in the development of SA more broadly and is not specifically the result of the Inclusive Governance Project. Consequently, we have not included this cost in our overall costings for the project.

> *"I would like to be more involved with the way forward in creating a more inclusive and better place for the autism community." WA*

> *"Openly and consistently communicate with autistic people so we know what is available." WA*

Concerns and anxieties about the potential involvement of autistic people's organisations in these recommendations have been raised with us throughout the project by some Board members and senior staff:

> *"Why APOs – go beyond that group." SS*

> *"APO orgs have potentially a 'louder' voice than those we directly support." SS*

> *"Is our relationship with APOs strong enough/trusting enough at this stage?" SS*

Although there were also positive comments from other stakeholder groups:

> *"When individuals and groups are represented, they are more likely to feel like their voices are heard and that their needs are being taken into account. This can help promote social cohesion and can prevent conflicts that may arise when certain groups feel like they are being ignored or left out of the decision-making process." WA*

> *"At [Scottish Autism service] the supported individuals we've got are highly dependent upon us, and then you've got the community … where they may be more high functioning, then it would maybe be beneficial to maybe tap into that sort of group for stuff like this." SAS*

> *"Other autistic people in Scotland should have an influence via a range of ways of engagement." WA*

We also note that, as detailed in the discussion of the meaning of inclusive governance above, the importance of plural and collective voices and not merely those of individuals was one of the themes initially identified by the Board and senior leadership as important for inclusive governance.

We believe concerns about the involvement of autistic DPOs to be misplaced. As a country which has ratified the UNCRPD, Scotland has recognised the importance of Disabled People's Organisations (DPOs). The Scottish Government has set out its intentions to move towards full implementation of the UNCRPD in Scotland and its delivery plan for doing so highlights the importance of full participation and involvement of DPOs in doing so (Scottish Government, 2016). The principle of 'Nothing about us without us' and the importance of involving both disabled people and their representative organisations is recognised throughout the UNCRPD. For example, Article 33 (3) states (emphasis added):

> *"Civil society, in particular persons with disabilities* ***and their representative organizations****, shall be involved and participate fully."*

There are also some key points we would like to make. Firstly, we are recommending engagement and development not only for Scottish Autism, but also for autistic DPOs. To date, many autistic DPOs have insufficiently included and represented certain groups of autistic people, particularly those receiving more extensive and residence-based support, such as many of those supported by Scottish Autism. We have recommended that supported individuals should be encouraged and supported to join their local autistic DPOs (see *recommendation 2.6* above). If this recommendation is acted on, this will inherently provide challenge to autistic DPOs to meaningfully and accessibly include those individuals.

Secondly, in many parts of Scotland, local autistic DPOs do not yet exist or are underdeveloped. We are recommending here that Scottish Autism support and foster the development of autistic DPOs. If Scottish Autism wants to improve its relationships with autistic DPOs, that will take openness on both sides and a willingness to move forward. This project has taken place because Scottish Autism took a brave and bold first step of seeking bids from autistic consultants to undertake the project. Throughout the project, IG team members have had access to confidential, internal SA documents and thinking, whilst also, in many cases, being active members of autistic DPOS which may well, at the same time, have been passionately disagreeing with Scottish Autism about many things in other forums. This requires ethics, boundaries and professionalism on both sides, but it is clearly entirely possible.

Thirdly, as Winston Churchill famously said, “Democracy is the worst form of government – except for all the others.”

Autistic DPOs which seek to be representative of their members should be focussed on doing so. This means that they will not always agree with Scottish Autism and may sometimes, or even often, take positions which differ from or are opposed to those of Scottish Autism. Autistic DPOs may also criticise Scottish Autism, in private or in public. However, that does not mean that autistic DPOs and Scottish Autism cannot also work effectively together. The involvement of autistic DPOs should be seen as that of a ‘critical friend’. The independence, responsibilities and priorities of **each** organisation will need to be respected by the other. Recognising and acknowledging autistic DPOs as autonomous organisations with diverging priorities but also many common interests is vital to improving relations. If Scottish Autism wants to not only become inclusive in its governance but also to be seen to be inclusive, it must engage with not merely with autistic people as individuals, but also with our representative organisations – autistic DPOs.

Finally, it is important to note that, in the wider worlds of public policy, health and social care, it is hard enough to get the topic of autism sufficient time and attention. Organisations of all types in the autism world must work together, even when, at times, they may disagree.

4.2. Increasing autonomy of services rooted in their local communities

Wider community engagement should also include engaging with the communities Scottish Autism services operate in more broadly, developing the networks needed to support implementation of *recommendation 2.5*. This should include effective two-way communication between the Advocacy Officer (*recommendation 2.5*) and services about attitudes and issues which arise around inclusion in their local area. This recommendation has no cost implications beyond those already stated elsewhere.

The stakeholder engagement findings suggested an overall view that the benefits of Scottish Autism's pooled resources and economies of scale outweigh the risks of conflict of interest. Staff interviewed highlighted the risk of disconnection and making communications harder, if different parts of the organisation were separated. They also felt that current positives, such as supported individuals taking part in marketing and campaigning could be lost. These views were echoed in other stakeholder groups.

> *"When services have autonomy, they are able to make decisions that are specific to their needs and goals, rather than having to rely on a centralised decision-making process." U*

> *"I can see how it would create response to the local need, creativity in developing services, but another thought is it's about sharing what services are doing across the board, sharing learning amongst service managers and across the organisation." SAS*

However, we do recommend that this localisation focus should include increased cultural shift towards seeing centralised services, such as Information Technology, Human Resources, Health & Safety etc., as serving the needs of rather directing the operations of localised services embedded in their communities. Similarly, we recommend that the existing progress towards empowering frontline staff and increasing the autonomy of services should be continued and furthered. At the same time, it is essential that there is external monitoring and scrutiny of services to minimise the risk of 'closed cultures' developing (CQC 2022).

Feedback from some senior leaders suggested that this is already the case and no further shift is needed. However, this was contradicted by the experiences and views of other stakeholder groups:

> *"That's what I think. They lose sight of the autism. You make suggestions, "Oh, you can't do this because of X, Y and Z," or, "You can't do this because of X, Y and Z." Well, if you can't do, then these people are going to be institutionalised, because you can't get them out there. To me, the red tape is actually making their lives more…restricted." FM*

> *"Give them [direct care staff] Autonomy. Allow them to involve service users more directly in their support." SAS*

> *"[previous manager] was a can-do person, whereas the present service manager is a no-can-do … they used health and safety as an excuse not to do anything." FM*
>
> *"It seems to be the bigger things, like, for instance, at [SA service] we were needing … new equipment, and it seemed to just drag on, and it was, 'It's got to go here for approval and it's got to go here for funding.' But in the meantime, there was a big gap, and some of the supported individuals were finding it difficult because they liked the [equipment], it was time out, it was de-stressing, stuff like that, but it just seemed to take for absolute ever. And it wasn't like the individual was… It was more like a corporate or a business, kind of, sense, not, like, the individuals' needs, if you know what I mean." SAS*
>
> *"Staff work each day with their service users so they know them most." SAS*
>
> *"I think this is the very important people to listen to they have hands on experience of the real world and real problems." WA*
>
> *Example given of significant obstacles and red tape to overcome before staff would agree to video a supported individual during a seizure, despite that being obviously in the interests of the supported individual's healthcare. FM*

4.3. Ensuring autistic influence on service quality

Currently, what is seen as service quality, is influenced significantly by commissioners, and inspectors:

> *"And it wasn't like the individual was… It was more like a corporate or a business, kind of, sense, not, like, the individuals' needs, if you know what I mean." SAS*
>
> *"There are things we have to do from a governance perspective. We need the policies as care inspectorate etc say we must have them. We put things in as we are directed to use specific phrases. Things we might not want to do but don't necessarily have a choice in doing." SS*
>
> *"Barriers are processes, cost, time, resources, also cultural, going against the grain of society and what local authorities are asking for in commissioning guidelines and what they will pay (and pay for)." SS*

Other significant influences from health professionals and guardians, in the direction of risk aversion, were identified by stakeholders:

> *"Health professionals – lock people up – difficult. Health protection Scot guidance very medical model – focussed on deaths in care homes in lockdown. Risk averse." SS*
>
> *"Don't want it to be their fault leads to risk aversion. Have tried to be more positive last few years. 3-way conflict: person – guardian – staff." SS*

> *“Guardians disagreeing with individuals, SA can end up advocating on behalf of SIs and having discussions." SS*

Some of this influence is unavoidable in the care sector; however, some risk aversion is also driven by misunderstandings of the legal framework and misplaced fears about liability.

> *“From a policy perspective there are huge barriers. It’s something that it regularly talked about at CCPS or different forums. Their get out of jail free card is that they point to being tied to legislation.” SS*

This should and must be challenged. Autistic people, particularly those using Scottish Autism’s services, should have increased influence over what is seen as ‘quality’ in services and that this influence should then be used, alongside rights-based and legally literate dialogue, to challenge commissioners, inspectors, health professionals and guardians when tensions arise.

Consequently, we recommend that the Autistic Advisory panel should have significant input into the autism practice improvement framework and should review and make recommendations regarding what is viewed as ‘quality’ in services (as in *recommendation 1.3*). We recommend that, in doing so, the AAP draw on the National Autistic Taskforce’s Independent Guide to Quality Care for Autistic People (2019), alongside Scottish Autism’s internal materials. This recommendation has no cost implications beyond those already included above.

Some family members suggested that family members should also have increased influence over practice and priorities in services. Our recommendation is that advice of family members should be listened to carefully and with respect, but not automatically followed in all cases. It is important that staff are clear that respecting adult autonomy and supporting adults to take their own decisions should take priority over the views of family members:

> *“Rely less on family when it’s a decision the autistic person/person being supported should be making and could be making.” WA and former SAS*

4.4. Ensuring autistic influence in inspection and appraisal of services

We recommend that members of the AAP should participate on an equal basis with existing compliance or quality staff within Scottish Autism in planned and unannounced service inspections or visits and in appraisal or quality review processes.

> *“I think [increasing autonomy] is only a good idea if the services are held accountable for their standards … Perhaps [a] mystery shopper type thing to check the standard.” WA*

We also recommend the creation of a clear and easily accessible whistle-blowing route to the AAP for supported individuals, staff and family members. The AAP would not have any separate or additional investigatory powers, but would be empowered to speak up both internally (to the CEO or, if the nature of the concern made it appropriate, directly to the

Board) and, if necessary, externally, about serious concerns. Individuals should be encouraged to raise complaints and concerns directly with Scottish Autism in the first instance, whenever possible. However, it is good practice and an additional safeguard for there to be an additional route to an autistic-controlled forum as a 'last resort' option. The need for this is illustrated by following experience recounted by an autistic family member of a supported individual:

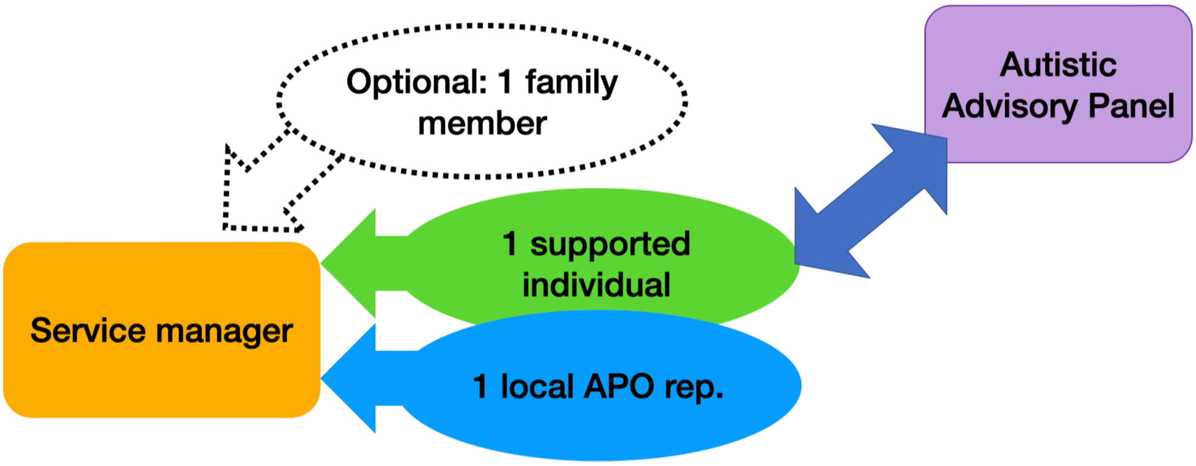
> *"That was basically just facts-drive, normal autistic communication. And they told me I was being disrespectful, and not to speak to them in that way. And then this has just slowly declined, and it's at the point where I'm not able to communicate with [Scottish Autism service], because they don't accept my method of communication." FM & WA*

This recommendation has no cost implications beyond those already stated elsewhere.

4.5. Manager reflection and coaching carried out by supported individuals and members of the wider autistic community

We recommend that, by the medium term, a significant proportion of reflection and coaching sessions for all service managers and regional managers should be carried out by a supported individual (for service managers, a supported individual using that service) supported by a representative from an autistic DPO or a member of the autistic community external to Scottish Autism (Figure 10). This could be an individual who has had training from the leadership development programme (*recommendation 2.7*). The role of the external autistic representative would be to support the supported individual in providing effective and constructive challenge and support to managers. It may also be appropriate to consider whether, in some cases, family members might also be able to contribute to this process as an additional member of the supervisory group (though this should not be a family member of the supported individual involved in that supervisory trio). In all cases, these supervisory

Figure 10: Appraisal model



pairs/trios would be overseen and supported by the Autistic Advisory Panel and the Centre for Practice Innovation (see *recommendation 4.6*).

This recommendation is projected to cost in £9,200pa[60], once fully implemented, although those costs would arise gradually over time as SA moves towards implementation.

This would build on some existing pockets of good practice.

> *"He gets up to service-level decisions, he likes to write reports on staff, for their annual reviews, and things like that. And it's really welcome." SAS describing current involvement of one supported individual*

> *"One of the things that we do have in our new annual appraisal, because they have actually just reviewed that for all staff, is that there is feedback within that from supported individuals and their families and/or other stakeholders." SAS*

The purpose of this recommendation is to increase the degree of influence of autistic people, particularly supported individuals, over service-level decision making and ensure that autistic perspectives can effectively counter-balance the prevailing commissioner, inspectorate and other influences over service-level decision making and the thinking and priorities of managers.

Concern regarding the involvement of individuals external to Scottish Autism can be addressed by collaboratively drawing up, in consultation with autistic DPOs who may be involved, an appropriate confidentiality and ethics agreement which those participating would need to sign in order to undertake the role.

4.6. Enhanced vertical communication between frontline staff and senior leadership

We recommend that Scottish Autism consider further steps to enhance communication between frontline care staff and those in senior leadership and governance positions. This was called for by multiple stakeholder groups:

> *"Staff work each day with their service users so they know them most." SAS*

> *"Leadership to know direct support staff better and have closer relationships with them." WA and former SAS*

> *"Provide better support for the support staff, ensure managers are listening to them and that they are passing on the views of the people they support." WA and SAS*

> *"Better mechanisms for communication within the organisation. Working groups or similar could be set up to feed back to board/senior management team. At the mo-*

---

[60] Based on 4 sessions per year costing £100 per session (£50 each for SI and DPO rep) for 17 service managers and 6 regional managers

> *ment information is fed up through the line management hierarchy but this doesn't work as managers choose what information to pass to the board/SMT." SAS*

> *"A bit of feedback from the employee and feedback from the supported individual as well back to staff that are a bit higher up in the organisation. I think that's something that's really important to get that right." SAS*

> *"I think we can influence the individual at ground level with their daily needs, their support plans, the setting them up for independent living, but I don't think we have much of a say further up the tree because, like, higher management, we can request and ask, but it seems to go to a manager and then they need to take it to their manager, then it needs to go to somebody else, and it's a very long process." SAS*

> *"Sometimes, how can I say, maybe the management is not listening to the staff." FM*

There were also several explicit mentions of the autistic employees forum, some of which mentioned a lack of effective communicative between that group and those in senior leadership and governance roles:

> *"There is an autistic employees forum but currently no communication between the forum and the board/SMT, regular meetings with the autistic employees forum might be helpful." WA & SAS*

We considered this carefully. We recommend that links should be developed between the autistic employees forum and the AAP. We recommend that the AAP be given an explicit responsibility to listen, engage and take on board suggestions from the Autistic employees forum.

We chose this option, rather than recommending direct communication between the autistic employees forum and the board or SLT, because it is important to ensure that the voices of supported individuals and the wider autistic community are heard clearly and any possibility of consultation with autistic employees being seen as sufficient or equivalent to consulting with the AAP is avoided.

We also recommend the creation of an anonymous route for staff to provide feedback to senior leadership which bypasses service and regional managers. Particular attention should be paid to situations where multiple staff have concerns. The route would need to be publicised within the organisation and trusted by staff, so that they can feel confident to raise whistleblowing concerns independently of their immediate managers:

> *"And the other thing as well, is that no matter what staff say, anyway, it's just put through, you know? … Then, staff leave because of it." FM*

These recommendations have no projected cost implications.

4.7. Locating Inclusive Governance staff in the Centre for Practice Innovation

We recommend an enhanced role for the Centre for Practice Innovation to support and further the Inclusive Governance agenda, although we do not expect this recommendation to have any cost implications beyond those already stated elsewhere. We propose that the Inclusive Governance staff and the Advocacy Officer needed to support the recommendations in this report should sit within the CPI, independently of operational staff. It is important, however, that communication between the CPI and frontline care staff is both effective and two-way:

> *"Services and CPI be much more connected and CPI to listen to staff more without assuming they are just complaining or less competent." WA and former SAS*

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. However, close co-ordination between the increased autistic influence recommended in this report and Scottish Autism's core practice development activity is essential to ensuring that the autistic influence recommended actually has a significant impact on practice. This will enable the CPI to become a knowledge hub and to amplify autistic voices by distributing that knowledge internally and externally.

Conclusions

What is the report grounded on? Whose views are influential?

Desk research

Early on in the project, we surveyed the academic literature, such as it is, on inclusive governance. We looked extensively at many case studies of organisations who have practices and policies designed to be inclusive. We developed topic-focussed case studies in some key areas, particularly service-level models, leadership development programmes and supported decision making. From these, many of our initial ideas formed and we have drawn extensively on the case studies in our recommendations.

Autistic perspectives and background knowledge

This project has been undertaken by a consortium consisting of two autistic DPOs, ARGH and AMASE, who democratically represent their autistic membership, and one autistic-led organisation, NAT, which focusses on providing autistic voice on issues concerning autistic people who are less able to advocate directly for themselves (but does not represent that group). All three organisations have many years of experience working with autistic people from all corners of the spectrum, a range of relevant public bodies, charities, care providers, other organisations and professionals. We have experience of directly supporting other autistic people, advocating for them and creating and inhabiting autistic space. Members of our team also have expertise in the legislative and policy context in Scotland and elsewhere. These perspectives have informed our recommendations and helped to ensure compatibility and an element of future-proofing with current and forthcoming law and policy.

Stakeholder engagement

Our autistic perspectives have been essential in providing credibility for the project with the wider autistic community. We have also benefitted from our connections in enabling us to gather views from the wider autistic community. Many SA staff and family members also seemed to strongly appreciate the relevance of our autistic perspectives and enthusiastically engaged with us. The voice of supported individuals has been of central importance to us throughout. Unfortunately, pandemic and staffing issues meant that our opportunities to meet directly with some supported individuals were fewer and less comprehensive than would have been ideal, and this had some impact on the information we could gather. Nevertheless, we were able to engage with supported individuals in a variety of ways and learned a great deal, not only from their spoken and other communicative responses to us, but also from observing their lives in services. All of our recommendations have been influenced extensively by the stakeholder engagement throughout the process.

We have also been supported throughout by the SLT and WLT, who have helped to ensure that our recommendations have been developed with an eye to existing structures and the practical contexts of Scottish Autism's work, whilst showing respect for the independence of the project throughout.

The development of 'inclusive governance' as a concept

The concept of 'inclusive governance' was not rigidly defined at the beginning of the project, and SA 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 particular decisions in a supported individual's life to broad strategic decisions made at board level. It became clear very early in the project that making an absolute distinction between board-level decisions and service-level decisions made little sense, and 'governance' could not be coherently conceived as relevant only 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. With this in mind *Recommendation 1: Representation in Governance* is about ensuring that autistic people are present and involved in decision making at senior levels of SA including sharing leadership with the CEO (who may also be autistic) and on the board. *Recommendation 1* also seeks to achieve both breadth (in the range and diversity of those included) and depth (in the level of involvement and degree of influence) of inclusion.

As well as inclusion of autistic people internal to SA, we also considered autistic people external to the organisation, and what role they might have. SA 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. The UNCRPD provides that disabled people, through their representative organisations, should be actively involved in any decisions affecting them (UNCRPD Article 4.3). While it would be inappropriate to give wholly external bodies and individuals concrete decision making power within Scottish Autism, it is vital to have some mechanisms for communication and influence to and from the wider autistic community. This is one of several functions that the Autistic Advisory Panel (AAP) (*Recommendation 1.3*) was conceived to realise, by recommending the wholly autistic AAP have a joint decision making role in a number of contexts. Historically there have been tensions between large autism charities and autistic DPOs but differences do not prevent co-operation where there is common ground (see discussion in *recommendation 4.1*). This project is an example. However, not everywhere in Scotland has local autistic DPOs that supported individuals can access and so we encourage SA to support their creation (*recommendation 4.1*).

After consultations, research and consideration, it was clear that an explicit development programme (*recommendations 2.1-2.4*) was necessary to develop the skills of autistic people broadly, but particularly supported individuals, so they can give effect to their will and preferences and further take part in governance in the areas their skill and interest permits, up to and including as far as the senior leadership and board. We realised that governance starts with control over an adult's day to day life and decisions. There is little point in proposing to 'involve' supported individuals in governance at an organisational level, if they have never experienced their own agency (making choices and taking decisions), let alone been effectively supported to direct their own lives in substantial ways, beyond mere choices of food or activity. 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 AAP would in part be comprised of autistic people from the wider community, will create connections between supported individuals and autistic people outside SA, and create a vital pocket of autistic space within Scottish Autism.

However, the lives of supported individuals are also constrained and impacted significantly by decisions made by staff, service managers and a regional, senior leadership and at board-level within SA. So, we concluded, further development opportunities are needed, ranging from greater participation and inclusion in society, communities (*recommendation 2.5*) and the wider autistic community (*recommendation 2.6*), to an explicit leadership programme (*recommendation 2.7*) to support individuals to develop the confidence and skills to undertake representation of others and leadership roles.

From many years of experience of directly employing our own support workers which exists amongst our team and in the wider autistic community, and from extensive comments from all stakeholder groups, it was abundantly clear to us that having the right staff and having direct influence and control over the recruitment and deployment of those staff is of critical importance to the degree to which supported individuals can effectively be included in governance of their own lives and of the services which support them. With this in mind we have made recommendations around values, recruitment and deployment of staff in *Recommendation 3*.

These recommendations too 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. There would be little point in autistic people being involved in decision making at higher levels of SA if we overlooked those people who have the biggest impact on the lives of supported individuals – the staff who work with them directly. 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.

Bringing our recommendations full circle, it became apparent that the involvement of the wider autistic community in Scottish Autism's governance needs to be a bidirectional process (*recommendation 4.1*) . Autistic DPOs can only be representative of the whole autistic spectrum if autistic people who live in and/or depend on formal care and support services are supported and encouraged by those services to participate in them. Scottish Autism also needs to become a better neighbour, acknowledging and respecting autistic DPOs as autonomous organisations, and offering support to, as well as listening to local autistic communities across Scotland.

Scottish Autism has already begun a shift in culture towards managers, leaders and staff at all levels being more accountable to supported individuals. Furthering this momentum is essential to enabling supported individuals to have real power and control in their services. Our recommendations around service autonomy and accountability build on this encouraging shift of focus (*recommendations 4.3 to 4.5*) . We recognise that SA must be considered as a whole and the concept of 'inclusive governance' applies at all levels. Our recommendations seek to strengthen vertical connections where they already exist and create them where they don't yet exist (for example *recommendation 4.6*) . These connections enable autistic people, who may find it challenging to navigate social hierarchies, to contribute to decision making and have significant influence at all levels throughout the organisation.

None of the recommendations in this report exists in a vacuum. Virtually all of the recommendations are necessarily interdependent. Consequently, our final recommendation to the Board of Scottish Autism is that the recommendations should be adopted as a cohesive whole, rather than taking a piecemeal approach. We can see the risk of a temptation to 'cherry-pick' those recommendations which seem most doable, less contentious and easiest to realise. However, we believe that each of our recommendations depends on other recommendations to work as intended. 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.

Summary list of the recommendations

1. **Representation in Governance**
    - 1.1. Data collection to monitor diversity
    - 1.2. Direct representation of autistic people (and others) on the Board
    - 1.3. Establishment of an Autistic Advisory Panel (AAP)
    - 1.4. Creation of a diversity taskforce
    - 1.5. Shared leadership – co-chairs alongside the CEO
    - 1.6. Inclusive strategic priority setting process
    - 1.7. Transparency in decision-making processes
2. **Developing agency and leadership**
    - 2.1. Development of supported decision-making for all Supported Individuals
    - 2.2. Involvement of Supported Individuals in ‘life admin’
    - 2.3. Universal high quality internet access in all services
    - 2.4. Modifying SA documentation to require inclusion of views of Supported Individuals throughout, including on restrictive practices
    - 2.5. Participation of Supported Individuals in their communities
    - 2.6. Participation of Supported Individuals in the wider autistic community
    - 2.7. Leadership Development Programme
3. **Values and recruitment**
    - 3.1. Review of SA values
    - 3.2. Language use policy
    - 3.3. Staff working for Supported Individuals including Staff/Supported Individual bubbles
    - 3.4. Prioritising autistic needs over organisational needs
    - 3.5. Diversity and neurodiversity in recruitment
    - 3.6. Strategies to enable raising staff pay
    - 3.7. Pilot of a self-directed support model
4. **Service Autonomy and Accountability**
    - 4.1. Services connected to, working with and offering services needed by their local autistic communities, including autistic DPOs
    - 4.2. Increasing autonomy of services rooted in their local communities
    - 4.3. Ensuring autistic influence on service quality via AAP input into autism practice framework

4.4. Ensuring autistic influence in inspection and appraisal of services (including whistleblowing route to AAP for autistic staff, family members, supported individuals)

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

4.6. Enhanced vertical communication between frontline staff and senior leadership

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

Costs overview

Ongoing costs

Element	Recommendation	Cost per annum
Inclusive Governance Officers	1.2	£97,000
Communication Support Workers	2.1	£66,000
Advocacy Officer	2.5	£40,000
Diversity Taskforce	1.4	£32,000
Leadership Development Programme	2.7	£25,000
Co-chairs	1.5	£14,000
Coaching/Mentoring of managers by SIs and autistic DPO reps	4.5	£9,200
Autistic advisory panel	1.3	£8,000
Supporting SIs to attend overnight autistic community events	2.6	£7,000
Support to encourage formation of autistic DPOs	2.6	£5,000
Support to facilitate the formation of Care Co-operatives	3.7	£5,000
Inclusive priority setting workshops	1.6	£750
Total per annum		**£308,950**

One-off costs

Element	Recommendation	Cost
Piloting 'Blue Sky' model based on SDS Option 1	3.7	£20,000
Modifying support plan documentation	2.4	£17,000
Inclusive Governance Officer (temporary) and start up	1.2	£16,300
Values and Language use workshops	3.1 & 3.2	£6,000
Autistic advisory panel (1st year enhancement)	1.3	£2,500
Workshops with practice advisers about Supported Decision Making and Agency	2.1	£2,500
Total		**£64,300**

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finally, and particularly, to **Dorry McLaughlin**, for her openness to challenge and autistic perspectives and commitment to the project.

NAT
National Autistic Taskforce
Bolder Voices, Better Practice

AMASE
Autistic Mutual Aid Society Edinburgh
Helping autistic people to help each other.

ARGH
Autism Rights Group Highland

References

Atkinson, H., Jayes, M., & Volkmer, A. (2023). *Supported Decision-Making Toolkit for People with Communication Difficulties*. National Mental Capacity Forum & Essex Autonomy Project. https://autonomy.essex.ac.uk/wp-content/uploads/2023/01/SLT-SDM-Toolkit81.pdf

Bell, K., & Reed, M. (2021). The tree of participation: a new model for inclusive decision-making. *Community Development Journal*, *bsab018*. https://doi.org/https://doi.org/10.1093/cdj/bsab018

Brown, W. (2000). The prevalence of inclusive governance practices in nonprofit organizations and implications for practice. In *Nonprofit Management and Leadership*.

Care Quality Commission (CQC). (2022). *How CQC identifies and responds to closed cultures*. Retrieved from https://www.cqc.org.uk/guidance-providers/all-services/how-cqc-identifies-responds-closed-cultures

Colenbrander, A., Argyrou, A., Lambooy, T., & Blomme, R. (2017). Inclusive governance in social enterprises in the Netherlands – a case study. *Annals of Public and Cooperative Economics*, *88*(4).

Davies, H. T. O., Nutley, S. M., & Mannion, R. (2000). Organisational culture and quality of health care. *BMJ Quality & Safety*, *9*, 111-119. https://doi.org/http://dx.doi.org/10.1136/qhc.9.2.111

Dekker, M. (2015). *A history of early autistic space* Autscape, Giggleswick, Settle, UK.

Dunn, Y. (2020). *Social work with autistic people: Essential knowledge, skills and law for working with children and adults*. Jessica Kingsley.

Employment Autism. (2023). *Alternatives to an interview*. Retrieved 24.02.23 from https://www.employmentautism.org.uk/faqs/alternatives-to-an-interview

Gleeson, B., & Kearns, R. (2001). Remoralising landscapes of care. *Environment and Planning D: Society and Space*, *19*, 61-80.

Hindberg, L. (2016). Investigating inclusive governance in work integration social enterprise.

Long, J. (2020). Reflective Practitioners and Participant Observers in Autism Services: Managing Knowledge in UK Social Care. In *Anthropology in Action*. https://doi.org/https://doi.org/10.3167/aia.2020.270104

Long, J., Panese, J., Ferguson, J., Hamill, M., & Miller, J. (2017). Enabling voice and participation in autism services: using practitioner research to develop inclusive practice. *Good Autism Practice*, *18*(2).

Maras, K., Norris, J., Nicholson, J., Heasman, B., Remington, A., & Crane, L. (2020). Ameliorating the disadvantage for autistic job seekers: An initial evaluation of adapted employment interview questions. Retrieved 24.02.23, from

Murray, D., & Aspinall, A. (2006). *Getting IT: Using information technology to empower people with communication difficulties*. Jessica Kingsley Publishers.

National Autistic Taskforce. (2019). *An independent guide to quality care for autistic people* https://nationalautistictaskforce.org.uk/wp-content/uploads/RC791_NAT_Guide_to_Quality_Online.pdf

Ottmann, G., Laragy, C., & Damonze, G. (2008). Consumer Participation in Designing Community Based Consumer-Directed Disability Care: Lessons from a Participatory Action Research-Inspired Project. *Systemic Practice and Action Research*, *22*, 31–44. https://doi.org/10.1007/s11213-008-9110-z

Reed, M., Vella, S., Challies, E., de Vente, J., Frewer, L., Hohenwallner-Ries, D., Huber, T., Neumann, R., Oughton, E., sidoli del ceno, J., & van Delden, H. (2017). A theory of participation: What makes stakeholder and public engagement in environmental management work? *Restoration Ecology*, *26*. https://doi.org/10.1111/rec.12541

Richter, R. (2018). The Janus Face of Participatory Governance: How Inclusive Governance Benefits and Limits the Social Innovativeness of Social Enterprises. *Journal of Entrepreneurial and Organizational Diversity*, *7*(1), 61-87. https://ssrn.com/abstract=3251981

Ryan, J. (2007). Inclusive Leadership: A Review. http://fcis.oise.utoronto.ca/~jryan/pub_files/incleadership.pdf

Scottish Autism. (2017a). *Service User Experience Survey 2016-17, Full Report*.

Scottish Autism. (2017b). Voice, Participation and Involvement in Autism Services: an evidence informed guide.

Scottish Government. (2016). *A Fairer Scotland for Disabled People*. Retrieved from https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2016/12/fairer-scotland-disabled-people-delivery-plan-2021-united-nations-convention/documents/00510948-pdf/00510948-pdf/govscot%3Adocument/00510948.pdf

Scottish Government. (2021). *Adult social care: independent review (Feeley Report)*. Retrieved from https://www.gov.scot/publications/independent-review-adult-social-care-scotland/

Scottish Mental Health Law Review. (2022). *Final Report*. https://cms.mentalhealthlawreview.scot/wp-content/uploads/2022/09/SMHLR-FINAL-Report-.pdf

The George Washington University. (2020). Equity vs. Equality: What’s the Difference? https://onlinepublichealth.gwu.edu/resources/equity-vs-equality/

Convention on the Rights of Persons with Disabilities, 2515 3-3 (2006).

Williams, P. (2021). The cold comfort of safeguarding. *Community Living*, *35*(1).

Appendix A: Organisational case studies

Appendix A.1: Case study - British Deaf Association

<table>
<tr><td>Name of organisation</td><td colspan="2">British Deaf Association</td></tr>
<tr><td>Link to short summary</td><td colspan="2">https://docs.google.com/document/d/1IVRu9moHXULQITrmCGhl_KzFtQIfwjAG/edit?usp=sharing&ouid=107661633502048802109&rtpof=true&sd=true</td></tr>
<tr><td>Description of organisation</td><td colspan="2">Formed by group of deaf men in 1890 (originally as BDDA). Run by Deaf people for Deaf people. To provide community services for Deaf people and promote its beliefs publicly, especially its commitment to Total Communication. Now purpose is to develop greater understanding throughout the UK of what deafness means, and to fundraise for its community development and campaigning programmes. Stands for Equality, Access and Freedom of Choice.</td></tr>
<tr><td>Comparability of organisation to Scottish Autism (similarities and differences)</td><td>Similarities
• Both charitable companies
• Board size 12 (SA) v 8 (BDA)
• Both are both a service provider and a lobbying charity</td><td>Differences
• Sensory disability v Autism
• SA formed by parents, BDA formed by deaf people
• BDA’s services are limited e.g. advocacy, mentoring and they don’t run care provider services unlike SA
• BDA Income £1.5m Expend £1.4m
• SA Income £31.1m Expend £30.1m</td></tr>
<tr><td>Who governs or sets the strategic direction of the organisation as a whole and how?</td><td colspan="2">Entirely voluntary until 1972 and then appointed paid executives. membership organisation – individual members 16+ resident in UK (don’t have to be Deaf)
Registered charity (charitable company)
From Companies House – has 8 current directors, max board size 11 (8 elected + 3 co-opted). Each member has a vote in electing Trustees.
Intersectionality a possible weakness (though hard to tell).
Trustees serve 3 year terms and can stand for further 3 year terms with no limit (except Chair max service 9 years).</td></tr>
<tr><td>What forms of inclusion does organisation use?</td><td colspan="2">Article 12.2.1 “All nominees for election or co-option as chair or trustee must be Deaf”
So a full DPO at 100%
Despite extensive efforts, we have unfortunately been unable to arrange a meeting with the BDA to seek further information. We would have liked to explore:
• The involvement/representation of Deaf people at all levels of the BDA, including amongst paid staff/volunteers and in the recruitment of paid staff.
• The involvement/representation of Deaf people who use your services in the decision-making and management of those services.
• Intersectionality and the involvement/representation of a diverse range of Deaf people in terms of age, ethnicity and other identities in governance and management at all levels.
• The involvement/representation of hearing family members of Deaf people.</td></tr>
<tr><td>What are the advantages of</td><td colspan="2">• Governance is explicitly and entirely in the hands of disabled people themselves.</td></tr>
</table>

this model for inclusivity of governance?	• Specification in the articles means that governance cannot become less inclusive over time
Other advantages	• Really clear declaration of who has the power
What are the disadvantages of this model for inclusivity of governance?	• Unclear what impact that does/doesn't have on the inclusiveness of the board across intersectional identities e.g. ethnicity, age etc. • Could potentially exclude some stakeholders, such as hearing family members of Deaf people. • Doesn't directly impact on governance at lower levels, although likely to indirectly do so.
Other disadvantages	• Could make trustee recruitment challenging and possibly jeopardise sustainability of board skills (simply on the basis of excluding up to 99% of the population).
Could this model be transferred to Scottish Autism? If so, how?	• Autism is more complex and problematic to define than being Deaf. • Potential issues with exclusion either way when defining autistic on the basis of formal diagnosis (excludes those who don't have/can't get) or on the basis of self-identification (excludes those who do not wish to identify either way). • Would also exclude non-autistic family members and professionals, potentially excluding those perspectives and expertise. • Would be a really huge change requiring 75% majority to change articles.

Appendix A.2: Case Study – Glasgow Disability Alliance

<table>
<tr><td>Name of organisation</td><td colspan="2">Glasgow Disability Alliance</td></tr>
<tr><td>Link to short summary</td><td colspan="2">https://docs.google.com/document/d/1yr8cBKhK7d-WyO_kPGvGYn56sz6S529-/edit?usp=sharing&ouid=107661633502048802109&rtpof=true&sd=true</td></tr>
<tr><td>Description of organisation</td><td colspan="2">Influential broad ranging pan disability DPO. 5,000+ members across Greater Glasgow.
Engage in a range of activities, from service provision through to lobbying the Scottish government.
Members can be individuals (predominantly), with some DPO membership.
Represents the Glasgow DPO Network (Deaf Scotland, Vox Scotland, People First, Glasgow Centre for Inclusive Living, Flourish House, Headway Glasgow, and Mental Health Network (Greater Glasgow)).

FYE 31.3.2020 Income/Expenditure: £1.22m/£1.03m</td></tr>
<tr><td>Comparability of organisation to Scottish Autism (similarities and differences)</td><td>Similarities
• Both campaigning organisations
• Both charitable companies
• Both seek to represent autistic people</td><td>Differences
• SA is large service provider, GDA provides a few limited services, mostly telephone support and some peer mentoring.
• GDA is membership org 5000+ members, SA Non-membership organisations.
• Different in size. GDA 31.3FTE SA 813.92FTE.
• GDA Income £1.22m, Expend £1.03m. SA Income £31.1m Expend £30.1m.
SA Autism specific, GDA pan-disability.</td></tr>
<tr><td>Who governs or sets the strategic direction of the organisation as a whole and how?</td><td colspan="2">Have 4 classes of membership: Individual, Organisational, Associate, Junior. Only Individual and Organisational have voting rights.
Individual: Disabled persons 16+ (either resident, in employment, or volunteers in Glasgow).

Organisational: Any community or 3rd Sector DPO which operates in Glasgow and is incorporated; or an individual nominated by a DPO which operates in Glasgow and is an unincorporated body.

The board (11 members) is composed of Member Directors and Co-opted members (max 4). Only Individual and Organisational Members can be Member Directors. Directors are nominated by and voted for, by Individual and Organisational members only. Individual members can nominate themselves to the Board. Elections take place at the AGM. Co-option happens ad-hoc, and they retire and must be re-considered etc., every third AGM. Elected directors serve a term of 3 years, upon</td></tr>
</table>

	which they retire and must be re-elected. There is no limit on the number of consecutive terms an Elected or Co-opted Director may be a member of the Board. This is somewhat potentially stifling and prone to becoming a revolving door, and not in line with what would be considered best practice. They have a minimum of 4 Board Officers (Convenor, Vice-convenor, Treasurer, and Vice-Treasurer). Associate and junior members can attend and speak at General Meetings only, so non-disabled influence, in theory is minimal.
What forms of inclusion does organisation use?	Member Led – controlled by full voting members. Pursues a range of activities, all of which are member led, ranging from peer support to training. Also provides some support services which are run by and for disabled people. Promotes active participation in consultations and services related to disabled peoples' issues (including promoting supported decision making) and as directed by members (do regular surveys of members, for example). Produce all reports, consultations etc in Easy Read and other formats as necessary.
Who makes decisions at middle management/service governance level and how?	As above.
Who makes decisions at a day to day/individual care level and how?	Strong promotor and supporter of SDS, especially full control and independent living for disabled people genuinely in control of their own lives and support.
What are the advantages of this model for inclusivity of governance?	Fully controlled by disabled people. Clear where the power is.
Other advantages	
What are the disadvantages of this model for inclusivity of governance?	
Other disadvantages	
Could this model be transferred to Scottish Autism? If so, how?	Challenges around the key differences i.e., membership and GDA being limited in service provision compared to SA. Member participation in service delivery, as well as focusing on member led activities. They seem to have an inclusive approach that covers the breadth of their activities. This has potential in terms of SA recruitment and HR practices being genuinely inclusive. Findings from their 'Future Visions' programme include that it would be helpful if social care more widely recognised that people need to boost their confidence and skills in order to "Dare to Dream" and to understand that they might have choices. This requires

	learning, capacity building, peer support and role models. Applied to SA this could tie in with findings from Leadership Development and Supported Decision-making case studies about the need to provide some sort of programme to develop skills, confidence and offer practice at decision-making and autonomy, recognising that many of the autistic people SA support may never have even learned the concept that they **can** make decisions for themselves!

*Appendix A.3: Case Study – Learning Disability England (LDE)**

*Some of the information here was given in confidence by LDE chief executive. Must not be distributed beyond project team and SA senior leadership without checking. Must not be published without explicit permission from LDE.

Name of organisation	Learning Disability England	
Link to short summary	https://docs.google.com/document/d/1LtYVdC-h152oXa-kz_rEC4F1ZnTVZkYT/edit?usp=sharing&ouid=107661633502048802109&rtpof=true&sd=true	
Description of organisation	Membership organisation requiring members to sign up to values, **founded in 2015, registered charity.** Self-advocate Gary Bourlet set up a national self-advocacy organisation called People First England, supported by Housing & Support Alliance, a charity promoting good support and housing for people with learning disabilities. those two organisations brought some like-minded people (self-advocates, families, organisations) together to create a movement for change.	
Comparability of organisation to Scottish Autism (similarities and differences)	**Similarities** • Both campaigning organisations. • Both charitable companies. • Both seek to represent autistic people with LD.	**Differences** • SA is large service provider, LDE does not provide services – apart from information. • LDE is membership org, 623 individual members, 136 organisational (inc small group) member, reach of approx. 11,000 through newsletter SA Non-membership organisation. • Very different in size. LDE 7 staff equivalent to 5 full time staff SA 973 and 813.92FTE. • LDE Income £400k, Expend £350k. SA Income £31.1m Expend £30.1m. • SA Autism specific, LDE LD specific.
Who governs or sets the strategic direction of the organisation as a whole and how?	Every member is equal, whether it is a big support provider or a self advocate, with one vote each for decisions and elections. Board of Trustees (6-8 trustees) chosen by the Representative Body. They advertise and recruit for Trustees but the Representative Body decides who is recommended to the members and then members elect. The Representative Body is an even split of 4 self-advocate reps, 4 families and friends reps, and 4 organisational reps (LDE currently has 100+ service provider members). There are 3 Co-Chairs, one for each membership 'voice'. Any member can put themselves forward to be on the Representative Body, and all members can vote. Length of terms – no information. Transparency in decision-making – nothing publicly available. Numbers – currently 18 (trustees and rep body combined)	

	Small staff team, largely administrative, so balance of power strongly with governance (Trustees and Representative Body) rather than executive. Chief executive works routinely with two co-chairs. CE clear that she doesn't represent the organisation on her own. Has process which, unless something has already been signed off as a policy position/priority, involves going to co-chairs and seeing what they think before responding as an organisation. She actively puts effort into always doing that – even when obvious – to avoid slipping into 'speaking for'. This requires a significant shift in attitude and behaviour.
What forms of inclusion does organisation use?	Each member also has an equal vote on who should represent them on LDE's Representative Body. The Representative Body acts on the behalf of members and makes important decisions about what LDE says and does. The Representative Body also plays a key role in deciding whether a member should leave or not when things go wrong. Values: • Rights • Choice • Inclusion • Independence Link to aims and values document: https://www.learningdisabilityengland.org.uk/wp-content/uploads/2016/08/Our-aims-and-values.pdf "We have spokespeople because Learning Disability England staff do not speak for people with learning disabilities. We believe people with learning disabilities and family members speaking for themselves will change the way society sees them." In Autumn 2020, LDE commissioned a 'governance support programme' – report at https://drive.google.com/file/d/1-lMtGSySNaPYlK58LYw5r0ijnWgyEqo6/view?usp=sharing Consulted trustees and members of the rep body and confirmed those involved think current model is right for LDE. They have an action plan to strengthen the model by investing in support mechanisms and ways of working by: • Providing training for the Representative Body in what they should do in their roles and how to involve more people across the country. • Making sure there are paid staff whose role is to support all the volunteers, the Representative Body, Trustees and Members. • Give information that explains what people's jobs are and what they do - the paid staff and volunteers. This will help people know who to contact and who makes what decisions. • Provide information or a detailed guide that explains how to deal with disagreements and difficult situations. • Plan how LDE will ensure that the 2022 elections lead to a wider range of people in the Representative Body - in terms of e.g. culture and lived experience.

- Use the buddy system to help new Representative Body members or Trustees settle in.
- Make it easier to find or use accessible information that explains the role of a Trustee and Rep Body member. This will help new people understand what they should and should not do in their roles.

Learning from 2020 Representative Body elections informed 2022 elections. Refined system by using departing Representative Body members as a shortlisting panel to shortlist applicants (because too many people stood). Have also clarified candidate info to require some experience of representing other people. Targeted recruitment by explicitly talking to members connected to people with high support needs and those from under-represented ethnic backgrounds.

Have a buddy system which pairs people on the Representative Body. Previously most pairs were within the group represented (e.g. 2 self-advocates, 2 service provider reps, 2 parents) but feedback has suggested mixing this up. (n.b. the danger of mixing this up is power imbalance and undue influence within the pairs). Buddies support induction of new members. Buddies read papers together in advance of meetings and discuss.

Avoid traditional meetings. Do have papers but routinely produce accessible versions ensuring people understand the strategic level issues (i.e., steering the ship). Often use ‘workshop’ style e.g. talk in pairs/small groups and then share thoughts, have a presentation rather than just referring to papers.

Accepting people’s accessibility needs and ways of doing things as a given. Requires significant shift in mindset and behaviour. One useful principle – ‘not just one way’ e.g. 2020 Representative Body elections required candidates to make a film, 2022 elections required making a film **and** simple written information, to maximise accessibility across different needs (this seems particularly important for addressing the tension between LD and autistic needs when they can diverge e.g. use of chat in meetings, which can be essential for autistics but inaccessible for some people with LD).

Relationship between Representative Body and trustees is that the Representative Body set strategic priorities e.g. say they think this should be a priority, then trustees look at how to resource this.

Intentionally remove the hierarchy of knowledge. Routinely provide contextual information and do not expect people to know. This requires self-awareness because it is easy to forget context that you are aware of that colleagues aren’t. Parity of esteem for lived experience knowledge. Real honesty about who can or should do what. Requires transparency to build trust. ‘Moments of beauty’ occur when everyone’s knowledge makes a contribution e.g. ‘Stay out late’ campaign – people were talking about how people with LD should have the right to ask support people to let them stay out late. Self-advocate rep said ‘Why should they have to ask?’ Requires slowing things down and checking in. Recognising that no-one has all the context and most non-disabled trustees don’t understand everything and take a lot on trust. Representative Body members and trustees need to get the ‘big picture’ stuff but don’t necessarily

	need to know/understand all the fine detail e.g. ‘If we do this, we can’t afford to do that as well’ but not follow all the figures. (I.e. they are steering the ship but can employ someone to fix engines!)
Who makes decisions at middle management/ service governance level and how?	Some project work e.g. Equal Treatment Project involves forming partnerships with other organisations representing diverse groups, which then improves intersectional awareness.
Who makes decisions at a day to day/individual care level and how?	Set policies and strategic priorities which enable chief exec and others to make some day-to-day decisions without extreme micromanagement. Most day-to-day decision making by consensus. LDE’s chief executive says “It’s not that hard. People who don’t want to give up power make it hard.” It requires a mindset that both big and small decisions need to be taken inclusively.
What are the advantages of this model for inclusivity of governance?	One member, one vote and the Representative Body approach are interesting. One member, one vote is an interesting model of how to redress power imbalance between individual disabled people and large organisations and the Representative Body choosing the Board of Trustees is an interesting shift in the balance of power and contrasts with Mencap’s voices council (see Appendix 1D).
Other advantages	LDE say making the documents accessible is not the hard bit! Getting people to share power is.
What are the disadvantages of this model for inclusivity of governance?	Constant tension between doing things in a way which is genuinely inclusive and shares power vs. efficiency in making a difference. Can slow decision making. Actually achieving and maintaining shared power is a constant battle. LDE’s model actually gives the chief executive more power in some ways, so depends on having a CE who is a facilitator-type of leader, not a command and control type.
Other disadvantages	
Could this model be transferred to Scottish Autism? If so, how?	LDE doesn’t have the tension between campaigning/advocacy and service provision. Service provision tends to produce very different mindset and requires(?) prompt decision-making/competitiveness. Also requires lots of contextual knowledge (but can that knowledge be made accessible – certainly at the big picture level?) Needs careful thinking about the impact on decision making. Governance vs Management line – who makes what decisions exactly? LDE is a membership org and many of its structures depend on that model. However, there is some transferability. The Representative Body choosing the trustees is potentially transferrable (though bear in mind that LDE’s Rep Body is not actually user-led because of their 1/3 orgs, 1/3 parents, 1/3 self-advocates model). Is the co-chairs model transferrable? How feasible is it in terms of decision making at the scale of SA with all the service provision for a Chief Exec to consult with co-chairs over every decision? Not sure, but may be possible to

	adapt model in some workable way e.g. regular meetings between CE and co-chairs to agree priorities/policies at more day-to-day level than the trustees (or any representative body). Might be particularly workable in relation to policy/advocacy rather than service provision aspects of SA – i.e. when 'speaking for/on behalf of' autistic people. What about at a lower level e.g. service managers having 'co-chairs' from within their service, or at least regular meetings with to set priorities? But how do we prevent this being tokenistic? (Requires radical change of mindset to see Supported Individuals as 'colleagues'.) Intentionally removing the hierarchy of knowledge is definitely transferrable but would require huge culture shift. Requires some paid staff whose job it is to make things accessible and support representatives as needed to enable them to effectively share power without being disadvantaged. This takes willingness to spend some money on this. Buddying and meeting modification are also both transferrable, certainly to the board and potentially to middle management/service-level structures. BUT achieving meeting modifications which are accessible to all is trickier – processing speed is particularly difficult to adapt for. The pre-meeting buddies reading/discussing papers together is crucial for this.

Appendix A.4: Full Case Study – Mencap

<table>
<tr><td>Name of organisation</td><td colspan="2">Mencap</td></tr>
<tr><td>Link to short summary</td><td colspan="2"><i>https://docs.google.com/document/d/1IaEi5jzYsh_aYBo1WEyGS_eemh7oj7NR/edit?usp=sharing&ouid=107661633502048802109&rtpof=true&sd=true</i></td></tr>
<tr><td>Description of organisation</td><td colspan="2">Very large. £220m income, £212m expenditure last year.
There are many local Mencap charities - they are linked to central Royal Mencap Society in some way.
Charitable objects: Advancing the health, education and the well-being of people with a learning disability and their families and carers (the beneficiaries) by providing, procuring or facilitating care, services and facilities and to advance equality and diversity for people with a learning disability.

They offer: Social Care Services, work support, social housing via associated charity, respite care, helpline, supported living, and more.

They support Positive Behaviour Support (PBS).</td></tr>
<tr><td>Comparability of organisation to Scottish Autism (similarities and differences)</td><td>Similarities
• Both large service providers
• Both campaigning organisations
• Both charitable companies
• Both seek to represent autistic people with LD</td><td>Differences
• Mencap is membership organisation via local affiliated associations, SA non-membership organisation
• Mencap about 5 times larger - 5,659 FTE inc. 207 staff with LD, SA 973 and 813.92FTE
• Mencap larger Income £220m, Expend £212m. SA Income £31.1m Expend £30.1m
• SA Autism specific, Mencap LD specific
SA Scotland, Mencap UK wide</td></tr>
<tr><td>Who governs or sets the strategic direction of the organisation as a whole and how?</td><td colspan="2">Trustee Board is separate from Executive Team.
13 Voluntary trustees. 4 year term, may serve 2 terms total.
No requirement in governing document about LD status. Policy that at least half of the trustees should have ‘experience of LD’, either personally or in their work – so no differentiation between adults with LD, family members, professionals. Currently have 1 trustee with an LD.</td></tr>
<tr><td>What forms of inclusion does organisation use?</td><td colspan="2">1. Voices Council (formerly LD Advisory Forum):
Webpage: https://www.mencap.org.uk/about-us/voices-council
Formed in 2018. It has a structure - Chair and Vice chair are both paid roles. Total 9 people with learning disabilities. No clear information on process of selection/recruitment publicly available.
Trustee Board decides if it exists or not. Currently, they will continue it until 2022.
Consultative/advisory only. Meet directly with the board 6 times a year.</td></tr>
</table>

	1. Appears to be **one LD member on Trustee Board** at present but no guarantee of even this. 2. **Our Voices** and **Include Me** group. Members have LD or are autistic. No further info about these on website nor how they interact with Mencap. 3. **PMLD Involve Me** project. Related to decision-making. They produced some booklets, but don't seem to be written by LD people. Here is page with PDFs at the bottom: https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmld/pmld-involve-me
Who makes decisions at middle management/service governance level and how?	Paid staff (most non-disabled)
Who makes decisions at a day to day/individual care level and how?	No information available
What are the advantages of this model for inclusivity of governance?	None
Other advantages	
What are the disadvantages of this model for inclusivity of governance?	Appears heavily tokenistic. All the power is with parents/professionals
Other disadvantages	
Could this model be transferred to Scottish Autism? If so, how?	Similar to current SA

Appendix B: Thematic case studies

Appendix B.1: Governance and leadership training programmes

Names of organisations considered	Disability Rights UK Leadership Academy (DRUK)
	The Sylvia Rodger Academy (Australia) (SRA)
Description of topic in more depth. (What is it we are looking at and how is it relevant to inclusive governance?)	Providing training/support to improve the ability/confidence of individuals to become involved in leadership/governance roles (DRUK) – pan-disability, disabled-led
	An initiative of the Autism CRC, the Sylvia Rodger Academy delivers nationwide programs aimed at empowering autistic adults. Programs are in the areas of leadership, corporate governance and research co-production. (SRA) Autism specific. Autistic-majority run within a non-autistic-led organisation.
Descriptions of how this is done in these organisations. (How are they doing it?)	Disability Rights UK's Leadership Academy is a career development programme which trains disabled people to take on leadership/governance roles within their organisations. The programme is run by Disability Rights UK as a 'recognised centre' of the Institute of Leadership and Management – ILM. For people in employment living with a disability or health condition. Each year since 2015 a range of employers have supported their disabled employees to attend the programme. More than 80% of participants have gone on to achieve new promotion opportunities, joined committees or disability networks and reported an increase in their confidence, motivation and self-belief. The programme challenges limiting beliefs, real and perceived barriers, and has the ultimate aim of removing obstacles for their career development aspirations. **How participants are selected** Nominated by their organisation and/or self-selecting within employer organisations. Very occasionally self-funding individuals. Max 20 participants per course programme. **The length, time commitment and costs of the programme** £1600 + VAT per delegate standard programme. In person, 4 site-based days (non-consecutive). Virtually, 13 x 2-3 hour sessions across Feb-July. Plus a graduation ½ day in Sept. Work-based project in 4-person teams. And mentoring (8 x 1 hour sessions with a mentor spaced between training sessions) **The content of any training/materials provided** Session titles:

	1. Background to DRUK & LAP, The Programme, Background to Mentoring, motivational alumni speaker. 2. Background to Disability, Reasonable Adjustments within the UK. 3. Leading Through Your Disability (Leadership and Characteristics) 4. Leading from within (Emotional Intelligence, Unconscious Bias, Focus, Productivity, Pacing) 5. Leading Authentically (purpose, values, capabilities, connection, teams) 6. Situational Leadership 7. Intentional Leadership: Enjoyment and motivation within personal behaviours 8. Intentional Leadership: Understanding Trust and gaining Community 9. Intentional Leadership: Rewards and resources. 10. The Changing World and what this means for Leadership / Introduction to Project 11. Unfreezing a difficult climate / culture. 12. Moving people towards a goal. 13. Refreeze: Systemise the change and culture. **The format of the learning/support** Virtual training sessions (Speaker + interactive), project work in teams and mentoring. **Any other information available about how the programme works** See accompanying docs in case studies folder **Any evaluative data about the impact of the programme on increasing the involvement of disabled people in leadership/governance** Not statistical data, but testimonials e.g. “The Disability Rights UK Leadership Academy Programme was professionally run and had a relaxed atmosphere. The speaker was excellent, and obviously had extensive and varied experience. Topics such as professional confrontation, planning, organisation and prioritisation will help me in my career development for years to come. The workshops taught me that I have to work fluidly, alongside my disability, working harder on prioritising producing outcomes when my disability hinders me, by working cleverly. I don’t have to pretend I’m not disabled, that it is part of me. I feel more empowered to be open about my disability, which is a diagnosis that can often be stigmatised. The course has given me confidence in the abilities I do have, and has given me good advice on how to use them to make the most impact.

An initiative of the Autism CRC, the Sylvia Rodger Academy delivers nationwide programs aimed at empowering autistic adults. Our Governance Program is Australia's first training program in corporate governance for autistic adults, enabling leadership in decision-making and capturing the strength of diverse thinking to make a broader contribution to the corporate and government sectors. As with all of our Programs, it was co-designed and delivered with autistic adults. There are number of training and development components to enable participants to have both knowledge and experience in corporate governance.

As of 2020, the Sylvia Rodger Academy has established and delivered three Programs – the Research Program (2015, 2017, 2020), the Future Leaders Program (2018, 2019, 2020) and the Governance Program (2019).' Evaluation report - https://drive.google.com/file/d/1gWQ5kuHx2RE2l1wkuAbwNrY0pVyXNBNG/view?usp=sharing

The objectives of the Program were to:

- increase the engagement of autistic adults in organisational decision-making
- establish a national network of autistic people with governance skills, enabling them to share experiences and opportunities
- provide participants with practical knowledge and experience and develop skills
- improve participants' understanding of governance structures and different organisational models.

How participants are selected

Following an open application process, 15 applications were accepted from autistic adults aged 25 to 59 to participate in the 2019 Program, with 14 of those applicants completing the program.

The length, time commitment and costs of the programme

The content of any training/materials provided

Five online training modules delivered in a custom built e-learning platform on the topics of:

- Introduction to Corporate Governance
- Director's Duties and Responsibilities
- Risk and Strategy
- Financial Literacy
- Board Effectiveness.

The format of the learning/support

Program consisted of:

5 e-learning courses - The modules included topic-related content, videos and activities. Through the completion of the modules, participants were encouraged to share their ideas and completed activities with other Program participants through the custom built e-learning platform discussion forum. Engagement and learning was supported by running fortnightly online sessions hosted by members of the Project Team, with a total of five online sessions held.

3.5 day residential workshop - The workshop extended the theory learned in the online modules and enabled participants to learn about, and practice, corporate governance skills. Participants engaged in a range of activities including: mock board meetings; sessions on topics such as financial literacy, risk, chairing meetings and strategic planning, and; question and answer panels with current and former board directors.

Observation of board meetings in organisation network - of one or two board meetings with organisations in Autism CRC's network. The placements provided a practical opportunity for participants to observe a board in action and to further develop their corporate governance skills. Participants were also provided with a reflection task to complete after their board observation to consolidate their learning. Participants could complete these via written submission or in virtual meetings with up to five other participants enabling them to hear about different experiences.

Any other information available about how the programme works
To ensure the Program met these objectives, development and delivery was undertaken by a majority autistic Project Team, with four of the seven Project Team members identifying as autistic.
To ensure the Program was relevant to corporate governance, five of the seven members had corporate governance experience and were either current or former company directors.

To support participants' wellbeing throughout the Program, a Preparation and Wellbeing Toolkit was developed. This enabled participants to explore the components of the Program and a) plan for how to reduce concerns and prepare themselves, and b) develop a crisis plan to be used by themselves and/or residential workshop support staff.

Following the completion of the Governance Program, participants have kept in touch with each other and Project Team members via email and a private Facebook group. Participants have posted and pursued board opportunities as well as personal triumphs, which would indicate that the second objective - establish a national network of autistic people with governance skills, enabling them to share experiences and opportunities – has also been met.

	Any evaluative data about the impact of the programme on increasing the involvement of disabled people in leadership/governance Survey data (7-10 participants from program) – Mostly ok-excellent about program content. Testimonials e.g. “Since the Governance Program, I now sit on two committees, one council and have just applied for my first board appointment.” Increased confidence significant theme in comments. Participants mostly saw wellbeing toolkit as unnecessary for them personally (had prior experience/knew how to cope etc.). Very positive about residential and describing autistic space. On Board observation “It was really great to see a board meeting, and to have a real example for referencing. The mock board meeting was enjoyable, but watching experienced board members was very informative.” They also have ‘future leaders’ and ‘research’ programmes with similar intent.
Comparability between organisations (Differences and similarities between how these organisations are doing it)	DR UK programme is pan-disability. SRA is autism-specific. DRUK is disabled-led entirely. SRA is majority autistic-led within a non-autistic-led organisation.
Advantages for inclusive governance	Potential to lead to more autistic people in more senior roles and exerting more influence/power
Any other advantages	
Disadvantages in terms of inclusive governance	SRA program looks as if it may not be hugely inclusive across the autistic spectrum – requiring speaking and significant literacy skills. DRUK program similarly. Is this modifiable or unavoidable?
Any other disadvantages	
Transferability to Scottish Autism (could this idea/aspects of it be applied to Scottish Autism? Initial thoughts on the benefits/difficulties of doing so?	SRA is more similar to SA situation, but DRUK version has some good features. At least 2 possibilities: (1) Internal SA programme along these lines – lack of disabled people in senior positions makes that hard, but not impossible. Likely to appeal to SA more than going external, although it would be a lot of work to set up and run. Perhaps providing internal mentors though? (2) SA accessing/funding the DRUK LAP for some of their staff/potential board members Plus also we should give consideration to a programme for supported individuals at a lower level seeking to develop greater autonomy,

	decision-making, communication skills and confidence etc. (maybe autistic identity too?)

Appendix B.2: Approaches to supporting communication

Names of organisations considered	Communication First, US - Campaigning and policy organisation representing non-speaking people in US (including autistic non-speaking people). Non-profit. Deaf Action – Deaf support charity Scotland
Description of topic in more depth (What is it we are looking at and how is it relevant to inclusive governance?)	Ways in which care and support services can support people's communication to enable them to be included more effectively in governance, both of their own lives, service and the wider organisation
Descriptions of how this is done in these organisations (How are they doing it?)	One of the services Deaf Action provides is Communication Support Workers. Although they only do this in education settings (mostly HE) the concept is of potentially wider applicability. The role is not that of a full interpreter, but is more highly skilled than a general support worker and is focussed on supporting communication in both directions. CommunicationFIRST is intentionally cross-disability in focus because everyone who finds it difficult to be understood when speaking faces similar discrimination, misperceptions, and low expectations, and because laws and policies around communication access govern regardless of the cause of the communication disability. They try to serve the interests of a diverse membership with speech-related communication disabilities, regardless of whether they have found the means to communicate effectively or whether they continue to search for robust augmentative and alternative communication supports that work for them. Our membership constituency includes people of all ages with over two dozen known and unknown expressive communication-related conditions and disabilities—congenital, developmental, and acquired later in life. Many of those involved are non-speaking autistic people. See the film 'Listen!' https://www.youtube.com/watch?v=H7dca7U7GI8 One of their goals is to reduce the barriers currently preventing the vast majority of people with speech disorders from accessing effective communication supports and systems. Another is to increase awareness, understanding, and comfort among the general public about how to interact with and support effective communication with an unconventional communicator,

	and how to respect and meaningfully include all people with communication disabilities.
Comparability between organisations (Differences and similarities between how these organisations are doing it)	Very different organisations but both have a fundamental focus on communication disability as a barrier which **primarily** requires reasonable adjustments and the use of alternative methods of communication, rather than focussing primarily on developing skills in the person with the communication disability.
Advantages for inclusive governance	Communication is fundamental to inclusion. If you can't communicate, you can't govern Side-benefits of emphasis on non-spoken methods of communication are likely to be: • shifting the hierarchy of knowledge by demanding equality for non-speaking methods of communication • greater accessibility for many speaking autistic people too
Any other advantages	Significant spin-off benefits for the quality of care and support generally, improving autonomy and access of non-speaking autistic people to the wider world
Disadvantages in terms of inclusive governance	Important to ensure consideration is given to multiple overlapping needs throughout e.g. dyslexia, LD
Any other disadvantages	Resource intensive and potentially expensive to significantly invest in AAC provision, training and the production of materials in a wider range of formats
Transferability to Scottish Autism (Could this idea/aspects of it be applied to Scottish Autism? Initial thoughts on the benefits/difficulties of doing so?)	Change of language to 'non-speaking' rather than 'non-verbal/pre-verbal' etc. and shift of primary emphasis from the autistic person's development of communication skills towards adjustments and AAC to overcome barriers. Consideration of development of a 'communication support worker' role to focus specifically on: • ensuring that each individual has access to appropriate means of communication and that staff supporting them are trained and comfortable using that method • developing methods of communication and access to communicative content for each individual to broaden and increase communication accessibility for non-speaking autistic people across SA

	SA potentially adopting goals: • to reduce the barriers currently preventing people with speech disorders from accessing effective communication supports and systems. • to increase awareness, understanding, and comfort among the general public about how to interact with and support effective communication with an unconventional communicator, and how to respect and meaningfully include all people with communication disabilities.

Appendix B.3: Service-level models of governance and recruitment

Names of organisations considered	Edinburgh Development Group Care Co-operatives (approached via website form 15/04/22 for further info) Enable North-West Care co-operative (approached via website form 15/04/22 for further info) Peace of Mind Small Supports (approached by email 15/04/22 for further info)
Description of topic in more depth (What is it we are looking at and how is it relevant to inclusive governance?)	These organisations all involve ways of delivering care services which are very different to the traditional model of large care providers and may involve significantly more inclusive governance at the service level of care provision. We want to consider whether these models have ways of working/structuring organisations which might contain ideas which could potentially be applied to SA.
Descriptions of how this is done in these organisations (How are they doing it?)	**EDG** – using a 'co-operative' model to support disabled people (and families) to come together to create care co-ops. So the professionals are involved to provide funding, support and know-how, but encourage small groups of disabled people and/or family members to group together to form co-ops. e.g. 'Our future in our hands' 8 families who are setting up a care cooperative to manage the support of 7 young adults with a learning disability. In the last year and a half they have spent time bonding, creating a charter, members agreement and memorandum and articles so they can register as a company. Their main reasons for coming together as families are so the young people can be supported to identify and follow their dreams, pool resources and access more cost effective and bespoke support. **Enable** – mostly fairly typical charity care provider **but** 'PA model' involves recruiting PA's with involvement (control?) from the service user to work with particular service user. Essentially an Individual Service Fund model. "Bespoke Personal Assistant team: Each individual will build their own bespoke team of Personal Assistants who are employed directly to support that individual to meet their outcomes and achieve their goals. Each Personal Assistant is contracted directly to the individual they support, having been selected by that individual to be employed in their support team. A team of skilled recruitment consultants facilitate the end-to-end recruitment and onboarding processes within the organisations sector leading ENABLE Recruits division. Individual Service Funds: Every person supported has their own Individual Service Fund, where the individual has full control and visibility of their support budget. The PA model works in conjunction with the four SDS funding options and allows each individual to deploy their budget in a way that meets their desired

	outcomes, whether it be through ordinary peer support, direct support, technology, be-spoke purchases or community services.” **North West Care Co-Operative** - administers support on behalf of Co-Op 'User' members (those receiving support) who control and direct it. Service company and a number of local co-operatives (currently 3 – significant recent growth, 1 with 15 principals and 2 x single principal member teams) Company limited by guarantee (not for profit) which acts as the employer for the PAs and provides the HR, training and payroll needed to support and manage employment. The control is with the local care co-operatives who control and direct their care. So all the regulatory oversight (CQC) can all be delivered by the service company. Service company employs a registered manager. User members (the disabled people), employee members (the PAs), supporting members (anyone who doesn’t fit into the first two e.g. parents of user members). Co-ops kept small – currently around 9, max 15-18 members in total. So each individual member is able to exercise a voice. Employee members – small, self-managing team. Delegate a lot of trust to employee members to deliver care. User members know all the employee members which provides cover seamlessly. Constitutionally hold 4 general meetings per year of co-op. Entire membership invited. Strategy/tone/direction governed by this on one member, one vote basis. Small management committee who deal with some day to day functions. Growth has required change - As part of this consolidation in its capacity as the ‘service company’ that supports each co-operative, NWCC will become a trading arm of Disability Positive . This will allow NWCC to draw upon organisational services provided by Disability Positive (HR advice, Accounting, etc) as well as being able use Disability Positive’s Charitable Status to avoid NWCC having to pay Corporation Tax on any surplus that we may generate. Also interesting that NWCC publish notes from their AGMs publicly. **Peace of Mind** – Social Enterprise. Offers support and social connection to DP recipients employing own PAs – e.g. with contracts and meeting others, potentially to pool budgets. They provide help with contracts - they have contracts that cover groups of people employing PAs. They don’t actually employ the PAs. Help people connect and share information. Keeps a secure database of service users it uses to find connections. **Small Supports** - The Small Supports partnership is between Beyond Limits, C-Change, NDTi, Positive Support for You and Local Government Association, funded by NHS England. We are working

	with local areas to help them create the best environment for small supports to emerge and flourish and with existing and emerging small supports organisations to develop and share great ways of working. The partners are not seeking to establish or grow their own support activity. Organisations have to commit to set of principles, which include the person having as much control as possible and this increasing. People choose where they live and who supports them. SS orgs don't withdraw support or sell on. SS orgs stay relatively small and don't grow by more than 3-5 people (assume SUs) per year. Largely focussed on changing procurement and commissioning to encourage SS orgs to develop.
Comparability between organisations (Differences and similarities between how these organisations are doing it)	Enable has strong similarities to SA £43m income, £43m expenditure last year. Others much, much smaller.
Advantages for inclusive governance	Co-operative model involves clear power sharing between SUs and those providing care and definitely increases the power and control of the SUs, although there are some question-marks about how independent the voice of SUs is from family members. Social and practical support for DP budget-holders (eg Peace of Mind) is likely to encourage and sustain take up amongst those who can, but unlikely to be sufficient to support those who can't (ie don't themselves or have a family member who can cope with being an employer) Small supports aims include explicitly 'Ensuring that the voices of people and families lead small supports'
Any other advantages	
Disadvantages in terms of inclusive governance	**EDG** - Some groups have become more like 'support groups' and not actually meaningful care co-ops. Reading between the lines it sounds like it has been difficult to find people with the confidence and skills to take on the responsibilities involved (e.g. forming a company) in their model. Heavily parent-led when it comes to people with LD (which probably includes some autistic people) **Enable** – Not clear to what degree individuals actually have control. Very similar to standard care provider models, with inherent conflicts of interest between service users and company priorities. Only real difference is in recruitment. **NWCC** – Higher pay for PAs needed and some flexibility to make it attractive to PAs. 'Personal Assistant' members provide personal and social care support to 'Client' members according to 'client' need and under 'client' direction, but in return 'clients' support

	'Personal Assistant' needs by paying them through the Co-Operative at above local market rates, respecting their professional judgement, and where possible accommodating their lifestyle needs (such as provision of childcare etc). Appears that they are struggling to recruit PAs (though general issue at the moment), but model means if they can't get PAs they can't provide care. **Peace of Mind** – limited. Only accessible to those with significant digital and communication skills or with support from family etc. Governance of organisation doesn't have any restrictions or guarantee of disabled-involvement. **Small supports** – lack of differentiation between SUs and family.
Any other disadvantages	
Ideas of potential interest to SA inclusive governance	A) Principles list used by Small supports: 1. From the first steps the person (and their chosen family and friends) has as much control as possible and there is a commitment to this control growing. 2. The starting point to developing great support is the person's aspirations about where they want to live and the life they want to have; conversation about support then follows from this. Compromising on control and aspirations is when things start to go wrong. 3. Supporters (staff) are recruited by and around the individual. They don't work across services. Staff are not a substitute for friends, community peers, co-workers and neighbours. 4. People choose where they live and who, if anyone, they live with. People are the tenant or owner of their own home or perhaps live with family. There is a clear separation of housing and support. 5. Funding is sustainable and is designed and used around the individual. 6. Small supports organisations stay with people. Change and challenges are expected so they don't withdraw support or 'sell' services on. 7. In their work, leadership, recruitment and actions, small supports organisations are rooted in their local community. 8. The organisations stay relatively small. Knowing each person well means not growing by more than three to five people a year and finding a natural size where people are known and valued, and the organisation is financially sustainable. 9. Small supports organisations are developed around these practices. Taking some of these practices and making them aspirations within large, segregated services will not deliver the desired outcomes.

	The principles themselves could be considered and adopted. Could SA consider breaking up some of its services and/or giving individual services much greater autonomy to be run by their own staff and SUs with SA providing pooled support, rather than centralised control? B) Budget pooling and co-operative care provider model – individual services being governed by the people who use them who have control over the staff who support them, the money used to fund their support, and how their support is designed (around them, not the needs of the service). Breaks conventional ‘service’ models. Does SA use ISFs? Could SA support people to use forms of SDS which increase their control – including possibly Option 1? Does budget pooling allow that? Could SA manage the HR/admin/regulatory/insurance requirements etc. for care co-ops? – Perhaps commit to beginning to move in that direction with one or two trials? C) Recruitment of PAs for and with the extensive involvement of the specific person they support. Definitely something here for SA potentially – although some need for ‘bank staff’ who can work across multiple SUs. All of the above need careful consideration of the distinction between: Supported Individuals; Family members the SI has chosen to be involved; Family members; and consideration of how control by SIs themselves is best ensured, whilst recognising and working with supportive family members.

Appendix B.4: Intersectionality

Names of organisations considered:	The Arc (US), A2nd Voice CIC, Mask Off CIC
Description of topic in more depth (What is it we are looking at and how is it relevant to inclusive governance?)	Autistic people are diverse in other ways. How can SA make governance more inclusive of autistic people, whilst also ensuring diversity in terms of other identities? e.g. age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation and other identities. This could also include diversity across the autistic spectrum in terms of speech, intellectual disability, support needs or other measures People living at the intersection of being autistic and other marginalized identities—such as BAME, the LGBTQ+ community, older adults, immigrants, and many others—face compounding discrimination and barriers. How can we ensure that SA's governance is inclusive of these multiple identities?
Descriptions of how this is done in these organisations (How are they doing it?)	The Arc began including people with IDD on their board in 1990s In 2015 released a Diversity Strategic Action plan (2016-20) and in 2019 created a Access, Inclusion and Equity Team including dedicated staff from across different sections of the organisation. Notable that there is a clear focus on rights. Adopted 'diversity' as a core value in 2000. A2ndVoice is a social enterprise non for profit organisation supporting the needs of autistic people and their families, raising awareness and understanding from different perspectives, outreaching also to the Africa, Caribbean, Asian and Minority Ethnic Communities (ACAME) and Dual Heritage Communities in tackling the taboos and myths around Autism. Aims include explicit focusses on intersectionality e.g. girls/young women, BAME communities, hard to reach parents, autistic mothers, fathers/single fathers/male workers, faith groups, autistic people in criminal justice system. Offer support, advice, resources, organise groups, webinars etc. Mask Off is a CIC but basically an individual working alone to 'raise awareness'. Managed to get interviewed by NAS Your autism magazine.
Comparability between organisations	The Arc is an Intellectual and Developmental Disabilities charity (parent-founded). Membership organisation with local 'chapters'.

(Differences and similarities between how these organisations are doing it)	Policy and advocacy work. Do offer some services but focussed e.g. employment, criminal justice, not care provision. A2ndvoice is a smallish CIC, London-based and mostly locally focussed. Difficult to tell but seems to be led by parents and autistic people (and both?). It is a service provider but on a small scale and not 'care provider' services.
Advantages for inclusive governance	Helps to ensure that inclusive is genuinely inclusive across multiple identities and increase the representation of other marginalised groups within and beyond SA.
Any other advantages	
Disadvantages in terms of inclusive governance	None of these orgs are care providers, so not everything is transferrable. Possible risk that excessive focus on intersectionality could lead to lack of sufficient focus on inclusion of autistic people specifically!
Any other disadvantages	
Transferability to Scottish Autism (could this idea/aspects of it be applied to Scottish Autism? Initial thoughts on the benefits/difficulties of doing so?	**IDEAS AND OPTIONS FROM THE ARC** (1) The Arc uses an analytical tool which could be applied to SA and includes asking: **Diversity** – who is in the room? – **Does SA know about diversity across its staff and amongst those using its services (including advice line)? If not, could and should such data be collected? Are documents/materials created by SA screened for diversity?** **Access** - Can everyone get inside the room or even the building? Can they participate?- **Does SA routinely produce information in a way everyone can understand, including considerations of language? Easy-read versions? (including of board documents, financial information etc.) How about other languages (including BSL, gaelic)? Information about events and services? Consultation documents?** **Equity** - Who built the room? Who received an invitation? Who has power in the space? It calls on us to understand the inequities of how power is allocated in society and the resulting injustices. Once we understand the role of power, we can work toward justice by shifting power from those who have more to those who have less. **Could we consider a 'power audit' of SA in some way? Can we assess inclusive governance options in terms of degree to which they shift power and make the distribution of power more equitable?** **Inclusion** - Does everyone in the room feel welcome? Like they truly belong? Inclusion means people feel supported to bring

their authentic selves into a space, knowing their differences will be embraced. **Autistic inclusion – equity of autistic norms e.g. text communication as privileged as speech (Advice line? Meetings?), what other 'autistic normal' should SA be routinely including? Intersectional inclusion – Documents/materials (including easyread) representative and diverse, what else?**

(2) Strategic Action plan to improve inclusion and diversity? Setting out specific actions and targets?

(3) Inclusion, diversity and equity team across departments? Would that result in positive change?

(4) Current SA values (according to SA website) are Collaboration, compassion, Change Makers and Contribution. Adding diversity? And/or Equity?

Also currently SA say "**What constitutes "enabled" from the point of view of our principal stakeholders?**
A) Service Users

- Opportunities to exercise informed choices, through education and experiences
- Engagement in their own lifestyle"

That's very limited!!!

(5) Collect demographic data on staff and board in a way which reflects the many identities and groups that are part of an incredibly diverse autism community, as well as identify groups who are not included. That would likely require some thought and research on categorisation – there might be some 'best practice' schema we could use, but we'd have to bepoke it for autism-related identities. Then make staff and Board demographic data available on website to increase transparency

(6) Review and reconsider inclusivity across the board e.g. routine identification of pronouns, checking position statements/training etc. to ensure inclusive of LGBTQ+ and other diversity,

(6) Website usability and digital accessibility across a range of access needs. Prioritize accessibility and services at events, such as Communication Access Realtime Translation (CART – instant subtitling), BSL interpretation, large-print programs, easy-read and just plain language (using simpler direct language) – what else? Seeking to reach communities speaking languages other than English? To do these things and work out whether it is cost effective to do these things, SA might need to collect some data to

	find out to what extent these needs exist among the autism community (inc parents and professionals) who currently are and (importantly) are not accessing their services. (7) (Arc) Support autistic people, especially those who are part of other marginalised communities, to participate and be counted as full citizens e.g. census participation, voter registration, participation in wider community groups, making healthcare decisions, support to form political opinions and vote. (A2ndvoice) (8) Aim/provide autism information, awareness raising and training at locations/communities which are marginalised in other ways. (A2ndvoice) Explicitly target groups/training/outreach to particular communities and tailor resources/training to needs of those groups. (Arc) Support autistic people and family members from marginalised communities to create and lead groups/activities. Consider partnering with and supporting campaigns on non-autism diversity/equity issues and build pan-disability/pan-marginalised group solidarity, including challenging other social justice groups to be more inclusive of disability-generally and autistic people specifically. Potentially including support for diverse employment. (9) Diversify talent pool when recruiting staff by partnering with small, independent organisations representing a range of groups esp. marginalised groups. Learning Disability England engages in some project work e.g. Equal Treatment Project which involves forming partnerships with other organisations representing diverse groups, which then improves intersectional awareness broadly (rather than focussed on staff recruitment particularly) (10) Seek to diversify board by prioritizing diversity in consideration of Board candidates, considering what % of potential board recruits have at least one diverse characteristic by age, disability, race/ethnicity, or religion. Targeted recruitment e.g. advertising in publications/locations/organisations where marginalised communities are. Learning Disability England have also used Targeted recruitment by explicitly talking to members connected to people with high support needs and those from under-represented ethnic backgrounds to encourage/solicit applications for the representative body (and possibly also for trustees). (11) (Arc) Explicitly work to diversify keynote speakers at SA conferences, by proactively recruiting individuals with more diverse identities, including consideration of the overall proportion

	of speakers who are autistic (whilst always focussing on speaker skill and expertise in relevant area). (A2ndvoice) Create/promote events run/delivered by autistic people from BAME communities.

Appendix C: Supported Decision Making – an extended thematic case study

In writing this document we have adopted the rhetorical device of asking questions (in bold and italics) from the point of view of an imaginary sceptical social care worker/manager in order to focus the discussion.

What is supported decision making?

It is helping someone to make a decision for themselves, instead of making it for them. Making a decision for someone else is called substituted decision making.

Another way to put the idea is that with supported decision making, decisions are ***made by*** the supported individual. With substituted decision making, decisions are ***made for*** the supported individual.

Why are we talking about it?

Because it is central to inclusive governance at Scottish Autism. It is clear why SDM is important at the level of supported individual governance of their own lives. Building on that, good practice of SDM is a step towards enabling supported individuals to more fully participate in the governance of their local service, the policy and practice of service delivery at Scottish Autism in general, the strategic direction of Scottish autism as a whole, the structure and governance of Scottish Autism, and the campaigning priorities of Scottish Autism.

Since the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006 there has been much interest in and discussion about how to ensure that people with disabilities enjoy their rights on an equal basis with others. There has been particular interest in Article 12 of the CRPD which concerns this directly. Article 12 calls for equal recognition before the law, which includes that persons with disabilities enjoy legal capacity on an equal basis with others. Therefore, supported decision making is a move toward CRPD compliance. The CRPD, while influential, is not yet incorporated into Scots law. There is currently a review of Scottish law related to capacity/incapacity which seeks greater compliance with the CRPD. In terms of current legislation in force now, the most obviously relevant legislation for Scottish Autism and the practice of SDM includes the Human Rights Act 1998, The Adults with Incapacity (Scotland) Act 2000, Mental Health (Care and Treatment) (Scotland) Act 2003, Adult Support and Protection (Scotland) Act 2007 and perhaps the Equality Act 2010. We will not tackle these in detail in this document. The current review of mental health law in Scotland will very likely significantly alter the legal landscape with regard to supporting the autonomy of supported individuals, whatever their disabilities. The practice of supported decision making will be possible to a greater or lesser extent under a wide variety of legal frameworks, and the general direction of reform is towards CRPD compliance, so the ideas covered in this document will likely be relevant in any eventuality. The Republic of Ireland has already enacted the Assisted Decision (Capacity) Act 2015 in an effort to fulfil its obligation to comply with the CRPD. While there has been much interest and discussion about this new legislation it has still not yet commenced seven years since it was passed, so there is still a shortage of practical experience and evidence of SDM in action in Europe. However, there was a very informative project in South Australia which was completed in 2012 in which they trialled SDM as an alternative to their guardianship system, with very positive results. A brief summary of the project is included in Appendix 3.1.

Why is supported decision making important?

SDM is important because everyone wants to live the life they choose, not have a life completely chosen for them by someone else. Being in control of one’s own life is called **autonomy**. Nobody has total autonomy and control of their life, but most people can choose where they live and who with, what kind of career to pursue, who to have as friends (or who not to have as friends), how fit they want to be, what they want to eat, where to go shopping, what clothes to wear, whether to eat meat, who to vote for, what newspaper to read, and so on, most of the time. Most people exist within a network of social relationships that make discussing decisions, finding information, weighing up the pros and cons of what to do easy and natural. Perhaps many people never even notice that they have this crucial network of informal support in which they can lead their autonomous lives.

There is a long history of the concept of autonomy under various names. Consider St Thomas Aquinas, a 13th century theologian:

> "The highest manifestation of life consists in this: that a being governs its own actions. A thing which is always subject to the direction of another is somewhat of a dead thing."[1]

And this from Madeleine L’Engle:

> “Take away a man's freedom of choice, even his freedom to make the wrong choice, is to manipulate him as though he were a puppet and not a person.”

More drily, from the Stanford Encyclopaedia of Philosophy:

> Put most simply, to be autonomous is to govern oneself, to be directed by considerations, desires, conditions, and characteristics that are not simply imposed externally upon one, but are part of what can somehow be considered one’s authentic self. Autonomy in this sense seems an irrefutable value, especially since its opposite — being guided by forces external to the self and which one cannot authentically embrace — seems to mark the height of oppression.

The idea of an authentic self, opposed to guiding forces from outside captures an important aspect of the autistic predicament. Autistic people are different from neurotypical people in respect of their whole being. This has been recognised among the autistic community since there has been such a community. In the words of autistic self-advocate Jim Sinclair in his seminal “Don’t Mourn for Us”:

> Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence.[2]

The idea that the mismatch between autistic perspectives and that of the wider society they are embedded in is to a very large degree the cause of disability is the essence of the social model of disability.[3] For those autistic people who depend on them, care and support services, to varying degrees, determine the environment an autistic person is embedded in, and constitute ‘external

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[1] Thomas Aquinas, On The Perfection of the Spiritual Life, Chapter 14

[2] https://www.autreat.com/dont_mourn.html

[3] For more on the models of disability, see: Wasserman, David, Adrienne Asch, Jeffrey Blustein, and Daniel Putnam, "Disability: Definitions, Models, Experience", *The Stanford Encyclopedia of Philosophy* (Summer 2016 Edition), Edward N. Zalta (ed.), URL = <https://plato.stanford.edu/archives/sum2016/entries/disability/>.

forces' that guide a supported individual's life. That also means that they can, unintentionally, be a cause of oppression and disability, even in the sincere good-willed act of providing support.

Upholding a person's autonomy involves more than just asking them what they want from time to time. It involves creating an environment in which their lives are shaped by <u>their</u> will and preferences in all respects as a matter of course.

Which decisions does SDM apply to? All of them?

All the decisions that actually belong to the supported individual. Decisions about daily activities of a supported adult would, by default, be theirs to make, just as they would for any non-disabled adult. Some decisions would not be theirs to make at all, for example, a decision about overall funding of a support package would be for the local authority to make in accordance with law and policy - the supported individual would not (ultimately) get to decide that, even though their views and preferences might well be considered and relevant. However, a decision to challenge that LA decision might very well be made by a supported individual.

Organisational-level decisions, such as Scottish Autism's decisions about what topics to campaign about and what positions to take on them, are more complex to look at in terms of supported decision making. But the principles of SDM can inform the approach taken to organisational decisions, particularly when the organisation is advocating on behalf of a particular group of people (autistic people in this case), as in the slogan 'nothing about us without us'.

Some **complex decisions** need analysis. For example: a supported individual decides they want to install a pole-dancing pole in their accommodation, and have pole dancers visit. But whose decision is that? This decision involves many smaller decisions, some of which might belong to the local authority, some of which to the housing association, some of which to the potential pole dancers, some of which to parliament in the form of statutory regulation of such activities, and some to the supported individual. In this case, supporting decision making is not simply carrying out the will and preferences of a supported individual regardless of any other consideration, it would be informing the supported individual of the necessary steps to achieve their aim, discussing ethics and rights, and which decisions are theirs to make and which are not, and, if it gets that far, even supporting the supported individual to make enquiries and engage with the necessary authorities.

It may be relevant to inclusive governance to consider the coverage of decision making and staff understanding of which decisions should be made by whom in SA staff training and development.

So how do we do supported decision making?

It very much depends on the supported individual, and the circumstances. In general, it is working to maximise the overall choice and control someone has over their lives, so if a provider is doing that, they are probably doing SDM in some form. There are several 'ways in' to working out how to practise SDM. We have already talked about the importance of figuring out which decisions belong to whom. In terms of a rather mechanical approach to support for particular individual decisions, we might make use of the indicators of 'incapacity' as listed in the Adults with Incapacity (Scotland) Act 2000 s 6:

> "incapable" means incapable of—
>
> > (a)acting; or
> >
> > (b)making decisions; or

> (c)communicating decisions; or
>
> (d)understanding decisions; or
>
> (e)retaining the memory of decisions.

From this definition, it stands to reason that if you can help someone understand, communicate, remember, make and execute decisions, then one could argue that they therefore *have capacity*, and should be free to make that decision without outside intervention. So SDM can sometimes simply be enhancing these abilities to maximise a person's ability to make a decision.

Of great importance in this list is 'understanding decisions'. Often individuals need more information. Supplying information relevant to a decision is often a crucial part of supported decision making, e.g.:

> "If you want to catch the bus, we'll need to start walking now."
>
> "You're not sure who to vote for? Let's have a look at the party manifestos and talk about what each party wants to do."
>
> "We could go and visit the other supported individual, yes. Remember that the other supported individual finds noise very distressing, which means we might have to come away, or go into another room, if we want to make a lot of noise."
>
> "Are you unhappy with how your support workers support you? They follow a thing called a support plan, and it is written down. Shall we look at it together and see what is in it? We can change it to something better if you don't like it."
>
> "Yes, I'll put pizza on the shopping list. I should just check that you know, if you have lots of pizzas, you can put on weight, which increases the chances of being ill in the future. Shall I remind you of that from time to time so you can control how much you eat? We can work out a plan if you like."

Working out the consequences and implications of a decision is also a huge part of understanding a decision. Very often autistic people have difficulty working out some of the implications of a decision in a world they may find extremely confusing.

'Communicating decisions', and indeed communicating will, preferences[4], wishes and feelings[5] is clearly also of huge importance in supporting people to make decisions. Only when we know what an individual wants is it possible to take steps to help them realise their aims, and that means getting that information from the individual. This is sometimes easy, one can just ask them. Sometimes this can be a much more subtle process of interpretation. Often a relationship with a staff member, family member or friend plays a hugely important role in allowing someone's will and preferences to manifest and be given effect to.

But supported decision making is not just about plugging the gaps in an individual's knowledge and skills for a particular decision. It is about embedding a person in an environment in which they naturally understand what is happening, have easy and ready access to people who listen to and understand them, with people who can translate the outside world into terms an individual can

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[4] 'Will and preferences' is the language used in CRPD Article 12

[5] 'Wishes and feelings' is the language used in the Adults With Incapacity (Scotland) Act 2000, s 1 (4) (a)

understand, feel safe, comfortable, feel they culturally belong, not too stressed all the time, and are able to easily communicate and exert control over their lives.

Relational autonomy: The importance of close trusting relationships.

> *The bird a nest, the spider a web, man friendship.*[6]

Joe Long on the importance of friendship between support staff and supported individuals at Scottish Autism (emphasis added):

> "Both the staff focus groups and talking groups with supported people found that questions around friendship and affective attachment did not just pertain to relations between supported people but often centred on relations between practitioners and those they supported. These insights led us to consider social care as a form of **relational support** in which interactions and relations with practitioners are central to the lived experience of supported autistic people."[7]

In the South Australian SDM Project, decision-supporters said:

> 'I am a trusted friend, not a carer.'
>
> 'We feel OK about going on [as supporters]. We have a friendship that will last. We love him.'

The cultivation of such trusting relationships in which a strong attachment develops between individuals is critical to being able to give effect to a person's will and preferences, and to support their autonomy. In current literature, this is called relational autonomy and is considered best practice among academics and expert professionals. The concept of relational autonomy is a development of an earlier more individualistic conception of autonomy, in which a person is to be left alone, undisturbed, to come to a decision that is most authentically their own. In the words of Kong and Keene:

> "An individualistic assumption of autonomy suggests that self-determination demands that we disengage and remove ourselves from social influences that make us who we are - I need to abstract from the influences that make me who I am, like my cultural or family history, my social background, my relationships, so I act from this authentic, oddly isolated core. By contrast, relational autonomy believes this is an impossible task."[8]

While close, trusting, positive relationships are clearly essential to the realisation of autonomy, very frequently autistic people are disabled by our relationships, and we must be careful not to misunderstand what relational autonomy should look like in the context of supporting autistic people. Sometimes, the more individualistic message of 'leave me alone to figure this out for myself' is the correct one in some circumstances. Autonomy-in-relationship should not be interpreted according to neurotypical norms, in which there can be a lot of chit chat, a lot of spending time in close proximity, surprises, and so on, precisely things that can have a disabling effect on autistic people. Some more detailed work about what relational autonomy might look like for autistic people

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[6] William Blake, *The Marriage of Heaven and Hell*

[7] Joseph J Long, 'Reflective Practitioners and Participant Observers in Autism Services: Managing Knowledge in UK Social Care'

[8] Camilla Kong and Alex Ruck-Keene, *Overcoming the Challenges in the Mental Capacity Act 2005* p 46

may be useful, indeed much of this work has already been addressed in the National Autistic Taskforce's Independent guide to quality care for autistic people.[9]

The practice of SDM in the South Australian SDM Project resulted in the development of close relationships involving elements of reciprocity, suggesting a greater equality between the supported and the supporter. In the words of one decision-supporter about the person they supported:

> “They communicate with me, are concerned for me.”

For relational autonomy to be realised, not just any kind of relationship will work, and it is critical to find the right people to provide these relationships. On that subject we need to consider:

Training vs recruitment

Clearly both are important. However, when ensuring a workforce has the right skills and knowledge, traditionally the focus has been on training rather than recruitment practices. Training, when delivered over a day or a week, is likely of very limited efficacy in terms of equipping people, from a standing start, with the skills and knowledge needed to enter into supportive relationships with autistic individuals. Consider what Joe Long has to say about the origin of skills in the workforce:

> “...much of the knowledge and skill of practitioners supporting autistic people are acquired through informal learning, peer-to-peer interactions, and ongoing relationships with the autistic people that they support. Many learnt skills such as personalised communication or stress reduction are constituted in the day-to-day support of individuals and may be tacitly held by practitioners rather than consciously deployed.”[10]

For what it’s worth, training might be developed based on, for example, Kong and Keene’s material on ‘hermeneutic competencies’ of attunement to impairment, recognition of the person as an agent, humility and a willingness to engage in ‘open dialogue’.[11] Also narratives of ‘respect’, ‘trust’ and ‘esteem’.[12] Maybe work on training could be a separate project. All that said, recruiting people with these important qualities in the first place is a huge shortcut which should be taken advantage of wherever possible. Further consideration should be given to the values used in values-based recruitment. Some qualities might be:

- **neurodivergence.** This applies, but is not limited to, conditions such as autism, ADHD, learning disability, dyslexia, and many more. Supported individuals with these, or a combination of these, may well benefit from support from people who share these conditions in order to maximise natural understanding and rapport between supported individuals and staff. Support staff who naturally recognise the needs of supported individuals as real and comprehensible are better placed to meet those needs. Recruiting which explicitly encourages neurodivergent people to apply for a role supporting one or more neurodivergent adults is likely to be a proportionate way of ensuring a staff

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[9] https://nationalautistictaskforce.org.uk/an-independent-guide-to-quality-care-for-autistic-people/

[10] Joseph J Long, ‘Reflective Practitioners and Participant Observers in Autism Services: Managing Knowledge in UK Social Care’

[11] Camilla Kong and Alex Ruck-Keene, *Overcoming the Challenges in the Mental Capacity Act 2005* p 58-78

[12] Camilla Kong and Alex Ruck-Keene, *Overcoming the Challenges in the Mental Capacity Act 2005* ch 4

team which includes neurodivergent members and is unlikely to be discriminatory, provided at least some roles are open to non-disabled applicants.

Lawyer Mary Condell noted the importance of having support from someone with a natural affinity for the supported individual:

> In my opinion, it takes a professional with a deep down belief in the fundamental human right of all persons to make decisions for themselves to accept that, where this particular relevant person is concerned, I am on my own not enough to honour that right of theirs with regard to this particular decision and they deserve the help of another. That other person may be another professional, or, as I found when unable to understand a question being asked of me by a gentleman with Down Syndrome, the assistance of someone more able to understand him, which in this case was his friend who also had Down Syndrome.[13]

- **experience of having choice and control removed from them, in any context.** Staff who know what it is like to lose control of their lives will be better placed to instinctively understand the importance of autonomy, and recognise when it is happening.

- **strong analytical and reflective skills**. Conceptual distinctions such as between stress and anxiety will be better grasped. Understanding of law and best practice is important for confident practice without fear of getting into trouble. We know that many educated, reflective and analytical neurodivergent people are underemployed. Not all will be right for working in social care, and some will not want to, but many will. It is a relatively untapped resource.

- **experience of minority spaces and cultures, especially neurodivergent ones**. Staff and managers who have strong experiential knowledge of what it consists in for a supported individual to be in a non-adverse environment, both physically and culturally. In that way they will be well equipped to recognise when policies, placements or staff are not a good fit for a supported individual. Feeling like one is in a foreign country, poorly understood and isolated reduces autonomy.

> *The apple tree never asks the beech how he shall grow…*[14]

But staff have to maintain a professional distance don't they? They are paid to do a job, they are not supported individuals' friends. They should not cross these boundaries.

Sometimes close relationships are discouraged in care services. It is thought that being professional is incompatible with being a friend and that supported individuals are best served by maintaining a very firm line between the professional and the personal. However, a recent case in the Court of Protection in England illustrates the danger of the general principle of the importance of boundaries being treated as an arbitrary and inflexible 'rule'. The case concerned a supported individual (P) with Lennox-Gastaut Syndrome, a severe form of epilepsy. He had no family and was supported in a residential home by a staff member TQ. He and TQ became very close. However, a decision was made to move P to a different placement, and TQ was prevented from visiting. TQ applied to be P's Personal Welfare Deputy (a role in England with some similarities to Scottish Guardianship). This application was reacted to very negatively by the care providers and public bodies involved, holding inflexibly to a 'rule' that this would always be inappropriate. The Court of Protection found firmly in

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[13] Mary Condell, "Personal Reflections as a Lawyer on Experiences with the Assisted Decision Making (Capacity) Act 2015", from *The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections* (2021) p 222

[14] William Blake, *The Marriage of Heaven and Hell*

favour of TQ, highlighting the importance of avoiding misconceptions about what appropriate 'professionalism' is, and low-level policy-following leading to unlawful decisions which do not respect the autonomy of supported individuals.

> 17. **The first statement of Ms Williams … almost arrogantly stated, "Staff at ER (including TQ) were involved solely in a professional relationship with P. It is our expectation that professional relationships are time bound, have a distinct role and purpose and have some structure."** She presented as rigid in her thought process, guided entirely by her belief that it was inappropriate to blur the boundaries of professional carer and friend in any circumstances, referring to TQ as "holding all the power and P as not any", despite agreeing TQ had never misused that power. She referred to her as being very close to P which "is endearing but hope all his relationships will be." Even when prompted under cross-examination **she did not think it was appropriate for TQ to be part of any best interests decision process**. She was quick to draw negative conclusions about TQ without being open minded to other possibilities.
>
> 18. **Sadly, I found her to be driven by a policy decision that TQ should play no part in P's adult life as she had cared for him professionally in the past, to the exclusion of all else.**
>
> 20. I have already expressed deep concern about the written evidence of Ms Fairgrieve. Her oral evidence showed the same reliance on a policy decision as Ms Williams. Despite admitting there had been no assessment of capacity in respect of contact she said her Operations Manager, Samantha Kilia, made the decision that as TQ's role as a carer had come to an end and **she was not a relative it was "a nonsense to say she could visit."** She supported her manager's decision. She was asked how that policy decision placed P at the centre of a best interests decision and responded it was a **safeguarding risk**. **She said she and her manager assessed her as being a risk 'because she is not a relative'**. Although she was aware TQ had taken him on holiday she did not regard that as altering the fact her role was professional and had come to an end.[15]

If relational autonomy is to be realised, appropriate relationships must actually be allowed to flourish, and not stymied by blinkered following of low-level policy and nonsensical assumptions. It may be of use to consider concepts around boundaries, professionalism, friendship, vulnerability, power imbalances, and so on, in the light of this CoP ruling. The CoP has no jurisdiction in Scotland, but a case like this is likely to be influential and in any case it illustrates the general point that important relationships are taken seriously by the courts and that there is no obstacle in law (in either England or Scotland) to a professional carer and a cared-for person forming a meaningful friendship or having that friendship extend beyond the boundaries of their professional association. There is often a false belief that 'safeguarding' prohibits such meaningful relationships, but this is a harmful misconception[16]

But isn't SDM very unsafe? We can't just let supported individuals do whatever they want. They'd be dead in a week. Or arrested. Or beaten up.

There are of course limits to what individuals should be supported to do. We have already talked about one limit - supported individuals may only make those decisions that are theirs to make in the

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[15] A (fact-finding) [2019] EWCOP 58

[16] Williams, Paul (2021) 'The cold comfort of safeguarding', *Community Living*, vol. 35, no. 1

first place. But there are other limits to autonomy as well. Just like everyone else, supported individuals are subject to the criminal law. Supporting supported individuals to commit crimes is clearly not required. The other main limit is balancing human rights. The right of a supported individual to live the life they want may be restricted if it endangers their own rights, say the right to life, or the rights of others and that outweighs the person's other rights (to freedom of expression for example). In the words of Mary Condell, a lawyer who worked on the Assisted Decision Making (Capacity) Act 2015 in the Republic of Ireland:

> the legislation is not just about 'the relevant person's' rights, it is about balancing and prioritising 'the relevant person's' rights against the similar rights of everyone else, whilst realising that systems have rules, not 'rights'.
>
> [...]
>
> My final cornerstone comes from my experience with a woman who asked me, after she had listened to a presentation I gave on the 2015 Act, 'whether it meant that her mother had the right to expect her to stay at home and look after her'. I promptly replied 'absolutely no, that she herself has her own right to make decisions for herself about how she wants to live her life'. The 2015 Act is (quite rightly) described as 'rights-based'. Its purpose is to ensure that the rights of 'relevant persons' are respected and honoured. It does not mean, however, that the rights of those people who surround a relevant person do not also have to be taken into account and balanced against those of the relevant person.[17]

Part of supported decision making is making rights-based risk assessments which considers all the relevant rights of everyone in a situation. It is important to distinguish between the severity of a risk, such as death and serious injury, and the likelihood of that outcome occurring. The principle of proportionality requires balancing both of these. So, for example, the potential risk of catching and dying from a serious illness (such as Covid) is a severe outcome, but may have a variable probability of occurring, depending on the current prevalence and precautions taken. On the other hand, if a person's family are not allowed to visit their home (in order to keep them safe from illness), that is a certainty of infringing the person's right to family life, with a seriousness which is affected by the length of time for which the exclusion persists. Death may be more serious than not having contact with family, but how likely is each outcome? A point will be reached at which the certainty of prolonged separation from family is a greater harm than the risk of death. That is positive risk taking. And it applies just as much to other areas of potential emotional and social gains, including having autonomy, when balanced against potential physical risks, which are usually the pre-occupation of services.

OK, but even within these limits, supported individuals will do a lot of foolish things that are not in their interests and which may even result in some harm. Do we just let them do those?

Quite possibly, if they fall short of the limits which would justify intervention. But consider that support workers, or even Decision Supporters (as provided for in the Irish 2015 Act and are being proposed for Scotland in the current review) are not advocates. They do not have to remain wholly neutral, and may offer advice and guidance to supported individuals according to their judgement,

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[17] Mary Condell, "Personal Reflections as a Lawyer on Experiences with the Assisted Decision Making (Capacity) Act 2015", from *The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections* (2021)

and if they have the trust of the supported individual may very well be able to support an individual to help them realise their goals most effectively and safely.

It is also important to consider the value of experience. We have all learned some of the most valuable and rewarding lessons from making mistakes. Invoking Blake again:

> *If the fool would persist in his folly he would become wise.*

The principle of allowing 'unwise' decisions is explicit in other jurisdictions such as England and the Republic of Ireland, and it is present in Scottish statutory guidance. Consider the Scottish Government's 2008 guidance on the 2000 Act, Communication and Assessing Capacity, A guide for social work and health care staff[18] pg 4:

> A person is not to be treated as unable to make a decision merely because he/she makes an eccentric/unusual or unwise decision.
>
> (5) Presented with similar circumstances many of us will make different decisions because we give greater weight to some factors rather than others. Factors influencing our decisions will be our own values, preferences and previous experiences. Some people are keener to express their own individuality or more willing to take risks than others. However, there may be cause for concern if an individual repeatedly makes unwise decisions and place him/her at significant risk of harm or serious exploitation. Concern may be triggered if a person makes a particular decision which defies all notions of rationality and/or is markedly out of character. In these situations it would be relevant to look at the person's past decisions and choices. While such situations should not automatically lead to the conclusion that capacity is lacking, they might raise doubts about capacity and indicate the need for further investigation.

Consider also that an obligation to develop decision making skills is explicitly present in s 1 (5) of the 2000 Act:

> (5) Any guardian, continuing attorney, welfare attorney or manager of an establishment exercising functions under this Act or under any order of the sheriff in relation to an adult **shall**, in so far as it is reasonable and practicable to do so, encourage the adult to exercise whatever skills he has concerning his property, financial affairs or personal welfare, as the case may be, and **to develop new such skills**.

Making mistakes and being exposed to the consequences of them is one way to acquire such skills and knowledge. By 'consequences' we mean *natural* consequences, of course, not artificial consequences imposed as punishments, which obviously have no place in support services.

On decision making as a skill to be learned:

> Would anybody have ever learned how to ride a bike without adequate support and a few failed attempts or falls? Stabilisers might be required for some time as well as someone to

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[18] https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2008/02/adults-incapacity-scotland-act-2000-communication-assessing-capacity-guide-social-work-health-care-staff/documents/0055759-pdf/0055759-pdf/govscot:document/0055759.pdf

> teach us or hold the bike, all with the purpose of one day being able to cycle without assistance and gain mastery of the new skill. It is no different for decision making.[19]

Consider also the MWC's 2021 Supported Decision Making - Good Practice Guide:

> 5.2.9 Allow for risk taking.
>
> Risk taking is an important aspect of decision making. In general, an adult should be entitled to take risks and learn from the consequences of them. In supporting a person, supporters may need to explain the nature and consequence of any potential risk to the individual. However, people have the right to learn from experience, to revisit decisions and change their minds and make decisions that others do not agree with.

Both the Government's guidance and the MWC's good practice guide are likely to be useful to inform and underpin recommendations on inclusive governance for SA, particularly around staff training and policy development.

On risk aversion regarding people with intellectual disability and sex (possibly a topic for further separate work):

> Historically, services have struggled with supporting the choices of adults that were considered 'unwise' or 'risky': "Where choices have been available between facilitating the sexuality of people with ID and protecting them from unwanted sexual encounters, services have typically sought to prioritise protection over empowerment." (Keywood and Flynn, 2003). **This has often resulted in individuals with ID leading safe but lonely and isolated lives.** [20]

Autistic people are typically a more vulnerable group, and this may lead to support being very cautious and overprotective. It is important to make a distinction between vulnerability and weakness. While it is important to protect vulnerable people from abuse, this is not the same thing as protecting them from the normal, and valuable, run of physical, intellectual and emotional difficulty and pain that a full lived life entails. Difficulty is essential to development, and (if we accept the principles above) supported individuals should not be shepherded away from it.

> *The road of excess leads to the palace of wisdom.*[21]

From a service provision perspective, incidents are typically considered bad things, to be avoided, if for no other reason than the paperwork. This analysis suggests that there is a need to consider the potential benefits of mistakes and 'incidents' and the possibility that some re-evaluation may be required to see (at least some) incidents within care services as indications of positive risk taking leading to a rich life for supported individuals with ample opportunities to learn and develop.

Consider the following impassioned appeals from Adam Harris of AsIAm:

> And just because the person may make a decision differently to other people, or may approach the decision differently, that their decision is invalid, or that they shouldn't be

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[19] Joanne Condon, 'Advocacy and the Assisted Decision Making (Capacity) Act 2015'

[20] Niamh Holland, *Responding to a Couple's Request for Support with their Relationship*, from *The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections* (2021) p 135

[21] William Blake, *The Marriage of Heaven and Hell*

> allowed to make decisions, or that they should be protected from the world. Autistic people should be allowed, and supported, to have the same experiences as everyone else and to make the same mistakes as everyone else….
>
> …Can you imagine what life would be like without risks? Without unwise decisions? Without doing crazy, impulsive things? These decisions can be what makes life interesting. But when we talk about autistic people and other disabled people, we forget that people actually want to live their lives and do things, and not just attend services, designed by someone else, until they are elderly. And this is how it has played out for so many people, and that cannot be allowed to continue. Hopefully the 2015 Act can change this and allow people to take risks, and to live the life they want to live.[22]

But sometimes people contradict themselves. What if they say they want two things that can't both happen? People don't always make sense. Sometimes they simply can't tell us what they want, and there's no way to tell. We must make substituted decisions then, mustn't we?

If we can't, despite our best efforts, get a coherent position from a supported individual, it may at times be necessary to make a decision on their behalf. But making a decision **on behalf of** the supported individual is not the same thing as making a decision based on what *somebody else* thinks is good for them.

Consider the following:

> An autistic man, Arthur, wants to be discharged from hospital. But he cannot be until a suitable bed has been installed in his home to prevent very serious risk of physical harm which would likely breach his rights to life. But, whenever he is asked, he says he does not want a special bed to be installed in his home. That means he can't be discharged from hospital. So, he both wants to go home, and doesn't want to have a new bed installed, and these two preferences are in conflict - doing both is impossible.
>
> A skilled Best Interests' Assessor, highly trained in the principles of the Mental Capacity Act (the English law which applies) consults thoroughly with Arthur's friends as well as professionals involved. She recognises that, in this situation, Arthur's overall autonomy would be best served by installing the bed in his house, even though he says he doesn't want this. It is apparent to friends who know him well that his overriding desire is to be at home and that he would probably get used to the new bed in time. He would be happier at home overall and have more control over his life at home. In this particular situation, making a substituted decision **on his behalf** after a finding of mental incapacity (with respect to this decision alone) was the best way to uphold his autonomy overall.

This type of decision is based on an interpretation of what we think Arthur would probably choose, if only he was able to think it through clearly, and draws strongly on knowledge of the individual concerned. Arthur's will and preferences are still determining the decision, even though he is not quite able to make the decision himself.

Scottish mental capacity law is a little behind at present with explicitly saying that all assessments of mental capacity should be made on a decision-by-decision basis, and capacity should be presumed. England and the Republic of Ireland both have this principle explicit in law now, and Scotland has it

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[22] Adam Harris, 'Living with Autism: the Contribution of the Assisted Decision Making (Capacity) Act 2015'

in guidance. The current review of mental health and capacity law in Scotland includes it in their proposals. It is hard to imagine the reformed law will not include this principle.

Under circumstances when we cannot adequately determine what someone's will and preferences are, even after strenuous effort, it may be consistent with promoting autonomy to make a **best-interpretation decision**, that is to say, a best guess as to what that person *would* choose, if they were able to. For social care workers to be able to do that requires a strong relationship with a supported individual, of the kind already described. Mary Condell again:

> …always assume that everyone is capable of being supported to make decisions about themselves for themselves, and if they patently cannot (for example, if they are in a coma), still honour their right as a human being to self-determine by finding out what they would want for themselves in these particular circumstances.[23]

If staff make friends with supported individuals, and earn their trust, won't that give them a lot of power in a relationship with a vulnerable person?

Absolutely, of course it will. But not all influence is undue influence. While close relationships carry a risk of undue influence, and emotional hurt and distress, these are normal parts of life for everyone, and an inevitable consequence of close relationships. There is no reason why a supported individual should be spared this facet of life, if its absence would mean isolation, loneliness, and diminished autonomy.

There may be sources of strong, perhaps undue influence in a person's life. There may be a domineering relative, friend, support worker, manager, psychiatrist. Perhaps the sources of undue influence are not personal but institutional, at the level of policy or culture. Close staff members may be ideally positioned to not only notice these but also be willing to act to protect individuals from such undue influence. Such risks can be minimised by encouraging multiple formal and informal relationships, such as a circle of support.[24]

A significant risk to supported individuals' autonomy and a barrier to developing trusting relationships are conflicts of interest. Staff are, typically, not actually answerable to supported individuals in any formal way. Even if a supported individual makes a complaint about a service, that complaint is then handled and resolved by others. Supported individuals cannot sack staff. It is a consequence of this structure that staff may be more focussed on the priorities of their line managers, the SSSC, the CI and local authority commissioners, than on the priorities of the individual they are supporting. It is very difficult for an individual to develop trust in a staff member who will prioritise everyone else's will before the will of the individual. Consideration may be given to creating formal structures of accountability throughout all levels of SA, so supported individuals have some genuine powers over their support staff, the wider service, managers and the organisation as a whole, in order to align the will of Scottish Autism with the will of the autistic population it serves.

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[23] Mary Condell, "Personal Reflections as a Lawyer on Experiences with the Assisted Decision Making (Capacity) Act 2015", from *The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections* (2021) p 218

[24] https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/c/circles-support-and-circles-friends

But if I start doing supported decision making, and making friends with supported individuals, and no-one else does, I'll stick out like a sore thumb. This is not going to be fun. I can't really do this in the culture I work in. A lot would need to change first.

Culture change has been commented on in the literature. In the context of the Republic of Ireland's recent reform of their mental capacity law, the prospect of culture change has been called a 'hurtling train' coming towards the health and social care system.

> …the cultural norms around decisions are learned and reinforced by employers through policies and procedures and by managers and colleagues on a daily basis.
>
> Yet these cultural norms are about to be challenged – significantly.
>
> It seems to me, as a manager in the health services, with 25 years of health and social care practice (in social care, social work and administrative management across various sectors and two countries) that Ireland is in a very early phase of major change and transition to a rights-based approach. It is really in the pre-implementation phase. That is, most staff are not fully aware of the train that is hurtling towards them.[25]

The principles of the Adults with Incapacity (Scotland) Act 2000 appear to have had little impact in 22 years on the broadly paternalistic culture that seems common in social care services in Scotland. It is to be hoped that the forthcoming reforms will be rather more far reaching in challenging existing culture and rooting care and support in principles designed to support autonomy. However, legislative change cannot bring about culture change entirely by itself. For example, in England following the commencement of the Mental Capacity Act, The House of Lords Post-Legislative Scrutiny Report highlighted (emphasis added) that:

> the 2005 Act has suffered from a lack of awareness and a lack of understanding and failed to achieve the cultural shift required, stating **"for many who are expected to comply with the Act it appears to be an optional add-on..." and that "the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded."[26]**

It is likely that, in addition to legislative changes, genuine culture change within care and support organisations, including Scottish Autism, requires changes (perhaps structural) to ensure accountability to supported individuals, who are the people it exists to serve.

Some analysis of the current culture within SA may be useful, but is beyond the scope of this case study.

I'm very uneasy about me being 'friends' with supported individuals. I don't restrain my friends. That would be awful and totally inappropriate, unless they were drunk or something and about to walk in front of a car. If I make friends with supported individuals, but then I have to suddenly become all professional and restrain them and control them, won't that completely destroy trust?

Quite possibly, yes. Looking seriously at relational autonomy and the critical importance of building relationships of trust inevitably requires reflection and reconsideration around policies on restraint and any culture of control.

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[25] Gerry Maley, 'Best Interests and the Transition to a Rights-Based Approach in Irish Health and Social Care'

[26] https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm

But we have to prompt people. If we don't get supported individuals to do things, they'll never do anything.

Prompting is not the same thing as taking away choice and control. Prompting is critical to helping people do the things they want/need to do. Prompting is good as long as that person wants and needs those prompts in order to maximise their overall autonomy. As we all know, autistic people can have great difficulty getting things done, even things they want to do. Sometimes this is called inertia. Inertia is well known among the community of autistic people and is now the subject of groundbreaking research[27].

But SDM is impractical. If we did it with every decision, we'd drive the supported individual crazy! We'd never get anything done; we'd spend all day trying to extract decisions from them.

Consulting someone over every single decision made in a day might indeed be impractical and counter-productive for everyone, although some supported individuals might want a level of fine-grained control depending on the context. Other individuals will find the social interaction involved in supporting them to make many decisions to be totally overwhelming. Asking someone what they want to do all the time might lead to chronic overload, perhaps resulting in a shut-down or a melt-down, in which they cannot make any decisions at all. Sometimes, the best way to support someone is to leave them alone. One way around this problem is to support a supported individual to make strategic decisions which are revisited from time to time. For example, a supported individual might decide how they want their room to be arranged. Then, if a support worker has to move anything, they know where to put it back without having to ask the supported individual. If a supported individual, perhaps with support, decides a weekly routine, then the staff can follow that without having to ask the supported individual every day what they should be doing. Many of these higher-level decisions about **systems** and **routines** can and should be recorded in a **support plan**. Which brings us to the next issue.

But staff have to follow the <u>support plan</u>, not what the supported individual says they want. Commissioners expect our staff to follow the support plan and they are the ones funding the support.

It is important to reflect on potential conflicts between what the supported individual wants to do, and what is written in the support plan. If there is such a conflict, then that should be taken as an indication that the support plan needs to be revised to ensure that it meets the supported individual's needs in ways that work for them and are consistent with their wishes and preferences. It is likely to be useful to regularly ask staff who work directly with supported individuals whether they ever feel conflicted and uncomfortable and/or whether they ever encounter situations in which there is a conflict between what they believe the supported individual wants and what the support plan, or a manager, or a colleague, tells them to do. Joe Long found that:

> "The staff workshops and practitioner resources that we convened to disseminate research findings emphasised the need for **authenticity of voice over third person authorship in service documents**; the use of media that were meaningful to the individual, rather than a reliance on written documentation; ownership of the process of producing supports; concrete outputs from choice-making activities to refer to and support self-advocacy; and a

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[27] Buckle, K. L., Leadbitter, K., Poliakoff, E. and Gowen, E (2021) "No Way Out Except From External Intervention": First-Hand Accounts of Autistic Inertia, Front. Psychol., 13 July 2021 | https://doi.org/10.3389/fpsyg.2021.631596

> shared understanding of choices made between individuals, their families, and support staff (Long et al. 2017, 12–13)."

The support plan is the obvious place where strategic decisions can be thought about, discussed, and ***made by*** the supported individual (not ***made for*** the supported individual) and recorded. To the extent that support plans determine what happens in a service, supported individual autonomy is promoted or thwarted to that same extent. A support plan could be either a mechanism for promoting autonomy, or an accidental means of oppression, depending on who controls it.

(NB - for the avoidance of misunderstanding, the way to avoid 'third person authorship' of a document is NOT to use 'I' statements which are written by anyone other than the supported individual themselves. Expressing the views of staff, family members or anyone else as if they were the views of the person themselves is poor practice and fundamentally at odds with SDM. Where a third person, such as staff or family members, has to do the writing/typing for whatever reason, that must be transparent. If a supported individual is able to express their view in words, then their actual words should be included in quotes.)

Within care services, support plans can function as a way for the organisation to communicate expected actions to staff and exert control over those actions. Where support plans are used, explicitly or implicitly, in this way, it can result in support plans being drawn up by staff and managers with relatively little direct input from supported individuals. A potential route to addressing this is to make structural and procedural changes to place the ownership of the support plan much more firmly in the hands of the supported individual. While the use of some type of support plan is inevitable within formal care and support services, it is critical to the autonomy of supported individuals that their will and preferences are given effect in the support plan and that the degree to which this is the case is reviewed regularly. This may require the involvement of an advocate or other independent person (such as a 'decision supporter' if such a role is created in legal reforms) with the skills to challenge staff and family perspectives as necessary. Other approaches which are relevant to ensuring the support plan is meaningfully owned by the supported individual and gives practical effect to their wishes and preferences over those of staff/family/organisation might also be explored.

This also requires that support plans must be accessible to the supported individual, both in terms of where it is stored and how and when a supported individual has access to it, as well as the format of the plan itself. If the support plan stored in a location the supported individual does not have ready access to, it may inadvertently signal that a supported individual's life does not really belong to them. The format of support plans is also important and should be accessible, perhaps as easy-read versions, or in other formats as Long suggests. This would enable supported individuals to remind themselves of what the service provider has agreed to, hold staff accountable and more easily indicate if they are no longer happy with something in the plan. If the support plan is an accessible tool for the supported individual to have control over their support, rather than a document expressing organisational or managerial intent, this would significantly increase a supported individual's control/governance over their life as a whole

This may require uncomfortable consideration of what the support plan actually is. Is the support plan the same thing as the will of the supported individual? To the extent that it is, a supported individual's will may override the written plan, which becomes out-of-date the moment a supported individual changes their mind. However, a supported individual may also wish their strategic level decisions not to be overridden by their own immediate responses (especially to spoken questions) and this should also be respected. Staff would need to have the confidence and skills to make judgements about when to follow the written plan, and when to think “Ah, what the supported individual is saying should take precedence over the written plan in this instance.” These might seem like very abstract philosophical questions, but it may well be worth giving careful consideration to what a support plan is, where it exists, and exactly the relationship between it and the will of the supported individual.

But some people find choice overwhelming. One reason we make decisions for people is so they feel secure and not overwhelmed with uncertainty and responsibility that they can’t understand and can’t cope with.

Yes, decision making can be very stressful and quickly use up a person’s supply of energy.[28] This is further evidence of the importance of supported individuals having broad strategic control of their lives, and over their support plan, in whatever ways they are able to manage, so they don’t get overloaded with a million little decisions.

But what if it does go wrong and a supported individual comes to harm? Won't staff get into trouble?

It is clearly important for staff and managers to know where they stand in terms of their own risk so that they can work confidently without fear. More work needs to be done on this to ensure staff at all levels have a good understanding of the limitations of liability and the legal foundation of positive risk taking. This is likely to require consideration of internal policy at SA, as well as understanding of SSSC expectations and wider law. The Adults with Incapacity Act 2000 contains an explicit limitation in s 82 (emphasis added):

> 82 Limitation of liability
>
> (1) No liability shall be incurred by a guardian, a continuing attorney, a welfare attorney, a person authorised under an intervention order, a withdrawer or the managers of an establishment for **any breach of any duty of care** or fiduciary duty owed to the adult if he has or they have—
> (a) acted reasonably and in good faith and in accordance with the general principles set out in section 1; or
> (b) failed to act and the failure was reasonable and in good faith and in accordance with the said general principles.

This is an expression of the broader public law reality that duty of care requires only decisions which are not negligent, rather than the elimination of all risk. The importance of work to combat significant fear of liability at all levels of staff should not be underestimated. This is a challenge in common across all care organisations. Staff can be greatly hampered in delivering good practice where they have a persistent, though unfounded, fear of being liable (both legally and in terms of blame within an organisation) if ‘something bad happens’. This fear exists at all levels of staff within care organisations, based usually on misconceptions of Health and Safety rules and duty of care. Gerry Maley outlines the prevalence of this culture of fear and blame:

> Also, whilst the HSE's Incident Management Framework 2020 outlines the positives of promotion of a ‘just culture’ and the risks involved in a ‘blame culture’, the writer’s experience is that many staff feel the sword of Damocles of the latter – perhaps less recently within the HSE, but mention is still heard of the courts or external inquiries, statutory or

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[28] https://www.edpsyched.co.uk/blog/autism-spoon-theory

> otherwise, which are not regarded as learning opportunities or reflective experiences; they are expressed in terms relating to fear and threat. This remains unhelpful.[29]

But we already ask supported individuals what they want and they don't say anything. They don't even want to make their own decisions.

Some people are so used to having decisions made for them that they struggle to even grasp that they are allowed to take some control of their lives. This can be the case where people continue to be treated as children even after they have grown up (infantilisation). Consider this comment from one of the supported individuals in the Australian SDM Project after they had begun to appreciate the benefits:

> "My feelings are angry. I don't want to be there. Maybe there will be light at the end of the tunnel. I feel free when I talk to... (his supporter). I feel a little bit scared because my [family] will be upset if my decisions work [for me]. My brain tells me I am a man... they think I am a baby."

It can also happen when a person has been in a service for a long time and has got used to decisions being made for them all the time (institutionalisation). Consider another comment from a supported individual in the South Australian SDM project:

> "[I] feel confident. [I] get confidence from having people believe I could do [these things]. A large percentage of people didn't expect me to survive, didn't recognise [that I could]. One said six weeks and you'll be back. That was nearly a year ago."

This fact has been recognised by the Court of Protection in England in case about where a supported individual (ZK) with impaired capacity should live[30]. The details of the case are not especially relevant, but a comment from Dr O Rourke, who assessed the capacity of ZK is very interesting and relevant to SDM (emphasis added):

> I am not suggesting that he is currently subject to undue influence or pressure, although he is aware of being in the middle of a dispute about where he should live. My comments reflect that, **in order to make a decision, first one needs to be aware that one is in a position to make a decision.** [ZK] has only recently begun to make very small decisions and assert his needs and is used to others telling him what to do. He does not experience himself as having agency and my concern is any 'decision' made by him would be a response to what he perceives others to want, rather than a consideration of what he himself would prefer.[31]

This highlights a very important step in the realisation of autonomy. For some decisions, before an adult can make their own decision, they first need to understand that they **can** make autonomous decisions. Typically developing people usually acquire this sense of *agency* gradually as they grow up. But often disabled people, particularly those with intellectual disabilities and/or autism, have not been given opportunities and support to develop this. If an adult doesn't experience the opportunities and support to realise that they are an autonomous adult and develop the confidence to make their own decisions, they are likely to just go along with what others think they may want.

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[29] Gerry Maley, 'Best Interests and the Transition to a Rights-Based Approach in Irish Health and Social Care'

[30] Re ZK (No.2) [2021] EWCOP 61

[31] [2021] EWCOP 61 between A LOCAL AUTHORITY - and - ZK (by his litigation friend, the Official Solicitor) -and-SB

This suggests that increasing the control of supported individual's over their own lives requires consideration of how to develop a supported individual's sense of being an *agent*, with the ability and power to make their own decisions.

From assessing capacity to building capacity

There is commentary in the literature, especially from the Republic of Ireland, on a change of perspective. Traditionally capacity assessments are made in order to determine if an intervention may be made. It's a judgement about somebody, and if the person fails the test their legal capacity gets taken away, and substituted decisions follow. There is now recognition that this is a very negative way to approach capacity and not at all consistent with the UNCRPD. It is now widely recognised that, instead, the first thought should be "How do we support this person to be able to make a decision." Consider the following extracts:

> The 2015 Act will mean a role reversal for us health professionals from capacity assessor to capacity enhancer.[32]

And this from lawyer Mary Condell again (emphasis added):

> I ask people to imagine, that as someone gradually becomes unable to make all decisions without support, they enter a tunnel which, naturally enough, becomes darker the further in they go. A professional is not facilitating a 'relevant person's' capacity by standing at the mouth of the tunnel and calling upon the relevant person to come and engage with them there. This is the old status approach where a 'relevant person' was marked down or defined by what they cannot do compared to a 'normal' person, as in for example the Mini-Mental State Examination (MMSE). Facilitating a 'relevant person's' capacity is the direct opposite to this. It requires the decision supporter to enter the tunnel themselves, locate where the relevant person is, stay there with them and communicate and work with them in their space in order to find and then **enhance whatever decision making ability they have**. It is this difference in approach, which necessitates a **complete change of culture** that is causing tensions amongst doctors and other professionals.[33]

Lessons from experience: Top tips from St Michael's House

The following reflections echo some of what has been said so far and are a valuable insight from a professional service who has already gone some way to implementing SDM practice in their service. We therefore quote in full the conclusion of the article 'Supporting Adults with an Intellectual Disability to Make Decisions: Reflections from an Organisational Perspective' by Elaine Teague:[34]

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[32] Seamus Moran, 'Social Work as Partnership', from *The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections* (2021)

[33] Mary Condell, "Personal Reflections as a Lawyer on Experiences with the Assisted Decision Making (Capacity) Act 2015", from The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections (2021)

[34] The Assisted Decision Making (Capacity) Act 2015: Personal and Professional Reflections (2021) p 127

So, now that we are one year on from the establishment of the ADM Steering group and using implementation science to guide us, what have we learned?

Start and Get Better

The feeling of not knowing where to start can be paralysing – sometimes it's easier to do nothing than start. Waiting for the 2015 Act to fully commence, waiting for case law to emerge, waiting for Supreme Court judgments, not having enough resources, being busy with other matters are all reasons not to get started. However, by starting, you learn what is needed. There is no such thing as the perfect time to get started – start slowly and get better over time!

Include the adults who use the service

By including adults who use the service to help guide the key messages and priority areas, it lessens the risk that it becomes a bureaucratic exercise. Service users keep us focused. They know what is important to them and it is our role to respond to that.

Don't overcomplicate it

Look at what you have in place – what can be useful to you? By using existing structures, you can reassure people that not everything will change. Pick a few key things to focus on and communicate those. We identified two key messages:

- *Will and preference instead of best interest*

- *Build capacity rather than assess capacity*

Culture eats strategy for breakfast

Culture is 'how we do business around here' – we learned that if you start with the willing (those who are already committed to a rights-based approach) you can win the hearts and minds of others. There will always be people who do not think ADM [assisted decision making] is necessary. Do not focus on convincing them – save your resources for those who are open to being convinced. Building case examples, one person at a time, one decision at a time can help to shift culture and show people the alternative way. It also allows the organisation to learn what is needed (e.g. policy updates/coaching for staff, etc.).

APPENDIX 1 - The South Australian Supported Decision Making Project

One well documented project was conducted in South Australia and the Final Report published in 2012.[35] According to the Final Report, it went very well (our bold):

> "The Supported Decision Making project has demonstrated that there were specific benefits to most of the participants. These were seen in their **increased confidence** in themselves and in their decision making. There was evidence of **improvement in decision making skills**. Participants described the growth in their support networks. Many reported that they felt **more in control** of their lives. Participants gave evidence that they had **increased their engagement** with the community, either through expanding their options or through making decisions that changed their circumstances.
>
> The evaluation gives evidence that Supported Decision Making was both a companion process and **viable alternative to substitute decision making** for participants who were initially on Guardianship Orders." (pg 4-5)

The arrangement was as follows:

Trialled with 26 people as a proposed replacement for Guardianship. Not all those included in the trial had a guardian. The mechanism is an 'SDM Agreement.' The supported person 'chooses' someone to be their supporter to 'assist me to make decisions'. The decision supporter is authorised to support with high-level decisions such as where to live as well as lower level decisions. In practicing SDM, the decision supporter helps by:

> "Providing information in a way I can understand.
>
> Discussing the good things and the bad things that could happen.
>
> Expressing my wishes to other people"

Where they make decisions which a Guardian is authorised to make, the Guardian retains final responsibility for these, however the Guardian agrees to take into account the SDM decision when making their final decision.

What did the supported individuals think of it?

> Johnny:
>
> '[I] feel confident. [I] get confidence from having people believe I could do [these things]. A large percentage of people didn't expect me to survive, didn't recognise [that I could]. One said six weeks and you'll be back. That was nearly a year ago.' (pg 19)
>
> Kathleen and her supporter believe that using Supported Decision Making 'helps to make things clearer', 'gives me a little bit of security about what to do,' 'helps me be the person I want [to be]' and does 'support decision making.' Kathleen said that she tried writing down her decisions, but did not use the project diary. She said that now she 'thinks about it before saying Yes.' (pg 25)
>
> 'I am more independent - I talk about [things] more.'

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[35] http://www.opa.sa.gov.au/files/batch1376447055_final_supported_decision_making_evaluation.pdf

‘I set my goals.’

‘I sent an email looking for an explanation about... The explanation made me feel better.’

‘I have confidence to make decisions, even if [it is a] mistake.’

‘It made me think before I do. Now I think, what do I want this for.’

‘I have learned to say no. I am happier ...’

‘My kids have noticed a big difference in me. [My daughter] said she is so proud of me. It made me cry.’

‘I get my independence. I think for myself - I feel good about making decisions. It’s my new life. [I have] confidence in myself that I never had before. I didn’t used to speak my opinions.’

‘Now I do my own shopping, look after myself. I am feeling good. Not as depressed.’

‘I go to [the] problem now, take advice. I’m thinking properly for myself. Life’s not too hard. There are people who can help me, and sometimes you’ve got to ask for help.’ (pg 31-32)

‘My feelings are angry. I don’t want to be there. Maybe there will be light at the end of the tunnel. I feel free when I talk to... (his supporter). I feel a little bit scared because my [family] will be upset if my decisions work [for me]. My brain tells me I am a man... they think I am a baby.’ (pg 33)

What did the families and friends of the supported individuals think of it?

Johnny’s sister said that his involvement in the project ‘saved his life and made his life worth living again as he was his own boss.’ His friends thought that Johnny had achieved a level of happiness in the last eighteen months of his life. (pg 19)

‘I see her differently. I let her go.’

‘It is important to consult [her] about holidays, as opposed to believing her capacity to decide is conditioned by communication, as [she] is non-verbal.’ (pg 36)

What did the decision-supporters think of it?

‘She is more opinionated about what she wants to do. I really enjoy that.’

‘I can see [he] has got stronger.’

‘has made a lot of difference. He can run [his] house on his own and pay bills now.’ (pg 35)

‘I am a trusted friend, not a carer.’

‘They communicate with me, are concerned for me.’

‘We feel OK about going on [as supporters]. We have a friendship that will last. We love him.’ (pg 35)

What did the professionals think of it?

Staff members from the state government disability agency saw benefits in the Supported Decision Making process …. The particular strength of the process from their point of view was that the SDM Agreement gave the participant ‘formal approval, a piece of paper, that said somebody is going to listen to me... it restores power.’ (pg 38)

The SDM Agreements were seen as having real advantages. They gave legitimacy to the participants to express their views and have conversations. The process underpinning the SDM Agreements also allowed for conversations that would not have otherwise occurred. One of the staff members from the agency said that ‘it gives permission and opens up an opportunity ... to start with the person and to be more personal. We can exchange information.’ (pg 39)

Appendix D: Example of Accessible Accounts from People First (Scotland)

People First (Scotland)

Accessible accounts summary 2020-2021

We are directors and trustees

People First
(Scotland)

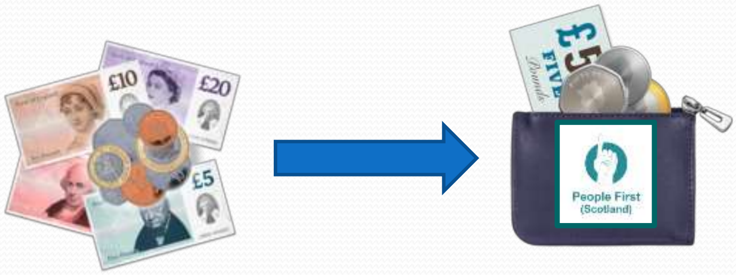
WHITELAW WELLS
CHARTERED ACCOUNTANTS
...*where people matter*

Report a Fair and True picture

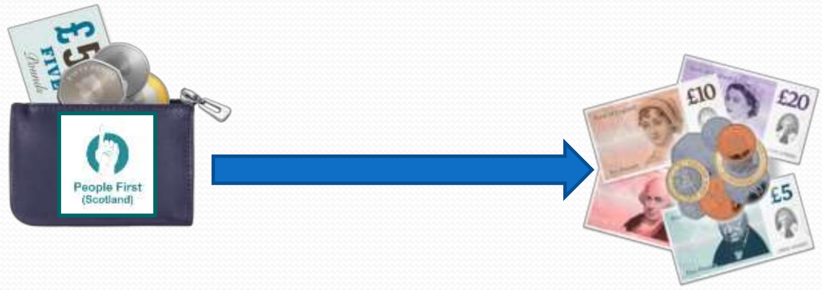
People First
(Scotland)

Clean Audit Report

The year before... 2019-2020



Money in
£610,228



Money out
£572,260

The year before - 2019-2020

People First (Scotland)

- In the year before People First received more money than it spent

- **£610,228** → → **£572,260** →

- **Last year People First had a surplus of £37,968**

But...

People First (Scotland)

→ COMIC RELIEF LOTTERY FUNDED ↓

- Some of the **£37,968** surplus was there for the Law and Human Rights Group work and the National work.
- **After the money was put aside we were left with a surplus of £37,822**

The year we are talking about (2020-2021)

- **The year we call "This year" started on 1st April 2020**
- **It ended on 31st March 2021.**
- **On 1st April 2020 we had reserves of £363,778.**

Unrestricted reserves

- This is the money that we have in the bank that is not "restricted", not set aside for any particular project.
- That means it can be spent on different things
- **We have a policy to keep reserves in the bank that would let us run for 3 to 6 months if our funding stopped.**
- **£363,778 is enough for just over 7 months running costs.**

Where the money came from this year (1).

Who paid?	What does it pay for?	How much is paid?
Scottish Government	(Core costs) (Keys to Life National work)	99,676 32,000
Scottish Government	(Parents project)	23,000
ARC Scotland	(SOLD)	43,455
Glasgow City Council Values Into Action Scotland	Local area work The Life I Want project	78,304 15,300
Fife Council	Local area work	82,842
Midlothian Council	Local area work	23,982
South Lanarkshire Council	Local area work	62,912
Clackmannanshire Council	Local area work	20,184
Edinburgh Partners in Advocacy	Edinburgh work	23,742
Big Lottery	National/Making Our Voice Stronger	48,670
Scottish Government – Learning disabilities hospital project		18,941

Where the money came from this year (2).

Who paid?	What does it pay for?	How much is paid?
National Emergency Trust	COVID-19 funding	£20,048
Members fees and donations		£5,000
Universities	Students on placement with People First	£2,540
Other money that was paid to us	Investment income, training income and monies paid back to us for events.	£4,516

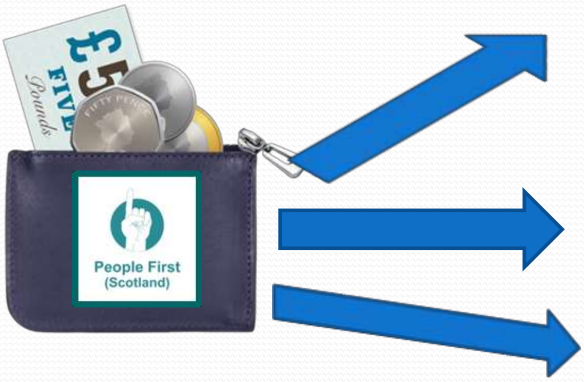
<u>During 2020-21 year People First was paid</u>

£604,955 in total

Also

- There was **£61,952** “restricted “ money kept aside from the previous year. We had that money to spend.
- When we add that to what we were paid it makes a total of
- **£604,955 + £61,952 = (£666,907)**
- **During the year we spent £581,401**

What the money is spent on



- Staff and volunteer costs

£ 472,949

(Last year **£455,458**)

- Office costs

£ 97,323

(Last year **£84,661**)

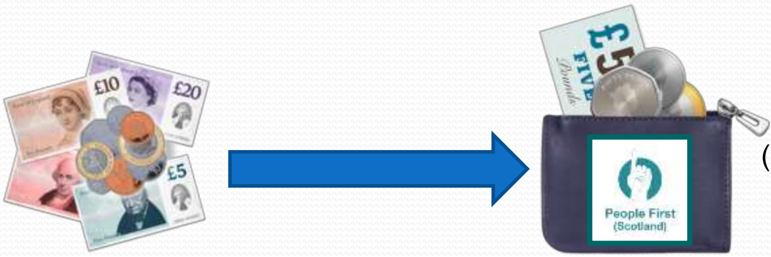
- Member expenses

£ 11,129

(Last year **£32,141**)

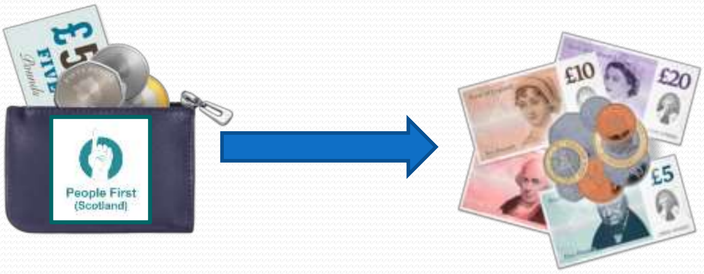
The year we are looking at -2020 -2021

People First (Scotland)



Money in
(£666,907)
(£604,955 + £61,952)

Money out
£581,401



= £85,506

But…

People First (Scotland)

LOTTERY FUNDED

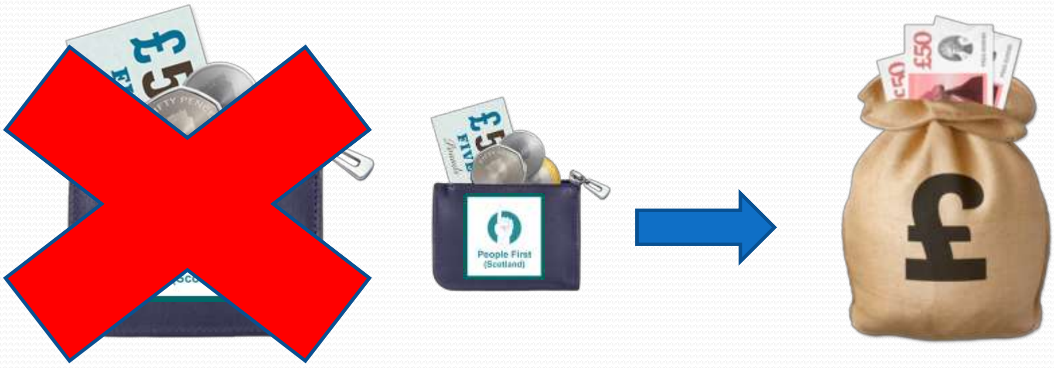
CLYDE GATEWAY

VIAS

- Like last year some of the **£85,506** surplus is there for the National work and Learning Disabilities Hospital Project.
- That money could not be used for anything else and is in the **restricted funds** it added up to **£74,111**
- **After that money was put aside we were left with a smaller surplus of £11,395**

Surplus this year - 2020-2021

- So People First received more money than it spent.
- The money which goes into our reserves is **£85,506**
- When we take away the restricted **£74,111**
- **That leaves the smaller surplus of £11,395 unrestricted funds**



The year we are looking at- 2020-2021

- **On 1st April 2020, the start of the year we had reserves of £363,778.**
- **We add in the £11,395 surplus.** (the money in the surplus of £85,506 that is not restricted)
- **That makes £375,173**

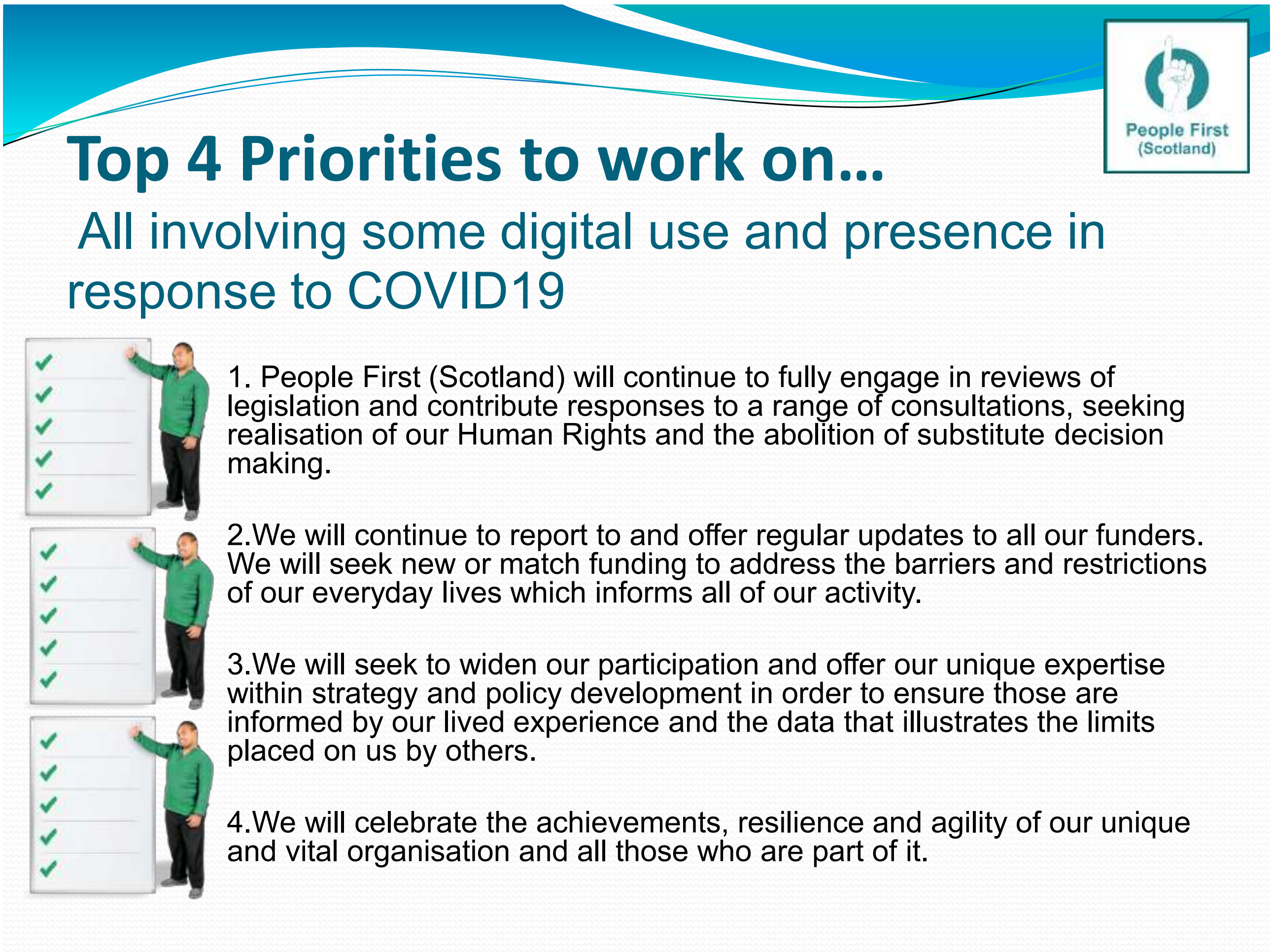
Still strong

- We are in a strong position

- £375,173 is just over 7 months running costs.

Top 3 Risks we face…

1. Difficulties developing and diversifying membership might be made worse by digital exclusion.
2. Funders may change what they fund and may not see People First and citizens with learning disability as a high priority.
3. 3. Exhaustion, isolation and poor health, directly or indirectly related to COVID19 may cause members to step back from activity resulting in reduced membership participation.



Top 4 Priorities to work on…

All involving some digital use and presence in response to COVID19

1. People First (Scotland) will continue to fully engage in reviews of legislation and contribute responses to a range of consultations, seeking realisation of our Human Rights and the abolition of substitute decision making.

2.We will continue to report to and offer regular updates to all our funders. We will seek new or match funding to address the barriers and restrictions of our everyday lives which informs all of our activity.

3.We will seek to widen our participation and offer our unique expertise within strategy and policy development in order to ensure those are informed by our lived experience and the data that illustrates the limits placed on us by others.

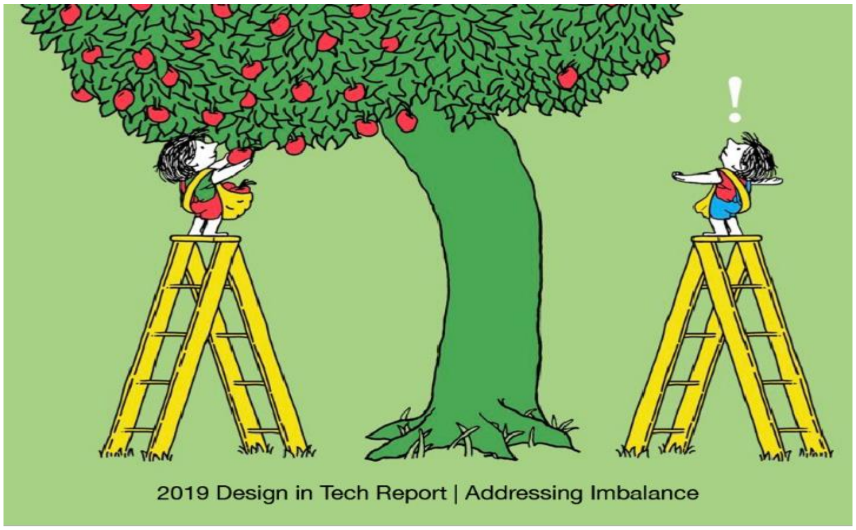
4.We will celebrate the achievements, resilience and agility of our unique and vital organisation and all those who are part of it.

Appendix E

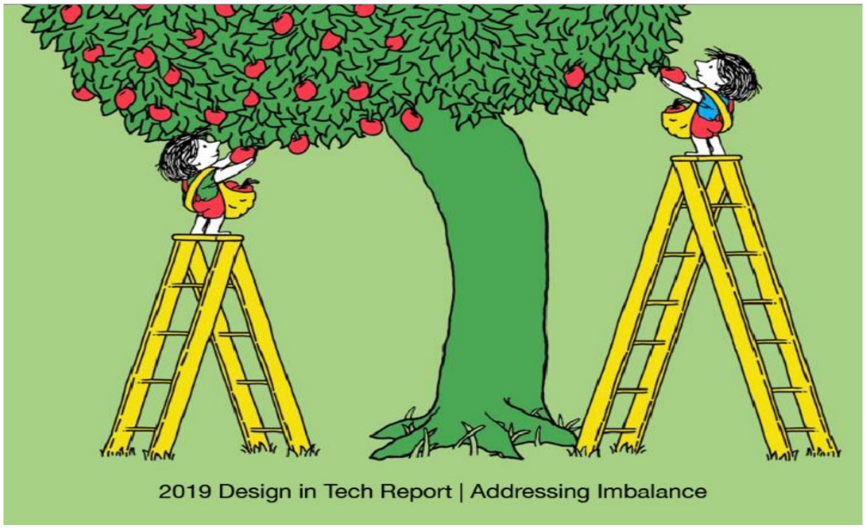
Equity vs. Equality: What's the Difference?

While the terms equity and equality may sound similar, the implementation of one versus the other can lead to dramatically different outcomes for marginalized people.

Equality means each individual or group of people is given the same resources or opportunities. Equity recognizes that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome.



Equality



Equity

In the illustration above, two individuals have unequal access to a system — in this case, the tree that provides fruit. With equal support from evenly distributed tools, their access to the fruit still remains unequal. The equitable solution, however, allocates the exact resources that each person needs to access the fruit, leading to positive outcomes for both individuals.

While the tree appears to be in a naturally occurring system, it's critical to remember that social systems aren't naturally inequitable — they've been intentionally designed to reward specific demographics for so long that the system's outcomes may appear unintentional but are actually rooted discriminatory practices and beliefs.

"The route to achieving equity will not be accomplished through treating everyone equally. It will be achieved by treating everyone justly according to their circumstances."

—Paula Dressel, Race Matters Institute

Equality and Equity are not synonyms.

The words *equality* and *equity* are often confused because, at a glance, they appear to mean the same thing. They both have to do with the way people are treated, and both are used in the fields of law, government, economics, and so on. Often, these terms are used to describe actions, laws, or rules that are attempting to end or oppose *injustice* or unfair treatment of people.

However, *equality* and *equity* as noted above are not synonyms, and the methods used to achieve them are often very different.

What does *equality* mean?

The word *equality* is defined as "the state or quality of being equal; correspondence in quantity, degree, value, rank, or ability."

Equality is usually simple to understand: three buckets that all contain five apples are in a state of *equality.* They all have exactly the same amount of the exact same items.

Under the law, Americans have *equality* in the sense that nobody can be legally denied their rights based on any personal quality.

The word *equity* is defined as "the quality of being fair or impartial; fairness; impartiality" or "something that is fair and just."

Equity is more complicated than *equality*.

The complication with *equity* is that people often disagree on what is "just" or "fair." These are subjective concepts and, as a result, laws and policies that attempt to achieve *equity* are often challenged in court or are controversial.

The use of the word *equity* has increased due to concerns about social justice and a desire for fairness for historically oppressed groups. In the law, minority groups may have equal rights but are still treated unfairly.

Historically oppressed groups such as LGBTQ+ people, Black people, and Indigenous peoples have not only fought for *equality*, but continue to fight for *equity* in society.

How do we use *equality* and *equity*?

The best way to show the difference between *equality* and *equity* is with an example.

For example, if I gave a rich woman and a poor woman each $100 that would be an example of *equality* since I gave both the same amount of money.

Alternatively, if I gave a rich woman $100 and a poor woman $200, then it could be said I am trying to achieve *equity* by “fairly” giving the poor woman more help based on her financial situation.

Ideally, we would be able to achieve both *equality* and *equity* when it comes to the law and society, but this is usually very difficult.

However, knowing the difference between *equality* and *equity,* will give you a better idea about what goal a person is trying to achieve and the proper word to use to describe it.