

Process evaluation of a new approach in leadership and engagement policy development

1. Introduction

Animate were commissioned by Inspiring Scotland to undertake a process evaluation of the work they are doing with the Learning Disability and Autism team within the Scottish Government Mental Health Directorate to support a new way of engaging with autistic people and people with a learning disability.

2. Background and context

Scottish Government and COSLA's aim is to establish a new leadership and engagement process that puts people's voices and experiences at its heart. This ambition was outlined in the Scottish Government and COSLA 2021 Towards Transformation Plan.

The Towards Transformation Plan states:

"We will put in place plans for everyone to work together through new leadership arrangements and for this work to be led by autistic people and people with a learning/intellectual disability. National and local organisations need to be involved in this."

"We want the voice of autistic people, people with a learning disability, and unpaid carers to be at the centre of work going forward."

"We will also be led by autistic people and people with a learning disability about how much of this they want to do together."

These statements succinctly express the ambition and intention of the leadership and engagement process.

3. Methodology

Animate undertakes evaluation from an appreciative perspective to determine *what has worked well* that can be built on, and what could be done differently/better going forward.

The process evaluation involved learning about the purpose and processes of the Leadership Framework journey to date, initially through reading programme papers and orientation conversations with Sally Cavers and Bee Vellacott. This was followed by a series of one-to-one conversations with a sample of 18 participants across the diversity of the leadership and engagement process (autistic Drivers, Allies, Engineers and the Scottish Government Team), and a focus group with six learning disability Drivers and support workers.

We developed a set of semi-structured interview questions designed to facilitate conversations that would enable us to capture participants' experience. The headline questions were further expanded to better suit the needs and preferences of some autistic participants, enabling them to send in written responses in addition and/or in place of online conversations.

4. Findings

What has worked well

The process evaluation found that participants believe that the SG and COSLA are genuine in their intent and endeavours to co-design a participatory process that puts the lived experience of autistic people and people with a learning disability at the centre.

Autistic Drivers and other autistic participants interviewed were appreciative of the political will to undertake the process, and the time, energy and financial investment behind it. They have felt well supported by Inspiring Scotland and feel that the Scottish Government have listened to how they could engage better, been flexible and have improved communication. They have found the online meetings easier to manage. While the recent in-person meeting at St Andrew's House had its challenges, participants appreciated the opportunity to meet with each other.

Learning disability Drivers appreciated that they had the opportunity to have their say and that they were listened to. One participant reported that being part of the group and made him feel important, that he had a stronger sense of self-worth, and that his mental health has improved. Although the St Andrew's House experience had been challenging, they felt that the meeting itself had been good: the language was much better, but they still need more time to convert information to easy read and more processing time.

Allies and Engineers valued the broad commitment of SG and COSLA to engage and listen to people with lived experience, and the desire to create a narrative that looks at change and policy development, holistically, based on the life experience of autistic people and people with learning disabilities. The SG have tried hard to get voices from across the autistic and learning disability communities. It was seen as the first serious attempt by SG to co-produce in this context, beyond consultation, and it was felt that it could be a blueprint for other SG initiatives.

Scottish Government and COSLA were pleased to try out this new way of collaborative working - trust building, being open and inclusive and giving up control rather than setting the agenda. They have tried hard not to over promise, to be open about the limitations of their power and to give the process time to engage people well.

What has been challenging

Autistic Drivers and other autistic participants stressed the need for meaningful participation as equals, and felt that many autistic voices were still unheard. There was a

great desire for everyone to receive the same information, presented clearly and consistently. They found some of the terminology and roles confusing. At times they felt that the process was slow and lacked a sense of urgency. There were differing views on the merits of focusing on mental health as opposed to upstream systemic issues, like education, employment, housing, health. There are diverse opinions about how to proceed. Some members want to lobby, while others are keen to collaborate and try things out. The in-person meeting at St Andrew's House proved daunting to some although they were pleased that there had been a good turnout of Drivers. It was felt that the lack of comprehensive travel support and a hybrid option had been exclusive. Some found the information unclear, and this led to the meeting overrunning though good progress was still made.

Learning disability Drivers find it stressful when too much is going on at the same time – and when there are too many voices in the room. They found it challenging to digest an easy read paper of 14 pages with only two weeks' notice. The in-person meeting in St Andrew's House was difficult. They found the security challenging and the room inaccessible for those with mobility issues. Working with four topics was too much at one time and confusing – they felt one would have been enough.

Allies and Engineers shared some confusion around role, though most saw it as amplifying and adding to what came from the Drivers. Some felt that the Autism Advisory Forum should be run by autistic people, and that the experience of autistic people's organisations (APOs) was being downgraded. There were also tensions around balancing speed, depth and convenience in the process. Timely and accessible information was seen as essential for all. There were some misgivings about whether the process had created unrealistic expectations in the Drivers, and there was a suggestion that the lived experience research needed to be strengthened with more academic research. Some felt COSLA and Scottish Government should have brought in more public sector Allies because they are local decision makers and local solutions will need to be developed.

Scottish Government and COSLA. The Scottish Government team found this new co-creative way of working with two communities with differing needs difficult initially and acknowledged that the whole process has taken much longer than anticipated. Providing timely information in accessible formats for the different groups continues to be a challenge. COSLA recognise that the process is challenging, and that it is difficult to get people focused on a single issue. They are aware that the process is taking longer than anticipated and are keen that proposals are brought forward. SG are confident that they have some trust and buy in, and are aware they need to be honest and clear about what is within their gift.

What could be done differently going forward

Autistic Drivers and participants want human rights principles, focused on empowerment and informed and meaningful participation, to underpin the approach. The voices of lived experience need to be heard and given equal weight to professionals. This meant getting all the roles round the table. They felt the secondary research should have come first so it

could have informed the primary research. They wanted to hear from a wider range of autistic voices and more involvement of people who make decisions e.g., Engineers from health and social care, NHS – people who train medical professionals. They wanted to increase the frequency of autistic Driver meetings to improve engagement and build in pre-meetings or linking meetings to help with flow/continuity. Some expressed a need for semi-independent oversight (governance). They were concerned to make progress on agreed actions.

Learning disability Drivers focused on how to better support their participation in the process. This included prior preparation for meetings, attention being paid to the scope and focus of meetings themselves, and the logistics of attending and taking part. They wanted the information they needed for meetings at the same time as autistic Drivers, in an accessible format and broken down into manageable chunks. It takes time to do this, and support workers need to get the information in good time to convert it to accessible formats. They wanted a plan for each step – the right information in the right format/language at the right time, travel support (including carers/support workers when necessary). They felt they would benefit from having people (support workers) with them to explain things to them and some more time and space to think and come up with ideas.

Allies and Engineers were concerned that clear shared expectations for the process be established. They felt it was important that the different stakeholders were brought together more often, to work on improving the system. They recognised the need to find creative ways of reaching missing voices. Others stressed the need to have budget holders in the room, that they should have been in from the beginning. Some felt that there is more overlap than difference between the two communities, and there is a need to take an inclusive approach and have some conversations in different places. The need for clear timely information in appropriate formats was seen as essential to enable successful communication and shared understanding. Different expectations of conduct at meetings were also seen as challenging. Some felt this could be improved with better facilitation, possibly adopting cofacilitation with an autistic facilitator who could play a translation/interpretation role. Clear shared expectations, a culture of learning and no blame for failure were seen as essential.

Scottish Government and COSLA. The Scottish Government team are aware that they need to be realistic and give clearer expectations of the process and limits of their power and to keep working on providing timely accessible information. They are committed to working collaboratively and are keen to get to a point where everyone can see progress.

5. Conclusions

The Scottish Government supported by Inspiring Scotland and the Assembly are working hard to co-design a new way of working which puts the lived experience of autistic people and people with learning and intellectual disabilities at the centre. It is complex and challenging work trying to meet the diverse information and communication needs of individuals and the differing hopes and expectations of the range of participating individuals

and organisations. The commitment, determination and dedication of the Scottish Government and Inspiring Scotland team to genuine co-production has been truly appreciated by Allies, Drivers and Engineers alike.

The need to keep clarifying the purpose of the process, the roles of the participants, and shared expectations on scope and timescale are paramount to the success of this initiative. It is also essential that participants are clear about the limitations of the process, what's within the power and gift of the Scottish Government team, and the demands of the internal Scottish Government decision-making system. There are ongoing tensions focused on speed, depth and convenience built into the co-production which are highlighted in the report. Some examples include:

- The need to move quickly on issues which affect the day to day lives and human rights of people with learning disabilities and autistic people and the importance of slowing down enough that everyone can get on board and understand the information which is presented to them
- The need to provide everyone with enough information without swamping them with too much
- The need to involve everyone with a stake in the process, from the outset but also at a time when they can make a genuine and meaningful contribution
- The need to make meetings accessible by working online whilst acknowledging the benefit of in person workshops to develop relationships and improve communication

The next stage of the process will involve the working groups coalescing around the prioritised options, and this will provide a natural opportunity to reset.

6. Recommendations

- 6.1 A wider range of voices from across the autistic and learning disability communities including younger people (18- 25 years), BME people, and those with more severe communication needs is heard.
- 6.2 All participants should receive the same information in accessible formats in sufficient time to prepare for meetings. The Scottish Government, Inspiring Scotland and Assembly teams should keep up the good work of liaising and collaborating with the people they support and with one another to enable ongoing learning regarding the production and dissemination of information to participants. Some participants also need travel support to attend meetings.
- 6.3 More frequent meetings with the Autistic Drivers could help the flow and continuity of the process. Smaller pre-meeting preparatory and linking sessions may also be useful in this regard.
- 6.4 More opportunities to meet together as Engineers, Allies and Drivers in separate groups as well as collectively will be useful in further developing trust and working relationships and a shared understanding of the process, its scope and imitations. The working groups will be a case in point.

- 6.5 A working agreement that is based on the PANEL¹ principles and captures what each party needs to collaborate and work well together should be developed to ensure good governance and enable meetings to run well.
- 6.6 The possibility of co-facilitating meetings with an autistic facilitator should be explored.
- 6.7 The Scottish Government and COSLA should continue to engage and bring in public sector Allies and Engineers with decision making powers and leverage to enable and accelerate change.

7 Next Steps

The next phase of Animate's work will focus on researching best practice, including the idea of co-facilitation with an autistic facilitator and developing accountability to people with lived experience. We will also focus on developing an evaluation framework.

"I really genuinely want to thank Scot Gov and IS for trying. I really appreciate the intentions to involve autistic people and trying to be open with us. Just because I don't think the process is how it should be quite yet doesn't mean I don't appreciate the trial and error in attempt to get there. It's better than I've seen before in policy work, so it's still a step forward in my eyes. I just really hope that it's not given up on, because I really do think it's possible to get it right and for it to be an easier and better pro – autistic participant

¹ https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

Appendix: the Findings in Full

The findings have been structured to reflect the different voices within the process. It differentiates between:

- Drivers - who are all people with lived experience of either learning disability or autism
- Allies – who are committed to working with people with lived experience to support them to make changes to improve their lives
- Engineers – who are Drivers working with local and national decision makers.

Our interviews showed that there were differences and commonalities in their feedback. When the views are the same, they have still been repeated to ensure that it is clear that they come from more than one constituency.

What has worked well

It is clear that participants believe that the SG and COSLA are genuine in their intent and endeavours to co-design a participatory process that puts the lived experience of autistic people and people with a learning/intellectual disability at the centre.

Autistic Drivers and other autistic participants interviewed were appreciative of the political will to undertake the process. They liked that it has gone into great depth with lots of time, energy and financial investment behind it.

This included being invited into partnership and given the opportunity to shape the process and underpin it with a human rights approach. They have felt well supported by IS to do that and feel that SG have listened to how they could engage better, been flexible and have attempted to improve communication which is now much better than it was in the beginning.

“The communication process from IS has been good, amazing: emails, paper copies, copies of papers awaiting us at meetings – a real comfort to me. Lots of well-structured emails; with actions, timescales, deadlines etc. They are very approachable, speak and behave respectfully – have huge trust from me.” - autistic participant

They have found the online meetings easier to manage. While the recent in-person meeting in St Andrew’s House had its challenges, participants appreciated the opportunity to meet with each other, and to be around other neurodiverse people – likeminded individuals.

“Lovely to be in a room with other autistic adults who are hugely, eloquently, articulately challenging the SG on the way forward – proud of them.” - autistic participant

They liked that time was taken to make them all feel ‘on top of it’, and their request for a follow up online meeting to complete the consideration of the four options was listened to

and is being arranged. It was referred to as a ‘really good extra structured, meaningful opportunity’.

Learning disability Drivers appreciated that they had the opportunity to have their say about what matters to them and that they were listened to.

“We got to say our piece and they listened to us – and we came up with good suggestions” – learning disability Driver

They felt that the SG were ‘pretty honest’, and they liked the opportunity to change things for the better for others in the future.

One participant reported that being part of the group and made him feel important, that he had a stronger sense of self-worth, and that his mental health has improved. He liked the chance to help other people. They reported that the Assembly includes autistic Drivers too – that some autistic Drivers find the Assembly more accessible than autistic Driver meetings.

As with the autistic Drivers the in-person meeting in St Andrew’s House had been challenging but they felt that the meeting had been good. People had listened and were honest about what they might not be able to do. They felt the language was much better in this meeting, but they still need more time to convert information to easy read and more processing time.

Allies and Engineers interviewed reported that they valued the broad commitment of SG and COSLA to engage and listen to people with lived experience, and the desire to create a narrative that looks at change and policy development, holistically, based on the life experience of autistic people and people with a learning disability.

Although the process has been lengthy, they felt that it has been given the time it needs, that it needs to be iterative and include cycles of reflection and action. They recognised that SG have tried hard to get voices from across the autistic and learning disability communities, though some are louder than others, and others not being heard e.g., 18-25 years with significant communication difficulties, and ethnic minority communities.

It was seen as the first serious attempt by SG to do co-production properly, beyond consultation, and that it could be a blueprint for other SG initiatives e.g., developing the National Care Service. They appreciated that it involved surrendering elements of power and control and the reversal of power relationships. The ‘microphone being with those with lived experience,’ and being invited to listen to lived experience without getting defensive, was moderately uncomfortable at times.

Scottish Government and COSLA were pleased to try out this new way of working - ‘giving up control, standing back, with more of a blank sheet of paper’. The expectation is normally that SG will set the agenda. This approach has been much more about ‘how do we do this together – trust building, being open, inclusive, open to ideas, especially with Autistic People’s Organisations (APOs)’. They have wanted to be collaborative, through the

Assembly and Forums. They have tried hard not to set it up to fail, and not to over promise. This has meant taking a lot of time and providing the support needed to ensure that everyone feels included and valued. Many of the autistic people are experienced activists, interested more in outcomes than in the design process itself.

“The voices of autistic people and people with learning disabilities have never been as meaningfully engaged in discussion and they feel more empowered. External 3rd sector people have told us this, that this is a more positive leadership approach than they have seen before, it is really encouraging.” – SG team member

The process has been about trying to manage timescales and money rather than expectations. They have tried to be open about and convey the Ministerial context and the budgetary position. The focus of the working groups will be to develop ideas and the SG team will promote them internally.

They brought Allies in as a kind of alternative Programme Board to help them develop and sell ideas – ‘we need their passion’. The SG can push for local implementation, changing how people are treated, and Allies can support this leading to changes in wider society.

What has been challenging

Autistic Drivers and other autistic participants stressed the need for meaningful participation as equals – professionals are fully salaried while people with lived experience are volunteers.

They were concerned that many autistic voices were still unheard e.g., BME autistic people. They need the voice of those in marginalised communities and they need to be properly resourced.

There were a number of concerns about information because not everyone receives the same information. They found some of the terminology confusing – some were unclear about the Engineers role and felt that they are not as engaged in the process. There was a great desire for information to be presented clearly and consistently.

“SG are all very nice people, keen to make a difference but the process is so convoluted – meetings about meetings.” – autistic participant

There were concerns expressed about the pace of the process. Some felt the process has been too ponderous, convoluted and intangible: the lack of urgency was ‘infuriating’.

“I turn up and express an opinion, ask direct and specific questions about budget, timescale etc because I have learned how complex and convoluted and slow these processes are – lots of talking without much action. I am action oriented, and I get frustrated with the slowness of the pace.” - autistic participant

Others felt that the focus on mental health was all very well, but the real need was to look upstream to address the systemic issues (education, employment, housing, health) – to see the big picture and deliver wholesale change.

There are diverse opinions about how to proceed. Some members felt that some colleagues with a strong sense of autistic culture are engaged in promoting a political agenda and can tend to focus on the negatives. Others feel there is a need to be respectful of difference and are keen to collaborate and try things out. They feel that when trying to effect change it needs to be both incremental and structural.

“Some APOs have very fixed ideas – if you are not with us, you are against us - but we won’t get anywhere by shouting, it is not useful and creates barriers. You can still speak clearly and call people out when necessary.” - autistic participant

Concerns were expressed about the ‘silo-ing of different groups’.

“Engineers were effectively separate till Drivers came up with the ask (mental health) – that’s systemically part of the problem – they didn’t have time to engage with the process – we don’t know who they are, they are not forthcoming.” - autistic participant

The in-person meeting at St Andrew’s House proved challenging to some although they were pleased that there had been a good turnout of Drivers.

The lack of comprehensive travel support meant some were unable to attend, and there was no hybrid option, so it was felt they were effectively excluded. Some found the building daunting, now being unused to face-to-face meetings, that lots of first-time meetings were a sensory challenge.

The meeting had overrun (three hours instead of two hours) but most stayed and it was good that SG were flexible.

Some found the wording used in places upsetting, and that some topics can be very emotive for people with lived experience especially in person. Others found it difficult to think about and differentiate what should be tackled in the short, medium and longer term because it downgrades some people’s experience.

Learning disability Drivers reported that they find it stressful when too much is going on at the same time. Sometimes, with support workers interpreting there are too many voices in the room – both online and in-person, and some had to block out the noise using ear defenders.

The workshops had to be delayed to enable recruitment of additional Assembly workers and because of this it has felt a bit rushed since.

The information provided can be a bit too much all at once. They found it challenging to have to digest an easy read paper of 14 pages (created from a 35 page document) with only two weeks' notice to prepare and understand the paper.

The in-person meeting at St Andrew's House was difficult for people. They found the security challenging and the room inaccessible for those with mobility issues. Being escorted to toilets, made them distrusted.

They also found the four topics too much to deal with at one time, and would have preferred to choose one topic and stick to it, because 'swopping about confuses people'.

Allies and Engineers interviewed experienced a range of challenges. There was some confusion around role, and some were unsure if and how much they were allowed to share with their organisations as they understood they were there as individuals. Most saw their roles as amplifying and adding to what the Drivers came up with.

"We are here to look at evidence from Drivers (research), collectively as people of influence and authority to look at and conclude what actions need to be followed up - with 'evidence informed policy' rather than organisational interest shaping events." - Engineer

Concerns were expressed that the Autism Advisory Forum is run by IS. They felt that it should be run by autistic people, and that the experience of APOs was being downgraded and not taken seriously.

There were also tensions around balancing speed, depth and convenience in the process. They wondered whether it might have been better if they had asked APOs how can we do this together and then co-designed it.

Some needed the information two weeks in advance so they could prepare properly for meetings. They stressed that people need plain language and simple words and pictures, easy read, talking mats etc.

Again, some felt that the focus of concern for people with learning disabilities should be in upstream systemic issues like hate crime, health care rather than simply on mental health.

Others felt that a reflect and learn approach should have been embedded into the process from the start.

Although essential, perhaps too much attention had been engaging and involving people with lived experience with not enough emphasis on the difficult tasks of decision making and implementation. The fear is that it created a high degree of expectation with the Drivers with little opportunity to stop, take stock and learn, and look together at how change really happens - what conditions need to underpin it and what barriers get in the way.

Some were concerned that the balance of the research hadn't been right. They felt that SG need robust evidence to inform policy and change e.g., through consultation at population level as well as engaging Drivers and the Scottish Learning Disability Observatory.

They felt SG should be saying some of this can't be done, but they have paying huge attention to Drivers, taking that responsibility on themselves without really having the power and authority to make things happen – which will inevitably lead to problems.

“We need to language things well and setting expectations is the most important thing. We may have got into a ‘you ask us, we tell you, you do it’ dynamic. When it needs to be a bit more nuanced than that. It happens to all of us but you have a different investment if you have lived experience compared to a professional. We are learning that we need more dialogue, to move away from ‘we tell, you do’ and work more in partnership, and it is challenging.” – ally.

Some concerns were expressed about the balance of Allies not being right: that there were lots of third sector people but not enough key decision makers from the public sector. They felt COSLA and SG should have levered key decision makers in but (it seems) were not able to do so, and as a result the change agenda lacks institutional leverage. For example, there is a lack of people from the NHS (both clinical and managerial). They felt more senior leaders would bring more energy.

We have forceful voices from learning disability and autism but not enough of the right people to hear them - ally

It was also recognised that the SG needs to be supporting local pathways as well as the national agenda.

Scottish Government and COSLA. The SG team found it difficult initially as this was a new way of working, and it took a while to co-create and develop a structure working with two communities with differing needs. The whole process has taken much longer than anticipated.

‘The timescales were unrealistic if you want to involve people with lived experience – would have crashed and burned on original timescales. We needed to balance range of perspectives – more realistic now.’ – SG team member.

People have high expectations and some lacked trust in the professionals and SG and want action now, but they know the SG system is complex and they are working on how to balance these different needs and expectations – they want system change and that is a long-term challenge.

COSLA recognise that the process is challenging, that there are tensions between those working on behalf of autistic people and people with learning disabilities and Disabled Peoples' Organisations and APOs and that it is hard to get people to focus on a single issue.

They are aware that the process is taking longer than anticipated and are keen that proposals are brought forward.

Providing timely information in accessible formats for the different groups has been and continues to be a challenge. People are there as individuals not organisational representatives – but there is some role confusion. Organisations come with their own, sometimes competing, agendas.

Lived experience is in the foreground and sticking to the four topics has been difficult. At the deep dive session some people/organisations circled back to focus on their own interests, rather than those which had been identified by the Drivers. The timeline had to be extended to include more preparation meetings, so that people are properly engaged.

SG are confident that they have some trust and buy in. 'Nobody has left, everyone is still there'. They are aware that there needs to be evidence of movement and progress or there is a danger that it will be seen as 'same old, same old', and that they need to be honest and clear about what is within their gift.

What could be done differently going forward

Autistic Drivers and participants ideas included the following.

Ensuring that human rights principles (PANEL) should underpin the approach, and that the voices of lived experience are heard and given equal weight to professionals who have no lived experience.

Developing a human rights approach needs people round the table together. This includes Engineers and Allies as well as Drivers. Some Drivers have been going to both learning disability and autistic groups and some are parents of people with learning disability. Ideas generated in one group such as GP training on sensory overload, are common to both groups.

"I have a strong sense of social justice/injustice and rights and that's what keeps me turning up, my purpose for being there. It may not help me but hopefully it will benefit my children." - autistic participant

Some felt that the review of existing research data was not inclusive enough – it was done with very rigorous academic standards and that meant that a lot of research wasn't included because it wasn't seen as robust enough. That causes a lot of frustration with the autistic community feeling like they are repeating themselves responding to questions they have already been asked and it also excludes a wealth of information. In terms of timings if it was to be replicated then the secondary research should come first so it can inform the primary research.

They expressed a need to hear from more unheard voices /left out people, including BME people, younger people, and those with more severe communication needs. There are a lot

of autistic people who are just struggling along and aren't linked with APO's (especially in West of Scotland where there are none).

"I know how challenging it is to try and reach these people and many of them will be worried about anonymity or just not have capacity to get involved. But it does make me wonder about how representative a picture we have. I think if it was being done again, we should think more about how to engage this wider audience – especially in the research stage. It's very challenging and potentially will add to research costs but it's important. – autistic Driver"

They were clear they need more involvement of people who make decisions – from SG and COSLA – and an inclusive process with parity of inclusion and co-production. It was disappointing that SG struggled to get Engineers involved specifically from health and social care and the NHS, particularly people who train medical professionals. They were concerned that without them the progress of the work could founder. They wondered whether more could have been done to engage them in the process and get them on board earlier.

For autistic Drivers, pre-meetings or linking meetings would help with flow/continuity. Social communication can be overwhelming, gets in the way of processing information, requiring those around them to be more flexible e.g., some become selectively mute when overwhelmed. At in-person meetings in the future they will be given a mobile number and an email address so their messages can then be read out.

"We need to encourage cross learning and not in silos. We have similar issues (stigma, low life expectancy) but our solutions may be different and might be difficult to achieve. We need more of a pan-disability model, more opportunities for cross fertilisation of ideas." – autistic participant.

They felt that there is a need to increase the frequency of autistic Driver meetings, as it is hard to engage with infrequent meetings (had a 4-month gap). Pre meeting preparation opportunities and post-meeting (consolidation) meetings could be useful.

Some expressed a need for semi-independent oversight (governance) – as they have a fear of things being dropped. For example, there are lots of research papers and they were concerned that these might not be considered.

A fear was expressed that SG might slip back to 'ticking the lived experience box'. They stressed that a human rights approach is about empowerment, that we need both desk research and lived experience, and informed and meaningful participation.

"Do autistic people and people with learning disabilities know their rights and that others are duty bearers? For example, in institutional living, people have set mealtimes, are locked in – there is a need for robust peer reviewed academic research to inform the process and, that it was not enough just working from first-hand experience" – autistic Driver

They were concerned to make progress on agreed actions. They felt that if they had a better preventative support system that would reduce the risk of harm later. For example, autistic/neuro-diverse people are overrepresented in the prison community.

They saw it as important that we learn from best practice models elsewhere.

“Engagement could be widened specifically for the autistic community - most of those involved are linked with APOs – they have a very strong sense of autistic culture, engaged in ‘the Autistic agenda’, and have a way of talking about autism which can be quite intimidating to someone coming into that.” – autistic participant.

Learning disability Drivers ideas were mainly about how to better support their participation in the process. This included prior preparation for meetings, the scope and focus of meetings themselves, and the logistics of attending and taking part.

They like to get the meeting agendas and use them to prepare for meetings. They want the meetings to then stick to the agenda and not include items that they haven’t had the opportunity to prepare for in advance.

They wanted the information they needed for meetings at the same time as autistic Drivers, in an accessible format (e.g., easy read), and that it needed to be broken down into manageable chunks. It takes time to do this, and support workers need to get the information in good time to convert it to accessible formats.

They felt they would benefit from having people (support workers) with them to explain things and time factored in to meetings to enable this. Some felt that having a quiet room would be useful, a place where people could pause and come up with ideas. Some people are non-verbal, and still need to be heard.

“They need to implement our ideas. I’m not 100% convinced till I see action, things happening – it is good that that they are listening.” – learning disability Driver

They were concerned that they get the support they need to travel to meetings. This requires good communication, individually tailored (only some are able to read), including reminders.

They wanted a plan for each step – the right information in the right format/language at the right time, travel support (including carers/support workers when necessary) – this could include Facetime support in places they don’t know.

They wanted the meetings to happen in different places in turn so that the same people don’t need to keep travelling. They also felt it would be good to include more Assembly members and others with experience of mental health services.

If they were being asked to hybrid meetings – Zoom and in-person – they need a good internet connection, and that needs to be checked in advance.

Allies and Engineers

Allies and Engineers ideas included making sure that there were clear shared expectations established for the process. Some felt that it might have been better to have brought the APOs and Disabled People's Organisations together with others at the outset and explained what the process was trying to achieve and asked, 'how shall we go about it?' Then the process could have been co-designed and co-produced with less separation of autistic people and people with learning disabilities and more thinking together about how to improve the system. They felt it was important the different stakeholders keep talking to each other.

'I don't agree with total separation of learning disability Drivers and autistic Drivers. Allies can go to both groups. Learning disability Drivers ideas would help our community – both need to be heard, value in both sets of ideas. Need the resource of our diversity, and some do sit in both camps. Need more coming back together feels more like parallel processes.' – autistic Driver/Engineer

Some were concerned that the process didn't have an underpinning 'theory of change' that was being tested or a culture of learning, rather that it was more a 'structure with status' instead. They were concerned that the work needed to be seen through and completed, that commitments have been made and must be followed through, and that they now needed an implementation plan with clear roles for Drivers and Engineers. If this didn't happen the process would be at significant risk. They wanted to go forward 'learning by doing', developing a culture to support that way of working.

Some felt it was important to revisit expectations and establish helpful mechanisms for discussion, debate and decision making and learn from them. That they need a broad church of representation, and perspective taking, and clear steps needed towards change e.g., how we go about influencing GPs/NHS other key stakeholders – including being able to adapt conversation.

They stressed the need to find creative ways of reaching and engaging 18 – 25 year olds and to think of co-production in smaller ways. They felt that it needs to be okay to have a safe space to have conversations, to think together, develop the trust base – people have been let down in the past. They reported that autistic people's priorities are well known, have been researched, and the emerging themes in this process are very similar. They stressed the importance of keeping this initiative going as an iterative process, and of building in evaluation (for impact and for learning).

It was seen as important that IS is providing a safe hub for autistic people to build their skills, learning to be partners in research, trying to balance power. That we all need permission to be human, to make mistakes, evolve our ways of working and keep learning.

Others stressed the need to have budget holders in the room, that they should have been in from the beginning. They felt there was a need to find Allies capable of bringing influence to bear on the process that the SG needs to use its 'soft power' to get people round the table,

that the Minister and/or senior civil servants need to send clear message ‘that they are needed at the table’.

On a more practical note, some felt that it would have been good if the Engineers had had more to time to prepare for discussions and that it would have been good to have a break to discuss what they had heard, some thinking time, before meeting with the Drivers.

It was felt that if the process worked well, people’s lived experience would be driving change. It is these experiences gathered at scale that need to be the focus of attention and used as levers of change. They felt it was the right trajectory but that there was a danger of getting stuck in organisational and campaigning perspectives dominated by individual and organisational experience, not the population level evidence, and that while that might be able to influence matters policy can’t be made that way.

Some felt that there is more overlap than difference between the two communities, and there is a need to take an inclusive approach and have some conversations in different places. It was felt that we needed to understand the gaps in education support, employment support, and health support. That some things could be done together and some separately and that a human rights approach is crucial to this.

Some were concerned that the SG engaged voluntary sector delivery partners but that there was no funding for their involvement in process and there would come a point when they can’t go on without it.

The need for clear timely information in appropriate formats was seen as essential to enable successful communication and shared understanding. Different stakeholders need information in accessible formats for particular purposes, for example the SG prepares concise summaries for Ministers, who are unlikely to find being directed to copious information collated on a website useful. Different expectations of conduct at meetings were also seen as challenging. Some felt this could be improved with better facilitation, possibly adopting co-facilitation with an autistic facilitator who could play a translation/ interpretation role. There is a need to recognise how information needs to be presented to be heard – e.g., summarising can be difficult for autistic people, and while easy read /simplification helps some people clear communications is more than that.

Clear shared expectations a culture of learning and no blame for failure were seen as essential. Setting up the principle of partnership is key to the work, but it might not have gone done well at the beginning, some may have felt policed, and seen it as constraining rather than been genuine listening. ‘Nothing about us without us’ was seen as a good principle.

Scottish Government and COSLA. The SG team are aware that they need to keep on top of expectations, that they need to be realistic and clearer about the process and limits of their power, and that they need to keep working on providing timely accessible information. Their normal role is to consult with people then work it out, then take to relevant policy team or put a proposal together to go to the Minister but are now supporting the process to

Animate



do that rather than doing it directly. They are committed to working collaboratively and are keen to get to a point where everyone can see progress.