

Inclusive Governance Webinar Frequently Asked Questions

Question 1

Do you have suggestions on how to involve people in a meaningful way, without people needing to attend lengthy committees and meetings?

Answer

This was a very important focus. Putting people on the board is pointless if it is not accessible. Included in the report is some examples of other organisations who have, for example, easy read versions of organisation accounts for review. The consortium also included a case study and recommendations around modifying lengthy meetings, for example, to have shorter meetings, between smaller groups, who might read the papers together and discuss ideas.

Communication may also be text based, or spoken and decisions may be made, not only at board level, but also down to meetings within care and support services, about how things are organised.

Question 2

This seems like a huge conflict of interest, regarding recommendation and rationale for Scottish Autism NOT becoming an APO.











It also goes against the grain of what the Scottish APO community says and pushes for in public, as well as the wider autistic community, nothing about us without us.

Other than feeling that Scottish Autism would displace grass roots APOs, is there any other meaningful reason why they should not do this?

The suggested approach seems protectionist, for a select few organisations, in the extreme. Power should be shared and disseminated across the sector... we are not a monopoly. There should be large, service provider APOs too... a whole range and variety.

Answer

There are various concepts around what constitutes an APO. Quite often people think of Autistic Led Organisations (ALO) but an Autistic People's Organisation (APO) is slightly different. Historically, a form of Disables People's Organisation (DPO) which is something that refers back to the United Nations and Convention of the Rights of People with Disabilities.

The opinion of the consortium as a whole was that because the APO movement in Scotland is still quite nascent, although more advanced than in other countries, to have a big organisation come in and essentially take up that space will then take up the voices. As a way of ensuring that there is a diverse range of voices geographically and otherwise, especially given that Scottish Autism largely operates in a limited geographical capacity, then we do not think it is particularly relevant.











In addition, for such a large organisation to make such a change would be very complex. We have already asked for many changes which have been uncomfortable for the organisation, but which they have bravely agreed to, and the consortium will work with them at taking these changes forward.

Scottish Autism becoming an APO is something that cannot be ruled out further down the line, but at the moment, this is as close as we can get. If you look at the distribution of power and the advisory panel, there is an argument to say that it comes close to being a form of APO.

Change is always best when it is done gradually and not all at once. Scottish Autism is better served to look at helping to build that geographical otherwise APO capacity, rather than being something else. If it was a large APO there would then be questions about would it be better to be an umbrella form of APO, and that would be such a complicated question and would change the nature of Scottish Autism as an organisation.

There are already APOs that are service providers and working together with them and other autistic related organisations, we can continue to grow those.

Question 3

Are the recommendations for the Advisory Panel to be a digital or in person panel and how often would the panel meet?











Answer

This is a decision that should be made by the Advisory Panel.

Question 4

Would it be possible to get a copy of the original tender (obviously redacted if necessary)? It would be interesting to see what Scottish Autism's thoughts were when entering the process compared to where the review took them.

Answer

The tender is available to view here.

Question 5

How was resistance dealt with? How would other organisations with higher resistance to taking seriously autistic people's involvement? What is the role of conflict in this process?

Answer

Initially the consortium met with Dorry McLaughlin, Chief Executive of Scottish Autism, to confirm that the organisation really meant to proceed with change and this was not a form of tokenism.

The consortium did encounter challenges and pockets of resistance and had to work collaboratively with allies within Scottish Autism who were on board to find ways to work around these challenges and that resistance. The consortium would not have undertaken this work if there had not been buy in already at the very senior level.











The consortium felt all the way through that there would be much higher resistance, and that the best way to influence this is to publicise this project as a way to throw down the gauntlet to other large professional run autism service providers and charity organisations. To say, here is an organisation who is serious about shifting power, how about you do this too?

Conflict is an inherent part of the process, and working through that conflict involves learning, and at times the consortium has pushed back, or Scottish Autism has pushed back and challenged each other's thinking. This is an essential part of shifting where the power is.

Question 6

Do you know what the training might look like for your Advisory Panel and Supported Individuals Board members? What topics you might cover and how it will be delivered?

Answer

The consortium did quite a lot of work around this in the course of the project, mostly in terms of desk research. The project report contains all of the case studies in the appendix. One of the case studies, was a thematic case study on supported decision making. This became so wide and broad that the National Autistic Taskforce has published a separate paper on this, on their website. You can view this here.

The consortium hope to work with Scottish Autism to develop training for supported individuals to develop supported











decision-making skills, drawing on the best practice that is set out in the case study from around the world in terms of approaches.

At the other end of that ladder around training for the advisory panel and supported individual board members, the consortium drew on a number of existing leadership development programmes including one by Disability Rights UK, and another from Australia, and began to explore some of the topics that might be covered, including the key information around the difference between representing other people and representing one's own perspective only. The importance of that training, including spelling out a lot of unspoken language that is not written down, which can be extremely difficult for autistic people to figure out and pick up, about how things actually run and how subtle soft power works, is important.

This will also involve some degree of coaching and mentoring to enable people to embed what they are learning in their experiences and opportunities to participate in representation as they move forward.

Question 7

What are the financial implications to the already planned actions and the wider desired actions? Is that a concern or a barrier?

Answer

The final report contains costings, and this can be found on the website.











There is no real concern about the financial implications, and the board members as a majority support the findings of the report and the recommendations.

Question 8

How do you think AI will impact inclusive governance?

Answer

This is a very interesting question. All has a place in social care but not at the expense of genuine human views. Deciding which is which will be the challenge.

The ChatGPT phenomenon became popular after the consortium had done the vast majority of the project.

On a rather practical note, AI might be good at things like working out rotas, spotting patterns in data, which might save human hours which can then be redirected to working with the supported individuals, but this has not been explored.

Question 9

How will (or have) those supported individuals with significant learning difficulties be (or have been) included in inclusive and meaningful participation?

Answer

The consortium visited approximately 4 or 5 services and met a couple of individuals from each. They were not always able to get abstract information from the individuals directly but could











form an impression of their experience from interacting with them, playing, watching them interact with staff, and observing the effects of the environment as best they could.

The consortium has recommended changing Scottish Autism's care planning and service decision-making processes to ensure that basic documentation cannot be completed without at least seriously attempting supported decision making with the individual. They have also recommended a lot of work on supporting individuals with that profile to develop their understanding of 'agency' (the idea of being able to make decisions for yourself) and do everything possible (which is a lot - see the full report) to support them to participate far more in decisions. Also, to use other autistic people to help exert influence via collaboration and observation using autistic peer empathy.







