

## Good practice in participatory approaches to working with autistic people and people with learning disabilities

### Introduction

The purpose of this concise paper was to identify supporting and additional elements of good practice in participatory approaches to working with autistic people and people with learning disabilities for the Scottish Government (SG) Learning Disability and Autism team to consider. It will further inform their work to establish a new leadership and engagement process that puts lived experience at its heart.

As described in our recent Process Evaluation Report<sup>1</sup> the approach being used by the Learning Disability and Autism team evidences:

- a collaborative process, underpinned by a human rights approach, which puts the lived experience of autistic people and people with learning and intellectual disabilities (Drivers) at the centre in identifying priorities for action
- a commitment to ensuring that autistic people and people with learning disabilities are provided with the same information in an accessible format in sufficient time to enable them to participate fully
- an iterative learning approach to creating online and in-person spaces where autistic people and people with learning disabilities are supported by Inspiring Scotland and The Assembly (hosted by VIAS) to participate fully, and
- the engagement and participation of wider stakeholders (Engineers and Allies) with the necessary expertise and decision-making powers to implement prioritised and agreed action.

These constituent elements feature strongly in participatory approaches used across Scotland. For example, ARC Scotland<sup>2</sup> supports a number of local and national fora that encourage the involvement of autistic people and people with and learning disabilities and service providers. Their National Involvement Network provides regular opportunities for people to meet, share their experience and learn from one another, have their voices heard and to influence change.

### Collaboration and Human Rights

An exploration of the evidence around the contribution of community-led approaches to social care and support to human rights and equalities outcomes (Dr Lauren Smith, May 2018)<sup>3</sup> reports that approaches that involve working with, rather than doing to, people and communities - referred to using a wide range of terms including person-centred and community-led - are widely reported in Scottish policy as resulting in beneficial outcomes.

---

<sup>1</sup> Process evaluation of a new approach in leadership and engagement policy development, Animate, November 2022

<sup>2</sup> <https://arcscotland.org.uk/networks-forums/>

<sup>3</sup> <https://www.iriss.org.uk/resources/reports/community-social-support>

A strong focus on collaboration, emerges from the Commission on the Future Delivery of Public Services (Christie 2011), while a rights-based approach allows policies and practices in social care and support to be delivered on a fair, robust and legal basis whilst making difficult decisions and prioritising budgets (The ALLIANCE 2017).

The centrality of a human rights approach is enshrined in UK law by the Human Rights Act 1998 (Scottish Government 2017a), and increases the ability of organisations, public bodies and businesses to fulfil their human rights obligations. It forms a solid accountability basis on which people can seek remedies when their rights are violated (Scottish Human Rights Commission, 2016). The SHRC strongly advocate a focus on addressing the barriers that hinder the full and effective participation of autistic people and people with learning disabilities in society on an equal basis with others.

In general terms, practice in Scotland seems to be similar to good practice elsewhere. A systematic review<sup>4</sup> - which pooled a sample of 28,154 study participants predominantly from studies in North America, the UK and Europe - examined the effectiveness, facilitators, and barriers of interventions for social, community and civic participation for adults on the autism spectrum, or with intellectual or psychosocial disability. It concluded that 'improved social and community participation requires purposeful strategies that identify meaningful participation preferences (e.g., where, when, how, and with whom) and provide support to build capacity or enable ongoing participation. Community capacity building, peer support and advocacy may also be needed to make the community more accessible, and to enable people to exercise genuine choice.'

### **Accountability**

The PANEL principles provide a useful 'checklist' against which to assess process outcomes, however a lack of practice-based research and evaluation evidence of co-productive approaches (Kaehne et al. (2018) in Dr Lauren Smith, May 2018) affirms the intention of the leadership and engagement process to adopt a robust, outcomes focused monitoring and evaluation framework to support the work plans.

There is ample evidence of a recent focus on the creation of 'lived experience panels', and similar, to act in an advisory capacity to programmes and initiatives. The National Advisory Council on Women and Girls (NACWG), established by the First Minister, has a 'participation panel' which acts in an advisory capacity to scrutinise the progress of the work to tackle gender inequality in Scotland. SCLD worked with SG setting up lived experience boards to support the development of Human Rights legislation, building members capacity to make suggestions beyond their personal experience.

SCLD's Include for Good programme is a co-designed, co-produced approach which brought together a board of people with lived experience as trusted advisors to call human rights

---

<sup>4</sup> Frontiers in Rehabilitation Sciences, Melita J. Giummarra, Ivana Randjelovic and Lisa O'Brien, August 2019 - <https://www.frontiersin.org/articles/10.3389/freesc.2022.935473/full>

duty bearers to account for ensuring the rights of people with learning disabilities are upheld. They took up the role of Rapporteurs - adopting Human Rights terminology – and are continuing to shape the programme with an emphasis on power and risk sharing. The principles that underlie the approach include:

- Equality of communication – right information in the right format at the right time
- Not limiting people to their personal experience, ensuring we move beyond underestimating their capacity, engaging them as thinkers and innovators
- Drawing on wider bodies of research in addition to lived experience

The Office for Disability Issues (New Zealand)<sup>5</sup> is working toward a vision of New Zealand being a non-disabling society - a place where disabled people have an equal opportunity to achieve their goals and aspirations. The Disability Action Plan 2019-23<sup>6</sup> responds to the main issues identified by disabled people, the Disabled People's Organisation (DPO) Coalition (in an advisory role) and government agencies working together. It is a package of 25 cross-government work programmes that are underway or are being planned that have an explicit disability perspective. The Action Plan includes several monitoring mechanisms to ensure agencies are held to account, including (but not limited to):

- submission of six-monthly status reports to the Office for Disability Issues
- bi-annual meetings of the Ministerial Leadership Group on Disability Issues
- DPO Coalition meetings with agencies, as required.

The plan advocates a Disability Data and Evidence Working Group and disabled people's involvement in decision-making as essential cross cutting themes. They have produced a NZ Disability Action toolkit<sup>7</sup> which advocates a range of useful organising and action pointers that both affirm and could enrich the approach being developed by the Learning Disability and Autism team. These include ideas for:

- Thinking about disability issues at the start of the policy process
- Engaging with the disability community
- Embedding disability into the policy issue
- Incorporating disability into the policy options
- Incorporating disability into Cabinet papers, information and communications
- Considering disability throughout implementation, and
- Considering how disability outcomes can be monitored and evaluated.

## Conclusions

The participatory approach being pursued and further developed by the SG Learning Disability and Autism team is in line with good practice in Scotland and elsewhere.

The Process Monitoring Framework, based on the PANEL principles will enable process reflection and learning, and adapting the LEAP framework<sup>8</sup> to better suit the learning

---

<sup>5</sup> <https://www.odi.govt.nz>

<sup>6</sup> <https://www.odi.govt.nz/assets/Uploads/disability-action-plan-2019-1-page-printable-version.pdf>

<sup>7</sup> <https://www.odi.govt.nz/disability-toolkit/>

<sup>8</sup> <https://www.scdc.org.uk/what/leap>

preferences of autistic people and people with learning disabilities will enable planning, monitoring and evaluation of progress towards the desired outcomes detailed in the workplans.

This commitment to the meaningful ongoing participation of autistic people and people with learning disabilities in the development of current and future workplans, places lived experience at the centre of policymaking and the co-creation of informed implementation on a more equitable basis. Their inclusion as key actors in these processes will over time build greater capacity in policymakers and in health and other service providers to trial and embed new ways working that better serve their needs.