

Glasgow Disability Alliance response

Scrutiny of the Scottish Statutory Instrument: SSI 2025/405: The Public Bodies (Joint Working) (Integration Joint Boards) (Scotland) Amendment Order 2025

About Glasgow Disability Alliance

GDA is a disabled people's organisation (DPO) controlled by our nearly 6,000 disabled members living across Scotland. GDA is the largest groundswell of disabled members in Europe and a leading and celebrated example of a grassroots community of identity driving improvements to disabled people lives and social change. Our work is built on foundations of individual and collective community empowerment and is based on peer support, and developing and drawing on disabled people's own strengths by:

- Building individual capacity through holistic programmes including learning and development, wellbeing, digital coaching and connections, support to navigate Social Care and welfare rights information, advice and representation.
- Amplifying diverse voices and perspectives of disabled people, supporting them to articulate and share lived experience and to participate in dialogue, deliberation and collective advocacy, which challenges inequality and exclusion.
- Collaborating for change with local and national government, communities and third sector, sharing insights and evidence to shape policy and co-design more accessible services and solutions to poverty, inequality and exclusion.

GDA's Social Care Expert Group is made up of now, over 120 diverse GDA members with lived experience of needing or using social care and includes disabled people who experience barriers accessing services such as social care and also intersecting barriers across a range of areas affecting life outcomes.

These barriers include, but are not limited to:

- ✓ **Structural and institutional barriers:** the way policies, services and infrastructure are designed and delivered, interacting to cause inequalities and injustice for disabled people e.g. work, education, services like social care, employability and even the justice system. This includes community-based services which can be inaccessible to disabled people whilst "available" to others in local communities.
- ✓ **Physical and environmental barriers:** the way buildings, housing, transport and the built environment are designed without disabled people in mind e.g. public buildings not having the entrance ramps or lifts; inaccessible buses which have limited space for wheelchair users to travel; and public realm projects which

prioritise active travel and remove accessible parking spaces from city and town centres.

- ✓ **Attitudinal barriers:** from low and negative expectations to discrimination and in extreme cases hate crime. Everyday stigma and exclusion of disabled people leads to isolation, lack of self-worth and a sense of hopelessness and despair.

GDA's Social Care Expert Group also includes disabled people experiencing intersectional barriers and oppressions which can be exponential if people have more than one protected characteristic so for example younger disabled people, older disabled people, Black, Asian and Minority Ethnic disabled people.

GDA's response:

The following response is intended to provide recommendations in relation to Scottish Statutory Instrument: The Public Bodies (Joint Working) (Integration Joint Boards) (Scotland) Amendment Order 2025, as well as offer broader recommendations to be considered during ongoing Integrated Joint Board reforms.

- GDA members welcome the opportunity to give written evidence to the Scottish Government's consultation to extend full voting rights across Integrated Joint Boards to representatives who access services, such as disabled people and unpaid carers as well as third sector representatives.
- GDA members believe that this consultation has come at a particularly pertinent time and is an opportunity to reenergise the Government's vision to build a social care system committed to the ambitions and recommendations of the Feeley Review, including the ask that, "Every member of the Integration Joint Board should have a vote. Membership should include but not be limited to representation of the workforce, people who use services, carers, providers, professionals, localities and local communities. [...] appropriate support will need to be provided to enable participants to fulfil their responsibilities."¹
- Disabled people and their organisations are still campaigning for the much-needed reform of social care in Scotland. This includes, but is not limited to:
 - a. National oversight and standards and an end to post-code lottery provision and delivery;
 - b. Fully implemented self-directed support and rights-based assessments which actualise Independent Living, as per Article 19 of the UNCRPD²;
 - c. Recourse to justice if rights are not met; and

¹ [Independent Review of Adult Care in Scotland](#)

² [Convention on the Rights of Persons with Disabilities | OHCHR](#)

- d. Transparency and accountability to disabled people, including the involvement of disabled people at all decision-making levels.
- The amendments made within the instrument, i.e. 12. (1) and 12. (2) and 12. (4), are welcome steps to fundamental reforms. Legislating for extended voting rights and powers to proxy vote will contribute to an equalisation of power and mitigate the dilution of disabled people voices in decision-making, who are by far the largest users of adult social care, but the least likely to participate in the processes which inform policy and practice.
- However, lack of voting rights is not the only barrier to the full participation of disabled people on Integrated Joint Boards. Full and meaningful participation and inclusion of disabled people and unpaid carers will need a commitment to ensure that there are appropriate support and resources provided to enable disabled people and unpaid carers to carry out and fulfil their board member duties. **The need for additional resources to cover access and participation must be legislated for to ensure that the commitment is upheld.**

The following access and support requirements must be fulfilled to ensure equity of participation and involvement:

1. Resource **transport** for disabled people to venues, “often disabled people fall at the first hurdle without transport and other supports to take part”.
2. Make sure that **venues are fully accessible** for participants including access to changing places toilets, ramp access, lifts etc. Provide accessible information about venues.
3. Resource and invest in **PA support** to ensure that disabled people have access to the right support and assistance to participate fully in meetings, “We’re not talking about personal care here but be aware that people might need a hand navigating the venue or getting lunch”.
4. Provide and/or reimburse **childcare and social care support** for those who have caring responsibilities or care needs, “People might need to increase their care supports to attend and this should be factored in”.
5. Ensure and resource access to **BSL and Language Interpreters and other communication supports such as note-takers**. “We need practical support like interpreters and PAs”.
6. Provide **equal, available and accessible access to information** and papers relevant to duties and decision making at IJBs. Ensure enough time is given for all members.
7. Hold meetings at **appropriate times** when people can contribute.

All quotes above are taken from GDA's Social Care Expert Group National Advisory Board 2025 Report, informed by participative co-design sessions held on 14th March 2025 and 3rd and 30th April 2025.

- Currently, for some IJBs, any access related costs are expected to be paid 'out of pocket' and individuals wait to be reimbursed at a later date. This is not a feasible upfront expense for most, if any, disabled people/ unpaid carers. The need to find an alternative to this is particularly pertinent as it is estimated that disabled households require an extra £1,095 each month to access the same standard of living as non-disabled people. This cost, known as the Disability Price Tag, is expected to rise to £1,224 per month by the 2029 to 2030 financial year³. A reasonable step to mitigate this would be **ring-fenced funds provided by the Scottish Government to cover costs, and a policy developed to ensure that actions are followed.**
- GDA and its members support the four overarching recommendations outlined within The Alliance and Coalition of Carers in Scotland shared report, More than Equal,⁴ as clear steps to value and support the expert contribution of people with lived experience. Those four recommendations are:
 1. Strengthen recruitment and representation
 2. Build capacity
 3. Support equity of involvement
 4. Evaluate impact
- In the rest of this short report, GDA will outline our key asks which will support these recommendations' ability to reach disabled board members.

Strengthen recruitment and representation

- **Involve disabled people and their organisations in the design and development** of accessible and inclusive recruitment processes.
- Utilise established routes, where they exist, within disabled people's organisations and carers organisations to source applicants for IJBs and resource organisations to provide the recruitment support.

³ [Disability Price Tag 2025 | Disability charity Scope UK](#)

⁴ [More Than Equal](#)

Training and Capacity Building

- **Further and more substantial and long-term investments for Disabled People's Organisations** which deliver the 'groundwork' of building capacity and confidence for disabled people to exercise their human rights and have their voices heard.
- **Resource and invest in peer support and capacity building as it is fundamental to ensure meaningful participation of all members of Integrated Joint Boards, particularly disabled people.** This is essential in the realisation of human rights, breaking down legal jargon and understanding the social care policy landscape.
- Throughout the co-design process of social care reforms, GDA members expressed that **disabled people, connected to DPO's, are best equipped to take on lived experience representation roles on Boards.** This is crucial to ensuring that a wide range of experiences, barriers and intersections are recognised and reflected. Members have consistently raised concerns that, if unsupported, disabled people will face a huge pressure to represent and speak on behalf of a diverse community of identity, leaving them feeling vulnerable and that they are 'the only voice in the room'.
- **Boards must be resourced for ongoing developmental opportunities**, so they have access to mandatory Disability Equality Training, Independent Living training and other equalities training. This is critical as high level decisions made about social care reform are a matter of equality and human rights and all those involved must have equality and human rights competence.
- There must be **specific support and resource structures within Integrated Joint Boards to engage with wider community**, including Disabled People's Organisations and carers organisations, so that EQIA's and any policy proposals are consulted upon by the communities most affected by changes.
- In cases where disabled people and carers are not supported by DPOs or Carers Orgs, GDA suggests a **triangulated approach to participation**. This means:
 - a) Lived experience representation on an IJB
 - b) Direct strategic feed-in from DPOs, Carers Orgs and DPO and Carers Networks and
 - c) Community engagement i.e. panels, groups etc – set up and facilitated by organisations with disability competence and be resourced to meet access needs.

Support equity of involvement

- For equalisation of power and participation, **give primacy to the views and experiences of disabled people so that decisions uphold rights to independent living.**

Evaluate impact

- GDA believes that there must be a **strengthening of the mechanisms holding Integrated Joint Boards to account** and this will be particularly important in relation to monitoring and evaluating the implementation of the voting rights. Additionally, there must be mechanisms which evaluate how well people are able to meaningfully participate; how money is spent on participation; and what steps the Board takes to make things accessible.