Inclusion Scotland is a national network of disabled people’s organisations and individual disabled people. Our main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people’s everyday lives and to encourage a wider understanding of those issues throughout Scotland. Inclusion Scotland is part of the disabled people’s Independent Living Movement.

Disabled people have told Inclusion Scotland of their concerns that Health and Social Care Integration is too dominated by health and that the wider role of social care in supporting independent living is being reduced to being just “healthcare in the community”. This is unfortunately reflected in the Committee’s Inquiry remit which refers to “patients” but not to users of social care.

The failure of Health and Social Care Integration Authorities to fully and properly engage with disabled people in developing Integration Strategic and Locality Plans exacerbates this marginalisation of social care. Disabled people do not believe that Integration Authorities are meeting their duties under the Public Bodies (Joint Working) Act to consult with the users of social care, or to take account of the needs, rights and dignity of service users, in integration planning.

In October 2015 Inclusion Scotland, funded by the Scottish Government, instigated a one-year pilot project designed to examine how the various processes being used to implement HSCI at a local level had engaged with disabled people and their organisations. This led to a further pilot Local Policy and Engagement project currently underway in the Highland Integration Authority area.

This response has been informed by these projects. In addition, Inclusion Scotland issued the Inquiry’s questions as a survey to disabled people and Disabled People’s Organisations (DPOs), which received 48 responses. Inclusion Scotland would have liked to have been able to do a more in depth engagement with disabled people and DPOs on this important issue, but this was not possible in the time available.

1. **Do you know how and when you can get involved with the Integration Authorities to influence decision making?**

1.1 There seems to be little public awareness about the establishment of Integration Authorities (IAs), or of any engagement carried out by them. There seems to have been a tendency for IAs to focus their engagement on organisations that were already known to Health Boards and Local Councils rather than to try to seek out new or seldom heard groups.

1.2 Only three of the respondents to Inclusion Scotland’s survey answered “yes” to this question. This reflects the results of work carried out as part of our HSCI Project that disabled people and DPOs felt excluded and ignored by the various consultations and events that took place prior to the establishment of Integration Authorities, and are unclear as to how they will be included in future plans and engagement activities.

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1 Disabled people have defined Independent Living as: “Disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”. This definition has been endorsed by the Scottish Government, NHS Scotland and COSLA in “Our Shared Vision of Independent Living In Scotland” [http://www.scotland.gov.uk/Publications/2013/04/8699](http://www.scotland.gov.uk/Publications/2013/04/8699)
1.3 Only 12% of those surveyed as part of our earlier HSCI project felt that Integration Authorities were in a position to understand the needs of disabled people or that feedback form disabled people wold be used by IAs to focus on their needs. Failure to consult with disabled people has resulted in HSCI being a health dominated process that excludes the principle of independent living for disabled people and reduces them to passive recipients of health focussed care.

2 Were you consulted in the preparation of the strategic plans or involved with the work of the Strategic Planning Group?

2.1 Again only 3 of the 48 respondents to our survey said that they had been consulted, and one of those only to a limited extent on the Housing Contribution Statement in one of six local authority areas they operate in.

2.2 Glasgow Disability Alliance (GDA) ran a large scale (400+) and smaller scale event (120 or so) to inform disabled people of the proposal and set priorities for the Plan. GDA’s CEO was then involved in writing the Disability part of the Plan based on this intel and analysis as well as recommendations from disabled people.

2.3 Disabled people felt that a lot of the engagement they became aware of or were invited to was tokenistic. They also reported that where engagement was being conducted in partnership between a statutory sector and third sector organisation then they had a more positive experience.

3 Have you been involved with the work of the Integration Authority following the publication of the strategic plan?

3.1 There appears to have been very limited involvement with disabled people and DPOs following the publication of the strategic plan.

3.2 One concern relates to the transparency of governance arrangements, and in particular how service user representatives are appointed. Among disabled people, our HSCI project found a near universal lack of knowledge of the Service Users representative on IJBs, how they were selected and how to contact them to raise issues. In many cases the Service Users Representatives seem to have been drawn from existing Health Board Patient Panels (or similar), again emphasising the dominance of health.

3.3 There appears to be a more developed relationship between carers organisations and the Carers Representative on IAs. Disabled people and DPOs on the other hand have no direct voice on Integration Authorities. Integration Authorities instead tend to confuse the Third Sector Representatives (usually the local Third Sector Interface) as being the voice of disabled people.

4 Have you been involved with the work of the localities/ what involvement would you like to have?

4.1 To date involvement of disabled people in localities has also been limited, with only four of our survey respondents reporting any involvement. GDA has worked with the North East Glasgow locality on priorities and its planning group. In Highlands, the Locality Group will be part of the local Community Planning Partnership (CPPs), but to date there has been an unwillingness from Councillors, Chief Officers and the CPPs to engage with disabled people.
5 Do you think that your involvement with the IAs has had an impact on decision making?

5.1 42% of disabled people and DPOs responding to our HSCI Project said that they did not know if their knowledge, research and understanding of the local area contributes to Integration Authority decisions. A number of respondents also wrote that given the fact that neither their local authority nor their local NHS Board had a strong track record in this area they felt this would not change in the new structure. In particular, DPOs stated that they had a lot of evidence about their services and the needs of disabled people that was not being used to help plan services.

5.2 There was also a feeling that, in the new HSCI strategic plans or the engagement events that helped establish them, there seemed to be little clear link between service plans and outcomes for disabled people. Where outcomes have been set for disabled people they are very much health focused as opposed to enabling independent living at home.

5.3 On the other hand, GDA reported that in terms of city wide this has worked at a planning level. For the locality of North East Glasgow they have been able to be more involved, build more relationships based on trust and respect and more meaningfully involve the voices of disabled people. North East Glasgow is around the same size or bigger than many LAs.

6 What could be done to improve the communication from the IAs?

6.1 Responses to our survey highlighted the need for greater publicity about the work of Integration Authorities and the opportunities to be involved. This includes direct mailings, surveys, face to face meetings, information at point of delivery (but not just health based delivery points such as GP surgeries). A number of respondents stressed the importance of contacting disabled people directly and through disabled people’s organisations.

6.2 DPOs and disabled people in the Highlands also reported that they found it difficult to engage across such a large geographic area as there was no local support specifically focused on disabled people. In other areas there were DPOs that covered the whole region such as DG Voice or Glasgow Disability Alliance or forums that enabled disabled groups to influence local policy.

6.3 Accessibility is also key. Communications in accessible formats, such as easy read and BSL, should be available at the same time as other documents. In our HSCI project, disabled people reported that they often find engagement to be an alienating process. Briefings and consultation papers can be unclear, full of jargon or issued at very short notice. These can present a significant range of problems for disabled people, often with no health or social care background beyond their own personal experience as users of services, who are expected to use a single meeting or event to influence decision makers and help set policy.

6.4 It can be extremely difficult to find information about your local Integration Authority online due to inconsistent approaches between authorities. Often you have to go through Health Board or Council, websites to find any information, and it can be difficult to track down specific information such as membership of the IA, localities and strategic and localities plans.
6.5 Much of the information is written from the perspective of the IA and not the service user. For example, Integration Authority minutes and papers, whilst available online, are often impenetrable to the ordinary member of the public, let also someone who requires communications support.

6.6 As a very minimum, Integration Authorities should be required to establish an accessible website where people can find all relevant information, including opportunities to participate.

7 What could be done to ensure greater collaboration and engagement in the decision making process of Integration Authorities?

7.1 As one respondent to our survey put it “First and foremost, we need to be invited to the table”.

7.2 There needs to be genuine partnership working with the third sector rather than telling them what to do and restricting their remit and ability to provide responsive service. There is a view that so far HSCI has been more about the management structures within the existing statutory authorities than developing effective partnership working and co-production with service users.

7.3 Ideally engagement with disabled people should be done in partnership with local third sector organisations who should be funded to do that engagement. The difference in how disabled people feel about HSCI engagement when a partner organisation is used is considerably more positive than when the local health and social care partnership engages on its own.

7.4 The most effective organisations to help support this engagement are Disabled Peoples Organisations (DPOs) as they draw upon local disabled people’s experiences and local knowledge. However, they may not have the capacity to support engagement with disabled people on their own. In many areas, Third Sector Interfaces (TSIs) are well placed to support this engagement, both directly and via the capacity building of DPOs.