Our voices  Our choices

Health and Sport Committee
NHS Governance – Corporate Governance
Submission from Inclusion Scotland

1  Inclusion Scotland

1.1. Inclusion Scotland is a network of disabled peoples' organisations (DPOs) 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.

1.2. This response is informed by the findings of Inclusion Scotland’s Highland Localisation and Empowerment Project (HLEP). Supported by the Scottish Government’s Promoting and Equality & Cohesion Fund, HLEP commenced in October 2016.

1.3. The overarching purpose of the project is to increase the number of disabled people involved in local decision-making and improve the quality of their experiences. This includes those opportunities for disabled people being involved in a representative role provided for within the Public Bodies (Joint Working) (Scotland) Act 2014, and emphasized in the Scottish Governments Localities Guidance published 2015. The evidence provided here is restricted to local evidence and views gathered from Highland disabled people and their organisations.

1.4. We believe that the adoption of the recommendations set out later within this response would contribute directly to meeting the ambitions identified in “A Fairer Scotland for Disabled People’ Scottish Government’s Delivery Plan on the UNCRPD”.

1.5. With specific relevance to Ambition 1, ‘Support services that promote independent living, meet needs and work together to enable a life of choices, opportunities and participation. Health and social care support services are designed to meet - and do meet - the individual needs and outcomes of disabled people.’

1.6. Highland has been operating a ‘lead agency model’ between NHS Highland and Highland Council since 2012. The governance arrangements for this model differ from the Integrated Joint Boards established in all other areas by 2016. Given the unique geographical size, differing governance arrangements and the maturity of the adopted model of Health and Social Care Integration in Highland, an individual response focussing on Highland was viewed as most relevant to the Committee’s work.
Do you trust NHS Boards to make decisions that are in the best interests of the public?

2.1 **Disabled People as Key Stakeholders:** NHS Highland, like other Health Boards, has the capacity to create adequate levels of advocacy, representative opportunities and the meaningful participation of disabled people to better inform their decision-making. Such provisions are fundamental to building trust between disabled individuals, their organisations and NHS Highland. NHS Highland’s recognition of us as key stakeholders is essential to the improved delivery of local Health and Social Care services.

2.2 **Levels of Disabled Peoples Representation:** A mapping exercise (see exhibit 1) of the structures within the Lead Agency model by the HLEP revealed a hierarchy of structures (NHS Board, Integrated Joint Monitoring Committee, Health & Social Care Partnership, Adult Strategic Commissioning Groups (ASCG), and 8 impairment related Improvement Groups).

2.3 Inquiries to the secretary of each of these statutory bodies revealed that there was no NHS Highland self-identified disabled person lay representative within any of these groups, other than the Improvement Groups. Although a self-identified disabled person is on the NHS Board in Highland, their remit is limited to the representation of the NHS Argyll & Bute Board geographical area.

2.4 At the lowest rung of participation, NHS Highland has informed the HLEP that Improvement Groups are no longer formally in place. Instead, the view of the ASCG was that ‘task and finish groups’ are now more appropriate to take forward any areas of work to be commissioned by the groups.

2.5 We believe that Improvement Groups are needed which seek to work in partnership with disabled people and their organisations. This would better inform the Adult Strategic Commissioning Group on disabled people’s service needs. What attempts have been made to co-produce, rather than impose a ‘task and finish’ structure on disabled stakeholders is unclear.

2.6 **Disabled People as Experts by Experience:** As Improvement Groups are currently in transition, no new membership can be sought, hindering opportunities to increase disabled people’s membership of these groups. It is also noteworthy that no pan-impairment Highland forum of existing disabled people’s membership of these groups (older people, mental health/dementia, learning disability, acquired brain injury, autism, carers, drug & alcohol, see/hear) exists or is planned.

2.7 The creation of such a forum would complement the existing fora, and would be an effective use of an existing resource. It would also provide an opportunity to gather the lived experience of barriers facing Highland disabled people in accessing health and social care services and would demonstrate that the Health Board valued experiential expertise.
2.8 **Advocacy**: The Highland Health & Social Care Partnership currently commissions the following independent advocacy services for disabled people across Highland. Advocacy Highland (independent issue based advocacy and citizen advocacy for people with a learning disabilities and lived experience of mental ill health); Spirit Advocacy (HUG and People First Highland, Collective advocacy for people with lived experience of mental ill health and learning disabilities respectively). All independent advocacy service level agreements are under review at present and the HLEP understands that there is to be reduced funding for these services in the future.

2.9 The Highland Third Sector Interface conducted a census report in 2015. A conservative estimate suggests there are at least 3390 Third Sector Organisations in Highland, with only two disability organisations being ‘by’ rather than ‘for’ at a regional level (Spirit Advocacy and Autism Rights Group Highland). A potential decline, rather than increase in the provision of independent advocacy of disabled people is unlikely to improve levels of trust between disabled people and NHS Highland.

3 Are NHS board decisions open and transparent?

3.1 **The Highland Local Community Decision Making**: Transparency interlinks with the processes in community engagement and participation. The Highland Community Planning Partnership (CCP) produces the *Highland Outcome Implementation Plan 2017-2027* at a regional level. The established nine Community Partnerships (CP’s) (Lochaber, Caithness, Inverness, Nairn and Nairnshire, Mid Ross, East Ross, Skye Lochalsh & West Ross, Badenoch & Strathspey, Sutherland) are further charged with the production of locality plans (as a requirement of the Community Empowerment Act (Scotland) 2015, and separate Adult and Children’s Plans (as a requirement of Public Bodies (Joint Working) (Scotland) Act 2014).

3.2 **Membership of Highland Community Partnerships**: The Community Empowerment Act (Scotland) 2015 requires the establishment of CPPs to conduct engagement and participation with communities. The 2015 Act expands the number of public sector bodies that are subject to statutory community planning duties.

3.3 The Community Empowerment Act Part 2: Community Planning Guidance states, ‘The CPP and its community planning partners should demonstrate a clear commitment to securing effective participation with community bodies throughout community planning, by engaging actively with communities of place and interest.’ No such arrangements for constituted community groups representing disabled people exist within the Highland CPP or within the current Highland CPs membership (with the exception of Lochaber, with the presence of the chairperson of the Disability Local Access Panel).

3.4 **Membership of Locality Groups**: The Public Bodies (Joint Working) (Scotland) Act 2014 Section 29 charges Integration Authorities to put in place a Strategic Commissioning Plan for regional functions and budgets under its control. In Highland the Health and Social Care Partnership (HSCP) (Lead Agency model) established the Adult Services Commissioning Group (ASCG) (which fulfils the function of the Strategic Planning Group) to write *The Highland Strategic Plan 2016-2019*. 
3.5 The Public Bodies (Joint Working) (Scotland) Act 2014 Section 29 (3) (a) requires each Integration Authority to establish at least two localities within its area. The NHS Leads on each of the nine Highland CPs produce separate Adult and Children’s Plans at a localised level. However, the presence of existing Locality Groups is absent from the NHS Highlands landscape of community engagement and participation.

3.6 The Localities Guidance 2015 further states with regards to membership of Locality Groups, ‘To ensure the quality of localities input to strategic planning, they must function with the direct involvement and leadership of: health and social care professionals who are involved in the care of people who use services; representatives of the housing sector; representatives of the third and independent sectors; carers and patients representatives; people managing services in the area of the Integration Authority.’

3.7 The lack of a disabled person’s direct lay representative (health service user and social care service users) at a community planning level in the drafting of Highland Adult and Children’s plans, and the dearth of community bodies at a local Community Partnership level is at odds with this Guidance.

3.8 Communities of Practice: Individual NHS Highland leads on Community Partnerships should positively inform Locality Planning. However complementary Locality Planning and Local Adult Health and Social Care plans are on the surface, they are two communities of practice with distinctly different memberships (Community Partnerships versus Locality Groups as described above).

3.9 The lack of engagement and participation of disabled people’s lay representatives at the Community Partnership level exacerbates the lack of openness and transparency between disabled people and NHS Highland. NHS membership of Highland Community Partnerships is no substitute for meaningful engagement with individuals, groups and organisations of disabled people. Closer fidelity to the processes enshrined in legislation and guidance are more likely to improve health outcomes and reduce inequalities.

4 How accountable do you feel NHS boards are?

4.1 Individual, Neighbourhood: Life-long community learning is crucial to building the capacity of disabled people to take-up new roles in community planning and decision making. The Revised Guidance Note on Community Learning and Development Planning 2018-21, is explicit in its role ‘Community planning partners should seek to maximise the impact of community learning and development by focusing activity on the most disadvantaged communities.’ (our emphasis). It goes on to say, “CLD partners’ engagement with communities should aim to: inform the Local Outcome Improvement Plans, Locality Plans, and other plans including Scottish Attainment Challenge plans, Health and Social Care Integration plans and Children’s Services Plans.’

4.2 A HELP pilot is underway in Mid Ross Community Partnership, with the backing of the Highland Community Planning Partnership and NHS Highland, to trial the roles of peer (disabled people’s) Community Learning and Development (CLD) practitioners. The Community Partnership in Mid Ross is chaired by an NHS Highland Board Member and
the role has been co-produced in partnership with disabled people, their groups and the community partnership’s decision makers. We believe that this approach should be adopted by all CPPs and CPs.

4.3 Community: Primary Care - There are currently 8 Patient Participation Groups (PPG) spread across 66 general medical practices. Some Patient Participation Groups choose to look beyond the practice to the decisions made within the NHS that directly affect their community. However only 12% of GP Practices are hosting a PPG, and there seems to be no accountability to a Locality Group structure. This reduces levels of professional and patient scrutiny and subsequent community level accountability.

4.4 Secondary Care - Patient Councils (PCs) are bodies attached to some of the larger hospitals (District General or Rural General). Prior to integration in NHS Highland Patient Councils convened at Raigmore, Belford, Caithness General or New Craigs. A Patients' Council is a group of patients, former patients, carers and others with an active interest in their local hospital. They are used to obtaining feedback on information required by patients, how best to deliver this information, and the best time to do it. They also have a hands-on role in survey work: participating in surveys, or assisting patients to complete survey forms. Not all are currently active, with Raigmore Hospital PC being the most active.

4.5 Organisational: Under the NHS Reform (Scotland) Act 2004, NHS Boards were required to establish Community Health Partnerships (CHPs); each CHP was given responsibility for developing a Public Partnership Forum (PPF) to assist it to maintain an effective dialogue with its local community. The Public Bodies (Joint Working) (Scotland) Act 2014 abolished CHPs, and, by default, PPFs.

4.6 Regional: On 1 April 2012, NHS Highland's three CHPs - North, Mid & South-East Highland - merged into a single CHP that was co-terminus with the Council area, named Highland Health and Social Care Partnership (HSCP). These new statutory bodies, taking over responsibilities from Community Health Partnerships could have continued to support the regional PPF Highland Health VOICES Network (coordinating and covering North, Mid, South-East Community Health Partnerships) but did not.

5 How effective are NHS boards at delivering health services and improving the health of their population?

5.1 We believe that the following actions which would improve governance, accountability, planning and commissioning of health and social care services are required to improve the delivery of health services and the health of the population.

5.2 Actions to Increase Trustworthiness

- Provision of Peer Advocacy at the service level agreement within the NHS Highland Independent Advocacy Plan 2018 – 2021.
• Co-production of, and support, to form a participative Highland, pan impairment disabled people’s working group to inform the work of the Adult Strategic Commission Group.
• Commission disabled people as Experts by Experience to provide disabled peoples leadership on decision-making bodies within NHS Highland.

5.3 **Actions to Increase Transparency**

• NHS Highlands to meet the statutory requirement placed on other Integration Authorities (under The Public Bodies (Joint Working) (Scotland) Act 2014 Section 29 (3) (a)) to establish at least two localities within its area.
• NHS Highland to promote the relationship between Community Partnerships and Locality Groups to further engage with disabled people as community stakeholders within the nine Highlands community partnership areas.
• The online provision of Plain English and accessible information on the new governance arrangements, including the promotion of representative and participative opportunities to disabled people and their organisations.

5.4 **Increase Accountability**

• Consider the recognition of a Disabled People’s Community of Practice (DHCP) based on the principles contained within Revised Guidance Note on Community Learning and Development Planning 2018-21. The membership to consist of disabled people, their organisations (‘by’ and ‘for’) and NHS Highland Health and Social Care Partnership representatives.
• Grow Patient Participation Groups at primary care level within NHS Highland medical practices. Supporting key partnership in membership of Locality Groups.
• Revitalise Patient Councils of (District General or Rural General) at a secondary care level to further develop participation opportunities for disabled people.
• Work with the Scottish Health Council to re-build a Patient Participation Forum, such as Highland Health VOICES Network, to feed into Health and Social Care Partnership work, including the training of Highland Pilot Disabled Peer Citizenship Advocates as lay voice practitioners.

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For Highland Children Leadership Group

Community Development Strategic Partnership

Gaelic Strategic Planning and Development

Health Inequalities Group

Highland Culture Strategy Board

Acquired Brain Injury

Autism

Cereb

Drug and Alcohol

See/Hear

Older People

Mental health/dementia

Learning Disability

Health and social care Improvement groups

Health and social care Improvement groups

Health and Social Care Committee

Adult Services Commissioning Group

Integration Joint Monitoring Committee

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