

Ready for action too?

The rights and reality of disabled people's lives
and the changes needed to improve this

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1. How ready are you?

Ready For Action was first published by the ILiS project in 2009 and summarised the key issues about disabled people's independent living in Scotland. Its publication showed that disabled people were ready to take action and that they were ready and waiting for others to do likewise. Specifically, it highlighted developments to date and priorities and options for future actions.

Ready For Action Too takes account of today's wider recognition and understanding of disabled people's everyday reality and the effects of the changes which have taken place in the intervening years such as the austerity and the impact of the welfare reform agenda as well as new legislation and policies including Self-directed Support, the integration of health and social care frameworks and the Scottish Government's programme of work on the United Nations Convention on the Rights of Persons with Disabilities (the UNCRPD).

Ready For Action Too is for those who have the power and a duty to make a positive difference to disabled people's everyday lives. This includes; national and local politicians, local authorities employees and those who scrutinise the work of public bodies.

Ready for Action Too contains straightforward ideas (see Sections 5 – 7) for making disabled people's rights a reality – ideas developed by disabled people, together with Members of the Scottish Parliament (MSPs), local authorities and scrutiny bodies at events run by ILiS in 2014 and 2015 (see Section 3 for more detail).

The ideas listed here are not exhaustive and not every subject area is covered. Nor are the solutions listed fully formed but, what the following suggestions do is offer a starting point and demonstrate some of the **practical ways that you can play your part in ensuring disabled people are treated as rights-holders and that the rights they have, are the reality they experience.**

2. Human rights and disabled people

‘Human rights are the fundamental entitlements and freedoms that we can, and should, expect in our lives. We should, for example, be able to expect to live our lives in freedom, to be free from torture and ill-treatment, and to have access to adequate education, housing and social security.’

Amnesty International (i)

All human rights belong to disabled people. In addition to this, disabled people’s human rights are further recognised within the UNCRPD ii) which was developed by disabled people for disabled people. It aims to ensure disabled people have full and equal enjoyment of all human rights and fundamental freedoms and it has been legally binding in the UK since 2009. Whilst signed by the UK Government, its ‘provisions... extend to all parts of federal States without any limitations or exceptions’ (iii). This means bodies which the UK Government have directly or indirectly delegated responsibilities to, have duties. In Scotland this includes the Scottish Government, Non-Departmental Public Bodies, Local Authorities, Health Boards and others. In addition, the Scotland Act 1998 states that the Scottish Parliament can only pass laws that are compatible with human rights.

Monitoring compliance with the UNCRPD

Compliance with the UNCRPD is monitored by a special international committee set up to do this. The committee examines evidence from disabled people, civil society, Independent Mechanism (iv) organisations and states themselves to determine if duty holders have met their duties to:

- respect, and not violate, disabled people’s rights
- protect disabled people’s rights and ensure that others do not abuse these rights
- fulfil disabled people’s rights, making them a reality in practice

Ensuring implementation of the UNCRPD requires a number of actors to play their part to make rights a reality for disabled people in Scotland. Both local and national government in Scotland are currently developing their Disability Delivery Plans, setting out how they will comply with the UNCRPD.

3. About ILiS and our work on human rights

ILiS works to support the delivery of the rights of disabled people including the rights in the UNCRPD. It works with Disabled People's Organisations (DPOs), which are led by and for disabled people themselves, to support them to collaborate, co-produce and influence change at national and strategic levels across Government and other statutory bodies. ILiS and DPOs are at the front line of this agenda, driving change and involving the direct lived experience of disabled people.

ILiS partners the Scottish Government in its wider approach to equality for disabled people via the national Independent Living Programme on the UNCRPD and is working with them on the development of the Scottish Government's work plan to progress the UNCRPD. The plan will run from 2015 and takes a cross-government approach.

Whilst the Scottish Government is a key player in delivering the UNCRPD in Scotland, ILiS recognised that MSPs, local authorities and scrutiny bodies have important roles to play too. During 2014 and early 2015 ILiS hosted seminars with these groups to:

- Help participants gain a better awareness and understanding of the UNCRPD, the obligations within it and the gaps between rights and the reality for disabled people
- Inspire participants to consider what role they could play in helping to make the rights in the UNCRPD a reality for disabled people, including through direct commitments where appropriate
- Ensure DPOs and participants were connected so that they can support each other to progress change

During each of the seminars, presentations were made on the UNCRPD (with the support of the Scottish Human Rights Commission) and disabled people's experiences of their human rights. These were followed by open discussion sessions which gave participants an opportunity to identify, in partnership with disabled people, ways that the rights within the UNCRPD could be realised. The ideas that came forward are summarised in sections 5 – 7 of this report.

4. The reality – why we must be ready for action

Disabled people's rights are not yet the reality they experience. Making their rights the reality they experience needs to be the starting point for developing and acting on commitments for change.

The UNCRPD is still a relatively new convention and so there is still significant progress needed on the realisation of the rights within it. The reports of the UK Independent Mechanism (the UK's equality and human rights bodies) and the UK Parliament's Joint Committee on Human Rights (v) summarise many of the current issues well. Some of these are set out below alongside disabled people's experiences of these rights in Scotland.

Article 8: Challenging perceptions

State parties to the Convention must take action to combat stereotypes and prejudices and to promote awareness of the capabilities of disabled people. However;

- Evidence shows that offences aggravated by prejudice against disabled people increased by 12% in 2014 (vi) and 67% of the public feel uncomfortable talking to disabled people (vii).

Article 9: Accessibility

Disabled people should have access to transportation, schools, housing, hospitals and workplaces, along with information and communications. Yet;

- 1 in 5 disabled people who require an adapted home live in one that is not at all, or not very, suitable for them (viii). Seventy five percent of disabled people report difficulties in using public transport (ix). And only 3% of Scottish schools and education authorities have a legally compliant accessibility strategy for disabled pupils (x).

Article 13: Access to justice

Disabled people should have access to justice on an equal basis with others. Despite this;

- 33% of disabled people in Scotland have civil legal problems as opposed to 25% of the general population and they are significantly less likely to resolve them (xi).

Article 19: Independent living

Disabled people should be able to live independently and be included in the community, choose where and with whom to live and to have access to in-home, residential and or community support services. However;

- There are still the same number of care homes for disabled adults of working age as there were 15 years ago (xii) and 20% of Scottish local authorities are unable to say how many of the people they assessed for care and support were offered self-directed support (xii). More people are being charged for their care and an increasing proportion of their income is being taken by local authorities to pay for it. There is emerging evidence which suggests that it costs more to administer these charges than they raise (and more research is required on this.)

Article 23:

Respect for the home and family

The Convention states that disabled people are entitled to an equal opportunity to be parents and to get married. Yet;

- Large numbers of parents with learning disabilities have their children taken away from them (xiv). Many disabled people are unable to take part in daily family life because they lack an accessible home, equipment and adaptations or simply the basic care and support they need to do so.

Article 24: Education

Disabled people should have equal access to primary and secondary education, vocational training and lifelong learning. However;

- 1 in 4 disabled people in Scotland have no qualifications, versus less than 1 in 10 of the general population (xv), and, only 0.2% of Scottish Modern Apprenticeships went to young disabled people (xvi).

4. The reality – why we must be ready for action (continued)

Article 25: Health

Disabled people should experience the same range, quality and standard of health services as provided for non-disabled people; and they should also receive the health services needed in relation to their impairment(s). Despite this;

- Only 40% of those with a limiting long term condition report being in good health and they have significantly lower mental wellbeing scores (xvii). In addition, women with learning disabilities die on average 20 younger than the general population (xviii).

Article 28: Adequate standard of living

Disabled people have a right to an adequate standard of living and social protection. However;

- 20% of families with a disabled adult in them, live in relative poverty (versus 14% of families with no disabled adults) (xix). Furthermore, it can cost £550 a month more to live as a disabled person than a non-disabled person (xx).

Article 29: Political and public life

Political and public life should be open to disabled people, and they should be able to stand for election and to hold office. However;

- Despite making up 19% of the Scottish population, disabled people only made up 12% of public appointments in 2012/13 (xxi). There is also no Scottish equivalent of the UK Government's Access to Elected Office for Disabled People Fund.

All of this suggests change is needed and this needs action. Disabled people are ready for action.

Who's Ready For Action Too?

5. MSPs – are you ready for action?

MSPs have a key role to play in making rights a reality. This section sets out some of the actions MSPs could take to support the realisation of disabled people's human rights.

“It was good to hear in unequivocal language what impact the UNCRPD legislation is having on a day to day basis on disabled people's lives”

MSP attending the ILiS seminar

a) Leading the way

MSPs are in a good position to demonstrate leadership and take action which challenges prejudice and negative attitudes towards disabled people, and inspires others to do likewise. They are also well placed to advocate for disabled people's human rights within the Scottish Parliament, during the development of legislation, legislative scrutiny and within the manifestos of their own political parties.

To do this, MSPs need to; build better connections with disabled people and their DPOs; to speak up with them as well as for them; and to support them by opening up opportunities for them to speak up for themselves.

b) MSPs – engaging for change

Through growing their awareness and understanding of disabled people's rights and the issues they have, MSPs will be better equipped to address their concerns through the development of legislation and other Parliamentary activity. Engaging regularly with disabled people through DPOs and using this to co-produce solutions is therefore essential. It will also be crucial to help to build the capacity and resources of DPOs to enable them to do this.

A specific example, in line with the Scotland Act, could be establishing new (and formal) ways of working with disabled people to check that legislation is compliant with the UNCRPD.

c) Support more disabled leaders

MSPs understand both the local political party constituency processes and the national political agenda so they are in a well-informed and influential place to encourage, mentor and support disabled people to stand as candidates. They should also take practical steps to improve the political representation of disabled people within their own parties.

5. MSPs – are you Ready for Action? (continued)

d) Challenge generalisations such as claims that support is 'unaffordable'

MSPs must recognise that human rights apply equally to all, regardless of geographical location, and that this cannot be overlooked when resources are restricted.

They should challenge generalisations such as 'unaffordable' accessible housing costs, or the 'burden on the state' of social care. These often cover up a lack of evidence and detailed scrutiny of options and alternatives and are regularly used to gate-keep essential support that would implement disabled people's rights.

e) Take action on key policy areas

There are a number of current opportunities where action can make a real difference including:

- supporting DPOs to strengthen community empowerment and capacity building
- taking action to address the shortfall of accessible housing
- advocating for disabled people to become statutory consultees within processes which impact on them and their rights
- investigating the impact on disabled people's human rights of the Mental Health (Care and Treatment) (Scotland) Act 2003
- considering steps towards ending charges for social care

6. Local Authorities – are you Ready for Action?

With their ability to influence people's lives from cradle to grave, it's clear that local authorities also has a key role to play. This section sets out some of the actions local authorities could take to support the realisation of disabled people's human rights.

"I feel quite inspired and realise how important it is, and how we forget, to include disabled people 'from the start' which benefits everyone and...can substantially cut costs"

Local authority (LA) participant at the ILiS seminar

a) Local authorities – engaging for change

It is important that local government uses its position to identify and promote rights held by disabled people and, in doing so, that they co-produce a review of the delivery of these rights via their policies and services.

At national level, collaborative, strategic working arrangements should be brokered between DPOs, local authorities and other influential partners including Scottish Government, Department of Works and Pensions, the Scottish Independent Living Fund and Transport Scotland and Regional Transport Partnerships, for example. Whilst there are processes already linking many of these partners, they do not generally focus on disabled people's rights so new or expanded processes are required.

b) Educating for change

Education plays a strong role in the promotion of rights. Local authorities (together with the Scottish Government) should ensure the UNCRPD is included within schools' curriculum activities, highlighted in community learning and development and that they provide support for the development of Councillors' knowledge in this area.

To this end, as well as work to implement Scotland's National Action Plan for Human Rights (xxii), local authorities should develop Independent Living Strategies for their area, with DPOs.

c) Getting there by taxi

As the body tasked with licensing taxis, local authorities can take steps to ensure taxis serve all members of the community. Outside of Scotland's urban centres, accessible taxi provision is very poor, particularly in the evenings. Local authorities could research and maintain information on the accessibility of the taxi fleet in their area and work with DPOs to establish reasonable quotas for accessible taxis 24/7, and options for addressing the additional costs of accessible vehicles.

d) Houses and homes

Decisions by social work and housing teams should start from a recognition of the right to suitable housing and independent living, rather 'than from a cost or easiest solution'; basis. People should be able to choose where to live and with whom they live. Well implemented choice-based letting systems can help with this, as would the provision of direct support from a single housing officer to navigate the housing system.

The means by which socially rented housing is allocated should recognise disabled people's needs both for accessible housing and enhanced communication. To ensure this, DPOs should be involved in reviews of local authority allocation policies.

Policies to increase the volume of accessible housing, across all tenures, types, sizes and locations, should be developed, and make people aware of, any attempts to reduce accessibility requirements in the current building standards.

6. Local authorities – are you ready for action? (continued)

e) Deliver employment and employability

With such significant workforces, local authorities can directly support disabled people's right to work and gain a living by making them a priority for recruitment. They can also enhance disabled people's employability directly by providing internships and indirectly by supporting employability services, run by and for disabled people.

f) Human rights at the centre of social care

Social care should support disabled people to live independently including playing a part in their community, accessing education and work and living as a family. For this to be a reality, significant steps need to be taken by local authorities to ensure social care has the capacity to deliver this, including that it is sufficiently funded, and the health and social care integration is an opportunity to do this.

DPOs need to be supported to be more fully involved in the integration process if the evolving frameworks are to realise the opportunities and prevent the creation of a new set of barriers, however unintentionally. DPOs involvement needs to be supported in through support to build their capacities and resources.

In addition to this, unmet need for social care should be recorded and assessments should be recognised across local authority boundaries. A formal, open and transparent right to appeal against decisions, which is independent of those making the decision, is a further step which would support human rights for disabled people.

In addition, the models for funding social care should be examined to ensure that they address the reality of the situation and that disabled people are treated fairly. An important step forward would be for local authorities to support the call for an open and formal dialogue on the funding of social care.

7. Scrutiny bodies – are you ready for action too?

Scrutiny bodies are in good position to support service providers and policy makers to embed a human rights approach to their policies, procedures and practices. This section sets out some of the actions that scrutiny bodies could take to support the realisation of disabled people's human rights

“All of the reps from the scrutiny bodies seemed very open to hearing from disabled people and DPOs, which is fantastic!”

Disabled person participant at the ILiS seminar

a) Scrutiny bodies – engaging for change

It is difficult to scrutinise services and service providers effectively in relation to the services they provide to disabled people without first understanding what the issues are for disabled people and what causes them.

A practical step towards this would be for scrutiny bodies to actively secure relevant data from DPOs prior to performing audits and inspections. A follow-up step would be involving disabled people from national and local DPOs in delivering and analysing the scrutiny activities.

Engagement needs to become routine and needs to be performed early enough in the process to ensure that it influences both the choice of subject areas for scrutiny and the means by which they are scrutinised. Investment in time and resources will be necessary to give disabled people the capacities to support the capabilities and experience that they would bring to the process.

b Setting the priorities

Besides engaging with disabled people directly to help identify issues and priorities, programmes of work could include cross-cutting themes such as adherence with human rights, non-discrimination and progress of equality. Sources of issues to be scrutinised could usefully take account of the reports developed by the UK Parliament (xxiii) and Government and by civil society, for the UN committee which scrutinises the UK's performance on the UNCRPD.

c) Increase learning and development

Disabled people are not only customers, service users, tenants or constituents; they are also rights holders. If scrutiny body staff are to recognise disabled people's human rights, and understand how these rights impact on the roles of those they scrutinise, they may well need to be provided with additional learning and development opportunities.

As part of their professional development, staff in scrutiny bodies could spend time shadowing staff in DPOs. Information packs for public bodies and services which are scrutinised could also be designed and developed in partnership with DPOs which would highlight the issues and offer guidance and case studies in what and how to change examples of ways in which who should also be involved in the design and delivery of any training in this area

7. Scrutiny bodies – are you ready for action too? (continued)

d) Work together to address systematic failures

Working together, scrutiny bodies could address all the components that have led to a failure in a policy area. An example investigated at the ILiS seminar for scrutiny bodies was housing as a number of scrutiny bodies could contribute to addressing the shortfall of accessible housing in Scotland. This would have a long-term positive impact for disabled people as well as saving valuable resources elsewhere, such as in health and social care. More accessible housing would be a valuable asset for Scotland as the population ages.

Potential areas of joint scrutiny include:

- the effectiveness of local authority Housing Need and Demand Assessments and Local Housing Strategies, in addressing disabled people's needs
- the allocation processes used for social housing
- the impact of poor housing on health and wellbeing and associated services
- the cost or saving to the public purse of either failing to or providing sufficient accessible housing and adaptations

8. Ready for action ...now

By signing and ratifying the UNCRPD, the UK Government recognised the rights disabled people hold and committed public bodies in across the UK to respecting, protecting and fulfilling these rights. **Human rights are not optional, and so disabled people, along with the UN, will continue to monitor and report when they are both implemented and ignored.**

You can play your part by implementing the recommendations in this document, or working with disabled people to identify others relevant to your area of responsibility.

DPOs are here to help.

They can give you real insight into the barriers faced by disabled people in every aspect of their life and will work with you to identify and design practical solutions.

You can find a directory of them on our website **www.ilis.co.uk**.

9. References

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- xxiii UK Parliament Joint Committee on Human Rights (2012) Implementation of the Right of Disabled People to Independent Living

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