



**A manifesto for change:**  
Disabled People taking control of  
state funded disability service

July 2024



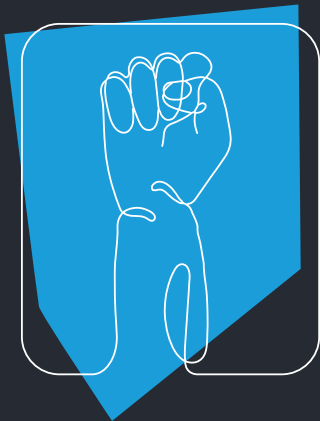
# Inside

 [Click on the page title or number to go directly to the page](#)

<b>Summary</b>	<b>5</b>
<b>Policy context</b>	<b>6</b>
<b>What do disabled people want from disability services?</b>	<b>8</b>
<b>A Manifesto for change:</b> Moving disability services from segregation to inclusion	<b>9</b>
<b>Inclusion of Disabled People in an Ireland of equals</b>	<b>10</b>
<b>A Manifesto for change:</b> Putting systems and strategies in place to ensure that Disabled People control disability services	<b>11</b>
<b>Governance, accountability, transparency and power</b>	<b>13</b>
<b>Setting and meeting targets to map a process for change</b>	<b>14</b>
<b>How can change be monitored and the role of DPOs to support change</b>	<b>15</b>
<b>Setting targets for change</b>	<b>16</b>

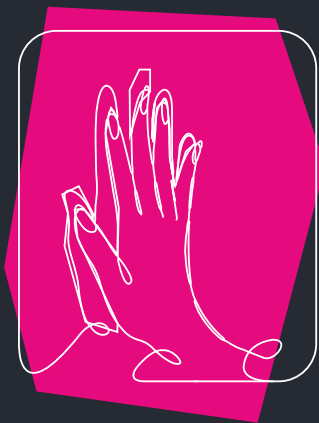


INDEPENDENT LIVING MOVEMENT IRELAND



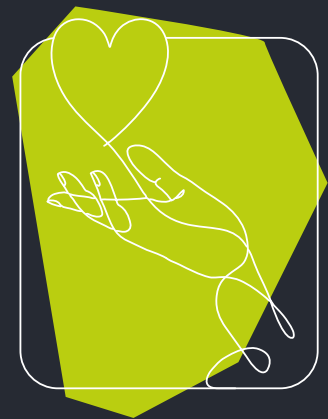
### Human rights

Promote and support disabled people's involvement in activism and their participation in collective action and decision-making.



### Collective empowerment

Secure a recognition of and supports for DPOs and their value as authentic autonomous spaces.



### Social justice

Shape and secure the policies, plans, legislation, services and resources that would ensure the full and active participation of disabled people in society.

**Nothing about us without us**

## Summary

**Independent Living Movement Ireland (ILMI) is a campaigning cross-impairment national Disabled Persons' Organisation. Our vision is an Ireland where Disabled Persons have freedom, choice and control over all aspects of their lives, and can fully participate in an inclusive society as equals. Our strategic values are human rights, collective empowerment and social justice, and these values underpin and guide all of our work.**



This ILMI position paper sets out standards that Disabled People want from State-funded organisations which provide services. There have been many commitments to greater investment in services to promote inclusion of Disabled People in society, and promises and commitments have been made to ensure greater choice and control for Disabled People. However, progress has been slow and, by the Departments of Health's own admission, the targets it has set have not been met.

ILMI contends that until disability services are governed and managed by disabled activists, "person-centred" policies will continue to pay lip-service to disabled people. Until disabled activists are controlling the disability industry, State funding will continually be funnelled into services and structures which limit our choices. Disabled People must be in control of the organisations that the State funds to provide our services. Until that happens, State-funding will continue to be used to provide segregated services that limit our choices, paternalise us and deny us our rights to agency and choice in our lives.

# Policy context

**Ireland annually invests over €2.2 billion to provide supports and services to Disabled People. Almost all of this money is managed by “disability service providers” through annual grants provided by the State. Disabled People have very little control or say in how that money is spent, or on the types of supports or services they receive.**

The Value for Money and Policy Review of Disability Services in Ireland (2012) proposed “a fundamental change in approach to the governance, funding and focus of the Disability Services Programme, with the migration from an approach that is predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports”.

It states that “future delivery of services and supports to Disabled People should acknowledge the views of stakeholders – that choice, control, independence and community inclusion are the keys to an effective, person-centred service”.

The “Transforming Lives” programme, tasked with implementing the recommendations of the “Value for Money and policy review of disability services in Ireland” (2018), stated its commitment to

**improving the delivery of health and social care services to people with disabilities, arising out of the Value for Money and Policy Review of Disability Services in Ireland, based on enshrining the principles of self-determination and autonomy in all service provision for those with disabilities. (Value for Money and Policy Review of Disability Services in Ireland, 2018).**

The HSE “New Directions: Report of the National Working Group for the review of HSE Funded Adult Day Services (2012)” is based on the principle of Disabled People being included in society, and recognises that segregated day services are contrary to that principle:

**Having choices, doing interesting and useful things with one’s time, learning new skills, meeting people and enjoying their company – these are things that most people take for granted. These are the ordinary experiences that people with disabilities tell us they want. The way in which adult day services has evolved over the years has tended to get in the way of these reasonable expectations. Our adult day services have, for the most part, been organised as segregated services, separate from local communities and offering limited options, experiences and choices. This report is making radical proposals and recommendations to change that. (New Directions, 2012).**

The HSE New Directions website notes that

the Benchmarking Exercise completed in 2015 confirmed that there is a commitment to change this and many service providers have moved ahead and commenced an approach to service delivery that focuses on the provision of supports. However, the day service sector is most diverse and significant service change and reconfiguration has yet to be progressed. (New Directions Website).

Indeed, an internal Department of Health review of Disability policy (2021) confirms that whilst the rhetoric of inclusion, mainstreaming and person-centred services is being used:

**There is little evidence of individualised service provision, with a lack of standardised needs assessment and provision largely based in groups. Even though many services purport to use person-centred planning, the quality of the person-centred plan can be negated if options are framed largely in terms of the current model of provision. For example, some day services may be described as supporting “community participation”, although this often involves service users attending a community setting as a group, on a special bus, often in a segregated manner (for example, a special hour for swimming or bowling). Those within the group usually have not selected that activity themselves. This is very different to an individual choosing to attend a swimming lesson, travelling to the swimming pool on public transport and taking the lesson with just a support person (not necessarily a health or social care professional).**



Furthermore, Ireland has policies such as “Time to Move on from congregated settings”, which is a national plan for the process of deinstitutionalisation of intellectually and physically Disabled People from congregated settings to the community, coupled with the publication of the “Wasted Lives” Report (2021) and the development of a new “National Housing Strategy for Disabled People 2022-2027” (2022). All of these reports convey that disabled people should be able to live in their communities with choice and control.

However, in the absence of Disabled People in positions of Governance and management, it is clear that State policies to promote inclusion are not being implemented, and that there is urgent need for reform of these services, particularly in ensuring that services that supposedly cater for our needs are actively managed by Disabled People.

The Action Plan for Disability Services 2024 – 2026 notes that the reform vision of the Transforming Lives programme has been hampered by “legacy issues in the service delivery landscape” (p6). This Action Plan seeks to reinvigorate and expand this reform agenda and this ILMI position paper gives concrete examples on how this reform agenda needs to be led and driven by Disabled People.

# What do disabled people want from disability services?

From consulting with our members, it is clear that disabled people want choice in what supports and services they access. Most importantly, we want to be in control of supports and services. Disabled People want these supports to be based on empowering us to be in control of our lives, so that we can enjoy lives of our own choosing. From consultation, Disabled People identified challenges they experienced in accessing disability services:

The relationship between service providers and Disabled People needs to change. Services are there for Disabled People, and providers need to listen and hear from us – the true experts in our own needs and wants;

There is no transparency on how money is spent in disability services, and specifically on how money spent is giving disabled people choice over our lives;

There is a feeling that there is no real process of auditing of what money is being spent on: money is acquired by large services, but to deliver what? And is it really benefitting Disabled People?

Disability Service providers need to commit to communicate with us in honest, transparent ways - not only about the individual supports we receive, but in how organisations are run. Disability service providers need to communicate with us in plain English and make all their services transparent; and they must be run with the consent of Disabled People, with options explained.

There needs to be clear pathways to make complaints about service provision. Disabled People may not feel comfortable complaining directly to service providers and it is not easy to find out how to make complaints about services provided by the HSE.

We need more Disabled People employed in meaningful ways in service provision. Sometimes Disabled People are employed, but very few are visible in key leadership roles.

There needs to be an investment in leadership of Disabled People to lead these organisations. This needs to more than a tokenistic approach in terms of Governance and leadership. There needs to be a commitment from 40% to a majority of the board of “disability organisations” comprising of Disabled People. Disabled People from outside the service provision needs to be supported, as Disabled People are not limited by their lived experience expertise to only one organisation.

Disability services need to explore supports, including stipends for boards (as per State boards), to encourage and resource Disabled People’s participation on boards.

We need commitments from service providers at a Constitutional level to ensure that there will be mechanisms to support the participation of Disabled People.

Mechanisms such as shadowing, governance training and peer mentoring need to be established. Participation of Disabled People to lead organisations needs to be resourced.

The Department of Equality, Children, Disability, Integration and Youth, in conjunction with the HSE, need to set clear targets for organisations commissioning for services in terms of participation of Disabled People on boards and in employment. This needs to be linked with the NDIS 6% target for meaningful employment.



# A manifesto for change:

## Moving disability services from segregation to inclusion

ILMI as a DPO recognises that many Disabled People receive services through Disability Service Providers that allow them to live independent lives, with freedom, choice and control. Many of these services are vital to ensuring that we as Disabled People can be part of society, living our lives in an inclusive way based on principles of rights and equality.



However, many disability services are clearly still mired in the old medical / charity model, which individualises disability and promotes the idea that people are disabled by their impairments or differences.

The medical model always focuses on people's impairments from a medical perspective. In some ways it still looks at what is "wrong" with the person, and not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their own lives. The medical / charity model never recognises the rights of Disabled People, and assumes that Disabled People need to be "looked after" or "cared for". The medical / charity model has professionals making decisions for Disabled People.

In order to drive change in moving from segregated services, Disabled People need to be empowered to manage and control the organisations that receive State funding to provide services.

# Inclusion of Disabled People in an Ireland of equals

ILMI's vision is an Ireland where Disabled Persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals. The provision of many disability services are diametrically opposed to inclusion.

We know that many segregated services (residential centres, day centres) which were established in the past were done so by non-Disabled people to keep Disabled people "safe", or to "look after" us. However, what they have done in effect is keep Disabled people out of society; they have ostracised us, and they have acted in a way that has prevented mainstream services and indeed Irish society from changing to become inclusive.

For example, Disabled People who should be accessing accredited learning provided by their local Education and Training Board are often instead directed to access learning solely with other Disabled People. Not only does this infringe on Disabled People's rights to access the education of their choosing (as per Article 24 of the UNCRPD), it also denies Disabled and non-Disabled people having a space to share as equals with the view to creating an inclusive society.



Services that are based on the premise that non-Disabled people know best and need to make decisions on what Disabled people want can never be inclusive. Not only should the selection and execution of "activities" that take place in day services be led by Disabled People, Disabled People need to be fundamentally in control of organisations, and consequently they must decide whether they feel it is appropriate to have spaces that segregate them and separate them from their non-Disabled peers; or whether those resources that finance separate services would be better used in providing Disabled People with the resources they need to participate in society as equals.

Ultimately, the €2.2 billion that is annually spent on disability services needs to be controlled and managed by disabled people themselves, so that the desires of Disabled People are reflected in how that money is spent.

# A manifesto for change:

## Putting systems and strategies in place to ensure that Disabled People control disability services

ILMI believes that it is unacceptable that in 2024, organisations that provide essential services to Disabled People are not delivered by organisations managed by Disabled People. Would it be seen as acceptable to have Women's Shelters managed and ran exclusively by men?

Any organisation that provides disability services that are financed wholly or partly by public bodies are under a requirement to implement the Public Sector Duty (Section 42 of the Irish Human Rights and Equality Commission Act (2014)). As part of their implementation of the public sector duty, public bodies are required to pass on the Duty under their funding function.

Section 42 of the Act, or the Public Sector Duty, obliges public bodies to have regard for the need to promote equality of opportunity, eliminate discrimination and protect human rights. This Duty addresses all functions of the public body, including their funding functions and how it encompasses Disabled People. As such, public bodies that fund services must pass on the Duty to organisations providing disability services.

The Irish Human Rights and Equality Commission Act (2014) Section 42 of the IHREC Act states that:

**42. (1) A public body shall, in the performance of its functions, have regard to the need to -**

(a) eliminate discrimination, (b) promote equality of opportunity and treatment of its staff and the persons to whom it provides services, and (c) protect the human rights of its members, staff and the persons to whom it provides services.

**(2) For the purposes of giving effect to subsection (1), a public body shall, having regard to the functions and purpose of the body and to its size and the resources available to it -**

(a) set out in a manner that is accessible to the public in its strategic plan (howsoever described) an assessment of the human rights and equality issues it believes to be relevant to the functions and purpose of the body and the policies, plans and actions in place or proposed to be put in place to address those issues, and

(b) report in a manner that is accessible to the public on developments and achievements in that regard in its annual report (howsoever described).

All organisations providing services for Disabled People are funded by public bodies and, thus, come under an obligation to implement the Duty.

To give effect to the Duty these organisations must:

assess the equality and human rights issues that face Disabled People and that have a relevance for their functions, including their corporate and employment functions. Such equality and human rights issues include the absence or limited number of Disabled People in the management of services for Disabled People;

take steps to address these equality and human rights issues through plans, policies, and actions in place or to be put in place. As such, to address this particular issue, there needs to be a transparent, planned process with timelines that organisations providing disability services commit and move towards a future where they are managed by and for Disabled People;

Report annually on progress made and achievements in addressing these equality and human rights issues, including this particular issue.

ILMI calls on all organisations that are funded by public bodies, and which provide services to Disabled People, to implement their obligations under the Public Sector Duty statement, in accordance with their SLA and in conjunction with their funding public body and, as part of this, to establish how they will work towards developing targets to ensure Disabled People are enabled and supported to lead and manage these organisations.

Disability Services Organisations should also, under their Public Sector Duty obligations, create a clear timeline to look at targets to employ Disabled People in their organisations and ensure there are effective pathways and supports for Disabled People to take on the leadership roles within those organisations.

Disability Service Organisations, as part of their obligations under the public sector duty, should set targets for, and put in place measures for, the employment and promotion of Disabled People, and report on those on an annual basis to show what measures are being put in place to meet these targets, and how those targets are being met.

Further, as per the National Disability Inclusion Strategy, Disability Service Providers as publicly funded bodies need to work towards clear targets “from 3% to 6%, the arrangement of special public service competitions and the opening up of alternative recruitment channels”.

Disabled People from both within and outside the organisation should be actively pursued to apply for all positions within Disability Services Organisations.

# Governance, accountability, transparency and power

ILMI calls on Disability Service Providers to amend their constitutions to reflect the following:

That their board legally must be composed of a majority of Disabled People;

That the chair must always be a Disabled Person;

That there are clear and transparent processes for Disabled People to be elected onto their boards;

That Disabled People who are on the boards need not only be “service users”, as disability service providers need the perspective of Disabled People who experience independent living, non-segregated spaces, and inclusion in society;

That Disabled People are supported under positive action as defined under the Equal Status Acts (2000-2016) and under the NDIS to actively recruit disabled people for all roles within the organisation;

That service level agreements between the HSE and Section 38 and Section 39 funded organisations makes reference to commitments under Section 42 of the Irish Human Rights and Equality Commission Act (2014);

That service level agreements between the HSE and Section 38 and Section 39 funded organisations refer to supporting disabled people to be actively involved in DPOs locally and nationally, as per State commitments under the UNCRPD.

Disabled People leading disability service organisations need to have the power to run services based on principles of inclusion and equality. They are the experts on their own lives and how society needs to change to reflect this. This includes Disabled People deciding whether segregated services are still relevant in the twenty-first century, and not solely on the basis that they have existed for a period of time, or that they were established on the basis of an outmoded medical / charity model of Disabled People.



# Setting and meeting targets to map a process for change

Disabled service providers need to set out in a clear manner, with processes and policies stated, targets set as part of their Public Sector Duty, and report on this on an annual basis. ILMI as a DPO can support and work with organisations based on our principles of participation, inclusion, equality and empowerment. As a DPO, we can also clearly communicate the message that change is essential and cannot be ignored or delayed.

Disability Service Providers cannot maintain that they speak on behalf of Disabled People, even if they are managed by a majority of Disabled People. Statutory bodies need to recognise that service providers do not have a representative role other than to report on how effective their services are, how money is being spent and that the provision of services are those needed by Disabled People to be part of an inclusive society.

External supports and schemes for supporting Governance such as the Charity Regulator, the Charities Institute and Good Governance Awards have a role in highlighting the need for greater inclusion on boards and review targets set by Disability Service providers to ensure progress is made by Disability Service providers in ensuring Disabled People are supported to take on key management roles.

The Action Plan for Disability Services 2024 – 2026 commitment to review “management information requirements and performance indicators to manage and monitor services, and putting in place of improved systems” needs to include measures in relation to recruitment of Disabled People and measures to ensure Governance of disability services by Disabled People. This review of Service Level Agreements (SLAs) needs to also enshrine commitments to support Disabled People to be involved in their DPOs, whether local or national. SLAs need to reflect that State monies are being used to uphold and implement the UNCRPD, including Article 4.3 of the Convention, and that disability service providers in receipt of State funding have a duty to uphold the Convention as they discharge their functions.

# How can change be monitored and the role of DPOs to support change

A DPO is a Disabled Persons Organisation. DPOs, unlike disability services providers, are led by and for Disabled People. DPOs work on a cross-impairment basis with Disabled youth and adults.

DPOs are about bringing disabled people collectively together to bring about a more inclusive, equal society through community development approaches. DPOs are social inclusion and collective spaces for Disabled People, informed through an equality, human rights and social model of disability lens.



DPOs should be the voice of Disabled People and as such, statutory, non-Statutory, media, cultural, sporting, economic, employment and social inclusion dialogues should reach out directly to local DPOs as the voice of Disabled People.

DPOs can be a driver for change in this process. They can support senior management and boards of large Disability services in how they plan for change. Disabled activists from DPOs can provide social model-led disability equality training to board and senior management to guide a process of transformation, thus enabling a move from a medicalised approach to disability to more emancipatory approaches informed by the social model.

ILMI is committed to working with Disabled People in services, as well as the staff and management of services to ensure that the targets set out in New Directions are realised and led by Disabled People. ILMI is committed to working with the Department of Children, Disability, Integration and Youth, HSE, politicians, policy makers and equality and human rights organisations to ensure that principles of the UNCRPD are practiced in State-funded services across the country.

# Setting targets for change

ILMI wants to see active engagement on this issue, and our members recognise its importance. In order to address whether there is progress on building inclusion within disability services, we are calling for the following targets to be set and monitored:

Each disability service, as part of their Public Sector Duty under section 42 of the IHREC Act (2014), set out tangible targets and processes to support Disabled People into Governance positions;

Each disability service, as part of their Public Sector Duty under section 42 of the IHREC Act (2014), set out tangible targets and process to target the employment of Disabled People in their organisations, as per targets set out in the National Disability Inclusion Strategy;

The Irish Human Rights Equality Commission (IHREC) commits to monitoring sectoral plans under the Public Sector Duty and targets are noted by the Disability Advisory Committee (DAC) of IHREC;

Each disability service organisation commits to disability equality training to inform vision, values and practices (annually) to senior management and board;

ILMI will commit to contacting all large service providers to engage in supporting their development to set goals and targets for the active participation of Disabled People. As part of this process, we will work with organisations to promote existing good practice and highlight commitments made to promote inclusion;

ILMI will develop a reporting template as part of a commitment to monitoring annually the large disability services to track progress in the sector, promote the best practice and by publishing annual reports, inform the State on how and where inclusion is being invested in by public funds;

The Department of Children, Equality, Disability, Integration and Youth and the HSE incorporate targets in Service Level Agreements, which are consistent with Section 42 the Irish Human Rights and Equality Commission Act (2014);

Service Level Agreement reform needs to include specific reference to Section 38 and Section 39 State-funded organisations supporting Disabled People who access their services to engage with DPOs, whether locally or nationally. State-funded disability services have a role to support the State realisation of the UNCRPD and specifically the growth of autonomous Disabled Persons Organisations under Article 4.3 and General Comment 7.



**Nothing about us without us**



**Independent Living Movement Ireland**

Carmichael House, North Brunswick Street, Dublin 7, D07 RHA8

Tel: +353 (0)1 873 04 55 Email: [info@ilmi.ie](mailto:info@ilmi.ie)



**[www.ilmi.ie](http://www.ilmi.ie)**