



**Disability Federation of Ireland**

**Feedback on Sinn Féin 'Priorities for Change in  
Health and Social Care'**

**April 2024**

## Table of Contents

|  |    |
|--|----|
| Introduction.....  | 3  |
| Under Section 1: Improve Affordability and Deliver Universal Healthcare and an Irish NHS ..... | 4  |
| Under Section 4: Towards a Sustainable, Skilled and Diverse Health Sector Workforce .....      | 7  |
| Under Section 5.1: Health Regions and Integrated Management .....                              | 10 |
| Under Section 8: Respect the Rights of People with Disabilities .....                          | 12 |
| Under Section 10: Improve Health Outcomes Across Ireland Through Targeted Strategies.....      | 15 |
| Conclusion .....   | 16 |

## Introduction

The Disability Federation of Ireland is a federation of over 120 member organisations working with people with disabilities to implement the UN Convention on the Rights of Persons with Disabilities and ensure their equal participation in society. Our member organisations cover the full spectrum of disability, physical, sensory, intellectual, neurological and psychosocial/mental health. They include a mix of direct service providers, Disabled Person's Organisations, information and advocacy organisations, condition-specific organisations etc.

This submission is based on our work across disability services, including engagement with our member organisations, our structures of representation within our health programme and our continuous policy analysis.

We welcome the opportunity to respond to *Priorities for Change in Health and Social Care*. Over the coming months, we will be engaging with our members on our manifesto for the general election and our positions and observations will develop further with this piece of work. There is a changing landscape in relation to disability health and social care, with:

- The transfer of departmental functions from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth. While we welcome this move, as it ties disability more to equality and integration, it does not negate other departments from their commitment to disabled people. Over 90% of people with disabilities will access mainstream health and social care services, under the remit of the Department of Health.<sup>1</sup> Therefore, mainstreaming disability has to be a priority.
- Changing demographics, with over 22% of the population identifying as having a disabling condition. Of these 8% (407,342 people) experience at least one long-lasting condition or difficulty to a great extent (Census, 2022).<sup>2</sup> The system will need to respond to ensure that population needs are met.
- Six years after the ratification of the UN CRPD, disability policy and legislation has not been reviewed or updated with the UN CRPD as the primary lens.

## Voluntary Disability Organisations

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<sup>1</sup> Department of Health. [Disability Capacity Review to 2032: A Review of Disability Social Care Demands and Capacity Requirements up to 2032](#), p.16.

<sup>2</sup> Census 2022 (2023). [Profile 4- Disability, Health and Carers](#).

Voluntary organisations are a key feature of our hybrid health and social care system. Up to 70% of specialist community-based disability services are provided by voluntary groups.<sup>3</sup> The majority are Section 38 or Section 39 funded organisations. As a result, they are integral to our systems of care, and not an add on. Their sustainability is essential for continued services. Current structures of funding, with continuing staffing retention and recruitment issues, is placing many organisations under enormous pressure.

## Health Outcomes of Disabled People

Disabled people face significant health inequalities, and worse health outcomes than the general population. Census 2022 showed that:

- 23% of people who experienced at least one long-lasting condition or difficulty to **any** extent reported very good health; with 12% of people who experienced at least one long-lasting condition or difficulty to a **great** extent reporting very good health, compared to 53% of the general population.<sup>4</sup>
- Just under one in five people who experienced a long-lasting condition or difficulty to a great extent reported bad or very bad health compared with just 1.7% of the general population.

There is a significant intersection between disability, poor health and poverty. CSO Survey on Income and Living Conditions data (2022) showed that 27.4% of people severely limited by a health problem in activities people usually do were also at risk of poverty.<sup>5</sup>

This paper offers specific comments and observations on a number of sections of the consultation document.

## Under Section 1: Improve Affordability and Deliver Universal Healthcare and an Irish NHS

### Cost of Accessing Health and Social Care Services

Disabled people face higher poverty levels than the general population, and this interacts directly with issues surrounding the affordability of accessing healthcare services. The Indecon *Cost of Disability in Ireland* report (2021), commissioned by the Department of Social Protection showed that disabled people face a range of additional costs linked to health, such as medicines, equipment, and accessing private disability

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<sup>3</sup> Disability Capacity Review, p.18

<sup>4</sup> Census 2022 (2023). [Profile 4- Disability, Health and Carers.](#)

<sup>5</sup> CSO [Survey on Income and Living Conditions 2022](#) (2023).

services as a result of insufficiently funded public services. The following table outlines the usage of a range of health and social care services by respondents to Indecon’s cost of disability survey. This includes information on the use and adequacy of publicly funded services, and the use of private services, as well as services provided by a charity.

| <b>Table 10.5: Usage of Services in the Last 12 Months by Respondents</b>                               |  |  |   |  |  |
|---|--|--|---|--|--|
|   | <b>Used publicly funded service, it was adequate</b> | <b>Used publicly funded service, it was not adequate</b> | <b>Did not use public service, it was not available or suitable</b> | <b>Used and paid for the service privately</b> | <b>Used services provided by a charity</b> |
| Respite care  | 35.6%  | 10.7%  | 38.5%   | 21.9%  | 17.5%                                      |
| Disability residential care   | 36.1%  | 6.2%   | 42.3%   | 14.4%  | 14.4%                                      |
| Day care services   | 51.2%  | 9.2%   | 23.5%   | 9.1%   | 15.5%                                      |
| Speech and language therapy services  | 33.1%  | 15.5%  | 35.9%   | 15.9%  | 9.0%                                       |
| Interpretive sign language services including Irish Sign Language                                       | 18.6%  | 9.8%   | 60.8%   | 11.3%  | 13.9%                                      |
| Occupational therapy services   | 47.4%  | 13.9%  | 24.5%   | 15.4%  | 5.9%                                       |
| Public Health Nurse   | 66.4%  | 10.9%  | 18.0%   | 5.2%   | 1.6%                                       |
| Home Help   | 27.7%  | 7.5%   | 43.2%   | 23.0%  | 4.6%                                       |
| Home supports   | 29.2%  | 6.1%   | 43.0%   | 20.0%  | 6.3%                                       |
| Personal assistance   | 27.9%  | 7.3%   | 39.8%   | 20.7%  | 8.7%                                       |
| Psychological or counselling services   | 39.0%  | 12.4%  | 21.0%   | 29.4%  | 9.6%                                       |
| Social work services  | 48.6%  | 13.7%  | 29.1%   | 3.6%   | 8.3%                                       |
| Physiotherapy   | 35.9%  | 13.3%  | 18.2%   | 38.5%  | 3.4%                                       |
| Dental, optical, audiology and ear nose and throat (ENT) services                                       | 47.0%  | 12.6%  | 8.5%  | 38.6%  | 1.2%                                       |
| Information, advice and use of an advocate  | 48.8%  | 12.3%  | 22.0%   | 10.4%  | 11.9%                                      |
| Other service   | 36.9%  | 10.6%  | 6.2%  | 30.6%  | 19.5%                                      |
| <i>Source: Indecon analysis of confidential survey for research on the ‘costs of disability’ (2020)</i> |  |  |   |  |  |

The table clearly shows significant proportions of respondents unable to access essential health and social care services due to the inadequacy of public services. It also shows that many used and paid for services they required due to their disability privately- a significant cost burden on

these individuals. Those who cannot afford to do so face a significant disadvantage.<sup>6</sup>

The expansion of Sláintecare is an important means of addressing some of these issues. The UN Committee on the Economic, Social and Cultural Rights in their fourth periodic report on Ireland in 2024 expressed concern about “large disparities that exist between different socioeconomic groups in access to healthcare services.” It also highlighted low budgeting and staff shortages as obstacles preventing access to health services for the most marginalised. It recommended that the State “Step up its efforts to ensure, in practice, a universal and comprehensive healthcare system and allocate additional resources to increase the capacity of Sláintecare, recruit and train additional healthcare personnel, reduce waiting times, and reduce obstacles that prevent access to health care for the most disadvantaged individuals and groups.”<sup>7</sup>

## **Medical Card Entitlement**

The commitment in the consultation paper to expand eligibility for the medical card is positive and should include those who require a medical card due to their disability. The entitlement of those on Disability Allowance to access a medical card is at risk if that person secures employment. While some progress has been made on extending access to the medical card, significantly more work is needed to address this barrier. A medical card should be made available to any disabled person who needs it, as part of a state package to address the extra Cost of Disability. A medical card entitlement should be based on medical need rather than means-testing.

As the OECD observed in 2021, “Larger earnings disregards for Disability Allowance (DA) recipients and Medical Card holders can alleviate the situation but cannot do away with the structural barrier. Linking health care access with benefit entitlement is a structural mistake from both an equity and a work incentives perspective. A much more fundamental and equitable solution – and one that goes way beyond the scope of this report – would be to ensure access to universal health care which would allow the government to abolish the Medical Card.”<sup>8</sup> DFI does not disagree with this analysis and recommendation, but in the interim our more modest recommendation regarding the medical card holds.

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<sup>6</sup> Indecon (2021). *The Cost of Disability in Ireland*, pp. 122-126.

<sup>7</sup> UN Committee on Economic, Social and Cultural Rights (2024). *Concluding observations on the fourth periodic report of Ireland*, p.11

<sup>8</sup> OECD (2021). [Disability, Work and Inclusion in Ireland](#), p.19.

## Cost of Medicines

The consultation paper states that “the cost of medicines under existing schemes, and especially for patients who may fall outside of subsidy schemes, can present major difficulties for individuals and families. Universal healthcare must address the cost of medicines.” (p.11) A majority of respondents in Indecon’s research on cost of disability faced additional costs in respect of medicines as outlined in the below table.

| Type of Cost             | Extra Cost | No Extra Cost /Do Not Need | State Help Given |     |
|--------------------------|------------|----------------------------|------------------|-----|
|                          |            |                            | Yes              | No  |
| Prescribed Medicines     | 60%        | 40%                        | 57%              | 43% |
| Non-prescribed Medicines | 54%        | 46%                        | 8%               | 92% |

*Source: Indecon analysis of confidential survey for research on the ‘costs of disability’ (2020)*

In spite of these high additional costs, in 43% of cases no state help was given to access prescribed medicines. This rose to 92% for non-prescribed medicines.<sup>9</sup>

## Under Section 4: Towards a Sustainable, Skilled and Diverse Health Sector Workforce

As stated above, voluntary organisations are an integral element of the landscape of disability supports, with a majority (almost 70%) of services provided by the voluntary sector.<sup>10</sup> A priority for government must be to resource and support a sustainable voluntary sector that can deliver for the people who use these services.

## Challenges of recruitment and retention

Essential services are threatened by a recruitment and retention crisis. The impact of the staffing and recruitment crisis on these organisations is creating a huge risk to their ability to provide adequate services to adults and children with disabilities. The recruitment and retention crisis is

<sup>9</sup> Cost of Disability, pp. 64-65

<sup>10</sup> Disability Capacity Review, p.18

exacerbated by insufficient pay and working conditions in Section 39 funded organisations, that makes them incapable of competing with the HSE or Section 38 funded organisations. These challenges are having a devastating impact on delivery of supports, leading to disruption, lack of continuity of staff and a cutting back of services in some cases. As stated in the consultation document, "Any serious plan for disability services must also address outstanding issues around worker compensation and entitlements across the sector." (p.78)

Funding to apply the WRC-negotiated pay agreement of October 2023 has still not been received by many Section 39 organisations, and there are significant administrative issues with the process. Furthermore, the pay agreement will not bring pay parity to most organisations. Research of DFI's member organisations showed an average pay gap of between 12-15% compared to the HSE; significantly higher than the 8% agreement. This research also showed a very diverse picture among our members with varied pay gaps and a mix of funding sources. Thus, further work will need to take place to achieve full pay parity. There is also a need to ensure that organisations receive funding for all pay-related costs, including pension costs.

A 2023 survey of DFI members showed that, of those who responded:

- 59% have concerns over the sustainability of their organisation due to retention of staff.
- 48% have reduced the level of service they offer due to reduced staffing levels.
- 62% have run an unsuccessful recruitment campaign in the last 12 months and posts remains unfilled.
- 71% have lost experienced staff to the public sector.
- 57% have lost experienced staff to the private sector.
- 43% have lost experienced staff to non-healthcare related posts.
- 33% (over one in four) have lost experienced staff due to burnout.
- 70% have concerns regarding the additional risks their organisation is carrying due to staffing issues.



*"I have really significant, irreplaceable staff coming to me in tears saying they love their jobs, that they don't want to leave, but the differential between what they get in pay and conditions in Section 39 and what they can get in Section 38 and from the HSE is just too wide. The economic factors leave them with no choice and we are faced with reducing and curtailing services."*

DFI Member Organisation

### **Section 39 funded organisations funding**

Many disability organisations may not be financially viable into the future, hugely impacting people who rely on these services. Voluntary organisations are operating with historic funding deficits linked to the recession, and facing an increasing cost of compliance due to growing regulations that organisations are not funded to meet. Fórsa's report *A New Systemic Funding Model: The voluntary and community sector in the 2020s* (2021) notes the overall reduction in funding during the financial crisis, which has never been redressed. Stating that "the government reduced funding for the voluntary and community sector by between 35% and 45%, its staffing by 31%, with funding lines now permanently flatlined at much lower levels."<sup>11</sup> Inflation also continues to place pressure on organisations, particularly in relation to energy costs.

Funding to voluntary organisations should cover the **full cost of delivering services**, including pay alignment with the HSE and meeting non-pay costs such as compliance related costs, electricity, insurance etc. In research commissioned by the Rehab Group on the not-for-profit sector *Who Cares? Building a new relationship between the not-for-profit sector and the State* (2018) one of the most pressing issues raised was the unwillingness of the State to fund the actual cost of delivering services, with all the organisations reporting an inability to deliver the expected level of service for the resources allocated by the HSE.<sup>12</sup>

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<sup>11</sup> Fórsa (2021). *A New Systemic Funding Model: The voluntary and community sector in the 2020s*, p.11

<sup>12</sup> Rehab Group (2018). *Who Cares? Building a new relationship between the not-for-profit sector and the State*, p.8

*"We are a small charity and reliant on continued funding from the HSE and other partners. This funding can be precarious and not guaranteed and can be withdrawn suddenly, so uncertainty is often an issue with the staffing."*

DFI Member Organisation

## **Strategic Workforce Planning**

Strategic workforce planning has to consider cross sectoral issues, and the impact on individuals receiving support. The consultation document contains a strong commitment to "implement a multi-annual strategic workforce plan to meet rising demand and deliver universal healthcare, and develop this plan with healthcare workers, the health service, and higher education institutes to address short-, medium-, and long-term workforce challenges" (p.53). It is important that disability workforce issues are considered as part of this process, and alongside challenges in other parts of the health sector. There is also a need to ensure that staffing in community services receives equal emphasis to staffing in acute hospitals.

To address urgent recruitment and retention challenges in older persons' services, a cross-departmental Strategic Workforce Advisory Group was established. This Group produced a report with recommendations spanning the areas of recruitment, pay and conditions, barriers to employment, training and professional development, sectoral reform, and monitoring and implementation. A similar approach should be taken to address workforce challenges in disability services.

## **Under Section 5.1: Health Regions and Integrated Management**

Development of the Health Regions has progressed since the development of the consultation document, with design that integrates acute hospitals and community care across six Health Regions. While it is welcome that movement is underway around implementation of Sláintecare, we must avoid a situation where priority is given to the acute system and the integration between acute and community, to the neglect of integration across community care and supports. Much work is required to achieve

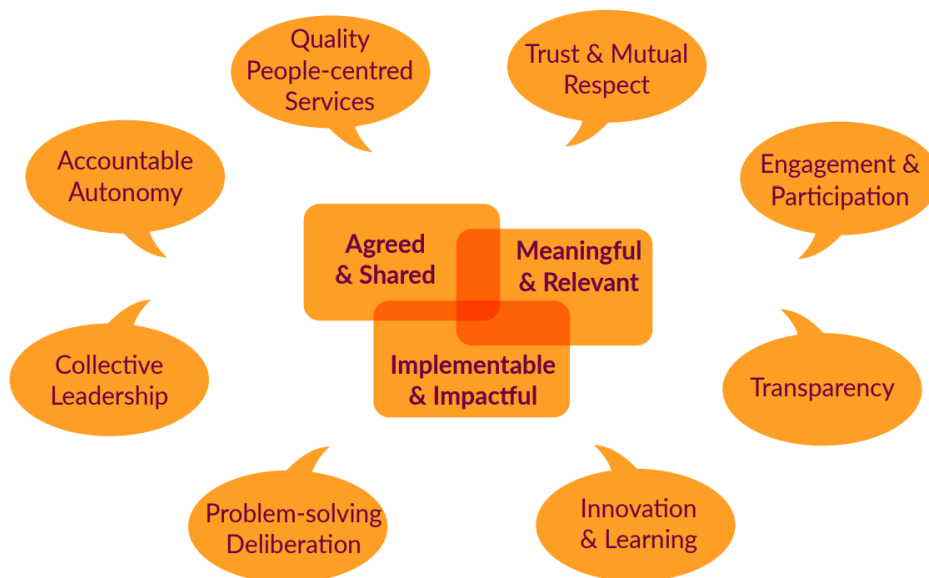
this. A key consideration is the need for integration across our hybrid system where public, private and voluntary providers are all part of the structure of service delivery in the community. As a result, voluntary organisations cannot be considered an add on but rather must be seen as an integral arm of the system.

Given the critical role played by voluntary organisations in the health and social care sector, there is a strong need for the State and voluntary sector to work in partnership to deliver the best outcomes for the public. The Health Dialogue Forum was established to develop more cooperative, productive and sustainable relationships between the State and voluntary organisations across the health and social care sectors. The Forum published an agreed statement of partnership principles to inform the evolving relationships between the State and voluntary organisations. These principles are set out in the diagram below.

## Dialogue Forum with Voluntary Organisations Partnership Principles

*Building A New Relationship between Voluntary Organisations and the State in the Health and Social Care Sectors*

*Voluntary organisations are an intrinsic and valued core component of your hybrid, public health and social care system*



Engagement between the State and voluntary organisations should be informed by these principles, whether at a national level or at a local level between organisations and Community Healthcare Organisations/the new Health Region structures. The partnership principles are informing the design of the Health Regions, but there is no implementation plan for

their application across the health system. Their realisation requires a culture shift, which will not happen without considered and targeted efforts of all stakeholders.

## Under Section 8: Respect the Rights of People with Disabilities

### **Within the frame of Health, what human rights does the UN CRPD (Convention on the Rights of Persons with Disabilities) adopt?**

The following UN CRPD articles relate directly to the rights of people with disabilities to access health and social care services that promote independent living with a high standard of health.

**Article 19- Living independently and being included in the community** recognises that persons with disabilities have an equal right to live in the community, with choices equal to others. This includes the right to access a range of in-home, residential and other community support services, including the personal assistance necessary to support living and inclusion in the community.

**Article 25- Health** recognises that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

**Article 26- Habilitation and Rehabilitation** recognises the right of persons with disabilities to maintain maximum independence and full inclusion and participation in all aspects of life. To that end, States must provide comprehensive habilitation and rehabilitation services, particularly in the areas of health, employment, education, and social services.

**Article 28- Adequate standard of living and social protection** recognises the right of persons with disabilities and their families to an adequate standard of living. The State must take appropriate measures to ensure this right, including ensuring access to appropriate and affordable services, devices and other assistance for disability-related needs, and assistance with disability-related expenses including adequate training, counselling, financial assistance and respite care.

The reference to the UN CRPD as the key international framework to ensure the rights of all people with disabilities in the consultation document is welcome.

## **Disability Capacity Review and Action Plan**

Findings of the *Disability Capacity Review to 2032* showed high levels of demographic and unmet need, which will increase in the future. The long-awaited *Action Plan for Disability Services 2024-2026* to respond to these findings was published in December 2023, as called for in the consultation document (p.78). It is now essential that funding is put in place on a multi-annual basis to deliver the Action Plan, and that this is committed to by the Department of Public Expenditure and Reform. The commitment in the consultation document to fund a 10-year investment programme to provide for future and unmet need, in line with the Disability Capacity Review, is an important and ambitious commitment. The Disability Action Plan is a hugely important document in implementing this and should be a living document that can respond and adjust based on the level of emerging need.

Increased and multiannual funding is required to support equal access to services in line with demographic trends in disability and population growth. Disability services that are essential to the right to independent living, including Personal Assistant Services, home supports, alternative forms of respite, personalised budgets etc. are underfunded and overstretched. Funding is also required to deliver equal access to services across the whole lifespan regardless of geographical location. The transfer of disability services to DCEDIY also brings an opportunity to focus on funding and developing innovative service models in line with the person-centred approach promoted by the UN CRPD.

## **Disability Act 2005**

The paper states that “The rights of people with disabilities were set out in the Disability Act 2005. This Act has provided some solid entitlements, such as the right to an assessment of need, but these have been undermined by a lack of services. The Disability Act should be reviewed with a view to modernising and strengthening the rights and protections for people with disabilities” (p.78). DFI support the need to re-examine the Disability Act 2005 with a view to strengthening rights and protections, particularly as the Disability Act 2005 was prior to ratification of the UN CRPD and should be re-examined in this context. There is also a need for a wider examination of equality and disability-related legislation, and a need to revisit legislation that has never been fully commenced. We are keen to engage further on this area.

## **Need for greater integration**

The siloed nature of service provision must be addressed, with a primary focus on supporting independent living. There is a need to look at health and wellbeing more broadly. People need integration between local community services and healthcare to live independently. To name a few examples:

- The need for accessible housing and social care supports like Personal Assistance services and home support services to live independently.
- The need for accessible transport options to enable people to access health care.
- The importance of supports like Personal Assistance services and assistive technology to support access to employment.

There is also a requirement for greater integration across public and voluntary healthcare provision. For example, the report of the first phase of the [neuro-mapping project](#), delivered jointly between DFI, the Neurological Alliance of Ireland and the HSE, acknowledged the key role that voluntary organisations play in providing community-based services to people with neurological conditions across Ireland and noted the need to harness opportunities to enable further integration between statutory and voluntary community-based services to optimise access. Phase Two will seek to further understand current service and support pathways between existing and developing statutory and voluntary community-services for people with neuro-rehabilitative needs in CHOs 2, 3 and 6.

### **Co-production with disabled people**

Co-production is a relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities. Co-production is a key concept in the development of public services. It has the potential to make an important contribution to all of the big challenges that face health and social support services in Ireland. Co-production starts from the idea that everyone has skills, abilities and contributions to offer. Disabled people have assets and value. Lived experience brings richness and diversity to organisations, but it is also crucial because people with lived experience often hold the keys to solutions to make things better for all. These individuals become experts in the systems they encounter regularly, they see the gaps, they see the difficulties, and often, they know the solutions.

Implementing co-production can support:

- cost-effective services which make the best use of resources
- improved user and carer experience of services
- delivery of better outcomes

- improved quality of life for people and communities
- more equal partnerships between people who use services, carers and professionals
- greater equality, diversity and access for disabled people
- the reform and transformation of services, including better integration of services
- increased community capacity through building stronger communities and active citizenship

Personal and Public Involvement (PPI), Co-Production and Partnership Working are established best practise models in health and social care services in Northern Ireland. For more information:

<https://engage.hscni.net/involvement-co-production-partnership-working/>

'People as Partners in Care' is one of the key elements in the 9 Pillars of Integrated Care, which are widely recognised international standards. The design of our health and social care support systems needs to be a process that is shared with citizens, patients and carers. It is time for a shift in power – to make the voices and choices of all, not just a few, count. For more information: <https://integratedcarefoundation.org/nine-pillars-of-integrated-care#1589383637997-e95e5a73-dff7>

## Under Section 10: Improve Health Outcomes Across Ireland Through Targeted Strategies

Specific reference and consideration of disabled people is required in this section, due to their poor health outcomes. **Globally**, people with disabilities face significant health inequalities:

- Some persons with disabilities die up to 20 years earlier than those without disabilities<sup>5</sup>.
- Persons with disabilities have twice the risk of developing conditions such as depression, asthma, diabetes, stroke, obesity, or poor oral health<sup>6</sup>.

(Census 2022 statistics showing worse health outcomes for disabled people than the general population were outlined in the introduction).

The [WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities, 2022-2030](#) was developed in consultation with Member States of the WHO European Region and organisations of persons with disabilities. The Framework envisages that, by 2030, persons with disabilities and their needs will be fully included and considered in all health care planning, delivery and

leadership across the Region, and includes targets and specific actions for Member States and stakeholders.

Over 90% of people with disabilities are supported through mainstream health and community services, rather than specialist disability services.<sup>13</sup> Almost all people with disabilities will depend on access to mainstream health services at some point in their life. As stated in the consultation paper, "For most people with disabilities, access to mainstream services can make a massive difference to their ability to participate in society." (p.78) Ensuring integration between specialist disability services and mainstream health services will be key in the context of the transfer of the HSE Disability Services programme to DCEDIY. There are ongoing issues with access to mainstream health services including staff shortages, long waiting lists and lack of funding and resources. Addressing the needs of disabled people must be a central element of Sláintecare implementation and cannot be siloed to specialist disability community services alone. This also needs to be carefully considered and planned for in the development of the Health Regions.

The consultation paper identifies the need for Department of Health to maintain an ongoing responsibility for the delivery of health services to disabled people, which is welcome: "disability issues should still be a top concern for the Minister for Health. The Minister for Health is ultimately responsible for the HSE's performance and is still responsible for many services which people with disabilities use. The two Ministers should work closely together on ensuring that disability services are improving year on year." (p.78) DFI feel that in order to ensure that Department of Health retains an ongoing focus on disability there is a need for a senior person responsible for disability within the Department of Health, particularly in consideration of the fact that 22% of the population identify as having a disabling condition of some kind.

## Conclusion

We would welcome the opportunity to further discuss the consultation document, the issues outlined in this submission, and the changing landscape of health and social care for disabled people. We are in the process of undertaking engagements with our member organisations to inform our general election. This will further develop the points that we

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<sup>13</sup> Disability Capacity Review, p.16



have made and may include additional comments and asks related to health.

If you would like to discuss the issues raised in this paper further, then please contact:

Ríona Morris, Policy and Research Officer

Mobile: [086 022 9606](tel:0860229606)

Email: [rimonamorris@disability-federation.ie](mailto:rimonamorris@disability-federation.ie)

or

Emer Begley, Director of Advocacy

Mobile: [086 035 6019](tel:0860356019)

Email: [emergbegley@disability-federation.ie](mailto:emergbegley@disability-federation.ie)



## **DFI's vision**

An Ireland where people with disabilities are participating fully in all aspects of society.



## **DFI's mission**

DFI is a federation of member organisations working with people with disabilities to implement the UN CRPD and ensure their equal participation in society.



## **Four-year goal**

Member organisations are actively involved in DFI, working to implement the UN CRPD and to achieve the equal participation of people with disabilities in society.

DFI, Fumbally Court, Fumbally Lane, Dublin 8

Tel: 01-4547978

Email: [info@disability-federation.ie](mailto:info@disability-federation.ie)

Web: [www.disability-federation.ie](http://www.disability-federation.ie)

Registered Charity Number: 6177 Company Number: 140048

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