



Disability Federation of Ireland

Submission on Disability Action Plan Framework

8th October 2021

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Introduction

Who are the Disability Federation of Ireland? (DFI)

The Disability Federation of Ireland (DFI) represents the interests and the expectations of people with disabilities to be fully included in Irish society. It is comprised of member organisations that represent and support people with disabilities and disabling conditions. The vision of DFI is an Ireland where people with disabilities and disabling conditions are fully included and enabled to reach their full potential in the spirit of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). DFI's mission is to advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of their lives. [Learn more about our work on our website.](#)

There are over 120 organisations who are affiliates or associates of DFI. DFI's members include a range of different types of disability organisations including service providers, Disabled Person's Organisations, condition-specific organisations, advocacy organisations, family-led organisations etc. They include organisations focused on physical, sensory, intellectual and neurological disabilities and disabling conditions. [Our full list of members is here.](#)

Consultation Process

DFI held a Zoom consultation event and advertised it to all of our members. The consultation included a presentation on the Disability Capacity Review and Disability Services Action Plan Framework. Then, members gave their feedback on the Framework in breakout sessions.

Members were also invited to provide written and/or verbal feedback outside of the event. The feedback from the consultation event, along with written and verbal feedback have all informed this submission.

Section 1: Overarching Issues

Working Group Representation and Decision-Making

People with disabilities and the disability sector need to be involved fully in the development of the Action Plan 2022-25. The consultation with people with disabilities, and umbrella bodies is important. However, representation on the Working Group developing the Action Plan is needed, to ensure that services are properly planned to meet the needs of people with disabilities. Voluntary organisations deliver close to 70% of disability services.¹ Given their expertise on service provision, the representation of voluntary disability organisations is critical.

Learnings from COVID-19 are that change is best agreed and implemented in a collaborative way with organisations and people with disabilities. The national disability umbrella organisations should have seats on the Working Group. The full involvement of people with disabilities in decision-making, in line with the UN CRPD is also needed to ensure that people with lived experience have a role in shaping the future of disability service provision.

The proposed representation of the Department of Public Expenditure and Reform, DPER on the Working Group is welcome. Their involvement in the Disability Action Plan from the beginning, to ensure that the necessary resources are put in place is critical.

The funding requirements to address both demographic change and unmet need outlined in the Disability Capacity Review must form the basis of the Disability Action Plan. There are some cases where the plan has underestimated unmet need due to a lack of data, and this should be addressed. There are also a range of mainstream health and community measures that will require funding alongside the investment in disability services. See [DFI's pre Budget submission](#) and the [Oireachtas Disability Group's joint pre Budget submission](#) for more details.

Funding of Voluntary Organisations

There are a number of longstanding issues for voluntary disability organisations that need to be resolved to deliver the Action Plan and Disability Capacity Review.

The multi-year planning approach being taken through the development of the Disability Services Action Plan is most welcome. It should be aligned with multi-annual funding, which would give providers the certainty to plan services more effectively over a longer term. This is something that the community and voluntary sector have been seeking over many years. Recently, the HSE Corporate Plan

¹ Department of Health (2021). *Disability Capacity Review to 2032: A Review of Social Care Demand and Capacity Requirements up to 2032*, p.18.

2021-24 expressed the HSE's intention for multi-annual investment in the disability sector.²

Voluntary disability organisations have long been underfunded. Many are not funded to deliver the full costs of services, and rely heavily on fundraising income to deliver essential services. This is a particular problem with smaller organisations. This income can fluctuate, to the detriment of the people who rely on the service. Many disability organisations are carrying historic deficits, with estimates placing the collective deficits at over €40m.³ The HSE acknowledged that many voluntary organisations risk becoming unsustainable in a report to their board seen by the Irish Times.⁴ The underinvestment in voluntary organisations that provide the majority of services to people with disability means is contributing to the huge levels of unmet need.

The Report of the Independent Review Group on the role of voluntary organisations in publicly funded health and personal social services (Catherine Day Report) should underpin the Action Plan. A plan for implementing the recommendations of this report should be included in the Action Plan.

Staffing Issues

There are longstanding issues regarding inequalities between Section 38 and 39 organisations. The lack of pay parity has an impact on the ability of Section 39 organisations to recruit and retain staff. COVID-19 spotlighted some of the inequalities, as staff in section 39 organisations did not have the same sick pay entitlements as their Section 38 and HSE colleagues. The inequality has made it difficult for section 39 staff to retain key staff who are offered higher wages and better conditions by moving to section 38 organisations, the HSE or private home care providers. DFI have seen this issue across our members, from therapy posts to personal assistants to day service staff. This high turnover is detrimental for the vital relationship between the person with a disability and their support staff. It is heavily impacting on the ability to deliver services. Understaffed services also contribute to the level of unmet need.

The Disability Action Plan must be accompanied by a robust workforce planning approach, that examines staffing levels in disability organisations and the factors affecting this. This should include the issue of pay parity, as well as other factors such as numbers of graduates from therapy disciplines. Without addressing staffing, it will be impossible to fully address the levels of unmet need. An early action of the Disability Capacity Action Plan must be to establish a Workforce Planning Working Group, with representation from both the statutory and voluntary side.

² HSE (2021). *HSE Corporate Plan 2021-24*, p.11.

³ Joint Oireachtas Committee on Health, 2019.

⁴ The Irish Times (3rd Aug 2020). HSE says provision of disability services by voluntary bodies not sustainable. <https://bit.ly/2QIOA6x>

Data/Evidence

DFI and our members are concerned that the evidence used in some areas of the Disability Capacity Review is not sufficient to capture the true levels of unmet need. Developing the Disability Action Plan must include ensuring that the evidence is sufficient to ensure that the appropriate services are delivered to meet people's needs.

The data in relation to community services. In relation to PA and home support, the Disability Capacity Review states that "data on unmet need has not been systematically recorded."⁵ DFI's members have reason to believe that the unmet need is considerable, and likely goes beyond what has been estimated in the Disability Capacity Review. Accurately gathering this data, so that those needs can be met must be a priority for the Disability Action Plan.

Chapter 9, on "other community services and supports" which covers a wide range of different community services that support people to live independently and well in their communities. Many of DFI's members provide services that fall under this heading. These include, for example:

- Information and advice/helplines
- Family support
- Health and well-being programmes
- Social programmes/Community integration programmes
- Individual advocacy
- Condition-specific peer support groups
- Aids and appliances
- Assistive technology
- Education and training
- Employment-related services
- Holidays/outings
- Local area co-ordination

The Disability Capacity Review does not attempt to estimate unmet need for these services, and the costings used are based solely on demographic change. This is despite acknowledgement in the Review that:

"where these roles are available, people with disabilities can be enabled to access mainstream activities and services, slowing down and reducing the uptake of more traditional disability services."⁶

The Disability Action Plan must take the potential of these service models seriously, and properly assess the demand and level of unmet need for these services. As the Disability Capacity Review acknowledges, this could have the positive impact of reducing the pressures on other forms of disability services as well. These types of

⁵ Department of Health, *Disability Capacity Review*, p.74

⁶ Department of Health, *Disability Capacity Review*, p. 132.

services are central to the UN CRPD, as they enable full inclusion in the community and links to mainstream services.

The National Ability Support System, NASS, is one of the primary means of gathering data on unmet need. However, currently the data collected through the NASS is not sufficient when it comes to community services. Furthermore, it only collects data in relation to the 9% of people with disabilities currently in receipt of some form of disability services. There are many more people who require services, but this is not measured.

To reliably plan services up to 2025 (and beyond), a focus must be placed on ensuring there is necessary data to determine true levels of need, particularly in relation to community services where this is particularly lacking.

Link to Mainstream Health Services

It is important to note that over 90% of people with disabilities are not supported by specialist disability services, but rather are supported through “general community health and social services.”⁷ A wide range of health services are vital to the wellbeing of people with disabilities such as primary care services, mental health services, neurological services, acute hospital services etc.

Many of DFI’s members, particularly those who work with people with specific conditions, including neurological and/or rare conditions primarily engage with these types of health services. DFI and our members are disappointed that mainstream health services to people with disabilities fall outside of the scope of the Disability Action Plan. We would ask that the scope of the Disability Action Plan be reconsidered, in this context.

However, even if the scope remains unchanged, an Action Plan for disability services must include the link to mainstream services. The link between specialist disability services and mainstream health services is crucial to ensure a coherent service for people.

It was noted by many DFI members that navigating the “system” can be very difficult. This is particularly true of people not already linked to the disability services programme, such as those who acquire disabilities, many people with neurological and/or rare conditions, people with different comorbidities etc. In the case of progressive conditions, people’s needs can change significantly over time and this should be recognised as well. A combination of disability and mainstream services is often what is needed. Ensuring integration between these services is important to allow people to have the services that they need, when they need them. DFI members expressed the potential of formalising a case manager/care co-ordinator who would act as an independent ‘quarterback’ to help people and families navigate the system, and variety of services that they need.

Ensuring integration of different health and social care services is particularly important in the context of the HSE Disability Services programme moving to the Department of Children, Equality, Disability, Integration and Youth (DCEDIY). Many important health services provided to people with disabilities will remain under the remit of the Department of Health. The Clinical Programme for Disability is concerned with many of the mainstream services that will remain under the Department of Health. Ensuring integration between these services overseen by the Clinical Programme and the Disability Services programme will be an important challenge when the move takes place.

Cross-Departmental Working

The links between government Departments are essential to delivering services to people with disabilities. The cross-Departmental nature of the Working Group is welcome. However, the absence of representation from the Department of Education on the Working Group should be reconsidered given the importance of the connection between Health and Education in the delivery of services to children.

Delivery of services to people with disabilities, and implementation of the UN CRPD, will require funding from a range of government Departments, not just Health (and DCEDIY when the transfer takes place). More explicit targets to be achieved by other departments, as well as the appropriate mechanisms to ensure effective cross-Departmental working on joint priorities is required.

Person-Centred Services

The Disability Capacity Review places a focus on traditional models of service funded through the disability services programme, such as residential, day, respite etc. In light of the UN CRPD there is a need for greater focus to be placed on person-centred services, with a particular focus on those that enable independence.

As already noted, Chapter 9 on community services encompasses a wide range of supports that enable people to participate in their communities and connect them with mainstream services. The lack of focus on what these services entail, and what the need for them is should be addressed in the Disability Action Plan.

The Disability Action Plan presents a valuable opportunity to commit to investing in community-based and person-centred services that enable people to live independently in their own homes. This has long been an aspiration of the state, as expressed in policies such as 'Transforming Lives' and 'Time to Move on From Congregated Settings.' While some progress has been made, it is slow. The health disability funding has long been orientated towards the traditional models of service, yet only a small percentage of people with disabilities are supported by these services.

There is an opportunity to transform service delivery and invest in the types of services that support people to live independently in their own homes. These include PA services, home support, respite, personalised budgets etc. It is time to consider

new models, like local area co-ordination, as a way of supporting people to participate in services and supports.

Personalised budgets enable people to have choice and control over the types of support that best suit them. The Disability Action Plan must enable this as a choice. There are learnings from the ongoing personalised budget pilot in relation to the challenges that will need to be overcome to enable this. For example, the level of administration needed can be burdensome for the individual and/or their family. This should be reduced. When individual funding is unbundled from services, it can be too low to provide for the level of supports that the person needs. How personalised budgets can be resourced so that they can work effectively to support people who choose that option should be examined as part of the Disability Action Plan.

COVID-19 has further demonstrated the importance of person-centred services. While many people continue to have a preference for in-person supports, there are others who preferred and benefitted from individualised, remote services. The Disability Action Plan must ensure funding is sufficient and flexible enough to support people to make this choice.

HIQA

The role of HIQA is particularly important to consider in the Disability Action Plan. HIQA already plays a role in regulating residential disability services, and there are key learnings from this process. The suitability of extending regulation to community service models must be addressed especially given discussions on extending HIQA's reach to other forms of disability social care services like day, home support and PA. Any regulation of disability services must be based on the principles of the UN CRPD.

There have been issues in relation to the cost of meeting HIQA regulation. These must be addressed in the Plan before considering expanding the regulatory powers of HIQA.

Section 2: Identified Priorities

Children's Services

The recruitment and retention issues are having a major effect on the delivery of children's services. Someone in a speech and language therapist role, for example, can receive better pay and conditions in a section 38 organisation or working for the HSE than they can in a section 39 organisation. High turnover of staff, and staffing shortages are having a detrimental effect on children. A robust workforce planning approach is essential to ensure that Progressing Disability Services for Children (PDS) can be delivered. The intention in the Framework to work with third level authorities on the provision of additional training places in different therapy services is positive. This should take place alongside addressing the pay issues outlined in Section 1 and establishing a Workforce Planning Group.

It is not always clear what the entry point to PDS is for the majority of the population, particularly those not already linked in with disability services. Greater clarity is needed for families. The Action Plan must examine how to improve the evidence base on children not linked to services to improve planning. There are no databases, for example, on children with acquired brain injuries or children who are deaf-blind-along with many other groups of children.

The connection between 'clinical' disability services for children, such as paediatric and therapy services and other types of services for children and families including family support service models, support groups, social clubs etc. is vital.

Intensive supports for young people with disabilities experiencing severe distress

Greater clarity is needed on what the support packages include, and how the individuals and families who require them are identified. Transparency is needed on the how the intensive supports can be accessed, and the criteria for accessing them.

It was unclear to DFI's members what the underpinning strategy behind this response is, and this needs to be clarified. It also needs to be clear to them, how and when they can signpost individuals for these supports.

Delivering an adequate, long-term response to people in severe distress is also heavily dependent on other types of services like PA and respite, and potentially mainstream services like mental health. Ensuring the links to these services is therefore critical.

Day service places for school leavers

The transition between school and adult day services needs to be more comprehensive and planned further in advance.

The issues regarding recruitment and retention are impacting on delivery of day services. There is also a clear gap in the cost of delivering a day service, and the funding that service providers receive.

The Disability Action Plan should consider how funding is currently allocated to day services, and whether it aligns with the New Directions vision of supporting people in their communities. The funding needs to be flexible enough to respond to people's individual needs and preferences. COVID-19 has brought huge learning in relation to day service delivery. For example, many of our members are reporting that large numbers of the people they support would prefer to retain the remote, person-centred service that they received during the pandemic to returning to a centre-based service. One member who did research with their service users found that 20% would prefer not to return to a centre-based service, while 80% would prefer to return. Meeting the preferences of both of these groups is essential, yet will require funding that is flexible enough to respond.

Service providers would prefer a person-centred model, but under current funding this will not be possible to maintain alongside an in-person service. Delivering these types of individualised supports alongside a centre-based day service will require additional resources, including staff, appropriate technology etc. The UN CRPD requires that person-centred service models be supported. Members also noted a need to link planning for day services to outcomes for people, as well as recognising and providing support for a broad range of unique needs.

Members noted that other ways of delivering day services should also be considered, such as evening services outside the traditional 9-5 services that would offer socialisation opportunities.

Linked to this is the importance of personalised budgets. Where someone would prefer to direct their own funding rather than attend a day service, this should be accommodated. However, there are many issues that would need to be addressed. For example, when funding is unbundled from a day service support it is often insufficient to meet the person's needs. Appropriate resourcing will be needed. The Disability Action Plan should seek to learn from the experiences of the personalised budget pilot so far, as well as best practice models from abroad.

There is a need to capture the needs of people who are currently receiving no services for day services. One such cohort is people with neurological conditions who are not currently linked into disability services. The neurorehabilitation strategy was supposed to map the requirement for these types of services for the neuro-disability cohort, but this work has stalled. The Disability Action Plan should include an approach to measuring and addressing the levels of need for those currently not receiving services, including people with neurological conditions. Awareness training for day service staff on specific conditions should also be considered.

There is also an important question to address in terms of how individuals with lower levels of need can be supported in their communities. Their requirement may not be for a five day a week day service, but they may require additional supports to enable them to link in with mainstream services, education, employment etc.

Personal assistance and home support

This section of the Framework relates to personal assistance (PA), home support and community-based services. There is a need to develop an accurate understanding of each of these services, what they encompass and how they are distinct. 'Community based services' references a wide range of services that are important in enabling independence and community participation. Historically, the appreciation for the potential of these types of service models has been poor. Ireland has ratified the UN CRPD, which requires an investment of the types of services that promote independence and inclusion, in line with Article 19. The Disability Action Plan needs to examine these types of services individually, who would benefit from them, how to meet the level of need etc. This warrants the same level of focus as the 'traditional' service models of residential, day etc.

The evidence in relation to unmet need for PA, home support and other community services is very poor. The Disability Capacity Review acknowledges that their figures are estimates due to the lack of data on unmet need. In relation to community services, the Disability Capacity Review budgets for demographic change only. The Disability Action Plan must plan for accurately capturing the unmet need for these services. The NASS is only capturing people in receipt of disability-funded services. There is a huge cohort of people with disabilities whose needs are met outside of that e.g. through primary care, who may have an unmet need for PA, home support or community services.

The recruitment and retention issues discussed in section 1 are having a particularly strong impact on delivery of PA services. The crisis in recruitment is very real for these services. Low hourly rates make recruitment very difficult, and there is competition with private providers who are in a position to offer higher pay. In some cases, the HSE rely on purchasing services from private providers or people pay out of their own pockets, due to the underresourcing of state-funded services. The same level of governance and oversight by the HSE of the service being delivered is not in place with private providers.

DFI members stressed the importance of these services in terms of rehabilitation, and maximising people's independence and capacity. They are an important part of the pathway from the hospital to living well at home for those who acquire disabilities. Specialist community neuro-rehabilitation services funded under 'community services' for example, play an essential role in rehabilitation- but these services are underdeveloped, underresourced, and there is huge unmet need.

There is a need to ensure an appropriate skill mix in PA services to meet varied needs. In the case of acquired disability, a rehabilitative need would need to be addressed alongside promoting independence. Parallel processes are not an efficient way of meeting both of these needs. If there is an assessment of need, the planned service should have the requisite skill mix to support the recipient to achieve their own personal social goals, and their rehabilitative goals. For example, with additional training PA and home support staff could deliver complimentary physiotherapy support in between sporadic consultations with physiotherapists. It

was also noted that PA and home support services are not designed around people with neurological conditions. Ideally, the skill mix would be matched to the needs of the individual.

It was also noted that day services and PA/home support should not necessarily be seen as mutually exclusive services- people should be able to access the services they need, at the time that they need them.

Central issues effecting delivery of PA services, like the “postcode lottery” people experience in accessing services, receiving insufficient hours to truly enable independence, staffing shortages, the need for truly leader-led services, the need to move to a demand-led service rather than resource-led etc. should be fully considered. Currently, the Action Plan Framework does not contain much detail on how improvements in line with the UN CRPD will be made. A more detailed examination of this is needed. A policy analysis, that includes gathering the views of people with disabilities, as proposed in relation to respite would be hugely beneficial.

Respite services, including alternative respite

As with PA, home support and community services, the Disability Capacity Review recognises that latent unmet need could be considerably higher than what is recorded. It notes that less than 1 in 4 parents caring for an adult or child with a disability receive any form of respite. The proposed policy analysis should address how this latent unmet need can be captured and responded to. It should ensure that the needs of people outside of disability services are included in this. The ‘entry point’ to respite services is important to consider- it should be an option available to any person with a disability who needs it, and not confined to those who are receiving disability services. It was noted, for example, that children with so-called “mild” disabilities would often not be considered eligible, especially if they are not attached to a service. Yet there may be a significant need for respite. Approximately 86% of those with intellectual disability, for example, are in the “mild” category. The importance of respite was summed up by one DFI member who recounted a mother who stated “If I go down the family goes down.”

The Disability Capacity Review identifies a major shortage of respite for carers of adults with intellectual disabilities. It also states that access to respite is considerably lower for people with physical and sensory disabilities. The Action Plan Framework only mentions intellectual disability. The Action Plan should take a broader focus on access to respite for people with disabilities and carers as a whole, regardless of the type of disability. Planning for respite in the Disability Services Action Plan should also take into account the trajectory of progressive conditions, and the impact this will have on need for respite.

The importance of a variety of forms of respite, including alternative models to centre-based respite should be examined. More detail is needed than currently in the Framework on what exactly “alternative” forms of respite will encompass. In-home respite is an important focus. There are also really important models such as home share, that warrant consideration. Members also noted the importance of condition-

specific residential respite provision, to allow for the development of infrastructure and practices orientated around the needs of that condition.

DFI members reflected on the importance of meaningful respite for the person with a disability. This includes ensuring that it is age and needs appropriate. The support of respite to family carers is valuable, but there needs to be a focus on a meaningful experience for the adult or child with a disability.

The distinction between respite, and other forms of breaks is important. For example, an opportunity for a family carer and person with a disability to get away together can be of huge benefit. It was noted that funders look for providers to provide weekend and holiday breaks as a form of therapeutic support. The focus of these breaks should be on meaningful experiences.

Additional residential care places in the community

In planning for residential services, there is a need to use demographics to plan for what currently becomes unpredicted, emergency need. It is also important for the Department to consider broader issues related to housing beyond just residential services to deliver the right to independent living.

A point that was emphasised by DFI members is that the UN CRPD and Assisted Decision-Making (Capacity) Act must be taken into account when planning residential services. People with disabilities should be able to decide where they live, the type of accommodation, who they live with etc.

The focus on cohorts including those inappropriately living in nursing homes and congregated settings in the Action Plan Framework is welcome. However, planning residential services alone is insufficient to respond to the need of these groups, and leaves out the broader housing needs of many other people with disabilities. In some cases, living in their own homes rather than residential services will be the preference of the individual. Therefore, planning community-based services that support people to live independent lives in their own homes are also critical.

Decongregation, and moving people inappropriately placed in nursing homes, should be grounded in the UN CRPD, with the will and preference of people in terms of where they live. Moving people from congregated settings, or nursing homes, to lower density community-based homes is not sufficient if people's preference is to live on their own, for example. If the Transforming Lives Programme is to live up to the principle of ordinary lives in ordinary places, there must be recognition that a lack of choice about who one lives with is not true to that principle. Planning to ensure the necessary housing and supports are in place to ensure people have a genuine choice is absolutely essential. The will, preference and choice of the individual must be at the centre.

To have a long-term impact on stopping inappropriate placements in nursing homes from occurring in the first place, a vision and plan for an alternative to the Nursing Home Support Scheme is needed. A statutory entitlement to a range of community-based services, including PA and home support is needed.

The stated intention for the Minister of State for Housing to work with the Minister for Housing, Local Authorities, and the HSE to ensure suitable and appropriately-located housing is welcome. The focus of this should be broader than residential services alone, and should be based on implementation of the upcoming Housing Strategy for Persons with Disabilities. The co-ordination between the different agencies involved in the delivery of housing and support services often creates issues for people with disabilities. The Department must therefore broaden its focus beyond just residential services, and include those who wish to live independently in their own homes, or in their family home. For example, an issue that frequently occurs for people who wish to live independently is that they are offered a home by the local authority, but cannot move in until they are guaranteed support packages of PA hours by the HSE, sometimes leading to significant delays. DFI, and others in the sector have called for the establishment of a national mechanism to drive interagency co-ordination between the Housing Agency, national HSE, Local Authorities, Department of Housing etc. At a local level, appointing Disability Housing Co-ordinators in each Local Authority would be of benefit in supporting access to housing for people with disabilities. Sufficient funding for support packages of PA hours will be crucial in the years to come to reduce the Local Authority waiting lists for housing.

The additional costs of regulatory compliance should also be addressed in the Action Plan. The disconnect between the expectations of the regulatory compliance arm of the state, HIQA, and the service commissioning and funding arm of the state remains problematic and burdensome. Service providers are caught in the middle.



DFI is about making Ireland fairer for people with disabilities.

We work to create an Ireland where everyone can thrive, where everyone is equally valued.

We do this by supporting people with disabilities and strengthening the disability movement.

There are over 120 member organisations in DFI. We also work with a growing number of other organisations that have a significant interest in people with disabilities.

DFI provides:

- Information
- Training and Support
- Networking
- Advocacy and Representation
- Research, Policy Development and Implementation
- Organisation and Management Development

Disability is a societal issue and DFI works with Government, and across all the social and economic strands and interests of society.

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