

Disability Federation of Ireland

Disability Action Plan Framework: Summary of Priorities 2022-25

8th October 2021

Overarching Issues

Working Group Representation and Decision-Making

- Learnings from COVID-19 are that change is best agreed and implemented in a collaborative way with organisations and people with disabilities.
- As voluntary disability organisations deliver close to 70% of disability services it is critical that their representatives are included in the Cross Departmental Working Group responsible for drafting the new Framework.
- The proposed representation of the Department of Public Expenditure and Reform 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.
- Funding requirements outlined in the Disability Capacity Review must form
 the basis of the plan. There are also a range of mainstream measures that
 require funding alongside the investment in disability services. See <u>DFI's pre</u>
 <u>Budget submission</u> and the <u>Oireachtas Disability Group's joint pre Budget</u>
 <u>submission</u> for more details.

Funding of Voluntary Organisations

- The multi-year planning approach should be aligned with multi-annual funding, so that services can be planned more effectively over a longer term.
- Voluntary disability organisations must be funded to the level of the full cost of delivering services. Many rely heavily on fundraising income to deliver essential services, particularly smaller organisations.
- Sustained, multi-annual investment is needed to meet the high levels of unmet need identified in the Disability Capacity Review and not just to respond to demographic need.
- A plan for implementing the recommendations of 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 be included in the Action Plan.

Staffing Issues

- The lack of pay parity with section 38 and HSE organisations is impacting the ability of section 39 organisations to recruit and retain staff.
- DFI are seeing this issue across our membership, from therapy staff to personal assistants to day service staff.
- High turnover of staff is detrimental to the relationship between the person with a disability and their support staff. Understaffing is also contributing to unmet need.
- It will be important that an early action is to establish a Workforce Planning Working Group, with representation from both statutory and voluntary side.

Data/Evidence

- Evidence used in some areas of the Disability Capacity Review is insufficient to capture true levels of unmet need, particularly the data in relation to community services including PA and home support.
- Accurately gathering this data and assessing the levels of unmet need must be a priority for the Action Plan.
- The data collected through the National Ability Support System, NASS, is
 insufficient 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 with an unmet
 need for services.

Link to Mainstream Health Services

- Disabled people often use a combination of disability and mainstream services to ensure their participation and access to services. Ensuring integration between these services is important. DFI members expressed the potential of formalising a case manager/care co-ordinator role who would act as an independent 'quarterback' to help people and families navigate the system.
- Over 90% of disabled peoples being supported outside of the Disability
 Service Programme. In addition, the transfer of the Disability Services
 Programme to the Department of Children, Disability, Equality, Integration and
 Youth (DCEDIY) means it is now essential that the scope of the Disability
 Action Plan must be expanded to include supports by mainstream health
 services such as primary care services, mental health services, neurological
 services, acute hospital services etc.

Cross-Departmental Working

- The cross-Departmental nature of the Working Group is welcome. The absence of representation from the Department of Education 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 Departments. More explicit targets to be achieved by other departments, as well as the appropriate mechanisms to ensure cross-Departmental working on joint priorities is required.

Person-Centred Services

 Targets and investments in services that support people to live independently in their own homes, in line with the UN CRPD should be prioritised. These include PA services, home support, personalised budgets etc.

- New models like local area co-ordination, as a way of supporting people to participate in the hybrid model of specialist and community services must be considered.
- The lack of focus and shared understanding on what is meant by community supports in Chapter 9 must be addressed through the Action Plan. This includes addressing the lack of data on the levels of unmet need for these services.
- Personalised budgets enable people to have choice and control over the types of support that best suit them. The Action Plan must enable this as a real choice for more people including for school leavers and those under 65 currently housed in nursing homes.
- COVID-19 has demonstrated the importance of person-centred services.
 There are some 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 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 UN CRPD.
- Issues relating to the cost of meeting HIQA regulations for service providers have not been resolved and must be addressed in the Plan before considering expanding the regulatory powers of HIQA.

Identified Priorities

Children's Services

- Recruitment and retention issues are having a major effect.
- It is not always clear what the entry point to Progressing Disability Services is for the majority of the population, particularly those not already linked in with disability services.
- The Action Plan should examine how to improve the evidence base, particularly in relation to children not linked to services, to improve planning.
- 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 in severe distress

- Transparency is needed on what the support packages include, how they can be accessed, and the criteria for accessing them, as well as the underpinning strategy behind this response.
- Delivering an adequate, long-term response is heavily dependent on other services like PA, respite and mental health. Ensuring the links to these services is 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.
- Recruitment and retention issues are having a major effect.
- Day service funding should align with the New Directions vision. It must be
 flexible enough to respond to people's individual needs and preferences.
 Many people would prefer to retain the remote, person-centred service that
 they received during the pandemic rather than return to their day service.
 Delivering these types of individualised supports will require additional
 resources including staff, appropriate technology etc.
- Receiving a personalised budget instead of attending a day service should be an option. However, when funding is unbundled, it is often insufficient to meet the person's needs. Appropriate costings and resourcing will be needed.
- The Disability Action Plan should include an approach to measuring and addressing unmet need for day services of those not already in disability services, such as many people with neurological conditions. The neurorehabilitation strategy was supposed to map the requirement for disability services for the neuro-disability cohort, but this work has stalled.

Personal assistance and home support

- 'Community based services' references a wide range of services vital to enabling independence and community participation, in line with the UN CRPD. Historically, the appreciation for the potential of these types of service models has been poor. The Disability Action Plan must comprehensively examine community services.
- The evidence in relation to unmet need for personal assistance (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. The Disability Action Plan must focus on accurately capturing the unmet need for these services.
- Recruitment and retention issues are having a strong impact on PA services.
 Low hourly rates make recruitment very difficult, and there is competition with private providers who can offer higher pay.
- Specialist community neuro-rehabilitation plays an essential role but these services are underdeveloped and underresourced, and there is huge unmet need.
- An appropriate skills mix in PA services to meet varied needs should be ensured. In the case of acquired disability, a rehabilitative need should be addressed alongside promoting independence. The skill mix should be matched to the needs of the individual.
- The Action Plan should consider central issues effecting delivery of PA services, like the "postcode lottery", insufficient hours to enable independence, staffing shortages, the need for leader-led services, the need to move to a demand-led service etc.
- 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

- The 'entry point' to respite services should allow any family who needs respite can access it, including those outside of disability services.
- The Disability Capacity Review states that access to respite is considerably lower for people with physical and sensory disabilities. The Action Plan should take a broader focus than intellectual disability alone and examine access to respite for people with all forms of disability.
- The importance of a variety of forms of respite, including alternative models to centre-based respite should be considered. A wide range of models including in-home, home share and condition-specific residential respite should be considered.
- Respite should be meaningful for the person, and age and needs appropriate.

Additional residential care places in the community

- The UN CRPD and Assisted Decision-Making (Capacity) Act should underpin residential planning. People with disabilities should be able to decide where they live, the type of accommodation, who they live with etc.
- Planning residential services alone is an insufficient response to those inappropriately living in nursing homes and congregated settings. Some would prefer to live in their own homes. Planning community-based services that support people to live independently in their own homes is also critical.
- To have a long-term impact on inappropriate placements in nursing homes, a vision 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 focus of the joint work between Housing, Health, DCEDIY, Local Authorities and HSE must be broader than residential services alone and based on implementation of the upcoming Housing Strategy for Persons with Disabilities.
- A national mechanism to drive interagency co-ordination between the Housing Agency, national HSE, Local Authorities, Department of Housing etc. should be established.
- Disability Housing Co-ordinators in each Local Authority should be appointed.
- The additional costs of regulatory compliance must be addressed in the Action Plan.



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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