



Disability Federation of Ireland (DFI)

Presentation to the Joint Committee on
Health

Introduction

DFI is the national support organisation for (120+) voluntary disability organisations in Ireland who provide services to people with disabilities and disabling conditions. We work to create an Ireland where everyone can thrive, where everyone is equally valued.

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

DFI welcomes the opportunity to express its support of the report published by the Independent Review Group in February of this year. The report is timely and presents a blueprint for how the relationship between the Government and voluntary organisations should function.

Timely report so why the pause?

The recommendations set out in the report have the potential to effect significant change in the disability and wider health sector. However, the report was published in February and the lack of movement on the recommendations in the report is a cause for concern. There are many innovative steps that can be taken to create a framework to allow for the implementation of the Report's recommendations.

DFI calls for immediate action to be taken on recommendation 8.4 which states:

“A Forum should be established to facilitate regular dialogue between the relevant State representatives and the voluntary sector to ensure their full involvement in future policy and strategic developments”.

This is a welcome and necessary step to ensure a healthy relationship is re-established between the State and the voluntary sector. It is of the utmost urgency that the Forum be established and subsequently chaired by the Department of Health. In order to maintain the integrity of the report, we also call for members of the Independent Review Group to be placed on the Forum.

Once the Forum is established, it is of high importance to draft an implementation plan. This plan should provide a framework to commence scoping and aid in the implementation of the Report’s recommendations. In analysing the report, DFI believes initial measures to begin implementation would be the following:

1. Target the Existing Challenge of doing Business as a Voluntary Organisations

Voluntary organisations are businesses and like all businesses, they are still facing the repercussions of the crisis years. There is both the immediate impact the cuts had on the organisations and also the growing level of unmet needs that must be addressed. During the time since the financial crisis, almost all operating costs have increased while funding has decreased. Voluntary organisations must also compete for staff with larger organisations and from the HSE itself who can offer better terms and conditions. With these factors complicating the work an organisation does, one would hope that the relationship it has with the State would be without any unnecessary obstacles. However, as the Report commented “the pressures of the financial crisis seem to have led to ‘mission creep’ and increased micromanagement by the HSE” (page 60). As voluntary organisations saw their funding decrease, a strain also appeared in their

relationships with the HSE. The lack of trust and communication from the HSE, as a representative of the State, and the lack of funding has created an impossible environment for voluntary organisations to agree on services to develop and to secure necessary budgets. In order to provide the best service possible to users, steps must be taken to adjust the manner in which voluntary organisations run.

An area that would make a significant impact on the capacity of organisation to deliver quality appropriate services is that of the Service Arrangements, between the State and the organisation. To quote the report:

“the HSE seems to have used the annual SA negotiations to impose conditions that have eroded the autonomy of voluntary organisations, irrespective of the scale of state funding to an organisation”. (page 60)

Following on from recommendation 8.4, we call for a redesign of the service arrangements between the State and section 39 organisations with an overhaul of Part 1 of the arrangement. It is not acceptable that Part 1 continues to not reflect the specificity of the services provided by disability voluntary organisations. Part 1 must be designed specifically for the service model it is talking about, a generic Part 1 is not fit for purpose and places the organisation with an impossible task to complete. A failure to move on this issue will undermine the importance the report placed on the need for a simplification of the arrangements.

Like any business, voluntary organisations must have the ability to plan for the future or the standard in the service they provide will decrease. It is impossible to prepare for the long term when an organisation only has the budget for the upcoming year. Organisations are constantly innovating in order to provide the best service they can and this can only be improved upon through the introduction of multi-annual budgets. DFI fully supports recommendation 8.9 found in the report which states:

“There should be a move to multi-annual budgets for 3-5 years in duration to facilitate strategic service planning and reform of services.”

It is essential that voluntary organisations have the ability to plan for their future. For an organisation to grow, have a well-educated work force and a strong engaged board, there must be a system in place that allows for them to budget for the future. This ties into recommendation 6.4, which calls for the training of board members in good corporate governance and proposes that the State co-fund this training for smaller organisations. An organisation can only improve with more training and make the lives of their service users better.

Case Study:

Epilepsy Ireland is the national organisation supporting and representing people with epilepsy in Ireland. Established in 1966, its vision is “to achieve a society where no person's life is limited by epilepsy”.

Epilepsy is a neurological disorder characterised by recurrent seizures associated with abnormal electrical activity in the brain. It is one of the most common neurological conditions, affecting 37,000 people in Ireland. An estimated 1,300 – 2,100 people are diagnosed with epilepsy each year.

While it is very much a treatable condition for many, there are 10,000 – 15,000 people with uncontrolled epilepsy in Ireland. For this group in particular, the condition can be a source of major long-term, yet often hidden disability.

Over the past five years they have seen their total number of client contacts increase from approximately 14,000 to 20,000 through innovative developments such as online support groups and phones apps.

They receive funding under seven HSE SLA's to provide a range of community-based services to people with epilepsy and their families across the country.

The service in each HSE region is very similar, although there is flexibility to tailor the service to the needs of service users in each region. However, the SLA funding for the service varies significantly from region to region and in no area does the SLA funding cover the full cost of delivering the service.

For instance in CHO2, the cost of providing the service is circa €50,000 per annum but the SLA is for just €3,800. In many CHO areas organisations are not allowed to record a deficit. In 2018, the total national cost of providing SLA-funded services is €926,000 but total SLA income is just €750,000.

Their total organisational deficit from 2013 to 2017 (per audited accounts) was €615,000 (€122k per annum). For an organisation that operates on €1.7m per annum, this is significant. The deficits are paid from their reserves, which are rapidly decreasing. The question must be asked, what happens when those reserves are completely emptied?

In order to provide a healthy environment for voluntary organisations the perform in, DFI calls for

- An overhaul of Service Arrangements to ensure they are specific for the service model in question.
- An introduction of multi-annual funding to allow for organisations to plan for the future.

2. The Reality of the Service provided by Voluntary Organisations

There is a crucial need to define what constitutes as an essential service as mentioned in recommendation 8.1. A dialogue must exist between the Department of Health and organisations delivering services to those with

a disability. We currently spend €1.9 billion in disability health and personal social services in Ireland. In 2019, 85% of the HSE disability budget supports over 8,500 people through a range of residential supports and 27,000 people in day places (HSE Service Plan 2019). Clearly the numbers in receipt of these core disability services fall significantly short of the 643,000 people with disabilities identified in the Census 2016. The reality is that the majority of people with disabilities in Ireland continue to live at home, accessing a mix of services and supports via primary and community disability services, quite separate from the core Disability Services Programme. It is of vital importance to the State and the users of services to move beyond expenditure for traditional models and to provide funding for models that allow people with disabilities to remain in their own communities.

Case Study:

In their 2016 Assistive Technology discussion paper¹, DFI/Enable Ireland identified a key example of how funding complimentary supports can result in a decrease in overall spending.

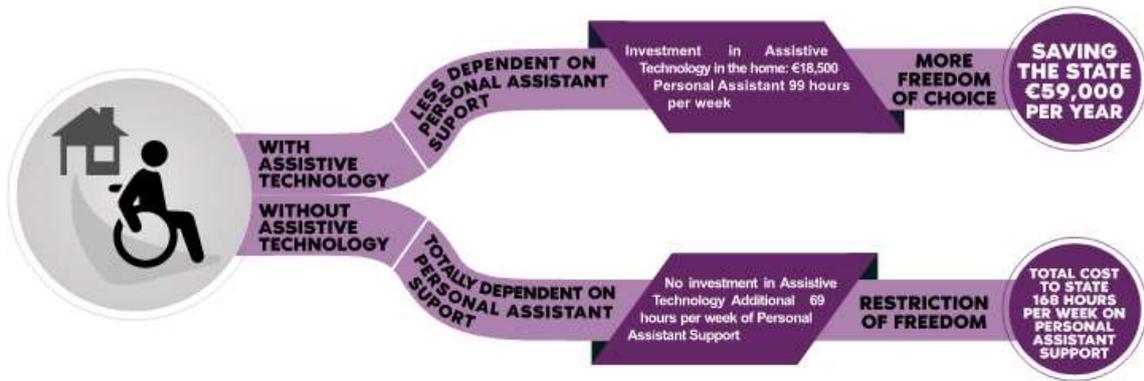
A woman, who is a wheelchair user, lives in her own apartment. She uses environmental controls to the value of €18,500. She also has 99 hours of Personal Assistant (PA) supports per week.

Without her environmental controls, she would sacrifice significant independence, and would require 168 hours of PA supports weekly (i.e. 24/7 support), at a cost in excess of €59,000 per annum.

The total cost of her AT was less than one third of the annual cost of round-the-clock Personal Assistant support

¹ Enable Ireland, "Assistive Technology for People with Disabilities and Older People A Discussion Paper" (November 2016), accessed from <https://www.enableireland.ie/sites/default/files/publication/AT%20Paper%20final%20version.pdf>

INDEPENDENT LIVING



It is imperative that the community based supports that serve 95% of people with a disability are recognised as essential services. The list must be sector specific and be respectful of the needs of people with disabilities. The majority of people with a disability would identify measures such as respite, P.A. hours or community programmes as essential services. The importance of community based services is emphasised when one witnesses the first hand impact it can have on its users.

Case Study:

MS Ireland runs a programme called Step it Up. It is a physiotherapy-led exercise and education programme designed to improve symptoms through knowledge, exercise participation and coaching.

One of their users is Mary, a 24 year old female nurse. She received a diagnosis of MS and was struggling to maintain her daily activity levels in her work. She spent every moment outside of work in bed recovering.

Based on a 12-week programme of Step it Up, she is now running with her dog and, as of last month, she was running up a hill.

Mary is a person who is now no longer concerned about not being able to work and she is no longer considering retiring at 27. She is actively participating in and contributing to society and paying her taxes and she now has better quality of life.

The reality is that much of the work done by the disability voluntary sector has an impact across the health sector. This can be seen on a basic level through the Blanchardstown Centre for Independent Living where their mobility van is now predominantly used to transport users to medical appointments. A service that once was used for social engagement is now supporting gaps in the health service. The funding for this transport is not coming from the HSE but it is stitching together different areas of the health sector.

Conclusion

It is crucial to recognise that voluntary organisations are businesses. In order to function they must have an open dialogue with the State, namely the Department of Health and the HSE, which can be facilitated through the establishment of the Forum. They need contracts that are fit to purpose and specific to the services they provide. Voluntary organisations must be provided with the opportunity to plan for the future through multi-annual budgeting. To allow for equity across the sector, the services that benefit all people with disabilities must be recognised as essential.

We recognise that the disability voluntary sector has its own issues that must be tackled and the implementation of the recommendations found in the Report will be a challenge to both the sector and the State. However it is of paramount importance that action is taken and real change occurs in the relationship between the State and the voluntary sector. A healthy working relationship stands only to better the lives of service users.

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.

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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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