



## **Submission to the Review Group on the Role of Voluntary Organisations in Publicly funded Health and Personal Social Services**

### **Introduction**

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 an umbrella body, comprising organisations that represent and support people with disabilities and disabling conditions. There are over 126 organisations within membership, or as associates, of DFI. DFI also works with a growing number of organisations and groups around the country that have a significant disability interest, from both the statutory and voluntary sectors. DFI operates on the basis that disability is a societal issue and so works with Government, and across the social and economic strands and interests of society, to enable people with disabilities to exercise their full civil, economic, social, and human rights.

### **Terms of Reference of Independent Review Group**

The terms of reference provide for:

- ☐ An examination of the role played by voluntary organisations in the provision of health and personal social services, including their contribution to the health service
- ☐ A consideration of issues currently arising, and those likely to arise in the future
- ☐ Recommendations on how the relationship between the State and voluntary organisations should evolve in the future

### **1. Role of Voluntary Disability Organisations**

It is clear that the voluntary sector plays an important role in supporting people with disabilities who are living in the community. The use of the term 'voluntary disability organisations' masks a wider diversity of organisations, service models, and funding relationships with the State. To understand the role played by these

organisations, we need to understand who these organisations are, the demographic profile of the people they support and the services they provide.

DFI's membership comprises both Section 39 and Section 38 organisations, the majority of its members though are Section 39 organisations.

**Table 1: Section 39 Voluntary Disability Organisations**

Funding	Number of Organisations
>€5m	19
€1m - €5m	41

Source: HSE Social Care Division Operational Plan 2017

Eighty-five per cent of the overall HSE disability budget funds residential, and day supports for a small cohort of people with disabilities. There are a limited number of disability organisations involved in this provision. However, we know that most people with disabilities – 1 in 4 - acquire their disability in adulthood, and live on the margins of communities, i.e. over a quarter of adults with disabilities live in consistent poverty<sup>1</sup>. They and their families are often users of a myriad of less formalised disability supports and services delivered through niche / condition specific organisations. The role they play is less obvious, and is often undervalued. These organisations are typically only partially funded by the HSE, and co-fund these supports through fundraising activities.

### **1.1 Niche / Specific Condition Organisations**

Within organisations funded up to €1 million, and those funded from €1m to €5m there are many niche / specific condition organisations, providing services to children and adults with physical, sensory, and neurological disabilities, as well as chronic illnesses, and conditions. They play a significant and important role.

Niche / specific condition organisations receive varying levels of funding from the HSE, some receive small grants, through Grant Aid Agreements - <€250,000 and some are larger Section 39 organisations, and are in receipt of funding up to €5 million. 19 Section 39 agencies are in receipt of funding over €5million.

### **1.2 Features of Niche / Specific Condition Organisations**

Some of these organisations serve quite a small constituency of people who have a specific disability / medical condition. In terms of their origins, they were frequently established from a sense of isolation and frustration felt by families in their efforts to secure vital supports and services.

In some cases, the low incidence and prevalence of a specific condition or disability can mean that there are gaps in understanding and information within the social and health care sector on these disabilities / conditions and the responses needed to tackle them. As the goals of these organisations are to support individuals with specific disabilities, they have acquired specialist

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<sup>1</sup> ESRI 2018 examination of SILC.

information, expertise and insights, which are utilised for the benefit of their members. The dissemination of this knowledge, and information serves and supports not only their client groups but also the wider community, which includes healthcare and research professionals.

Niche organisations 'translate' or dis-entangle complex information – whether scientific or policy-related – into readily understandable, relevant and accessible resources and services for people with a condition and their families. This role supports health literacy and ensures that evidence based well-being interventions; coping condition management strategies; self-management education are supported.

Many organisations have programmes of capacity building which give voice collectively and individually. The role organisations play in peer support is enabling. It can take a number of forms such as mentoring, counselling and listening. Research and development is a unique aspect of organisations work; both health research and social research. People with a condition are well placed to provide qualitative empirical data. The involvement of condition specific organisations in data collection helps researchers and decision makers.

Another category of voluntary disability organisations work across disabilities and conditions.

### **1.2.1 Complexity as Strength**

The voluntary disability sector is complex, diverse and therefore difficult to capture. This complexity, and diversity, however, should not be perceived as a weakness, on the contrary, it has been argued that the voluntary sector's core strength lies within its very complexity<sup>2</sup>. The sector is complex and diverse because each voluntary organisation arose to address a specific issue or meet the needs of a specific group of people<sup>3</sup>.

Many disability organisations were founded by people with a disability, and / or people with an enduring experience of disability, and have evolved to exhibit both the characteristics of statutory administrations as well as the features of a user-led, membership based organisation (Costello & Cox, 2013). These features enable voluntary organisations to respond more sensitively, and appropriately than for example, private agencies, or statutory agencies. This is particularly true for groups whose needs are not adequately addressed by government.

These organisations work to try and find solutions to meeting unmet needs, even engaging in fundraising activities in order to provide core services, e.g. respite. Services and supports such as these are not understood as part of the core responsibilities of the HSE, in the same way as traditional service models, such as residential services are. Instead they are perceived as auxiliary supports, yet they are critical for many people with disabilities, supporting them to live with

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<sup>2</sup> Billis, D. and Glennerster, H. (1998) 'Human Services and the Voluntary Sector: Towards a theory of comparative advantage'. *Journal of Social Policy*, Vol. 27 (1): 79-98.

<sup>3</sup> Costello, L. & Cox, W. (2013) *Living in the Community: Services and Supports for People with Disabilities*. Dublin: DFI and NfPBA.

health and well-being, as well as offsetting the need for more intensive, specialist services.

The Department of Health's (2012) Value for Money and Policy Review of Disability Services in Ireland, failed to adequately describe the sector in its entirety, excluding in particular, the types of community services and supports provided by these organisations, due to a lack of data. Six years on, and we are still grappling with inadequate data.

### **1.2.2 Independence and Trust**

In disability services and elsewhere, community and voluntary organisations have traditionally been able to innovate and develop responsive services. State agencies have often then supported the mainstreaming of these services. There is great concern that this ability to innovate is been lost. Disability organisations are now bound to heavily regulated contractual relationships to continue to provide very specific services to a very specific cohort of people. This level of regulation is imposed regardless of the size of the organisations, the level of funding provided for the service or the number of people benefiting from the service.

The UN CRPD has just been ratified. This is the time when disability services in particular, need to accelerate their level of innovation and responsiveness to people with disabilities' changing needs.

Great changes have come about in regulation and governance of services, changes that DFI and others have sought for many years from the State through the establishment of the Charities Act etc.

Greater balance is required between the need to account for money invested and the need to ensure that best outcomes are being achieved from that investment. Society is changing and people with disabilities' needs of services are changing. We need an administrative system that can better balance the need to account and govern, and the need to respond and innovate.

### **1.2.3 Advocacy**

Many voluntary disability organisations play an important advocacy role, advocating for improved treatment by statutory health and social care services of people with a particular disability / condition, and fundraising for relevant research. In recent years, and particularly so, during the austerity period, there has been the sense of restriction on using government funds to engage in advocacy issues, and amongst the community and voluntary organisations in general, there is evidence of statutory bodies using binding Service Level Agreements, which specifically prevent State funds from being used for advocacy purposes.<sup>4</sup>

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<sup>4</sup> Harvey, B. (2014) Are We Paying for That? The Advocacy Initiative. Available at: [www.advocacyinitiative.ie](http://www.advocacyinitiative.ie)

## **2. Consideration of issues currently arising, and those likely to arise in the future**

### **2.1 Regulation**

The issue of over-regulation is one that many DFI member organisations have raised, in terms of the extra administrative and financial burden it places on organisations. This is an issue for those involved in the provision of residential services and supports, regulated by HIQA.

It has been demonstrated elsewhere that over-complex, output-driven levels of regulation and inappropriate forms of accountability can compromise voluntary organisations' independence and undermine the trust they have traditionally enjoyed from their clients and society at large.

There is a sense among many organisations that there is an over-emphasis on regulation and accountability, to the detriment of actual outcomes for individuals.

The introduction of EU directives and legislation, e.g. the European Working Time Directive, is having a direct impact on the recruitment and retention of employees. The combination of over-regulation with cuts to disability services of 9.4% from 2008 to 2015, despite the increase in demand for services, puts additional pressures on voluntary organisations, to adequately respond to service needs.

### **2.2 Increased Governance and Accountability Requirements**

Systems of oversight, transparency, and accountability by their nature are standardised, and in many instances, these procedures are implemented in a blanket fashion for all disability organisations, and can be less applicable for smaller organisations, with more community type services.

Organisations have reported to DFI on the cumbersome reporting procedures relating to the HSE's Service Arrangements that can be disproportionate to the funding amount received.

While acknowledging the need for full accountability for public funding received, there are capacity issues in meeting these requirements, which more and more involve increased bureaucracy, paperwork etc., particularly in the absence of additional resources.

Another issue raised is where the HSE's governance procedures are also applied to organisations who are co-funding services, in the context of where the HSE funding amount is minimal.

### **2.3 Side-Lining of 'Non-Major' Voluntary Disability Organisations**

Too often the experience has been that the voluntary disability sector, is understood by the HSE / Department of Health as the 'large providers', S.38, and some S.39 organisations. This serves to de-value the legitimacy and role of the specialist and niche organisations within the sector, who are providing supports to enable people live in their communities.

A recent manifestation of this, is the issue of pay restoration for Section 39 organisations, and the more precarious situation for smaller organisations who duly implemented pay cuts as directed. There is evidence of stress, exhaustion, increased sick leave, and turnover affecting staff of Section 39 organisations. There are serious challenges for these organisations in terms of their ability to retain and recruit the best possible people in what is an already very difficult and competitive employment market.

## 2.4 Relationship Confusion

The continued vulnerability of organisations in the post-recession period is compounded by the lack of understanding or / and appreciation for the autonomy and independence of organisations. It is important to understand that it is not only a matter of funding that is at play here. What is equally needed is an understanding of the "relationship confusion" which exists within HSE and elsewhere.

This is illustrated by the recent issue of the recruitment of National Children with Disabilities Network Manager Posts which the HSE were proposing will be employed via the HSE, rather than the relevant lead agencies involved in the provision of these services.

It is clear that there is confusion about who does what and why.

As noted elsewhere in relation to the voluntary and community sector in general, and which also applies here, recognition for and support to the voluntary disability sector has been inconsistent, with the sector being the junior partner in a very unequal relationship<sup>5</sup>.

## 2.5 Traditional Service Models and Changing Expectations

Even though the goal and vision for disability policy is to support people with disabilities to live with health and well-being in their communities, it is predominantly traditional service type models that continue to consume the majority of the HSE's disability budget. See table 2 below for a clear illustration of this fact:

**Table 2: HSE Disability Budget Spend, 2017**

<b>Type of Services</b>	<b>Proportion of HSE Disability Budget spending</b>
Residential and Day Services	85%
Personal Assistant Service and Home Support Service	5%
Multi-disciplinary therapy services	5%

<sup>5</sup> Lee, A. (2016) 'Acknowledging the 'vital role of the community and voluntary sector' (Programme for Government 2011): A View from the Coalface in The Institute for Social Sciences in the 21st Century (ISS21), University College Cork, *The Changing Landscape of Local and Community Development in Ireland: Policy and Practice*. Conference Proceedings 21st October 2015, University College Cork

Respite	2%
Other Community Services and Supports	3%

Source: HSE (2018) Transforming Lives. Report on Future Needs for Disability Services. Working Group 1. Feb 2018

The ratification of the UN CRPD will change people's expectations of service models. Of particular relevance, are Article 19, relating to community living, as well as Article 26 on Rehabilitation and Habilitation.

<b>UNCRPD Article</b>	<b>What it means</b>
Article 19 – Living Independently and being Included in the Community	Sets out the <u>right</u> of a person with a disability to live where they want. It also includes the <u>right</u> to be fully included in the community. States must provide the <u>supports needed</u> to achieve these outcomes, including Personal Assistance. All mainstream community services should be available to people with disabilities.
Article 26 – Habilitation and Rehabilitation	Requires States to help people with disabilities achieve the <u>highest level of independence</u> and social inclusion possible. To achieve this, States must provide services <u>in all areas of life</u> , including health, education, employment, and social services.

Meanwhile, the Taskforce on Personalised Budgets is currently finalising their report, which contains 18 recommendations for a framework for Personalised Budgets. This will provide more choice for individuals, and should support the movement towards more person centred services in the community in line with the objectives of the UN CRPD.

## **2.6 Community Services and Supports**

As already referred to in this paper, community services and supports are vital for people with disabilities to enable them to live independently in their communities. Currently there are supports of these nature being provided in the sector, but they are neither fully appreciated nor are they being prioritised, as the figures under section 2.5 above demonstrate. Research on the services of 15 organisations underlined the multi-faceted nature of many of these organisations, and the wide range of roles and profiles among the group as they respond to different aspects of disability<sup>6</sup>.

Their orientations include:

- ☐ providing clinical and therapeutic services.
- ☐ providing social, emotional and practical support to individuals and families.

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<sup>6</sup> Costello and Cox (2013)

- advocating for improved treatment by statutory health services of people with a particular condition, and fundraising for relevant clinical research.

The table below shows that organisations engage in responding to the whole of a person's life, in as much as is possible.

<b>Number of Organisations</b>	<b>Nature of Services provided</b>
12+	Information Advice Family support Social programmes Transport Assistance with access to statutory services Public awareness.
8 – 11	Individual advocacy Day services Helpline Local support groups Aids and appliances Assistive technology Education / training Employment-related services Planned respite care Assessment of need Referral to statutory services Lobbying / campaigning Training Providers in statutory services, particularly health services personnel
5	Supported employment Housing-related services Psychological assessment Specialist nursing Speech / language therapy Residential services 3 provided clinical / medical services 3 provided Group Therapy 1 organisation provided a psychiatric service

As well as those listed above, of huge importance to supporting community living is the Personal Assistant service, which has not received any extra funding since 2008.

## **2.7 New Service Models**

As well as existing community services and supports that are currently being under funded, including the Personal Assistant and Home Supports service,



respite, and multi-disciplinary therapies, what new service models and funding models will support the policy objectives contained in the UN CRPD?

Of note here is one approach that has been successfully evaluated in other countries<sup>7</sup>, i.e. Local Area Coordination, an approach that supports people with disabilities, with mental health difficulties, and older people to live in their communities. See box below for more information about Local Area Coordination.

Local Area Coordination is a community based intervention for people with disabilities, older people and people with mental health difficulties designed to integrate people into their community and help reduce reliance on services.

Local Area Coordinators help form links in the community that make the community more interconnected and resilient.

A Local Area Coordinator might work with an older person who has become isolated, helping them to re-establish connections with family, and to find community groups who interest the person, and could provide them with social connections.

They might also work with a person with an intellectual disability who is just entering the community after leaving a residential setting. They could help this person form connections in their community and create a social network that supports them to live independently, separate from formal service providers.

These kinds of connections and social supports help people to lead more interconnected, independent, and fulfilling lives, without always relying on formal services.

Of course, a Local Area Coordinator might also help someone to find voluntary bodies in their area that provide services the person may find useful. They do not replace voluntary organisations, but act as a supplement to them.

Another area where there are gaps in existing services is in relation to the inappropriate placement of younger people with disabilities in nursing homes. Younger people with disabilities continue to be placed in nursing homes, which are considered by the HSE to be appropriate to their medical needs. However, anecdotal evidence from individuals themselves show that these facilities are not suitable for the medium to long-term, and do not support independent living<sup>8</sup>. Research elsewhere has pointed to the need for alternative care options for people following their discharge from hospital, to address the significant

<sup>7</sup> Swansea University (2016) Local Community Initiatives in Western Bay. Formative Evaluation Summary Report.

<sup>8</sup> DFI has commissioned research in this area, which will explore the appropriateness of these placements.

shortage in post-acute rehabilitation beds, rehabilitation expertise, and long-term community supports.

The current methodology for planning and enhancing services does not allow for the development of new service models - the existing funding lines are tied to more traditional models of service, that are targeted at a very specific cohort of the disabled population.

## **2.8 Lack of Coordination**

DFI recognises that there are indeed a considerable number of voluntary disability organisations providing much needed services, but that overall, there is a lack of coordination across the sector.

As more and more people with disabilities are choosing to live in the community, another issue is the readiness of mainstream services to respond to their needs. Of note here for example, is that the Healthy Ireland strategy is being rolled out without any alignment to disability service provision.

DFI has for many years been highlighting the need for greater joined up planning and coordination of public services across public services, that impact on the lives of people with disabilities, not alone in relation to health, but also to education, housing, transport etc. It is probably fair to say that integrated / joint actions have reduced over the past 10 years, rather than having increased.

A key consideration here is the need to review the HSE's disability budget, and the services it funds, as well as other relevant department's responsibilities to provide services for people with disabilities.

A key question to consider is in what ways can voluntary organisations work together in the goal of providing coordinated and seamless service provision to improve the outcomes for people with disabilities?

Another important question is how can voluntary disability organisations work with mainstream public services to improve the outcomes for people with disabilities?

How can we see funding and viability for community service models when we are tied to traditional funding streams?

## **3 Recommendations**

### **Sustainable Services**

- Multi-annual funding must be provided to allow for a more sustainable basis for the work of voluntary disability organisations, as well as for long-term planning.
- Funding packages need to be targeted at the types of services that support people with disabilities to live in their communities, to - amongst other things - avoid the on-going placement of younger people with disabilities in nursing homes.

### **Remove Inequities in the System**

- Remove differential treatment and inequity between S. 38 and S.39 organisations by urgently resourcing S. 39 organisations' pressure points, i.e. pay restoration, and emergencies, so that they can continue to provide services for people with disabilities.

### **Governance and Accountability Measures**

- Audit and reporting requirements placed on disability organisations should be proportionate to the public funding they receive, and take into account the size and structure of the organisation.

### **Unmet Needs**

- Immediately introduce a systemic approach to collect evidence of unmet need relating to physical, sensory, and neurological disabilities.
- There are serious deficiencies in the measurement of services and supports outside of the traditional service models. Unmet need is not captured either adequately or systematically for vital services such as the PA service and Home Supports service. Records of unmet need exist in each CHO area which have not been evaluated and compiled.

### **Good Practice**

- Mapping of models of good practice should result in change in practice where outcomes are poor. The current system is poorly designed to recognise the value of coordination and collaboration across providers and other functions.
- Local / regional services / programmes that are proving successful in terms of outcomes should be supported to be rolled out in other areas.

### **Engagement with the HSE and the Department of Health**

- There is an urgent need for a new definition of the relationship between the statutory health bodies and voluntary disability organisations, one which is based on trust, respect and integrity.
- A partnership approach should be re-introduced and developed.

### **Systemic Change**

- There is a fundamental need for systemic change in the ways that health and personal social services are planned, coordinated and delivered. This systemic change should bring about real community living and demonstrate efficient cost effective quality of life outcomes for the individual.
- New service models with demonstrated successful outcomes for people with disabilities, older people, and people experiencing mental health difficulties, as discussed in section 2.7 need to be resourced. Local Area Coordination provides the much needed coordination of services that not only result in a more seamless service experience for the person with a disability, but also has a positive impact on service providers, and voluntary organisations through...

**Increased Coordination**

The Department of Health should take a leadership and coordination role, and 'push back' other departments, in support of the integrated delivery of outcomes for people with disabilities. Ultimately most people who have a disability are not concerned with who provides the services, but with having a seamless experience of supports and services.

**Involvement of People with Disabilities**

- Ensure that the voice of people with disabilities and wider community participation is included in the planning and delivery of actions to address their needs.

