



Ireland

FINANCING OF CARE SERVICES FOR PERSONS WITH DISABILITIES

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Executive Summary

Disability services in Ireland are merged with the health services and overseen by the Irish Health Service Executive (HSE). While the HSE provides a certain amount of services itself, the majority of service is provided by non-statutory providers, mostly in the voluntary, not-for-profit sector. The HSE sometimes contracts for-profit providers as well. However, their share in the provision of disability services is still limited.

The Department of Health and the HSE oversees the development and implementation of national health and social care policy and provides funding for these policies. Meanwhile, nine local Community Healthcare Organisations (CHOs) deliver services in different geographical areas. The decision to contract certain providers is taken jointly sometimes between the HSE nationally and CHOs.

Funding instruments depend on the type of provider not-for-profit and for-profit. The not-for-profit providers negotiate the funding yearly and sign Service Arrangements or Grant Aid Arrangements (for amounts smaller than 250,000 euros) with the HSE and CHOs. The private for-profit providers participate in public tendering procedures, which are published when the need arises. Finally, at the time of drafting this report in late 2020, Ireland is piloting personalised budgets. However, the project is small and cannot be considered as an important instrument for funding currently.

Due to historical reasons, the not-for-profit providers (of all health and social services, disability included) can be divided into two big groups, depending on the Health Act (2004) section regulating their funding. Section 38 organisations tend to be bigger and to have a longer history of engagement with the state, and are considered as delivering services “on behalf of it.” Section 39, meanwhile, covers a more varied group of not-for-profits that are regarded as providing services “ancillary to” the HSE. Many of these were established by families and friends of people with disabilities and sought financial assistance from the state along with their own fundraising. In practice, these organisations deliver similar services and for the most part fulfil similar requirements to obtain the HSE funding: to be registered as charities, to have Public and Employer liability against the claims, and (if applicable) to fulfil standards set by the Health Information and Quality Authority (HIQA), which certifies residential and some respite services. The main differences between them are related first to the differing status of their employees. Those of Section 38 are considered public

sector employees are aligned to consolidated pay scales and enjoy public pensions, while Section 39 workers do not. Second, Section 39 organisations cover Public and Employer liability themselves, while the state covers Section 38 organisations.

Despite these differences, both types of organisations annually negotiate their funding with the CHOs in the region(s) in which they operate, or the HSE directly for the national-level service provision. As providers and experts interviewed for this factsheet observe, funding criteria are varied, and providers' abilities to increase their income are limited.

Funding might not cover all service providers' costs, forcing them in some instances to limit services, some Section 39 organisations engage proactively with the funder seeking additional resource from a finite budget. Since governmental funding is by far the primary funding for most providers, the providers sometimes argue that they are carrying deficits. COVID-19 worsened this situation in some instances, as many service providers had to invest more in the service provision, while at the same time seeing their revenues from charity disappear. The CHOs stepped in and supported the organisations with personal protection assistance, and other costs are to be funded. These problems are shared by those delivering different disability services, be it day care or personal assistance.

Main findings

- ★ Some providers claim that current funding levels are insufficient to maintain the current service provision level or address additional needs accumulating due to society's demographic changes, HSE continues to analyse this.
- ★ Some not-for-profit providers run deficits and cover their operational costs with the money from the new clients they accept. Section 39 providers, especially the smaller ones, seem to be vulnerable. COVID 19 worsened their situation in relation to fundraising.
- ★ Existing financial limitations negatively impact service provision levels relative to demand: people have to wait for residential services, day supports, personal assistance service, or respite care. Moreover, services may vary somewhat from provider to provider and from one CHO to another. People have to accept the services available in their region, even if it is not entirely what they need.

- ★ However, in many cases, the services are of good quality. The interviewees consider that the HIQA standards are very relevant for the assurance of the quality of residential services.
- ★ Due to the existing arrangements, Section 39 organisations' are not always aligned to consolidated pay scales and cannot access the public sector pension schemes. In some cases, their salaries may be lower than those of their counterparts in Section 38 organisations (however, it does not seem to be a

generalised problem). These differences make it more difficult for Section 39 organisations to retain their staff.

- ★ While Ireland aims at supporting person-centred and de-institutionalised disability services, its funding is in some instances geared towards institutional type care. Both supported living services (personal assistance and home care) and respite care – essential to the independence of PwDs – receive the smallest amount of financing.

Introduction

Ireland's disability services evolved from a medical model,¹ **resulting in merging health and community and social care services (disability included) jointly governed by the Irish Health Service Executive (HSE).** Established in 2005, the HSE sets the requirements for service providers and has primary responsibility for providing disability services to eligible persons with disabilities in Ireland.

HSE delivers some (but only a limited number of) services itself. For the rest, it funds provision by locally-based voluntary, non-statutory organisations² - non-profits, and, to a lesser extent, private for-profit providers. Different interviewees – both providers and policymakers – agree that private non-profit (or voluntary) providers deliver the majority of disability services; while for-profit organisations deliver only a small share. The latest available data from 2010 shows that non-profits provide about 90% of intellectual disability services and about 60% of physical and sensory disability services.³ Similarly, another 2012 report found that in 2009, for-profit providers received only 1,25% of the disability budget⁴.

Quality of services is overseen by the Health Information and Quality Authority (HIQA), which certifies residential and some respite services, including for PWDs.

In 2014, **nine Community Healthcare Organisations (CHOs)**, each covering a number of local health areas, were established (see Figure 1)⁵. CHOs cover primary care, social care (involving services for older persons and persons with disabilities), mental health and health and well-being. While the HSE central office decides on overall funding of health and community services (disability included), the CHOs plan and manage service delivery in their area. In July 2019, the government announced the HSE's future restructuring according to a programme named Slaintecare and its plan to create six regional areas with responsibility for budgets, management, planning, and delivery of health services in their area overseen by a smaller central HSE⁶.

A number of documents describe different aspects of services provision for people with disabilities. The main ones, defining the main principles guiding the provision of different services for people with disabilities are the

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- 1 Working group 1. 2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 11
 - 2 Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., McConkey, R., & Staines, A. 2014. Mapping the National Disability Policy Landscape. Dublin: School of Social Work and Social Policy, Trinity College Dublin. P. 10.
 - 3 National Disability Authority. 2010. Advice paper to the Value for Money and Policy Review of Disability Services Programme. A Contemporary Developments in Disability Services Paper, p.14.
 - 4 Department of Health. 2012. Value for Money and Policy Review of Disability Services in Ireland, p. 77, <https://www.hse.ie/eng/services/list/4/disability/newdirections/value-for-money-policy-review-of-disability-services-in-ireland.pdf>. Date accessed 2020 08 26
 - 5 Nine Community Healthcare Organisations to be established, <https://www.healthmanager.ie/2014/11/nine-community-healthcare-organisations-to-be-established/>. Date accessed: 2020 08 01
 - 6 Wall, Martin, Leahy, Pat. 2019. Political dangers to HSE break-up process many and varied, The Irish Times, <https://www.irishtimes.com/news/health/political-dangers-to-hse-break-up-process-many-and-varied-1.3959703>. Date accessed: 2020 08 05

FIGURE 1 | CHOs in Ireland

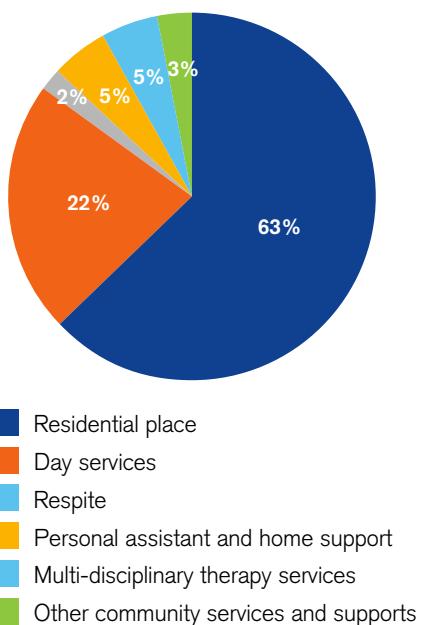


Source: HSE.ie

Disability Act (2005); the report “New Directions – Personal Support Services for Adults with Disabilities” (2012); a strategy for community inclusion “Time to Move on from Congregated Settings” (2011); and “Value for Money” policy review of disability services (2012). **These strategies lay the basis for efficient, person-centered, and community-based supports for people with disabilities.** This vision departs from the historical model of care for PWDs and is more aligned with the UN convention on the Rights of Persons with Disabilities (UN CRPD), which Ireland ratified in 2018.

In general, the disability budget suffered cuts after the 2008 economic crisis (gross spending on disability fell by 7% between 2009 and 2016).⁷

FIGURE 2 | Components of expenditure HSE disability budget 2017



Source: Author, based on Working group 1 (2018), p. 19

While later the budgets recovered – in 2019 the HSE allocated a total of €1.904 billion for disability services, €51.9 million more than in the 2018 budget – it seems that “soft services” such as respite have suffered the most cuts. As shown in Figure 2, the biggest share of the disability budget goes to the residential and day-care services, while personal assistance and home support receive less funding.

The HSE has increased funding for Disability Services by 21% in the 3 years between 2017 and 2019, reaching a total spend of €1,988m in 2019. In 2020, the HSE Disability Services received an additional €30.5m for school leavers, disability needs assessments, autism services, residential protocols and respite services⁸.

⁷ Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 17.

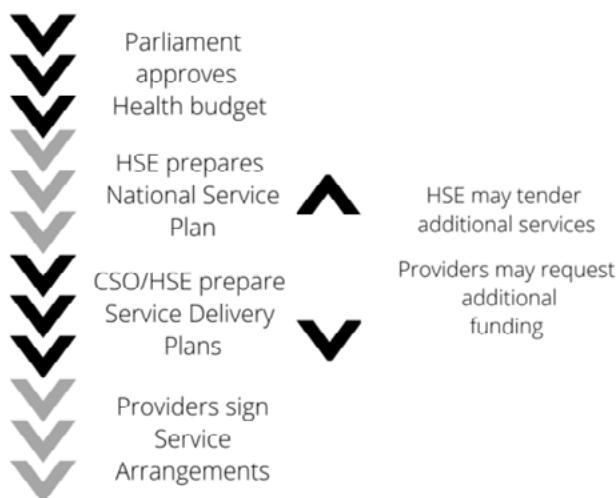
⁸ HSE. 2020. Annual Report and Statements 2019 and 2016, HSE Performance Reports 2019 and 2016, HSE Service Plan 2020.

Funding mechanisms across care services for PwDs

The funding mechanisms for disability services in Ireland are the same as for other health and social services. Consequently, this factsheet first presents the overall funding mechanism for health and community services and later discusses each disability sector's peculiarities.

The HSE takes the major decisions regarding the amounts of funding directed for different health and social care services in different CHOs. The yearly funding of disability services depends on the budget assigned to the health services by the parliament. The second step is the elaboration of the National Service Plan (NSP) that the HSE develops based on this budget. This document defines health and social service delivery of the main strategic directions and the amounts assigned for different services, including disability. The third step is the preparation of CHO Operational Plans. These plans, detail types and amounts of services to be delivered in each area. Finally, based on these plans, the not-for-profit providers negotiate with the CHOs. This negotiation procedure (see Figure 4 further below on funding procedure for health and community services) is repeated annually. If there is a need for additional services, the HSE may launch a public procurement

FIGURE 3 | funding procedure for health and community services



Source: Author

procedure and contract for-profit providers to cover the need. Meanwhile, as explained by the interviewed provider of a broad range of disability services, providers that need additional funding have to prepare a “business case” and request additional funding.

Funding instruments depend on the type of the provider, not the kind of service. The **not-for-profit providers** negotiate the funding yearly and sign Service Arrangements with the HSE. The **private for-profit providers** participate in public tendering procedures, which are published when the need arises. Finally, at the time of drafting this report in late 2020, **Ireland is piloting personalised budgets**. However, due to its limited scope and early application stages, it is not considered a relevant funding model for this analysis. The following section examines the main three funding mechanisms more in detail.

Box 1 | Funding instruments:

- ★ Non-profit providers: Service Arrangements
 - ★ For-profit providers: Public tendering
 - ★ Clients: Personalized budgets (pilot)

Funding of non-profit providers

Procedure

Ireland does not have a fully uniform funding mechanism for the not-for-profit health and social service (including disability) providers. Their funding amounts are negotiated yearly, based on the previous year's funding, and new services they plan to deliver. Sections 38 and 39 of the Health Act 2004 lay out the rules regarding the financing of non-profit providers.

Section 38⁹ covers 44¹⁰ (data from 2014) not-for-profits. The majority of the so-called “Section 38 providers” have evolved from religious orders. According to the Health Act, these not-for-profits deliver services “for and on behalf of” the HSE: they are considered part of the public sector and their employees enjoy public sector pensions and pay. Section 38 providers are funded through the Section 38 Service Arrangements.

⁹ HSE, Section 38 Documentation. <https://www.hse.ie/eng/services/publications/non-statutory-sector/section-38-documentation.html>. Data accessed: 2020 08 25

10 <https://www.kildarestreet.com/committees/?id=2014-07-22a.34>, Data accessed: 2020 08 20

Box 2 | Differences between Section 38 and Section 39 organizations

- ★ Section 39 organization employees are not considered public employees (worse social security packages and pensions)
- ★ Section 39 organizations have to cover their Public and Employer liability against the claims, while section 38 organizations are covered by the state insurance.
- ★ Section 39 organizations more varied in size (from very big to very small), while section 38 tends to be big.

Section 39¹¹ covers more than 1800 not-for-profits¹² (data from 2014). The majority of these “Section 39” organisations have evolved from parent and friend organisations. Moreover, they tend to be newer than Section 38 providers and more varied in size. As they are considered as delivering services “ancillary to” the HSE, their employees are not considered public employees, and, consequently, they are not entitled to the pensions and pay scales agreed by the state. Among section 39 organisations, there are both very small and very big organisations. Consequently, while Section 39 providers are funded through Section 39 Service Arrangements, a simplified version, the Grant Aid Arrangement, is offered for those receiving amounts smaller than 250,000 euro.

While there are differences between Section 38 and Section 39 organisations (see Box 2), **the requirements to receive funding and funding procedures are similar**. Both types of organisations have to register as charities; to fulfil HIQA standards when applicable, and to fill in similar documentation. After the negotiation, each provider has to sign the Service Arrangement. The Service Arrangement document has two parts. The first part, agreed with and co-signed by the HSE, lays out the general information: i.e., the principles of arrangement, rules of funding, roles, and responsibilities of the HSE and the provider. The second

part of the arrangement, agreed with and co-signed by the CHO (or HSE if the agreement covers national level services), describes the services that will be delivered, the quality assurance and monitoring process. As explained by the one interviewed personal assistance provider, **if a provider delivers services in more than one CHO, it has to negotiate and sign separate part 2 agreements with each of them**. Consequently, a large provider might have more than ten service arrangements signed with different CHOs and directly with the HSE.

Box 3 | Types of funding arrangements foreseen in Section 38 and 39 of Health Act

Section 38: Service Arrangement

Section 39: Service Arrangement (amounts above 250,000 euros)

Grant Aid Arrangements (amounts below 250,000 euros)

Amounts

According to the data of the Benefacts.ie database, registering the non-profit organisations in Ireland, in 2020, there are 254 not for-profit organisations providing services for people with disabilities. However, in reality, **a small number of large providers dominate the delivery of disability services**. For example, in 2017, the largest five service providers received 33% of total disability spending (548 million euros).¹³

Based on interviews and the data available in Benefacto. ie, **the government is the primary funding source (80-90%) for Section 38 and Section 39 providers**. The absolute majority of this income comes from the HSE. However, other state agencies (i.e., Department of Education and Skills, city councils) may also fund certain services. The additional 10%-20% of income is generated from different activities, e.g. fundraising or charity.

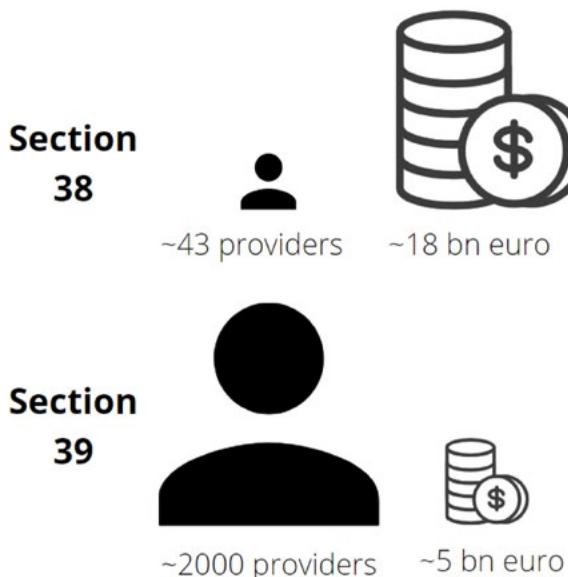
11 <https://www.hse.ie/eng/services/publications/non-statutory-sector/section-39-documentation.html>

12 <https://www.kildarestreet.com/committees/?id=2014-07-22a.34>

13 Health Service Executive. 2017. Transforming Lives Programme, <https://www.hse.ie/eng/services/news/media/pressrel/transforming-lives-programme.html>, Date accessed: 2020 08 25

As shown in Figure 4, **section 38 organisations receive significantly more funding from the government than section 39 ones**. During the period 2009-2015, slightly more than 40 Section 38 organisations received nearly 18 bn euros, while roughly 2000 Section 39 organisations shared less than five bn euros¹⁴. Despite the differences, nearly all interviewed providers claimed they have insufficient funding.

FIGURE 4 | Government funding for Section 38/39 organizations



Source: McInerney, Chris and Finn, Cian, 2015, p. 14

For-profit providers

In case of need, **the HSE may also commission services from for-profit providers through the governmental e-tendering system**. These tenders are public and competitive, and various for-profit private providers might participate. The bidders compete for financing to provide services and are judged according to their tender specification and price.

Person-based funding: personalised budgets

In 2016, the government established a task force on personalised budgets.¹⁵ The initial proposal of the Task Force presents personalised budgets as optional and foresees three different ways for PWDs to manage the funds received from the HSE. First, the person could receive the funds and make decisions himself/herself. Second, they can manage the budget together with the HSE or disability service provider. Finally, a person can ask the help of a broker responsible for giving the information and helping to plan the services needed. The Task Force concluded that the final design of any system of personalised budgets needs to be evaluated in a series of initial pilot projects.¹⁶

The first stage of the project commenced in October 2019, and the second started in September 2020. It is planned that 180 adults with disabilities would participate in the pilot project.

Impacts of funding models on the providers and the services

- ★ **Regarding levels of funding**, some providers of various disability services interviewed for this factsheet confirm that **current funding levels are insufficient to maintain (and even less to increase) the service supply**. Moreover, they complain about the annual negotiations, the lack of clarity in the negotiation and funding process, and the division between Section 38 and 39 organisations.
- ★ Disability system functions with deficits. Except for 2014, where spending was marginally below budget, spending on disability services has consistently exceeded the Budget allocation since 2012.¹⁷ In 2019, the nine of the biggest disability service providers formed a Disability Action Coalition, aiming to lobby

14 McInerney, Chris and Finn, Cian. 2015. Caring - at what cost. Rebuilding and refinancing the community and voluntary sector. Dublin: IMPACT, p. 14.

15 Amount of funding which is allocated to an individual by a state body so that the individual can make their own arrangements to meet specified support needs, instead of having their needs met directly for them by the State.

16 Department of Health. 2017. Towards Personalised Budgets for People with a Disability in Ireland Report of the Task Force on Personalised Budgets, p.17

17 Bruton, L., Gibney,S., Collins, D. 2020. Social Impact Assessment Series: Specialist Disability Services for People with Intellectual Disabilities, Government of Ireland, p.13

for the future of their services, claiming that they need €20m extra a year between them to resolve their immediate funding deficits.¹⁸

★ Spending and staffing restrictions at a time of growing numbers have harmed the level of service provision relative to demand:¹⁹ people have to wait for residential services, therapy appointments, or accept the services available in their region (which might not be entirely what they need).

★ **Regarding yearly negotiations, the organisations cannot plan their spending a few years in advance.** This does not allow the long-term planning necessary for the stability of organisations. Moreover, the providers criticise the current funding model as, according to them, the state can dictate its price for the services with little regard to service providers' needs. While this cannot be generalised one interviewed expert observed that some providers feel that prices offered are lower than the costs of the services. The "Disability Action Coalition" claims that there are no mechanisms to recognise deficits.²⁰ At the same time, many of these organisations' fundraising capacity had diminished, even before COVID-19 (due to the public loss of trust in charities²¹ and their falling desire to support charitable causes). COVID-19 will potentially affect this ability even more: for example, the Irish Wheelchair Association²² had to close its charity shops and looks at fundraising losses of about one million euros this year. Similarly, Enable Ireland²³ faces potential losses of 1,5 million and Rehab – 400 000 euros to their income in 2020²⁴.

★ **Regarding the differences between Section 38 and Section 39 organisations,** the latter seems to feel in a more fragile position in terms of funding. While it cannot be generalised, one day and residential care provider explained that some organisations prefer to accept more service users in order to cover their functioning costs. The interviewed HSE experts

observed that over 100 million euros were invested in recent years in day services willing to cover all the existing need.

★ Another prominent provider of disability services observes that despite being a big organisation, they continuously operate having only five weeks of cash reserves, making them very vulnerable to any funding changes.

Moreover, section 39 organisations also face additional expenses in the form of insurance (Public and Employer liability against the claims). One interviewed prominent provider of disability services observes that between 2016 and 2020, the price of annual insurance rose from 450,000 euros to one million euros. Section 38 organisations are covered by the State's Claims Agency (State's insurance body) and do not finance these costs themselves.

Finally, the situation of employees in Section 39 organisations is worse, as those working in the Section 38 agencies are considered public employees, and thus receive the corresponding benefits and guarantees. Meanwhile, section 39 workers are not entitled to receive them. For example, when the Section 38 worker automatically received the restoration of their salaries cut after the 2009 economic crisis, the section 39 ones were not entitled to it, but a process was put in place to at least partially address. Interviewed experts and providers of different services observe that these workers' wages are sometimes lower than their counterparts in Section 38 organisations, creating challenges for organisations to keep their staff.

The abovementioned funding procedures and their impacts reflect the situation in all disability services. The following sections discuss the peculiarities of each disability sector separately.

18 The Disability Action Coalition, <https://tdac.ie/about-us/>, Date accessed: 2020 09 04

19 Working group 1. 2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland‘, Report on Future Needs for Disability Services, p. 43.

20 The Disability Action Coalition, <https://tdac.ie/about-us/>, Date accessed: 2020 09 04

21 McInerney, Chris. 2020. Who Cares? Building a new relationship between the not-for-profit sector and the State 2018. Rehab Group. P. 57.

22 Irish Wheelchair Association is a large 39 provider, providing personal assistance, daycare services. <https://www.iwa.ie/>

23 „Enable Ireland“ is a large Section 39 provider, providing personal assistance, day care, vocational rehabilitation services. <https://www.enableireland.ie/>

24 The Disability Action Coalition. 2020. Key Recommendations for COVID-19 Committee. https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/submissions/2020/2020-09-30_submission-gillian-murphy-communications-manager-the-disability-action-coalition-scc19-r-r-0387_en.pdf Data accessed: 2020 08 27.

Day Support Services

Day support services in Ireland are delivered in day (care) centres, providing a range of social and rehabilitative services, such as day activation, recreational and leisure facilities, and specialised clinical facilities that provide a combination of medical and rehabilitation services²⁵. According to the latest available data from 2008, more than 90% of day supports services were delivered by not-for-profit organisations, usually also providing other services such as residential and respite care. The HSE itself delivered the remainder. All of the day support services are funded by the HSE²⁶ and are free (not counting some activities that may require extra payment, such as visiting museums or swimming pools).

Day supports services are among the largest HSE disability expenditure components, receiving 22% of the whole budget or 364,4 million euros in 2017. These services cover 18,000 people, the price per day care place being 20,200 euros per year²⁷. The funding of day care services follows the pattern of the financing described earlier.

While in general being satisfied with the overall quality of the service as delivered, interviewed day care providers and experts observe that:

★ The funding levels do not match existing service needs in some instances. The interviewed day care providers observe that the funding has not recovered after the 2008 financial crisis and does not reflect the services' real costs in all situations. While the authors of this report cannot generalise, one interviewed provider sustained that some not-for-profit organisations had either to cut services (offer fewer activities) or break them down (i.e., to offer 2-3 days instead to a full week.)

- ★ **The available day care services depend on the provider operating in the area.** While more providers are operating in some areas, in other ones (primarily rural), there may be only one provider available, offering only specific types of day care activities.
- ★ **The shortage of day care places in general does not seem to be a big problem.** However, the report on future needs of disability services indicates existing, though difficult to quantify, unmet need of this services (i.e., for people who acquired the disability older than 18 years old, people who were transferred from congregated settings to smaller community-based services).²⁸
- ★ **This shortage may increase:** the Irish government has calculated that due to the high birth rates in 2008-2010, the demand for day care services in 2026 will be 17% higher than in 2016.
- ★ **HSE has invested 25m euros per annum each year in recent years** for people leaving schools and accessing day services and facilitate some people not taking up a place until the try out other avenues preserving funding for the time being

Independent/Supported Living

The principal forms of personal support services funded by the HSE are *home support/home care* and *personal assistant services*.²⁹ These categories may be used interchangeably: in some instances, home support is seen as a more flexible option than a personal assistant³⁰. As observed in the report about the future needs of disability services, published in 2018, the small numbers of hours recorded for most personal assistance users in official data suggests that they are getting primary personal care

25 Day centres and day care. https://www.citizensinformation.ie/en/health/health_services/health_services_for_people_with_disabilities/day_centres.html, Date accessed: 2020 08 15.

26 <http://www.inclusionireland.ie/content/page/day-services-new-directions>, Date accessed: 2020 08 19.

27 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 20.

28 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 51-52.

29 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 64.

30 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 64

only, not a personal assistant service³¹. A broad range of providers offers these services. Nonetheless, in personal assistance, the not-for-profit sector's role is enormous as a big share of personal assistance services are provided by one section 39 organisation, the Irish Wheelchair Association.³²

Out of the overall disability budget **in 2017, only 5 % (79 mln. euros) was dedicated to personal assistance (27 mln. euros) and home care services (52 mln. Euros)**. This amount was divided among 9,784 people, in other words, the cost of an independent living service was 8,100 euros per person.³³ Different types of supported living services are funded using the same mechanisms already described in this factsheet.³⁴ The services are free of charge for the service user.

The interviewed providers of personal assistance services and home care observe that the quality of services is rather good; however, there are problems with accessibility:

★ **There is a significant unmet need** for home care and personal assistance services. Based on the available expert estimations,³⁵ while less than 10,000 people received home care and personal assistance services in 2017, the potential need for these services

might be around 23,000 for personal assistance and 56,000 people for the home care.³⁶ The increase in funding for disability services led to a 6% increase in the provision of home support hours and a 10% increase in personal assistant hours for between 2017 and 2019³⁷.

- ★ Currently, there are **waiting lists for the home supports**, and as observed in the report on long term care in Ireland, the funding increases usually just respond to urgent needs and are not planned thoroughly.³⁸
- ★ **Regarding personal assistance, the existing resources are spread very thinly**, and the allocation of the resources is often guided by the need to divide limited funds to cover as many PwDs as possible. As observed in the 2018 report on the future needs of disability services, the HSE Service Plans have generally kept the total target hours provided at the previous year's level.³⁹ In 2017, 1.51 million service hours were delivered to 2,470 people. Nearly 85% of people with personal assistance received fewer than three hours per day on average. Less than half of them had an average of just 42 minutes each day.⁴⁰ This amount of support is clearly insufficient to ensure independent living.

31 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 64.

32 Interview with large Section 39 provider.

33 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 20.

34 Some specific additional arrangements are foreseen to support informal carer: different types of payment for informal carers, such as Carers Benefit, Home Carer's Tax Credit.

35 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services

36 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 65

37 HSE. 2020. Annual Report and Statements 2019 and 2016, HSE Performance Reports 2019 and 2016, HSE Service Plan 2020.

38 Daly, Mary. 2018. ESPN Thematic Report on Challenges in long-term care Ireland. European Commission, p. 4.

39 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 66.

40 Cawley, J. 2019. Opinion: Disabled people in Ireland need the right to personal assistance. theJournal.ie. <<https://www.thejournal.ie/readme/right-to-personal-assistance-for-disabled-people-4892357-Nov2019/>> Date accessed: 2020 08 27.

Long Term Residential Care

Long term residential care in Ireland is taking place in two types of settings: first, so-called “congregated settings” where ten or more people reside in a single living unit or are campus-based;⁴¹ second, smaller community-based services, typically taking the form of a house in a residential area that provides a service to people in a house-share arrangement. Both types of settings have to register with HIQA.⁴² In 2018, there were 1183 designated centres taking care of people with disabilities in Ireland.⁴³

In 2017, residential care services constituted 63% of disability expenditure, over one bn euros. About 90% of this is for people with an intellectual disability⁴⁴. According to the Service plan 2017, this amount of money was allocated to 8,371 users, indicating the yearly unit cost of a residential place to be 127,100 euros.⁴⁵ The funding of residential services follows the pattern of funding described earlier.

People placed in the residential settings in section 38 organisations are expected to cover a part of their living there (usually the food and utilities) by paying a so-called Long-Stay Contribution.⁴⁶ The amount people have to pay varies depending on the level of service and their personal situation (e.g., assessment of their income). The interviewed residential service provider indicates that they charge 140 euros per week per PwD, which is similar to what other providers charge. Charges are carefully defined

Interviewed experts and residential care services providers consider services to be of good quality, mostly due to HIQA's quality standards. However, representatives of PwDs suggest that many of the residential centres would not correspond to the requirements established by the UNCRPD as they still do not ensure the independent living of PwDs.

However, the interviewed residential service providers, policymakers, and experts observe some challenges related to the funding of long term institutional care:

★ **There is a huge unmet need for residential services.** According to a governmental report, at the end of 2017, there was a waiting list of 800 people for these services.⁴⁷ Some are emergencies, and others are contingencies that will come through as need in the near future. According to the interviewed policymakers, there is a need for 90-100 new residential places each year, and the available places do not cover this need. Moreover, they observe that de-institutionalisation efforts also led to the loss of some of the available places, as in these cases, the PwDs live in smaller living arrangements with fewer peers.

★ **The number of those who need residential services is growing** due to demographic changes: a number of PwDs older than 50, a period when they are more likely to require residential care than day support, increased significantly in the last few years.⁴⁸ Moreover, around 15% of over-60s with intellectual disabilities in 2018 lived with family members, usually with siblings or parents. Bearing in mind their age,

41 HSE. 2018. Time to Move On From Congregated Settings: A Strategy for Community Inclusion. Review of Policy Implementation 2012-2017, p. 5. <https://www.lenus.ie/handle/10147/623862> Date accessed: 2020 09 02

42 HIQA. 2017. Exploring the regulation of health and social care services Disability services, p. 12

43 Disability Services <https://www.hiqa.ie/areas-we-work/disability-services>, Date accessed: 2020 09 04

44 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 5.

45 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 20.

46 Long-Stay Contributions for Residential Support Services, https://www.citizensinformation.ie/en/health/health_services/health_services_for_people_with_disabilities/long_stay_contributions.html , Date accessed: 2020 08 26.

47 Working group 1. 2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland‘, Report on Future Needs for Disability Services, p. 8.

48 Ibid., p. 8.

these arrangements are not sustainable. The report on the future needs of Irish disability services, published in 2018, suggests that 95% of these people will need residential places. The authors of the report calculate that the needs of these people (currently at home with family members) would require 370 extra places by 2025.⁴⁹

- ★ The unmet need in some instances with specific complexities forces **placing people in hospitals or nursing homes.** In 2018, 1,200 people under 65 lived in nursing homes and similar facilities, primarily designed for older persons. These residents include people with long-term disabilities (e.g., acquired brain injury) who are inappropriately placed in these settings. How many of those 1,200 people are inappropriately placed is not known.⁵⁰ However, a few interviewees said that due to the lack of residential places, relatives and medical staff are forced to keep people in hospitals longer than needed or place them in the settings not adapted to their needs.
- ★ **HIQAs requirements affected the provider's financial capabilities.** While the majority of the interviewees agree that HIQAs standards were extremely relevant to the improvement of quality in the residential and respite care, they observe that these improvements came at a cost. Governmental reports⁵¹ also recognise high costs to meet requirements set out by HIQA. For example, many HIQA inspection reports recommend that additional staff be employed to meet adequate levels of care or standards of safety. The HSE itself has estimated compliance with HIQA

requirements raised disability services cost by €57m in 2015.⁵² The HSE was also forced to allocate resources to address the deficits in some residential services to ensure that people are supported in safe and compliant environments.⁵³ However, in some instances the providers had to cover costs of additional staffing needs by themselves.

Respite care

The main form of respite service is overnight care away from home, with limited domiciliary respite and day respite services.⁵⁴ Schemes of respite care, sometimes called "Breakaway" or "Friendship" schemes,⁵⁵ are provided by the HSE or by local or national non-profit organisations. Often, respite services are offered by organisations, providing long-term institutional care and take place in residential settings.

From the overall budget dedicated to disability services in 2017, **only 2% (41,6 mln euros) was given to respite, foreseeing these services for 6,320 people. Hence the cost of a respite care place was 6600 euros.**⁵⁶ Respite services are funded in the same way as other disability services – through the Service Arrangements with not-for-profit providers or by contracting for-profit providers in the case of need. One more funding instrument for respite services is the Carer's Support Grant (1,700 euros), an annual payment of 1,700 euros made to carers by the Department of Employment Affairs and Social Protection (DEASP).⁵⁷ The carers can (though

49 Ibid., p. 8.

50 Ibid., p.9.

51 Working group 1. 2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland‘, Report on Future Needs for Disability Services.

52 Working group 1. 2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland‘, Report on Future Needs for Disability Services, p. 21.

53 HSE. 2018. Time to Move On From Congregated Settings: A Strategy for Community Inclusion. Review of Policy Implementation 2012-2017, p. 7. <https://www.lenus.ie/handle/10147/623862>, Date accessed: 2020 08 27.

54 Bruton, L., Gibney,S., Collins, D. 2020. Social Impact Assessment Series: Specialist Disability Services for People with Intellectual Disabilities, Government of Ireland, p.2

55 Respite Care https://www.citizensinformation.ie/en/health/health_services/health_services_for_people_with_disabilities/respite_care.html, Date accessed: 2020 09 03

56 Working group 1 .2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland“, Report on Future Needs for Disability Services, p. 20.

57 Carrers Support Grant, <https://www.gov.ie/en/service/16220307-carers-support-grant/>, Date accessed: 2020 09 04

are not obliged) to use this money to purchase respite services from providers.⁵⁸ In general, respite services are free of charge for the users.

The quality and accessibility of respite services have some limitations:

★ **The existing provision does not correspond to the current needs for this type of service.** As one provider of residential and day care services observes, respite "almost disappeared in the past years." According to the Social Impact Assessment Study on the Disability services for people with intellectual disabilities, both the number of people who received respite services and the number of nights they received decreased between 2011 and 2017.⁵⁹ The Irish government has recognised this unmet need. For example, in 2018, it announced the "New Additional Respite Programme for Persons with Disabilities," assigning an extra 10 million euros for the provision of additional respite houses and placements (8 million) and alternative respite options (i.e., the respite in families, 2 million euros).⁶⁰ However, the interviews conducted while preparing this factsheet indicate that respite opportunities still are limited.

Limited funding after the 2008 economic crisis is not the only reason for such a decline. First, it seems that similarly to the residential care sector, those offering respite services in residential institutions struggled to accommodate HIQA requirements, which led them to decrease the number of services delivered. As an example, one can mention "a restriction on the number

of wheelchair users who can receive respite in the same house at the same time means that opportunities for respite care now more restricted for those with more complex disabilities than in the past"⁶¹. Finally, in some cases, respite beds are being occupied on a long-term basis by individuals for whom no residential place is available, thus reducing the availability of respite.⁶²

★ **The respite services are far from the desired community based and individualised services that Ireland aims to create.** One interviewed provider of personal assistance services observes that the respite services are those with the most claims about insufficient quality from their users. However, this perception is not shared by the HSE experts.

★ **There are differences in the type of respite services a person can expect** (residential centre-based or of a more home-based style), **depending on the provider.** The differences are especially acute in rural areas where the availability of services might be further complicated due to the travel costs, as PwDs have to travel further distances to the places where services are available. In the words of one interviewee, "Often the people receive a service, but it may not be the exact service they need, but it's the only one available in the area."

★ **The demand for respite services is growing.** The estimates of the Health Research Board show that people with disabilities have said that about 1600 additional people with intellectual disability in 2017-2021 require respite services⁶³.

58 Carrers Support Grant, <https://www.gov.ie/en/service/16220307-carers-support-grant/>, Date accessed: 2020 09 04

59 Bruton, L., Gibney,S., Collins, D. 2020. Social Impact Assessment Series: Specialist Disability Services for People with Intellectual Disabilities, Government of Ireland, p.34.

60 HSE. 2018. €10 million Govt. Investment New Additional Respite Programme for Persons with Disabilities 2018. <https://www.hse.ie/eng/services/news/media/pressrel/national-respite-programme-infograph.pdf>, Date accessed: 2020 09 04

61 Working group 1. 2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland', Report on Future Needs for Disability Services, p. 43.

62 Bruton, L., Gibney,S., Collins, D. 2020. Social Impact Assessment Series: Specialist Disability Services for People with Intellectual Disabilities, Government of Ireland, p.34.

63 Working group 1. 2018. Transforming lives programme to implement the recommendations of the „Value for Money and Policy Review of Disability Services in Ireland', Report on Future Needs for Disability Services, p. 9.

Interviews

- ★ Sean Abbott, CEO of COPE Foundation (Section 38 provider & EASPD member), Provider, Interview on 23rd of July, 2020
- ★ Sarah Craig, Health Research Board, Head of National Health Information Systems, Expert/Regulator, Interview on 20th of July, 2020
- ★ Éamonn Donnelly, Head of division: Health & Welfare IMPACT Trade Union, Representative of employees, Interview on 19th of August, 2020
- ★ Rosemary Keogh, Chief Executive Officer at the Irish Wheelchair Association (Section 39 provider), Provider, Interview on 26th of August, 2020
- ★ Chris McInerney, Department of Politics and Public Administration at the University of Limerick, Expert, Interview on 14th of July, 2020
- ★ Robert Murtagh, Policy coordinator Inclusion Ireland, Representative of PWD, Interview on 26th of August, 2020
- ★ Mark O'Conner, Community Engagement Manager Inclusion Ireland, Representative of PWD, Interview on 26th of August, 2020
- ★ Marie Vaughan, Adult Service Manager Enable Ireland Provider (Section 39), Interview on 23rd of July, 2020
- ★ Valerie Walshe Economist, Planning and Performance Regulator, Interview on 20th of August, 2020
- ★ Liam Quinn, Chief Executive Officer at Kingsriver Community Holdings, Provider (Section 39), Interview on 20th of August, 2020
- ★ Gerry Tully, Disability Specialist, HSE, Regulator, Interview on 20th of August, 2020
- ★ Bernard O'Regan, Head of Strategy and Planning HSE Disability Service, Regulator, Interview on 20th of August, 2020

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EASPD is the European Association of Service providers for Persons with Disabilities. We are a European not-for-profit organisation representing over 17,000 social services and disability organisations across Europe. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.



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