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SPECIALIST SUPPORT FOR PERSONS WITH DISABILITIES LIVING IN THE COMMUNITY

REVIEW OF THE INTERNATIONAL LITERATURE

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ABBREVIATIONS

AHEAD	Association for Higher Education Access and Disability
ÁT	Áiseanna Tacaíochta
CHO	Community Healthcare Organisation
CRPD	Convention on the Rights of Persons with Disabilities
DARE	Disability Access Route to Education
EU	European Union
HSE	Health Service Executive
IWA	Irish Wheelchair Association
NASS	National Ability Supports System
NCSE	National Council for Special Education
NDA	National Disability Authority
NDA	National Disability Authority
NDIS	National Disability Insurance Scheme
NIDD	National Intellectual Disability Database
NPSDD	National Physical and Sensory Disability Database
PSSRU	Personal Social Services Research Unit
SNA	Special Needs Assistant
UK	United Kingdom
UN	United Nations
US	United States

EXECUTIVE SUMMARY

This report presents an exploratory examination of the international literature on the provision of specialist support for persons with disabilities living in the community, in the context of Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). Academic literature and international evidence in transitioning to person-centred service provision, personal assistance services, individualised funding, measuring need for support services and costing models of service provision are all considered.

Overall, despite the widespread ratification of the CRPD, there is considerable variation evident across countries in how community living is supported in practice. This variation appears to stem both from the policy origins in different legacy welfare state models and their underlying ideologies, but also from varying trends in the development of service provision over time. Of course, it is possible that the COVID-19 pandemic will lead to further shifts in the provision of specialist disability support, and the literature comparing different support settings could benefit from accounting for additional factors such as risk of infection.

The review of international literature in this area has revealed several key issues that are relevant to disability service provision in Ireland.

There is a need to continuously monitor evolving service provision at a local level, particularly in countries where chronic under-funding is coupled with a lack of individual legal rights to community living support. Statutory provision of a transparent assessment of needs in order to make unmet need for support services a matter of public record, complemented by a comprehensive and standardised tool to assess needs, is regarded as one approach that could help to ensure that inequalities in service provision do not arise over time.

Personal assistance services can facilitate independent living at home by assisting with activities of daily living, in the workplace or in education. A central challenge in establishing and facilitating personal assistance services is ensuring that the control of the service user is adequately promoted and supported. There is evidence that the focus of personal assistance services can gradually narrow to basic healthcare, with the erosion of support for other elements of community living, and thus user control, particularly as demand for personal assistance increases.

Individualised funding, where funding for supports follows the service user, is considered an alternative to more traditional funding routes for support services that have been characterised as inefficient. Evidence from international literature suggests that individualised funding models work best when complemented by a

central government ensuring service quality and policy coherence, as well as independent support brokerage and clear eligibility criteria. It is also important to consider the potential implications for support workers and assistants of individualised funding schemes.

A trade-off is identified in the literature between the generosity and the coverage of individualised funding schemes in the context of budgetary constraints. In terms of financing disability support services, some countries have adopted a social insurance model, such as the National Disability Insurance Scheme (NDIS) in Australia.

Closely related to this is the importance of systematic and comprehensive data collection, including data on anyone provided with a needs assessment and longitudinal data on service users. This is required for monitoring and evaluating service outcomes as well as for estimating future needs from a life-cycle perspective. The data landscape in the area of specialist disability services in Ireland is expected to improve with the development of the National Ability Supports System (NASS) database.

Systematic data collection is also required to accurately cost models of specialist support service provision and project future expenditure. The establishment of a dedicated research unit similar to the Personal Social Services Research Unit (PSSRU) in the UK would improve Ireland's capacity to calculate unit costs for various support services. A theme that arises across most countries is the notable dearth of published data specifically measuring unmet need for, and unit costs of, specialist disability supports. This gap can only serve to hinder efforts to make the achievement of individualisation, as set out in Article 19 of the CRPD, a reality.

This exploratory review of international literature is an initial step in a wider research programme that examines the provision of specialist community living and personal assistance supports in Ireland, and in particular the extent of need and supply for these specialist services.

1. INTRODUCTION

Article 19 of the Convention on the Right of Persons with Disabilities (CRPD), adopted by the United Nations (UN) in 2006 and ratified by Ireland in 2018, recognises ‘the equal right of all persons with disabilities to live in the community, with choices equal to others’ (United Nations 2006). Ireland’s National Disability Authority (NDA) defines community living as:

... comprising the same range of accommodation available to the general population, in the same locations where the general population reside, offering people with disabilities choice over where and with whom they live and providing the necessary supports for community participation (NDA 2010).

This report presents an exploratory review of international literature across several key areas in supporting community living for persons with disabilities. In this report, we consider specialist support for three different population groups with widely varying support needs; namely intellectual disabilities, physical and sensory disabilities, and emotional and mental disabilities.

The disability sector in Ireland has experienced unprecedented policy change in recent years (Linehan et al., 2014), with policy developments including the publication of *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* (HSE 2011) and *Value for Money and Policy Review of Disability Services in Ireland* (Department of Health, 2012). The *Value for Money* report presented an extensive evaluation of the effectiveness and efficiency of disability services in Ireland. It found current services to be resource-intensive and founded on a medical model of disability, and argued for a need to move towards a model of individualised supports delivered via mainstream services. The Transforming Lives programme was established to oversee the implementation of the recommendations of the *Value for Money* report. In this review, we draw on some of the work conducted by the Transforming Lives programme’s Working Group 1, which was tasked with forecasting future need for specialist disability services (Working Group 1, 2018).

Section 2 considers the wider shift in specialist disability support services to more person-centred models of support. Section 3 focuses on personal assistance services, regarded as an integral support for a fundamental manifestation of community living. A central element of personal assistance is a system of individualised funding, and this is examined in Section 4. Another important aspect of independent living is measuring need, and in particular unmet need, for specialist services, which is discussed in Section 5. Section 6 explores how different models of specialist disability support can be costed. Finally, Section 7 concludes by summarising key issues arising in this review.

2. TRANSITION TO PERSON-CENTRED SPECIALIST SUPPORT

Under the UN CRPD, ratified by the European Union (EU) and all European states other than Vatican City and Liechtenstein (Crowther, 2019), community living is deemed an individual right.

This section first discusses how disability policy in Ireland is gradually moving towards a more person-centred model of support. The conceptual background of modern approaches to disability support is then outlined, drawing on academic literature. This is followed by a review of international evidence in this area.

2.1. CONTEXT IN IRELAND

Linehan et al. (2014) provide an overview of the approach to intellectual disability policy in Ireland, where community support has been acknowledged to provide a better quality of life relative to institutional settings for persons with disabilities at state level since 1965. As in other countries, disability in Ireland has historically been treated with ‘paternalism, medicalisation and segregation’, with a heavy reliance on religious organisations and institutionalism (Cullinan, Lyons and Nolan, 2015). Linehan et al. (2014) note that disability support services are now in transition towards a more personalised model of support, but that progress is slow and has previously occurred in the absence of a formal process for monitoring this progress. The major role of non-profit organisations in providing services with little state oversight, considered in line with international trends, is also highlighted as part of a consistent picture of poor implementation of required changes and poor funding transparency (Linehan et al., 2014).

A key element of this shift towards more personalised disability support is deinstitutionalisation. Linehan et al. (2015) broadly define deinstitutionalisation as ‘the gradual abandonment of large residential institutions and their replacement by small scale services to enable people to live well in the community’. In international practice, Tatlow-Golden et al. (2014) point out that there are many definitions of deinstitutionalisation, some simply focusing on the size of facilities or the profile of residents, while others encompass attitudes, values and norms to account for the possibility of institutional practice migrating to community settings. Current Irish policy on this issue is outlined in the *National Disability Inclusion Strategy 2017–2021*, in which Action 94 ‘aims to reduce the number of people living in congregated settings by at least one-third by 2021 and to ultimately close all congregated settings’ (Department of Justice and Equality, 2017). As summarised in Table 2.1, 826 individuals with disabilities in Ireland were moved out of congregated settings between 2012 and the end of 2018, 165 of whom transitioned during 2018. Meanwhile, 2,136 individuals remained across 83 congregated campuses or centres (HSE, 2019a).

TABLE 2.1 STATUS OF CONGREGATED SETTINGS IN IRELAND, 2012–2018

Individuals moved out of congregated setting by end of 2018	826
Individuals residing in congregated settings at end of 2018	2,136
Congregated campuses or centres closed by end of 2018	11
Congregated campuses or centres in operation at end of 2018	83

Source: HSE (2019).

2.2. ANALYTICAL FRAMEWORK

2.2.1. Welfare state models

First, it is worth outlining various forms of overall disability service provision and their characteristics. Mansell (2006) discusses the three ‘ideal’ types of capitalist welfare state defined by Esping-Andersen (1990), each of which has given rise to different forms of disability service provision over time: social democratic, liberal and conservative. In the social democratic model, such as in Sweden and Norway, universal public services are provided as a right. This results in services being undertaken on a collective basis by the state, rather than services being traded in a market, or ‘commodified’. In addition, the rights-based approach means that services are not rationed through the use of waiting lists, but rather through the needs-assessment process. It has been pointed out in the literature that the rights-based approach therefore invests considerable power in the professionals or officials who are responsible for the needs-assessment process (de Chenu, Dæhlen and Tah, 2016). A different ideology underpins the liberal model, apparent in some English-speaking countries; namely, that the private life and freedom of the individual should remain untouched and that the state intervenes only in the absence of individual solutions. In practice, this means that welfare is typically means-tested and that legal entitlements are less extensive compared to social democratic systems. Mansell (2006) also notes that, under the liberal approach, often characterised by a high degree of service commodification, welfare recipients can be stigmatised as means-testing renders the welfare system socially stratified. A final type of capitalist welfare state discussed by Mansell (2006) is the conservative model, such as in Germany and France, which is founded on ‘normal’ employment relationships and families. Claims to welfare are based on contributions made, resulting in social rights being linked to social class and status. There is thus a higher degree of service commodification than in a social democratic model, although not to the same extent as in the liberal model.

Ireland, regarded by some as historically similar to the UK in terms of disability policy and practice while generally lagging behind in terms of implementation (Fleming, McGilloway and Barry, 2016), can be considered a hybrid of the liberal and conservative models of welfare. One study places Ireland in an alternative ‘Southern European’ model of welfare state, which is characterised by a preference

for social protection over individual freedom, along with Poland, Luxembourg and southern European countries (Tschanz and Staub, 2017).

Mansell (2006) points out that most countries employ a mixture of the three main approaches proposed by Esping-Andersen (1990). The study notes three separate trends evident in evolving models of service provision. First, responses to increasing expenditure on welfare, coupled with efficiency targets, can foster the development of market-based approaches to resource allocation and decision-making. These can include personal budgets, designed to dismantle corporate structures that control service provision, and the further rationing of services using eligibility criteria. The NDA has previously reviewed the use of individualised funding as an alternative method of allocating resources (NDA, 2015; SQW, 2013; NDA, 2011). A second trend is the 'de-differentiation' of services, stemming from the ideology of normalisation that promotes the mainstreaming of services, as well as from the spreading of deinstitutionalisation to other groups of service users, such that disability service reform becomes part of a general modernisation of social care. General policies and structures may take the place of more specialised, separate services, which can result in competition between different groups for prioritisation of resources, and in reduced recognition of specific disability issues.

Cullinan, Lyons and Nolan (2015) also discuss the mainstreaming of disability services. In addition, however, the authors highlight the emergence of a 'life-cycle approach', in which supports are flexible to account for the changing profile of an individual's support needs over time. Moreover, they point out that supports are increasingly provided on a bespoke basis, in contrast with earlier concerns of Mansell (2006) that the mainstreaming of services can lead to the dilution of more specialised services. A final change noted by Mansell (2006) is the rise of the rights-based social model of disability, which can remove some negative aspects of market approaches. Overall, having originated in different forms of capitalist welfare states, a country's model of disability service provision typically evolves to incorporate a mixture of the social democratic, liberal and conservative approaches as a result of experiencing trends such as these to varying degrees.

In addition to shaping a country's model of disability support, a further influence of a country's welfare state context worth noting is suggested by O'Brien (2015). This study finds that residents of more generous welfare state regimes, such as social democratic welfare states, are significantly more likely to report a disability. This may indicate that the 'welfare state may directly shape what it means to be disabled', perhaps through the establishment of a broader conception of disability or through a lower level of stigmatisation in relation to disability (O'Brien, 2015).

2.2.2. Independent living and community integration

The concept of independent living is intrinsically linked with the transition to person-centred disability support. While various descriptions of independent living

are evident in the literature, the UN Committee on the Rights of Persons with Disabilities defines independent living as a situation in which:

... individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives (UN Committee on the Rights of Persons with Disabilities, 2017b).

Morris (2004) outlines a framework for understanding this concept, and describes three elements that are woven through various definitions of independent living: persons with disabilities are given the same opportunities for choice and control as the rest of the population, traditional interpretations of 'independent' are challenged, and service users themselves control assistance. The NDA (2010) lists seven essential services required to realise independent living: information provision, peer counselling and advocacy, skills training, housing, technical aid, personal assistance and transport. Morris (2004) also points out: 'Independent living itself is a means to an end: it is a way of people accessing their human and civil rights'. Linehan et al. (2015) identify three distinct stages in a country's journey towards supporting independent living. The first step is the transformation and reform of institutional care, involving the separation of accommodation and support service provision, which are traditionally combined in institutions. Following this initial step, community living options are developed, with supports made available in the community. The final step is the realisation of independent living, where persons with disabilities are supported to live in their own homes and can exercise choice and control through independent budgets.

Closely linked to the notion of independent living is the concept of community integration. This concept is defined by the Committee on the Rights of Persons with Disabilities as:

... living a full social life and having access to all services offered to the public and to support services offered to persons with disabilities and to enable them to be fully included and participate in all spheres of life (UN Committee on the Rights of Persons with Disabilities, 2017b).

This has become a central tenet of successful service provision, based on ideas such as normalisation, with institutional care regarded as the 'antithesis' to community integration (Cummins and Lau, 2003).

2.2.3. Person-centred outcome measurement

The NDA (2019) details the purpose, challenges and limitations of outcome measurement in the area of disability services, and argues that outcomes of various forms of disability service provision must be assessed at two distinct levels. First, an individualised measurement approach is crucial given the development of person-centred services, in that the success of disability services must be viewed in terms of the progress of individuals towards their desired goals in various

quality-of-life domains.¹ In addition to this, however, overall service quality and value for money must still be assessed, using more standardised outcome tools and indicators (NDA, 2019a).

One example of the measurement of person-centred outcomes is the established literature that supports the idea that deinstitutionalisation can have a positive effect on the quality of life of persons with disabilities (McCarron et al., 2019; Chowdhury and Benson, 2011; Walsh et al., 2010; Kozma, Mansell and Beadle-Brown, 2009). McCarron et al. (2019) present a systematic review of literature on the effects of deinstitutionalisation on the quality of life of adults with intellectual disabilities, finding deinstitutionalisation to be associated with improved quality of life for persons with any level of intellectual disabilities in both quantitative and qualitative studies. Moving to community settings is found to result in an improved sense of wellbeing, freedom and independent decision-making, although results are found to be mixed in terms of social integration into the wider community, which in turn is found to be highly dependent on support from residence staff (McCarron et al., 2019). In another literature review, Chowdhury and Benson (2011) also find positive quality of life changes after relocation; for example, increased choice, increased involvement in leisure activities and outings, increased interaction with staff and other residents, improved material wellbeing, and increased levels of dignity. The review also notes, however, that quality-of-life increases appear to level off over time, that a lack of community integration persists after relocation to community settings, and that the reality of the change in quality of life depends on the effort of community service providers.

It is worth noting that, in the literature cited comparing different forms of disability support, the relative risk of infection in different settings is generally not considered as a factor in person-centred outcomes. However, in light of the COVID-19 pandemic, infection risk may well become a crucial consideration that motivates a re-evaluation of all forms of disability support. For example, staff entry and re-entry has previously been found to be the most important determinant in the control of influenza in residential care facilities in a pandemic scenario (Nuno et al., 2008). The organisation and staffing structures of various forms of disability support, therefore, may expose service users to different levels of infection risk. This suggests a need to add to existing evidence in this area with further research that accounts for the relative levels of infection risk in different disability support arrangements.

2.2.4. Progress towards independent living

Slasberg and Beresford (2019) present a discussion on how progress in disability service provision, specifically towards supporting independent living, can stall and actually reverse over time, citing the United Kingdom (UK) as an example. They

¹ The NDA (2016) proposes a framework of nine quality-of-life domains for outcome measurement in person-centred disability services.

argue that, since the UK Direct Payments Act 1996 does not establish a legal right to independent living, it remains at the discretion of each local authority whether the support of independent living is possible. Slasberg and Beresford (2019) indicate that, despite the hourly cost of independent living being lower than traditional residential services, the total cost of independent living is, on average, 80 per cent higher than traditional services due to the higher number of hours required. The lack of legal obligation on local authorities to provide an adequate level of support, coupled with chronic under-funding and austerity, can result in persons with disabilities being placed in residential care rather than being supported for independent living, in order to reduce costs. This is achieved using assessments of 'needs' that are resource-led rather than based on need, an approach that Morris (2004) explains is underpinned by a medical rather than a social model of disability. Slasberg and Beresford (2019) suggest that this subtle policy shift can have a higher impact on people who are less able to self-advocate and negotiate with authorities, as local authorities can remain vulnerable to skilled advocacy. Moreover, Morris (2004) argues that the lack of a legal entitlement to services, combined with resource-based rationing of services, results in a denial of independent living by default, which in turn can lead to geographical inequalities and poor overall service quality.

According to Slasberg and Beresford (2019), the ideal solution to this is to adopt a rights-based approach to independent living, but they acknowledge that this would be at the expense of expenditure control within a given budget. They suggest a compromise, whereby control of spending is maintained but statutory provision of a transparent assessment of needs is established. This approach could ensure that unmet assessed need becomes a matter of record, such that a funding gap is explicitly identified for government to declare how it intends to eliminate it. In Ireland, for example, children with disabilities are entitled to a statutory assessment of needs under the 2005 Disability Act, although geographical inequalities still exist due to local variations in the implementation of this process (NDA, 2011).

This, however, still does not legislate for the possibility of less subtle policy shifts in relation to independent living; namely, the suspension of statutory service provision. The abrupt suspension in the UK of several duties which local authorities are obligated to carry out under the Care Act 2014, including a statutory assessment of needs, in response to COVID-19 (UK Department of Health and Social Care, 2020) could be regarded as an indication of the precarious nature of progress towards independent living in some countries.

2.3. INTERNATIONAL PRACTICE

The United States (US), the UK and the Scandinavian countries are typically highlighted as leaders in the area of deinstitutionalisation, with movements

emerging in these countries in the 1960s and 1970s (Tatlow-Golden et al., 2014). Sweden and Norway are considered exceptional in successfully closing all institutions (Wiesel and Bigby, 2015).

2.3.1. Europe

Crowther (2019) presents a report on progress in European states towards independent living for persons with disabilities. While almost all European states have ratified the CRPD, Crowther states: 'Arrangements bearing the hallmarks of institutional care persist across all... countries, with tens of thousands of children and adults with disabilities systematically denied their human rights'. Indeed, institutional care is found to be still consuming more public expenditure than community-based alternatives across Europe. Some examples of small-scale experimental projects designed to increase choice and control of persons with disabilities are noted, such as user-led personal assistance schemes, individualised budgets, and the provision of peer support. However, the authors highlight a focus among European states on simply relocating residents of institutions, rather than on broader reform and social change towards independent living (Crowther, 2019).

The UN Committee on the Rights of Persons with Disabilities highlights welfare reforms in the UK as having a disproportionately negative impact on persons with disabilities, with the ability to participate in community life hampered by a reduction in support (UN Committee on the Rights of Persons with Disabilities, 2017a). This is an example of a country being found to have regressed in relation to realising individual rights established in the UN CRPD.

2.3.2. Post-socialist Central and Eastern Europe

Central and Eastern European post-socialist countries are highlighted in the literature as laggards in developing person-centred disability supports, despite the signing of the CRPD by most of these countries (Mladenov and Petri, 2019; Završek, 2017). This is evident, for example, in the UN Committee on the Rights of Persons with Disabilities' recent inquiry into progress in implementing the CRPD in Hungary, in which it is clear that institutionalisation continues to be relied on and to receive public investment. More broadly, the inquiry notes that disability inclusion has yet to become mainstream in general policies in Hungary on education, health, employment and housing (UN Committee on the Rights of Persons with Disabilities, 2019). In addition to deinstitutionalisation only beginning to expand to these countries after the fall of communism at the end of the 1980s, studies point to underlying attitudinal differences; for example, the predominance of a home care model in which care is almost exclusively provided by family members, and usually by women (Završek, 2017). Under the definition of disability in state socialism, the productivity-enhancing function of segregated provision is emphasised, such that the rationale for institutional care is to release relatives from care obligations (Mladenov and Petri, 2019). Završek (2017) also notes an apprehension in post-socialist countries that deinstitutionalisation would

represent an expensive change to the existing welfare system that would in turn result in unemployment, and that a paradigm shift from a medical model of care to community services has thus not materialised. The example of post-socialist countries in Central and Eastern Europe indicates that the process of deinstitutionalisation is 'culture-specific, contextual and dependent on traditions, politics and financial means' (Zaviršek, 2017).

2.3.3. Australia

Australia, on the other hand, is cited by some as a leader in deinstitutionalisation, with steady progress since the first wave of deinstitutionalisation in the 1960s and 1970s. Wiesel and Bigby (2015) note a more recent ideological shift away from one of the foundations of deinstitutionalisation, the concept of normalisation, towards the idea of choice and control. More recently, the National Disability Insurance Scheme (NDIS) has been established in Australia as a new policy framework for the funding and provision of disability services, with deinstitutionalisation now fundamentally tied to this nationwide scheme (Wiesel and Bigby, 2015). The NDIS is considered in more detail in later sections of this report.

3. PERSONAL ASSISTANCE SERVICES

Personal assistance is regarded in the literature as a ‘leading symbol’ of independent living in practice (Askheim, 2003), and as ‘one of the most significant innovations in disability policy’ (Mladenov, 2019). Personal assistance services are evident in three distinct spheres of community living for persons with disabilities: (a) assistance with activities of daily living, (b) employment and (c) education. The current state of affairs in relation to personal assistance services in Ireland is outlined in this section. The section then discusses theoretical approaches to personal assistance services considered in academic literature, before outlining international evidence. A central enabler of personal assistance is individualised funding, which is discussed separately in Section 4.

3.1. CONTEXT IN IRELAND

Relative to residential services, other specialist support services account for a small proportion of the Health Service Executive (HSE) disability service budget. In 2017, €79 million was spent on personal assistance and home care, constituting 5 per cent of the budget for specialist disability services, and this supported 9,784 users (Working Group 1, 2018). The HSE defines a personal assistant as someone ‘employed by the person with a disability to enable them to live an independent life. The personal assistant provides assistance, at the discretion and direction of the person with the disability, thus promoting choice and control for the person with the disability to live independently’ (Buchanan, 2014). In theory, this assistance extends far beyond basic healthcare needs, also helping with dressing, transport, communicating, household tasks, and (higher) education or work-related tasks (Buchanan, 2014; European Network on Independent Living, 2013).

3.1.1. Assistance with activities of daily living

In Ireland, personal assistance originated among a small group of persons with physical and sensory disabilities in the early 1990s (Buchanan, 2014). Keogh and Quinn (2018) indicate that personal assistance to support activities of daily living is now the responsibility of the HSE, and is delivered through the HSE and funded service providers² across nine Community Healthcare Organisations (CHOs). Each CHO has a chief officer who leads a local management team that focuses on all specialist services in that area, including personal assistance. The HSE operates a case manager system, in which each person referred as needing a care package is assigned a case manager and provided with a needs assessment. It is worth noting, however, that no standardised tool for assessing needs is currently in place (Keogh

² Where the HSE is unable to provide service at a regional level, responsibility for service provision is transferred to local, voluntary, non-statutory organisations, termed Section 38 or Section 39 organisations. Keogh and Quinn (2018) note that approximately 78 per cent of personal assistance hours in Ireland was covered by one Section 39 organisation in 2016.

and Quinn, 2018), and that needs-assessment procedures thus vary between CHOs (McCarthy and Toner, 2018). We understand that the HSE is in the process of introducing a standardised tool for use in the Home Support Service and Nursing Home Support Service (HSE, 2020b), although it is important that such a tool can assess support needs that extend beyond basic care for it to be applicable to specialist disability services such as personal assistance.

Buchanan (2014) discusses the characteristics of personal assistance in Ireland, and finds that service information is inadequate, the service has become increasingly under-funded, and delivery is area-dependent. Buchanan contends that the emphasis of personal assistance in Ireland has narrowed to basic personal care needs, with reduced attention on supporting independent living, in spite of the HSE's definition of a personal assistant, as cited above. Buchanan also suggests a discrepancy in the number of personal assistance hours received between established and new users, with newer users more likely to receive less than 25 hours per week. The fact that the service is situated in the HSE despite successful personal assistance extending far beyond health and basic care needs is also underlined as a cause for concern (Buchanan, 2014). Furthermore, it is clear from the HSE's National Service Plan 2020 that the provision of disability support services in Ireland is resource-led rather than based on needs: 'Delivery of the planned level of services is dependent on the requirement for all services to manage and prioritise costs within available budgets' (HSE, 2019b). The Disability Federation of Ireland indicated in 2018 that no additional funding had been allocated to personal assistance since 2008, and that consequently no new personal assistance hours were created during that period (McCarthy and Toner, 2018). While the concept of personal assistance is regarded as a 'child' of the independent living movement in the literature (Askheim, 2003), the Disability Federation of Ireland views the service as 'an orphan in Ireland's social policy framework' (Buchanan, 2014).

3.1.2. Personal assistance and home care

Working Group 1 (2018) indicates that the principal forms of personal support services funded by the HSE are the Home Support Service and personal assistance hours, and that the numbers in receipt of these services are weighted roughly two to one in favour of home support. The Home Support Service provides home care, typically understood in Ireland as support at home with cleaning, cooking and other light household tasks that an individual is unable to do due to a disability, although this scope has expanded to include assistance with personal care such as hygiene and dressing (Kiersey and Coleman, 2017). Home support and personal assistance services are provided primarily to persons with physical and sensory disabilities; persons with disabilities over the age of 65 are not eligible for personal assistance in Ireland (Working Group 1, 2018). Working Group 1 (2018) suggests there may be a degree of interchangeability between these two services for persons with disabilities, and that most personal assistance users report receiving

under ten hours of support per week. Such a limited weekly time allocation is likely to result in assistance being limited to basic home care, rather than forms of personal assistance that truly enable independent living. The Disability Federation of Ireland has pointed out that the understanding of personal assistance varies across CHOs, with the service viewed as social support for community participation in some areas, but as a personal care service that is equivalent to the Home Support Service in other areas. Moreover, they note that some who apply for personal assistance are provided with home support instead, perhaps reflecting the lack of a needs-assessment process that is standardised across CHOs. They consider this practice 'deeply problematic' as it obscures any measure of demand, or unmet demand, for personal assistance, with applicants being removed from waiting lists on the basis that they are provided with home support instead (McCarthy and Toner, 2018).

3.1.3. Employment

The unemployment rate in Ireland is over two times higher among persons with disabilities than among individuals who do not have a disability (NDA, 2019b). The NDA has previously analysed reasonable workplace accommodations in Ireland, including the process for requesting and receiving such accommodations. Reasonable accommodations may include ensuring recruitment processes are accessible, adapting the working environment, modifying working times and providing assistive technology in the workplace (NDA, 2019b).

Personal assistance services in Ireland, however, have previously been described as focused on providing assistance with activities of daily living and with education, with the provision of workplace personal assistance services receiving little policy attention (Cork Centre for Independent Living Limited, 2004). Grants to fund the employment of personal readers are available from the Department of Employment Affairs and Social Protection to private-sector employees with a visual impairment who require assistance with reading, while public-sector employers are required to facilitate this support using their own budgetary resources (Citizens Information Board, 2020).

The NDA notes stakeholder concerns over a lack of access to workplace personal assistants in Ireland (NDA, 2020). It is our understanding that workplace personal assistance support may often be conflated with personal assistance for activities of daily living at home, with service users receiving a fixed level of support to be used either at home or in the workplace. This scenario presents service users with a trade-off between two forms of personal assistance, in which workplace personal assistance is provided at the expense of personal assistance at home. Particularly in a context of an inadequate allocation of personal assistance support, this could lead to service users exhausting their support allocation at home on essential assistance with activities of daily living. As discussed in Section 3.2, workplace personal assistance can be clearly distinguished from personal assistance at home

as it specifically allows them to make an economic contribution in employment.

At present, there is a notable dearth of evidence and research on workplace personal assistance in Ireland. We hope to address this research gap to some extent as part of future work in our research programme.

3.1.4. Education

Students with special educational needs at primary and secondary level may be supported by paraprofessionals, termed in Ireland as Special Needs Assistants (SNAs). Schools may apply through an independent allocation system for SNA posts specifically to assist them in providing for students with disabilities who have a significant medical need, a significant physical or sensory disability, or whose behaviour may be a risk to themselves or other students. A key objective of SNA support provision is identified as facilitating the development of a student's independent living skills and thereby to reduce their future support needs (Department of Education and Skills, 2011). The role of the SNA is regarded as including basic personal care assistance as well as 'a range of therapeutic, behaviour management and pedagogical activities' (Keating and O'Connor, 2012). There is evidence that the role of SNAs in Ireland has expanded beyond the original objectives of the state-administered SNA Scheme, partly due to a lack of understanding by schools and parents of the purpose of the scheme and of the support allocation system. For example, the Department for Education and Skills note evidence that schools increasingly assign educational tasks to SNAs in addition to care duties (Department of Education and Skills, 2011). Recent evolution of support provision for students with special educational needs in Ireland is discussed in detail by Kenny, McCoy and Mihut (2020).

In higher education, 6.2 per cent of the total student population across 27 responding institutions in Ireland was registered with disability support services in 2018-19 (Hynes, 2020). The use of personal assistance services in further and higher education is found to be widespread in Ireland, although pathways for progressing from secondary to post-secondary education have previously been considered to be localised, with emerging, rather than established, support infrastructure (McGuckin et al., 2013). The transition from secondary to higher education is supported in Ireland by targeted access initiatives, including a supplementary admissions system, the Disability Access Route to Education (DARE),³ although some concerns have been raised about this scheme; for example, in relation to the requirement to have a recent psycho-educational assessment, which in turn incurs additional costs to applicants (McGuckin et al., 2013). A non-profit organisation, the Association for Higher Education Access and Disability (AHEAD), also provides support to students with disabilities transitioning

³ The DARE website is at: <https://accesscollege.ie/dare/>.

to, and completing, postsecondary education, as well as later finding employment.⁴

Each Irish higher-education institution has a disability officer who oversees a disability service, which in turn is driven by a needs-assessment process for students with disabilities on entry to the institution. Specialist disability supports provided by educational support workers may include an academic personal assistant, a notetaker, an interpreter or an academic tutor. An academic personal assistant helps with campus mobility, educational tasks such as photocopying or notetaking, and some personal care needs (McCarthy, Quirke and Treanor, 2018). Ireland is well regarded in supporting disabilities in education relative to other European countries, and as having ‘a highly developed support infrastructure for disabled students’ (Biewer et al., 2015). However, the Disability Federation of Ireland points to constraints on personal assistance services in higher education. While an individual may receive personal assistance support for higher education, this support can be confined specifically to assistance with educational participation and may not include support for independent living more generally. Furthermore, this support can then be lost at a crucial juncture when the individual moves to employment following the completion of education (McCarthy and Toner, 2018).

3.2. ANALYTICAL FRAMEWORK

3.2.1. Assistance with activities of daily living

Ratzka (2004) proposes a model for personal assistance service provision where service funding follows the user instead of remaining with the provider and where users are free to choose their preferred degree of control over service delivery. The Committee on the Rights of Persons with Disabilities comments in relation to Article 19 that personal assistance entails ‘person-directed/“user”-led human support’ and is a ‘tool for independent living’. The committee also defines the distinguishing elements of personal assistance based on Article 19. These include user-controlled funding that is based on a personalised needs assessment and life circumstances, the user tailoring service delivery by either contracting a service from their chosen provider or acting as an employer, and a one-on-one relationship between the user and their personal assistant (UN Committee on the Rights of Persons with Disabilities, 2017b). User control, under this conception, is central to ideal personal assistance services. Personal assistance is typically organised in the form of direct payments, so that service users have maximum freedom to hire their own assistants and set their duties (Mladenov, 2019; Askheim, 2005). Mladenov (2019) conducted a survey of personal assistance users across several European countries to identify the service characteristics that most affect the extent of their choice and control, and the study highlights important factors in promoting choice and control. These include the user being able to choose their own personal

⁴ The AHEAD website is at: <https://www.ahead.ie/>.

assistant and set times for service provision, a transparent and straightforward appeal procedure for needs assessments, the user being able to keep their existing level of assistance when moving to another region in the country, and the recognition of personal assistance as a right (Mladenov, 2019).

3.2.2. Distinguishing personal assistance and home care services

As is evident in Ireland, when personal assistance is not well defined and understood it can be conflated with home care services. It is therefore worth drawing a distinction between these two support services. According to the Organisation for Economic Cooperation and Development, home care is provided to persons 'with functional restrictions who mainly reside in their own home' (Kiersey and Coleman, 2017). Based on this definition, home care can appear to be very similar, if not equivalent, to personal assistance. However, home care is understood to be based on a medical model of disability, whereas personal assistance as envisioned in the CRPD is based on a model of independent living (European Network on Independent Living, 2013). In practice, a key difference highlighted between these services is user control, in that while service users cannot choose a home care provider, they can choose their own personal assistant, and can also directly design and manage the support they receive in order to facilitate independence (Crowther, 2019; European Network on Independent Living, 2013; Westberg, 2010). The emphasis of personal assistance thus extends beyond basic personal care as supported by home care, incorporating the concept of independent living.

3.2.3. Employment

A further aspect of personal assistance is the extension of assistance services to the workplace. There is typically a disproportionately low level of employment among persons with disabilities relative to the wider population (Dowler, Solovieva and Walls, 2011). In a study of the experiences of persons with disabilities in employment and in education, Watson, Banks and Lyons (2015) find that different challenges to employment exist depending on when in the life-course a disability emerges. Watson, Banks and Lyons suggest that individuals for whom a disability emerges later in life may be less likely to adapt in an employment context than individuals affected by a disability during school years. The study also examines the links between employment and access to support services and aids, finding that unmet need for services is associated with non-employment for certain types of physical and sensory disabilities (Watson, Banks and Lyons, 2015).

Workplace personal assistance is considered a support service among 'a spectrum of work accommodations' for employees with disabilities (Stoddard, 2006), along with other disability accommodations such as changing work schedules or moving individuals to another location (Solovieva et al., 2009). Dowler, Solovieva and Walls (2011) present a review of literature on the use of personal assistance in employment, noting three broad models of service provision: consumer-directed,

agency-directed and informal support. Services entail task-related assistance at work, such as readers, interpreters, and help with lifting or reaching. Services may also include assistance relating to personal care required while at work, such as help accessing a building, adjusting seating, using the toilet, dressing, taking medication, eating or drinking (Dowler, Solovieva and Walls, 2011; Stoddard, 2006). Dowler, Solovieva and Walls (2011) also highlight constraints to such services, including the availability of assistants, unclear boundaries between personal care-related and work-related assistance, and undefined responsibility for funding assistance.

Literature on the costs associated with workplace accommodations for persons with disabilities is relatively sparse (Nevala et al., 2015). One study estimates that these costs are minimal for individuals without a personal workplace assistant, but three times greater for individuals with an assistant. The study also notes, however, that benefits of personal assistance accommodations include increased productivity, increased diversity, improved interaction with co-workers and increased workplace morale (Solovieva et al., 2009). These impacts suggest that workplace personal assistance should be considered distinct from personal assistance for activities of daily living at home. Workplace personal assistance services allow persons with disabilities to make an economic contribution that should be taken into account when considering costs associated with such accommodations. Indeed, it is possible that the alternative to workplace personal assistance for some individuals with disabilities may be unemployment and an increased need for personal assistance at home or for other support services, at the expense of any potential economic contribution in the workplace. In addition to this economic contribution, workplace personal assistance services can also benefit service users in terms of their physical health and mental wellbeing by facilitating their employment and independent living. Another study examining workplace personal assistance services indicates that the perception of employees with disabilities of their own functional abilities increases once personal assistance services are implemented (Solovieva et al., 2010).

3.2.4. Education

Closely related to employment-related personal assistance are assistance services in education. Askheim (2019) points to research that concludes: 'education is even more important for (persons) with disabilities than for those without disabilities and could be seen as a main avenue of entrance into the labour market'. Another study concludes that personal assistance while in education has 'a potentially crucial role in accessing the labour market' (Biewer et al., 2015).

We draw on a review of literature conducted by the National Council for Special Education (NCSE) in Ireland, which details the role of paraprofessionals in supporting students with special educational needs in primary and secondary education. The NCSE ultimately concludes that paraprofessionals can positively

contribute to the education of students with special educational needs; for example, in improving literacy outcomes, improving academic performance and reducing inappropriate behaviour. However, it also cautions against excessive use of paraprofessionals in the classroom, citing evidence that the use of teaching assistants can sometimes undermine the inclusion of students with special educational needs (NCSE, 2018b). Other research underlines the importance of supporting students with disabilities during the transition from primary to secondary school, with students with special educational needs less likely to experience a successful transition (McCoy, Shevlin and Rose, 2020).

Research on students with disabilities in post-secondary education is sparse (Kutscher and Tuckwiller, 2019), but we identify two broad issues considered by studies in this area: (a) the transition from secondary to post-secondary education, and (b) student persistence in post-secondary education.

First, similar to the transition from primary to secondary education, the transition from secondary to post-secondary education represents a major change in the academic and social life of all students, but this is particularly pronounced for students with disabilities who must also negotiate and manage new support infrastructures, including new personal assistance arrangements in the case of students with more profound levels of disability (McGuckin et al., 2013; Stumbo, Martin and Hedrick, 2009). Indeed, some research indicates that students with disabilities incur additional costs in attending post-secondary institutions as a result of their disability (McCoy et al., 2009).

Second, students with disabilities who do transition to post-secondary education are considered less likely than the wider student population to complete this education, and several studies thus focus on persistence in post-secondary education among students with disabilities (Newman et al., 2020; Kutscher and Tuckwiller, 2019). For example, students with disabilities who accessed either universal or disability-specific student supports have been found to be more likely to persist in college programmes (Newman et al., 2020). Both issues are particularly relevant in a context where employment is increasingly dependent on the successful completion of post-secondary education (Stumbo, Martin and Hedrick, 2009).

3.2.5. Trends in service provision

As with overall disability service provision, discussed in Section 2, Askheim (2005) indicates that different models of personal assistance that have developed over time can be traced back to the welfare state they originate from. Market-based, non-interventionist approaches of liberal or conservative welfare-state models suffer due to the market not operating well in the welfare sector, while social democratic, more paternalistic approaches can be overly bureaucratic, inefficient and characterised by poor levels of service individualisation (Askheim, 2005).

Askheim also notes that the independent-living ideology actually represents an overlap of these two broad political perspectives. It challenges an individualistic rehabilitation paradigm by focusing on barriers that prevent persons with disabilities from participating in society, and yet is also influenced by a market-based consumer ideology in focusing on consumer autonomy.

Personal assistance services generally originated as bottom-up initiatives among persons with physical disabilities who organised services for themselves (Bonfils and Askheim, 2014). The bottom-up characterisation of these initiatives distinguishes them as services established and organised by individual service users, instead of by a healthcare system or by service providers. The scope of these services has broadened considerably to support a more diverse group of persons with disabilities, including persons with intellectual disabilities. A key element of this extension is the development of models where someone other than the service user is the manager of the arrangement, termed 'surrogate decision makers' by Askheim (2003). This produces a trade-off between maintaining the ideological foundation of personal assistance services, whereby user control is maximised, and extending the service to other disability groups where users may not have the capacity to manage the arrangement on their own (Askheim, 2003). In the context of growing heterogeneity in the composition of service users, Askheim et al. (2013) describe an increasing polarisation between 'ideologues', who maintain that user control must continue to be maximised, and proponents of a 'rehabilitation' ideal, who contend that assistance should be as safe as possible. In a study of home care in the US, Wiener, Anderson and Khatutsky (2007) contrast an agency-directed model of home care, where users have no formal control over service provision and which is underpinned by a medical model of disability, and a consumer-directed model. They note that the consumer-directed model is gradually becoming the dominant form of home care provision internationally. Bonfils and Askheim (2014) point out, however, that the assumption that users are always well informed and competent at managing services could lead services to favour more articulate, informed users at the expense of others. The study suggests the need for a more nuanced approach, with user empowerment in the form of the coproduction of welfare policy between users and the welfare sector. This would account for concerns that the independent-living ideology is over-reliant on the market by establishing a top-down process led by the welfare state, while acknowledging the competence of users and including them in decision-making (Bonfils and Askheim, 2014).

Askheim (2003) highlights the promotion of user control as a primary challenge of personal assistance systems, as control is shifted from official authorities to an interaction between the user and their assistant, and additionally their manager in a surrogate decision-maker arrangement. In the case of children with disabilities, parents play a pivotal role as they typically manage personal assistance arrangements. Askheim (2003) notes that, in such arrangements, parents can become over-protective and tend to infantilise grown-up children, but that parents

are also typically best placed to determine the needs and wishes of their child and to represent them against a service administration. In some cases, such as the Swedish personal assistance system, parents of children with disabilities are allowed to be paid either in tandem with, or in lieu of, an external personal assistant. Boren et al. (2016) argue that this leads to variation in service provision, not least in the child's activity selection where a personal assistant, either external or parental, plays a crucial role. For example, a parent's goal may be to construct routines that are most practical for the family. Boren et al. (2016) discuss this variation in the context of the bio-ecological systems theory, which proposes that healthy development is contingent on the types of activities a child undertakes. This theory implies that, to reinforce social skills, children need interaction with a wider social context than the family or personal assistant setting. Boren et al. (2016) suggest that external personal assistants are more likely than parental personal assistants to involve children with disabilities in socially integrative activities. Other research finds higher levels of family control over the management of an individual's personal assistance services to be associated with increased levels of service satisfaction and increased community involvement, with relatives tending to hire other family members, friends or neighbours as personal assistants (Caldwell and Heller, 2003).

An assistant's attitude towards the user is underlined as an influential factor in the extent of user control in personal assistance arrangements. Askheim (2003) outlines three different 'ideals' in social work: the rehabilitation, care and service ideals. In the rehabilitation ideal, the user is viewed as an object to be changed or improved and thus has minimal influence. The care ideal focuses on emotional, subjective and relational aspects, but the user's influence may still be minimised by a care worker operating on a basis of knowing what is best. Finally, in the service ideal, the focus is on the user's right to decide, and the relationship with a care worker resembles ordinary employment. Askheim (2003) argues that the extent to which opportunities for independent living are realised through a personal assistance system depend on how the service is organised by local government. For example, a high level of professionalisation among assistants could result in the rehabilitation ideal gaining dominance, whereas the service ideal may be better promoted if the competence of assistants is developed informally at the direction of the user, or by someone familiar with the user tasked with ensuring user control (Askheim, 2003).

Another trend in personal assistance services noted in the literature is an alternative labour-market policy approach, whereby support is made conditional on actively preparing for employment, essentially 'a transition from welfare to workfare' (Mladenov, 2016). 'Workfare' refers to policies whereby individuals must undertake work to receive benefit payments, and this concept is characteristic of an approach to social policy whereby state intervention is minimised and incentives are used instead of restrictions as a means of governing. Bonfils and Askheim (2014) discuss this as a concept of empowerment in liberal societies, in

which a fear of losing service provision is exploited as a disciplinary power to shape the user's behaviour in certain directions. They argue: 'By assigning the management of the service to the user, from a governmentality perspective, personal assistance can in many ways be seen as a perfect disciplining instrument within the modern welfare state' (Bonfils and Askheim, 2014). Mladenov (2016) points out that persons with disabilities can be particularly vulnerable to conditional programmes such as workfare as they typically ignore barriers to personal fulfilment; for example, impeded social mobility, lack of social support or labour-market exploitation, so that individuals tend to be blamed for structural failings.

3.2.6. Increasing demand

As the target group for personal assistance broadens, and as systems become more established, demand for personal assistance services increases (Askheim et al., 2013). Askheim et al. (2013) note that, as this happens, local government can become gradually more restrictive and more controlling in the allocation of resources, which can in turn affect user control by offering less opportunity for flexibility in arrangements. The study also notes evidence that persons with intellectual disabilities may be receiving more assistance than persons with physical and sensory disabilities. This issue is closely related to the stalling or even the reversal of progress in the area of independent living discussed in Section 2 (Slasberg and Beresford, 2019). In the absence of a capacity to maintain control of expenditure within an economic framework under a rights-based approach to service provision, Askheim et al. (2013) stress the need to monitor the evolving provision of service by local government in the context of increasing demand.

3.3. INTERNATIONAL PRACTICE

The US, the UK, Denmark, Norway and Sweden are highlighted by some as leaders in the area of personal assistance services (Bonfils and Askheim, 2014; Askheim, 2003). Personal assistance programmes emerged as bottom-up initiatives, first in the US in the late 1960s (Askheim, 2003), and then in the 1970s in Denmark, the 1980s in Sweden and the 1990s in Norway (Bonfils and Askheim, 2014).

3.3.1. Assistance with activities of daily living: Europe and the US

Using the findings of Mladenov (2019) discussed above, Mladenov, Pokern and Bulic Cojocariu (2019) propose a checklist for assessing the extent to which a country's personal assistance scheme supports independent living.⁵ The checklist scores countries across five dimensions: the context of personal assistance schemes, funding, needs-assessment procedures, service provision and the working conditions of assistants. Mladenov, Pokern and Bulic Cojocariu (2019) apply this checklist to Belgium, Bulgaria, Ireland, Serbia, Slovenia, Spain, Sweden

⁵ This checklist is available at https://enil.eu/wp-content/uploads/2019/02/Mladenov_Pokern_Bulic-PA_Checklist.pdf.

and the UK as a pilot study, with Sweden scoring highest for overall choice and control. Ireland is found to score particularly poorly in terms of scheme context, which refers to the ideological, policy and legal context in which personal assistance schemes are situated, and needs-assessment procedures. The needs-assessment dimension of the checklist determines whether assessments are user-led, resource-based or needs-based, are subject to an appeals process, or are conditional on factors such as family status. However, Mladenov, Pokern and Bulic Cojocariu (2019) acknowledge that these results are based on a pilot study and should be treated with caution due to limitations in their preliminary approach.

Askheim (2005) considers the different origins of personal assistance in the US, the UK, Sweden and Norway. Personal assistance services originated in liberal welfare state models in the US and UK. In the US in particular, personal assistance emerged within the context of a deeply rooted societal attitude that such services are primarily the responsibility of the family, and paid assistance is thus used to supplement family care or in cases where family care is not available. The US model of service delivery is also historically controlled by the medical establishment, which may have implications for the attitudes of assistants towards users, as discussed above. In the UK, Askheim (2005) argues, rather than being purely ideologically driven, the introduction of direct payments for personal assistance was strongly influenced by cost-effectiveness and accountability goals. In practice, delivery mechanisms in the UK are thus characterised by extensive processes for assessing needs, audit systems and some cases of cost ceilings.

In contrast to the US and the UK, personal assistance programmes are based in social democratic welfare-state models in Sweden and Norway (Askheim, 2005). Personal assistance programmes in Scandinavian countries, particularly in Sweden and Norway, also reflect opposition to a medical rehabilitation paradigm, seeking to replace this with an independent-living ideology (Bonfils and Askheim, 2014). Within this context, however, these two neighbouring countries have diverged over time in their approach to personal assistance. Sweden has moved away from the traditional social democratic welfare-state approach by adopting a consumerist rights-based type of model. This shift resulted in public expenditure on personal assistance increasing well beyond expected levels in Sweden at a time when welfare services more generally were subject to reductions in funding. Meanwhile, the Norwegian system has maintained a higher level of public responsibility and control for service provision (Askheim, 2005), and is characterised by a greater degree of paternalism (Bonfils and Askheim, 2014). The Norwegian system is also where a co-production approach to welfare policy is most evident. Users are supported in acting as personal assistance managers through formal courses and advisory services in both Norway and Sweden, as well as neighbouring Denmark (Bonfils and Askheim, 2014).

The European Network on Independent Living (2015) notes that, while there are

generally no restrictions by form of disability to accessing personal assistance, in practice some service users, such as those with intellectual disabilities, receive very little support. In some countries, for example the Netherlands, individuals with disabilities can only hire personal assistants with a personal budget and are thus assessed for eligibility by their ability to manage a budget. Personal assistance is not age-restricted in the UK, Norway or the Netherlands, but is limited to individuals under the age of 65 in Slovenia, Sweden and Switzerland. Means-testing is employed in France, Italy, the Netherlands, Norway, Spain and the UK, whereas there is universal entitlement to services in Latvia, Denmark, Sweden and Switzerland. Most countries are found to restrict the number of hours of personal assistance that can be allocated to individuals, but there are no such restrictions in Denmark, France, Sweden or the UK. Another limitation on services noted by the European Network on Independent Living is that personal assistance in France, the Netherlands and Spain generally ignores support needs for social or leisure activities. There is a choice of personal assistance providers in several countries, including Denmark, France, the Netherlands, Norway, Sweden and the UK. Table 3.1 provides an overview of access to personal assistance services in European countries.

TABLE 3.1 ACCESS TO PERSONAL ASSISTANCE SERVICES

Country	Age restrictions	Means-testing	Restricted hours	Choice of provider
Bulgaria (Sofia)	No ^a	No	Yes	No
Denmark	Must be 18-65 ^b	No	No	Yes
France	No ^b	Yes	No	Yes
Italy	Must be 18-65	Yes	Yes	Yes
Latvia	No	No	Yes	Yes
Norway	No	Yes	Yes	Yes
Spain	No ^c	Yes	Yes	Yes
Sweden	Must be under 65	No	No	Yes
Switzerland	Must be under 65	Yes	Yes	No
The Netherlands	No	Yes	Yes	Yes
United Kingdom	No	Yes	No	Yes

Source: European Network on Independent Living, 2015.

^a Priority given to younger persons in municipality of Sofia.

^b Individuals in Denmark and France already receiving personal assistance may retain service upon reaching age of 65 years.

^c While no national age restrictions exist in Spain, some regions restrict access to individuals over age of 18 years.

In some countries, personal assistance services are only available in certain areas, for example in the municipality of Sofia in Bulgaria. A personal assistance scheme was adopted by the municipality of Sofia following successful local advocacy, although demand for this service is considered to have outstripped supply. The

scheme in Sofia was adopted in the absence of any national initiative, funding or policy, and other regions of Bulgaria have not yet followed suit (Mladenov, 2016). European countries also differ in whether they are willing to fund parents as personal assistants. As highlighted above, this is an important issue arising in services for children with disabilities. This practice is permitted in Spain and Bulgaria, and permitted with restrictions in Sweden, the UK and the Netherlands. Switzerland is an example where paid parental personal assistants are not allowed (European Network on Independent Living, 2015).

Workfare programmes are traditionally associated with countries that have liberal welfare-state models, but Mladenov (2016) also points to personal assistance users being required until 2009 to document certain levels of activity in order to continue receiving services in Denmark. Mladenov (2016) primarily discusses workfare in personal assistance services in the municipality of Sofia in Bulgaria, an example of a post-socialist country, where eligibility for personal assistance is conditional on being either in education or in paid employment. He argues that the legacy of state socialism, characterised by segregation, paternalism and the medicalisation of service provision, combines with post-socialist neo-liberalisation trends to result in low funding levels, unequal service distribution, weak monitoring of regulations and the gradual incorporation of workfare conditionality in disability policy and support.

As is the case in relation to supporting independent living more generally, as discussed in Section 2, some post-socialist countries in Central and Eastern Europe have yet to adequately introduce personal assistance schemes. For example, the UN Committee on the Rights of Persons with Disabilities has indicated that Hungary needs to sufficiently resource personal assistance, and that public investment in disability support, including the investment of EU funds, needs to be redirected from institutional to community-based supports, including personal assistance (UN Committee on the Rights of Persons with Disabilities, 2019).

3.3.2. Employment: Europe and the US

Another labour-market approach to disability, as noted above, is to support employers or educational institutions to provide various types of accommodations and supports for persons with disabilities. Askheim (2019) examines public measures for including persons with disabilities in working life in Norway, where personal assistance specifically for the workplace has been established as 'functional assistance' since 1997. Functional assistance is defined as a labour-market service, and covers expenditure for tasks an employee is unable to perform due to a disability. Employees who are users of functional assistance are responsible for recruiting their own assistants, as well as training them and setting their tasks, while a grant is provided to the employer to support the arrangement. Assistants are mostly recruited externally, although in some cases work colleagues are also employed as assistants. Askheim notes, however, that functional

assistance services were only provided to 270 people in Norway in 2018, indicating that the measure is very limited in scope thus far. Other Scandinavian countries such as Denmark and Sweden are highlighted as supporting arrangements similar to functional assistance. The target group for this service is much wider in Denmark, while there is a range of labour-market measures specifically targeted at persons with disabilities in Sweden, including wage subsidies and sheltered public employment (Askheim, 2019).

Stoddard (2006) identifies trends and practices regarding workplace personal assistance services in the US. As in other countries, these services cover both task-related assistance and personal care, although Stoddard (2006) finds that many employers are more familiar with the provision of task-related assistance. The study finds evidence of several different funding sources for workplace personal assistance; for example, with employers funding the accommodation in some cases and public benefits such as Medicaid being used by employees in others. Evidence of delays lasting several months in receiving workplace personal assistance after requesting support is also found. Barriers to the expansion of these services are found to include negative attitudes among co-workers and the cost of such accommodations.

3.3.3. Education: Europe and the US

Education is regarded as a crucial facilitator of employment for persons with disabilities in particular, with the completion of secondary education underlined as being ‘of immense importance’ (Askheim 2019). In primary and secondary education, schools are typically responsible for employing teaching assistants or paraprofessionals to support the inclusion of students with special educational needs in general education classrooms, in line with the idea of mainstreaming. Paraprofessionals are also variably termed teacher aides, paraeducators, special needs assistants and integration aides. Their role in supporting students and educators includes administrative or clerical tasks, personal care support, acting as an intermediary between student and teacher, and monitoring students in non-classroom activities (Sharma and Salend, 2016; Keating and O’Connor, 2012). Studies across various countries also find evidence of teaching assistants performing pedagogical, assessment, socialisation and behavioural roles, including small-group teaching (Sharma and Salend, 2016).

We refer to work undertaken by the NCSE, which conducted a review of international practice in the use of paraprofessionals in supporting students with special educational needs during primary and secondary education (NCSE, 2018a). It points out that direct comparisons across countries are not possible due to differences in administrative and education systems. In general, evidence suggests that paraprofessional support roles do not formally require high levels of qualification, with secondary-level education sufficient in most countries and little requirement for formal training. Common mechanisms for implementing support

schemes are found to include formal assessments or diagnoses of the presence of disabilities. These may be conducted by a wide range of different professionals, such as educational, psychological or medical professionals through school- or national-level structures. The NCSE further indicates that resource allocation for paraprofessional support is mostly done on an individual basis, although there is some evidence of general block allocations being made instead (NCSE, 2018a).

In Norway, Askheim (2019) states, public policy measures at post-secondary level include supporting institutions to provide students with reading or secretarial aid or with interpreters if required. Public funding is available for students with disabilities at university level in Spain. Students with physical disabilities or visual impairments in Austria can apply for a personal assistance at the workplace, and, if successful in their application, can also rely on this personal assistant for study support (Biewer et al., 2015). The Czech Republic, meanwhile, has been highlighted as an example of a post-socialist country in which disability support in post-secondary education is 'seriously underdeveloped', with no legislative support and considerable variation in the range and competence of services available in post-secondary institutions (Biewer et al., 2015).

In the US, secondary schools are legally mandated to provide personal assistance to students with assessed needs, and are thus generally responsible for providing this service, with students or their parents not involved in the process. No such legal mandate applies to post-secondary institutions, however; instead, responsibility for providing personal assistance can transfer to the student, which exacerbates the challenges of transitioning to post-secondary education (Stumbo, Martin and Hedrick, 2009). Hedrick et al. (2012) note that the extent of disability support services varies considerably across higher-education institutions, and that only a minority of institutions offer personal assistance as a support for students with disabilities. Given this variation, students with disabilities in the US are burdened with the task of finding post-secondary institutions that will best support their needs, and those with more profound physical and sensory disabilities may be limited to choosing to attend a post-secondary institution close to home to maintain familial support (Stumbo, Martin and Hedrick, 2009).

3.3.4. Increasing demand: Europe and the US

Few countries have established access to personal assistance as a legal right. Sweden is one country that adopted a rights-based approach at an early stage, with individual rights to personal assistance since 1994 (Askheim, 2005). However, Askheim et al. (2013) note that the Swedish system is regarded as having exceeded its original scope; the number of people receiving personal assistance services is now far beyond the extent planned by public authorities. Having piloted personal assistance services in 2012, Iceland has also adopted a rights-based approach to personal assistance, establishing a legal entitlement in 2018 (Crowther, 2019). Askheim et al. (2013) describe political support in Norway for making personal

assistance an individual right, but this is balanced by concerns over the need to manage the costs of these programmes and over the possibility that increasing demand could lead to a decrease in hours allocated to users.

4. INDIVIDUALISED FUNDING SYSTEMS

User control is highlighted as a core element of a successful personal assistance system in Section 3. A mechanism used to provide user control is individualised funding, also known as personal budgets or cash-for-care, which is discussed in this section. The term ‘individualised funding’ covers ‘types of funding models which offer service users more control over the choice of services and the use of the funding they receive’ (Anand et al., 2012). In its General Comment No. 5 on living independently and being included in the community, the UN Committee on the Rights of Persons with Disabilities recognises that personalised, disability-specific support services include personal budgets or cash transfers (UN Committee on the Rights of Persons with Disabilities, 2017b).

4.1. CONTEXT IN IRELAND

In Ireland, the Department of Health’s Task Force on Personalised Budgets (Department of Health, 2018) proposed a detailed model for personalised budgets as a future mainstream option in Ireland. This model envisions individuals assessed as eligible being offered a choice between retaining traditional services or receiving a personalised budget, which can then be user-managed, co-managed with a chosen service provider or managed by a broker. A HSE demonstration project based on the proposed model is currently in the field; the second of two phases is due to commence in September 2020 (HSE 2020a). Previously, four small-scale individualised funding initiatives funded by a non-profit organisation, Genio, were piloted in Ireland and evaluated by Fleming, McGilloway and Barry (2016).

Direct payments are currently available in Ireland through third-party organisations such as the Irish Wheelchair Association⁶ (IWA) and Áiseanna Tacaíochta⁷ (ÁT), although ÁT reports significant unmet demand in the form of waiting lists due to a lack of state funding, which suggests that the direct payment model is not yet a mainstream option in Ireland (ÁT, 2019). The IWA provides personal assistants to persons with physical disabilities and supports users, known as ‘Leaders’, in choosing and directing their preferred way of using allocated resources through its Assisted Living Service (IWA, 2020). Similarly, ÁT acts as an intermediary between service users and the HSE, negotiating personal budgets on behalf of users and then facilitating a cash transfer to purchase support based on service users’ needs. The organisation also supports users in setting up a company limited by guarantee, through which funding is transferred and the user, also designated as a ‘Leader’, assumes the role of employer or contractor (Keogh and

⁶ The IWA website is at <https://www.iwa.ie/>.

⁷ The ÁT website is at <https://www.theatnetwork.com/>.

Quinn, 2018).

4.2. ANALYTICAL FRAMEWORK

Individualised funding is regarded as ‘one approach for personalising adult social care’ (Carr and Robbins, 2009). Individualised funding systems promote user control by placing the service user at the heart of the decision-making process (Keogh and Quinn, 2018). Specifically, individual service users or their assistants are responsible for purchasing support services to meet their own needs, either through a direct allocation of funds or through individualised commissioning arrangements, such as through service brokers (Mansell et al., 2007). Individualised funding can be in the form of vouchers for the purchase of services, direct payments to the user or to someone in their informal support network, or allocations to a broker (Anand et al., 2012). Keogh and Quinn (2018) present a literature review on the benefits of individualised funding models, including increased choice and control and improved relationships with family and others. Cost savings are also generally found relative to more traditional funding mechanisms for a given level of support needs, although Keogh and Quinn (2018) stress that this is a secondary benefit and that individualised funding should not be seen simply as a cost-saving measure. While there are benefits to personal budgets, it is also noted in previous research that such funding systems are not necessarily appropriate for all persons with disabilities, and that the availability of a range of service delivery options is important to ensure responsiveness to all forms of disability (Anand et al., 2012).

4.2.1. Alternative funding routes for support

Before considering individualised funding schemes in detail, it is worth considering how funds are raised to finance specialist support services, as well as other mechanisms for allocating this funding. Various approaches to this are listed in Table 4.1. Similar to other elements of disability support services, methods of financing support services are influenced by existing welfare-state funding structures (Carr and Robbins, 2009). Various forms of financing are employed in international practice, including central taxation, a mixture of local and central taxation, private insurance, user charges, and social insurance programmes (Carr and Robbins, 2009; Mansell et al., 2007). Most support systems use a combination of these methods to raise funds, such as central taxation complemented by some user charges. Potential issues have been identified, stemming from the practice of incorporating user charges into the support system; namely, that user charges can lead to the under-use of required support services, can discourage a move to community settings if such a move was associated with increased exposure to user charges, and can have negative equity implications given that persons with disabilities are typically in low-income groups (Mansell et al., 2007).

TABLE 4.1 FUNDING SPECIALIST DISABILITY SUPPORT SERVICES

Financing methods	Funding routes
Central taxation Mixture of local and central taxation Voluntary/private insurance User charges Social insurance	Grant to service provider Capitation/needs-weighted fee to service commissioner Individualised funding

Source: Carr and Robbins, 2009; Mansell et al., 2007.

Funds raised centrally can be allocated directly to service providers, or ‘supply-side’ bodies, through grants which may have performance-related incentives attached (Mansell et al., 2007). Instead of funding being routed directly to supply-side bodies, central finances may instead be allocated to service commissioners, or ‘demand-side’ bodies, which are responsible for contracting service providers. This may be done on a capitation basis whereby a fixed amount of funding is allocated per user, or funding may instead be weighted by need. Funding may also be linked to performance conditions in this mechanism (Mansell et al., 2007).

In practice, as with financing methods, Mansell et al. (2007) state that, typically, a variety of funding routes is established in countries, each with different incentives and conditions attached, each subject to different levels of political interference, and each affording different levels of power to the service user. In this context, they argue that central government has a key role in ‘marrying up different funding arrangements and the organisational behaviour they encourage or delimit’ (Mansell et al., 2007).

Traditional processes of support management, which typically involve the pre-purchasing of services for users, have been criticised as being inefficient. Such processes can be overly bureaucratic and can result in resources being misdirected, funding streams being multiplied, creativity being minimised, and the expressed needs of users being inflated in order to receive support (Hatton, 2008). An alternative option for allocating funding for support services is individualised funding, which is considered to have the potential to reduce such system inefficiencies. Most individualised funding schemes are found to share the goal of cost reduction to some extent (Carr and Robbins, 2009).

4.2.2. Development of individualised funding schemes

Carr and Robbins (2009) review literature on the development of personal budget schemes for adult social care. A personal budget combines resources from various funding streams and can be deployed by the user in the form of a direct payment, or alternatively by a support manager, by a trust or by a service provider. Studies note different country-specific welfare-state contexts for individual funding schemes, resulting in schemes being aimed at different eligible groups and being

established for different objectives (Da Roit and Gori, 2019; Carr and Robbins, 2009). For example, objectives behind individualised funding include increasing freedom of choice, reducing expensive residential care, countering the fragmentation of rural service provision, increasing efficiency and job creation (Timonen, Convery and Cahill, 2006). While some schemes aim primarily to promote independent living, others seek to improve the capacity of families to take on responsibilities for support. For example, individualised funding schemes in European countries are found to have helped establish a scenario where families are encouraged to provide family care, but are given alternatives through the provision of market care (Le Bihan, Da Roit and Sopadzhiyan, 2019). Fused with these various policy objectives, common influences for reforming services in favour of individualised funding include consumerism, disability lobby groups and the shifting of the 'locus of care' from the state to the community, home and individual (Carr and Robbins, 2009). Internationally, the rationale for reforming welfare is often varied, incorporating a mixture of social justice and economic objectives (Anand et al., 2012).

Previous research has identified three primary approaches to providing personal budgets, each located on 'a continuum involving the relative level of control between professionals and service users' (Anand et al., 2012). In a 'professionally monitored' model, care managers are responsible for monitoring the services received by a user over time, and these managers provide mandated guidance to users. Care managers or brokers assist users in accessing funding and coordinating support in a 'professionally assisted' model, whereas in a 'service user-directed' model, users are allocated cash periodically based on an assessment of needs and consequent support plan, with independent advice available as an option. User choice and control are regarded as being maximised in the user-directed model, albeit with a potentially higher administrative burden borne by users (Anand et al., 2012). Accountability – for example, for support outcomes, public expenditure, support workers and market function – can also be affected by a move to individualised funding schemes. Some research suggests a trade-off exists to a certain extent between user choice and accountability (Malbon, Carey and Dickinson, 2018; Dickinson, Needham and Sullivan, 2014). In general, accountability is considered to be most enhanced in the professionally monitored model (Anand et al., 2012).

Carr and Robbins (2009) state that 'support brokerage' is 'an almost inevitable outcome of direct payment schemes in social care'. In a support brokerage model, a third party acts as a broker, or intermediary, between the service provider and the user. The broker ensures adequate access to services and that providers act on behalf of individuals, rather than the state. A broker can provide information, support and guidance to users to allow them to manage their own support (Anand et al., 2012). Maintaining the complete independence of the broker from funding agencies and service providers is considered essential in a support brokerage model (Carr and Robbins, 2009). One issue raised in the literature in relation to a

shift to individualised funding schemes is that, due to the challenges associated with administering a personal budget and finding appropriate care, such schemes may favour more educated or wealthier users (Ginneken, Groenewegen and McKee, 2012). In this context, the parallel provision of support brokerage in administering individualised funding schemes is considered important.

Ultimately, Carr and Robbins (2009) find that ‘no universally successful and applicable scheme has been demonstrated by international research’. However, as with Mansell et al. (2007) in relation to a country’s overall system of allocating support service funding, they argue that one common theme is that the role of central government is vital in ensuring policy coherence, aligning funding streams for use in personal budgets and ensuring quality (Carr and Robbins, 2009). Anand et al. (2012) also find that government involvement and leadership is crucial for establishing a comprehensive legislative and policy framework for personal budgets.

4.2.3. Increasing demand

Hatton (2008) highlights the potential of user-directed supports and individualised funding models to increase demand for support services. Whereas many service users may have been deterred by the relative unattractiveness of previous systems, improved choice and direction in decision-making may increase demand. A systematic review of research on the effectiveness of individualised funding schemes across several countries has found that fears in relation to the overwhelming of the social care system’s capacity due to an introduction of individualised funding are not supported by evidence (Fleming et al., 2019). However, it has been pointed out that, as demand for social protection begins to exceed budgetary limitations, governments face an inevitable trade-off between the coverage and the generosity of the support system. Where support is considered a universal right unconditional on income, age, contributions made or other eligibility criteria, the coverage and generosity of supports are instead determined by the definition of a need for support, which can deviate considerably between countries (Ranci et al., 2019).

4.2.4. Labour-force considerations

While individualised funding schemes are focused on service users, it is also important to consider the impact of a shift in service provision on disability support workers or assistants. A distinction has been drawn in the literature between a ‘high road’ to creating support employment, where public investment in social services enlarges the labour pool and ensures quality jobs, and a ‘low road’ where labour-market deregulation allows the development of lower-quality jobs (Da Roit and Moreno-Fuentes, 2019; Folbre, 2006). Increased use of policy on individualised funding to foster either informal or low-paid social care is noted as a common trend among some European countries (Da Roit and Le Bihan, 2019). One issue highlighted by Carr and Robbins (2009) in relation to the establishment of

individualised funding schemes is the emergence in some countries of an unregulated 'grey' market for assistants. The authors note debates in some countries regarding a balance between maximising individual choice and control for service users and regulating the market for assistants.

Unregulated markets for social care workers are found to be heavily gendered and reliant on migrant labour, and are characterised by poor working conditions (Carr and Robbins, 2009). Indeed, a combination of increased user empowerment and the distancing of support work from public view could in turn increase potentially gendered risks for the exploitation of migrant support workers (Christensen and Manthorpe, 2016). In addition, individualised funding schemes are found to increase short-notice requests for support workers employed through support organisations, giving rise to an 'on-call workforce' (Cortis et al., 2013). Support workers who are directly employed, as facilitated by individualised funding systems, are exposed to substantial risks associated with contracting work, including risks to income security, healthy work environments and representation rights (Cortis et al., 2013). Another study finds that new skills are required by disability support workers to adequately support choice and control following a shift to individualised funding (Moskos and Isherwood, 2019).

4.2.5. Dynamic between service user and personal assistant

Several studies analyse the implications for the relationship between users and their personal assistants of different direct payment, or cash-for-care, schemes (Shakespeare, Stöckl, and Porter, 2018; Christensen and Manthorpe, 2016; Christensen, 2012). Direct payment schemes have implications for the independence of persons with disabilities, but also for assistant roles in work that can be oppressive and that is historically gendered (Christensen and Manthorpe, 2016; Christensen, 2012). Indeed, there is evidence of conflict arising in relationships between these two parties in arrangements based on direct payments (Shakespeare, Stöckl and Porter, 2018). Christensen (2012) proposes a two-dimensional model to establish a theoretical framework of user-assistant relationships in direct payment systems. First, a structural dimension determines the distribution of power in the relationship, specifically whether the relationship is symmetrical or hierarchical. This involves a dilemma between a high degree of user control, requiring a hierarchical relationship where the assistant is subordinated, and closeness, requiring a symmetrical relationship. A second dimension is based on interaction, specifically the extent to which the relationship is personalised and to which parties are emotionally involved with each other. This is described as being on a spectrum between a relationship where the assistant is subordinated and is only weakly involved in the relationship, and a relationship where there is over-dependence between the assistant and user and the assistant is highly involved. For example, an assistant being reliant on a user for accommodation in a 'live-in' arrangement is considered a relationship of over-dependence on this interaction dimension.

As an extension of this theoretical framework, Christensen (2012) outlines three broad types of user-assistant relationships that emerge under direct payment systems. First, a servant-master relationship established by a traditional, hierarchical concept of community care can be inverted by the introduction of direct payments, with the user being afforded unlimited power. Furthermore, a particularly high level of individualisation could actually result in this dynamic being inverted again if the user becomes entirely reliant on an assistant to represent them against a service administration. Highly individualised direct payment systems can thus result in master-servant relationships where either the user or the assistant is at risk of exploitation. A second form of relationship is a solidarity-based relationship, where direct payments involve a collective dimension and the personal assistant becomes a 'social asset' for the user, something that could develop into unpaid work via an overly emotionalised dynamic. A final relationship type described by Christensen (2012) is essentially a balanced relationship, termed a 'professional friendship', where the professional element of the relationship is emphasised by the setting of clear limits, such as employment contracts or regulations. Christensen (2012) argues that third parties with a regulatory or supervisory mandate can play a key role in fostering this middle ground and balancing the need for independent living with the need to respect personal assistants.

4.3. INTERNATIONAL PRACTICE

A range of different individualised funding models is employed in Canada, Australia, New Zealand, the US, the Netherlands, Germany, Sweden and the UK (Keogh and Quinn, 2018; Fleming, McGilloway and Barry, 2016; Pike, O'Nolan and Farragher, 2016). Such schemes have been evident in long-term social care in many European countries since the 1990s, becoming a pillar of long-term care in some countries (Da Roit and Gori, 2019). Pike, O'Nolan and Farragher (2016) review approaches to individualised funding for persons with disabilities in Australia, Canada, England, Scotland, the Netherlands and New Zealand.

4.3.1. Europe

The funding of personalised budgets varies between countries. Individualised funding models are funded through general taxation in many countries, including the UK where funding is almost entirely through central taxation but is complemented by user charges for social care. Some countries such as Germany and the Netherlands instead employ long-term social insurance models (Keogh and Quinn, 2018; Carr and Robbins, 2009). While individualised funding schemes are generally governed at a national level in Europe, they are administered at different levels in different countries. Such schemes are centrally administered in the UK and Italy, at local authority level in France and by a social insurance fund in Germany, for example (Gori and Morciano, 2019).

Keogh and Quinn (2018) point to Sweden as ‘the gold standard’ on direct payments, where personal assistance is a legal right regardless of cost. The Swedish system does not involve means-testing or incorporate user charges, and local authorities assess needs. There is a single, centralised source of funding, the National Social Insurance Fund, which makes tax-free direct payments to users so they can purchase a service from their chosen provider, operating in a competitive market. Users are given the choice of receiving direct payments into their own bank accounts or mandating the payment to be made directly to their chosen provider. Payments are designed to cover personal assistant wages, employee insurance, employer social insurance, training costs, transport or entrance costs for accompanying assistants, administrative fees and meals (Keogh and Quinn, 2018).

In the Netherlands, eligibility for disability support is assessed on request by an independent body, the Centre for Needs Assessment (Ginneken, Groenewegen and McKee, 2012). The Netherlands is considered an example of a user-directed model (Anand et al., 2012), and access to a support broker is compulsory (Carr and Robbins, 2009). Since 1997, individuals deemed eligible can choose between receiving support in kind through a standard provider or a personal budget. This personal budget can be used to purchase assistance from a professional organisation or from non-professionals such as neighbours, family or friends (Ginneken, Groenewegen and McKee, 2012).

However, demand for personal budgets exceeded budgetary limitations in the Netherlands. Based on arguments by the Dutch Ministry of Health that the overall cost of the personal budget scheme had become unsustainable, access to the scheme has been considerably restricted since 2014. This was due to a tenfold increase in the number of personal budget holders between 2002 and 2010; there was a major increase in uptake, particularly among children with intellectual disabilities who had previously received only informal care. In 2014, eligibility for a personal budget was restricted to persons who would otherwise have no choice but to move to a residential home for support, a group estimated to account for only 10 per cent of previous budget holders (Ginneken, Groenewegen and McKee, 2012). Based on the Dutch experience, Ginneken, Groenewegen and McKee (2012) argue that ‘it is difficult to reconcile the open-ended character of personal budgets and budget ceilings’, and that clear eligibility criteria that are not too broad are crucial.

In the Dutch case, the definition of need for personal budget support was narrowed to reduce the coverage of the scheme in response to demand outstripping budgetary constraints. Different countries opt for different strategies to deal with this trade-off between coverage and generosity. Ranci et al. (2019) compare the strategies of several European countries in the overall area of long-term care, which encompasses support for older persons as well as for persons with

disabilities. Austria is found to be one of the most generous countries in terms of total expenditure on long-term support, with relatively broad coverage of support. Italy and particularly the UK are also regarded as having support programmes with extensive coverage and relatively high levels of generosity, but a difference between these two countries and Austria is that support payments in Austria are highly progressive. In other words, much higher levels of support are provided to users with higher levels of need in Austria. Support is not considered progressive in Italy or the UK, where all users receive a relatively generous basic level of support but users with the highest level of need receive insufficient support (Ranci et al., 2019). Indeed, the UN Committee on the Rights of Persons with Disabilities notes evidence that personal budgets in the UK 'do not necessarily allow persons with disabilities to have access and control over social care services' (UN Committee on the Rights of Persons with Disabilities, 2017a). Meanwhile, Germany is viewed as providing progressive and comparatively high levels of support, but to a more restricted group of users. Support coverage is also relatively lower in France and Spain, although generosity is considered lower than in Germany (Ranci et al., 2019). While European countries evidently opt for different strategies in support resource allocation, there is also evidence of a gradual convergence of support coverage and generosity between countries over time (Gori and Morciano, 2019).

The system of direct payments in the UK is regarded as an example of a professionally monitored model of individualised funding (Anand et al., 2012). Christensen (2012) compares direct payment schemes in Norway and the UK with regard to the implications of these schemes for user-assistant relationships. She highlights a fundamental distinction between these systems: while both systems empower the user to choose their personal assistant, in Norway the user assumes the role of the assistant's manager whereas the user is the employer of the assistant in the UK. Overall, the system in the UK is considered by Christensen (2012) to be more strongly individualised; the user makes the initial decision on whether to avail of a direct payment scheme (this decision is made by local government in Norway), with the user taking on an employer role in a free market that offers considerable variation in services. In Norway, the employer role is delegated to a non-profit cooperative organisation, which in turn assumes a third-party regulatory role in user-assistant relationships. Moreover, unlike in the UK, one non-profit organisation, Uloba,⁸ is the only important third-party support organisation for personal assistance in Norway, which promotes a more uniform system across regions. Christensen (2012) argues that the results of these different structures is that, in the UK, master-servant and solidarity relationships are most evident between users and their personal assistants, while a relationship of professional friendship is most prevalent in Norway. In short, compared with the UK, individualisation is tempered by more third-party regulation in Norway, and this is thought to encourage more sustainable user-assistant relationships.

⁸ The Uloba website is at <https://www.uloba.no/en/>.

4.3.2. Australia

The Australian National Disability Insurance Scheme (NDIS)⁹, piloted in 2013 and currently being rolled out across all Australian states, is a recent example of a paradigm shift in a country's approach to disability service provision. The NDIS has been described as 'the most profound change in Australian disability history' (Reddihough et al., 2016) and as 'one of the most ambitious personalised funding schemes in the world' (Carey et al., 2017). Under this scheme, following initial consultation and an assessment of needs, eligible persons with disabilities are given a choice between two options. The first option is to receive an overall service package from the NDIS, where the user can choose a service provider from a competitive market and opt to be supported by a disability support organisation acting as a broker on their behalf. The second option is to receive a direct payment and to act as an independent employer of support workers using this payment. The NDIS also reassesses the need for funded support at 'key transition points' in the user's life; for example, when they leave school, when they commence employment or when they leave home (Reddihough et al., 2016). This choice of individualised funding mechanism can be viewed as a hybrid between the schemes described by Christensen (2012) in Norway and the UK. One criticism of the NDIS argues that the scheme represents a market-based approach to disability support, which can have negative equity implications in the absence of careful policy design and implementation (Carey et al., 2017).

The Australian NDIS is another example of the social insurance model of financing specialist disability support. Reddihough et al. (2016) set out the argument that disability can be compared with workplace or road accidents in that it is an unfunded liability. Therefore, an insurance scheme similar to the fully funded no-fault insurance schemes in place for workplace and road accidents could be considered most appropriate in catering for the needs of persons with disabilities. Based on this, the NDIS was proposed in 2008 to underwrite sustained, long-term improvements in meeting such needs (Reddihough et al., 2016). In a study analysing the insurance principles underpinning the NDIS, Walsh and Johnson (2013) highlight two fundamental principles: community responsibility and comprehensive entitlement, both of which stem from established models of long-term personal injury insurance. The Australian NDIS, therefore, employs a social insurance-based statutory entitlement model in the provision of specialist disability services, where the Australian state governments act as insurers and where the entire premium ultimately comes from general state taxation. This also uses the concept of risk pooling, where a rare and expensive liability that is unaffordable to the individual is met through pooled resources. Another key difference highlighted between the NDIS model and more traditional models of social welfare is the identification of an 'aggregated expected cost of claims', whereby an aggregate premium is collected from general taxation to meet the

⁹ The NDIS website is at <https://www.ndis.gov.au/>.

entire discounted cash flow of the future lifetime benefits of those insured. This is in contrast with traditional approaches to social welfare, where future demand predictions are primarily reliant on past consumption (Walsh and Johnson, 2013), known as 'incremental budgeting'. Key to the NDIS approach, according to Walsh and Johnson (2013), is the systematic and comprehensive collection of longitudinal data for monitoring and evaluation, which is considered in Section 5.

5. MEASURING UNMET NEED FOR SUPPORT SERVICES

In order to accurately plan for the adequate future provision of specialist support services, a clear picture of current levels of unmet need is required. Wren et al. (2017) discuss how different definitions of unmet need are used in literature on healthcare services, and that there is no universally accepted definition. We follow Wren et al. (2017) in defining unmet need as an individual identifying a need for support that is not provided. We also follow Wren et al. (2017) in distinguishing this concept from the narrower definition of unmet demand, where a support service is specifically requested but not provided, which can be measured in the form of a waiting list.

5.1. CONTEXT IN IRELAND

There are very few examples of countries that publish data on either need or demand for specialist disability supports, let alone unmet need for these services. Ireland's 'Master Data Set' tool is noted by Crowther (2019), which collects data on the number still living in congregated settings, the number that has transitioned into the community, and the status of congregated settings. These figures, reported by the HSE, are summarised in Table 2.1 earlier in this report. This data, however, is focused on the process of deinstitutionalisation rather than on overall need or demand for broader specialist disability support.

In terms of demand for supports, Brick, Keegan and Wren (2020) estimate current use of specialist disability services as an initial step in projecting future demand for these services in Ireland. Multiple data sources are employed, including the Irish Health Research Board databases, the National Physical and Sensory Disability Database (NPSDD) and the National Intellectual Disability Database (NIDD), and the HSE Disability Service's Key Performance Indicators. The paper considers data on residential services for persons with intellectual disability to be of sufficient quality for inclusion in a projection model, but indicates that existing Irish data on residential services for persons with physical and sensory disabilities or on home care or personal assistance services is not yet reliable, particularly due to the poor coverage of the NPSDD. This situation is expected to improve when data become available from the recently developed National Ability Supports System (NASS) database (Health Research Board 2019), which merges the NPSDD and NIDD and also collects additional information (Brick, Keegan and Wren, 2020; 2019).

While waiting lists can theoretically be used to measure unmet demand, the Disability Federation of Ireland has stated that inconsistent definitions and validation of actual personal assistance service provision between and within CHOs prevent a systematic nationwide measure of unmet demand in practice (McCarthy and Toner, 2018). The NPSDD and NIDD collect data on unmet demand for services

as identified by service providers (Doyle and Carew, 2018; Hourigan, Fanagan and Kelly, 2018). The poor coverage of the NPSDD (Brick, Keegan and Wren, 2020) reduces the reliability of this dataset, at least until data become available from the NASS database. The HSE Disability Services also maintain a database of individuals waiting for a new or enhanced day or residential support service (Brick, Keegan and Wren, 2020).

The proportion of the Irish population under the age of 65 who need specialist disability services is estimated by Working Group 1 of the Transforming Lives programme, employing three methods. First, Australian estimates of the proportion of the population who require support from the NDIS, estimated at 1.6 per cent of the Australian population, are applied to the Irish population. Second, Irish census data on the number of persons with functional difficulties are used, giving a prevalence estimate of 1.4 per cent. Finally, a prevalence estimate of 1.3 per cent is obtained from the NPSDD and the NIDD, with adjustments to account for the poor coverage of the NPSDD (Working Group 1, 2018).

5.2. APPROACHES IN ACADEMIC LITERATURE

Several studies in the academic literature attempt to measure unmet need for personal assistance services or for community-living support more broadly. Gibson and Verma (2006) note different approaches employed in the literature. One particularly prevalent approach is the use of surveys to gauge the individual perceptions of persons with disabilities, where need is typically defined as requiring assistance with activities of daily living or instrumental activities of daily living (Mitra et al., 2011; Casado, Vulpen and Davis, 2010; Gibson and Verma, 2006; Komisar, Feder and Kasper, 2005; Newcomer et al., 2005; LaPlante et al., 2004; Lima and Allen, 2001; Desai, Lentzner and Weeks, 2001; Allen and Mor, 1997). This approach relies on self-reported data and also requires the use of proxies for persons with profound intellectual disabilities (McCarron et al., 2019), although LaPlante et al. (2004) point to the relative cost-effectiveness of the individual perception approach as a significant benefit. In addition, this approach allows a distinction to be drawn between persons with disabilities who receive inadequate support and those who receive no support at all, which is highlighted as important by Lima and Allen (2001).

A variant of this approach is to survey individuals in paid employment who provide informal support to family or friends, termed 'working carers' (Brimblecombe et al., 2017). There is some evidence that working carers may perceive a higher level of unmet need for formal support services than the individuals to whom they provide informal support, which in turn raises the question of whose perception of unmet need is more accurate or more important (Brimblecombe et al., 2017).

An alternative approach evident in the literature is to infer levels of unmet need

using evaluations of aggregate unmet demand by public health professionals; for example, using estimates of waiting lists at a regional level (Harrington et al., 2002). LaPlante et al. (2004) note that the determination of need is an important measurement issue, with a potential conflict between the 'normative need' determined by professionals and the 'felt need' perceived by service users. A further, more aggregated approach in the literature is to use large-scale, nationally representative population surveys to compare the number of persons requiring assistance with the number of persons employed as assistants over time (Kaye et al., 2006).

5.3. INTERNATIONAL PRACTICE

5.3.1. Europe and the US

Crowther (2019) indicates that, where data in relation to need for disability support does exist in European countries, it is overwhelmingly focused on numbers leaving institutional settings, similar to Ireland's Master Data Set tool, rather than on unmet need for specialist support services such as personal assistance. France has recently developed indicators to measure deinstitutionalisation progress, such as the reduction in the number of institutional residents and the increase in inclusive services. The National Health Service in the UK publishes monthly statistics on the number of persons with disabilities in hospital inpatient units. The Latvian Ministry of Welfare specifies a list of indicators on deinstitutionalisation to be aggregated at local authority, regional and national level. These include the number of requests for social services on behalf of children with 'functional disorders', the number of children to whom services are provided, and the number of children whose quality of life has been improved by social services (Crowther, 2019). These indicators may be useful in charting progress in relation to deinstitutionalisation, but in isolation do not indicate unmet need for specialist support services such as personal assistance.

Indicators of community living have been developed in some countries. The Danish Institute for Human Rights publishes statistics on ten recently developed outcome indicators comparing the situation of persons with disabilities in Denmark with the CRPD, labelled the 'Gold Indicators'. These are published on a dedicated website, the 'Handicapbarometer',¹⁰ based on large-scale surveys conducted every four years. The fifth Gold Indicator refers to the theme of independent living and community inclusion, and measures the number of persons with disabilities exercising influence over their own lives. The Danish Institute for Human Rights specifically decided against including measurements of personal assistance services in the Gold Indicators as the service only covers a small target group (Larsen, 2015). The Dutch Institute for Human Rights also collects data on various indicators of the implementation of Article 19 of the CRPD, including the

¹⁰ The Danish Institute for Human Rights 'Handicapbarometer' website is at <https://handicapbarometer.dk/>.

percentages of persons with disabilities owning their own house, able to choose their house and able to choose with whom they live (Crowther, 2019). The Norwegian statistics bureau, Statistics Norway, gathers data on the quality of life, life satisfaction, sense of belonging and psychological difficulties among persons with disabilities relative to the general population (Crowther, 2019). In the US, statistics on the outcomes of services provided to persons with intellectual disabilities are collected through surveys and published at state level, named the 'National Core Indicators'.¹¹ Outcomes measured include employment, the realisation of rights, service planning, community inclusion, choice and health (National Core Indicators, 2017). While useful, however, these indicators still fall short of providing a picture of overall unmet need for specialist support services.

In 2008, the Personal Social Services Research Unit (PSSRU) in the UK published its first projections of demand for social care and disability benefits for adults under the age of 65 in England, based on a new projection model (Wittenberg et al., 2008). The PSSRU projection model is a macro-simulation model that employs a cell-based approach to project four key variables: the number of younger adults with disabilities, the likely level of demand for formal and informal social services and disability benefit among younger adults, the costs associated with meeting this demand, and the social care workforce required. A wide range of data sources, encompassing survey and administrative data, is combined for these projections. The PSSRU model is updated regularly as new data become available, and now projects the number of persons with disabilities receiving publicly funded home care, direct payments and residential care (Wittenberg, Hu and Hancock, 2018). However, specific demand for personal assistance is not projected by the PSSRU.

5.3.2. Australia

Need for specialist disability services is now measured in Australia, with the advent of the NDIS. The Australian Productivity Commission (2011) presents an extensive report on the establishment of the NDIS. The NDIS defines three distinct populations of 'customers' relevant to the scheme, categorised in 'tiers'. Tier 1 includes the entire population, as everyone is insured against costs of support. Tier 2 encompasses all persons with disabilities to whom information and referral support is provided. Tier 3 includes the subset of persons with disabilities for whom NDIS individualised supports are deemed most appropriate; for example, persons whose needs are not otherwise met through mainstream healthcare services (Productivity Commission, 2011). The estimated proportion of the Australian population accounted for by Tier 3 is one of the three measures employed by Working Group 1 of the Transforming Lives programme in Ireland to estimate need for specialist disability services (Working Group 1, 2018). Given that the vast majority of the cost of the NDIS is accounted for by Tier 3, estimating the size of this population group is regarded as crucial to the functioning of the NDIS

¹¹ The US National Core Indicators website is at <https://www.nationalcoreindicators.org/>.

(Productivity Commission, 2011). For the purposes of establishing the NDIS, the size of Tier 3 is estimated using cross-sectional population and disability prevalence data. Individuals in Tier 3 are then divided into groups based on the frequency with which they require support with activities of daily living, and support packages assumed to be most appropriate are assigned to each group. The longitudinal data actively collected by the NDIS are expected to improve on these cross-sectional estimates over time, especially since the aim of the NDIS is to support persons with disabilities over the life-cycle (Productivity Commission, 2011).

The Productivity Commission (2011) also identifies important features required of data systems to be established under the NDIS. These include compatibility across states and the creation of longitudinal databases of participants capturing data on disability types, personal plans, costs of support, services provided and outcomes. This data could then be employed in actuarial modelling of the number of users and expected costs, as well as in economic analyses of specific interventions (Productivity Commission, 2011). Transparency, within the bounds of confidentiality, is also a key element of data collection in the NDIS. The Australian Department of Social Services publishes an online map of projected need for the NDIS, or the forecasted size of Tier 3, by postcode. This is estimated by employing regression techniques on a combination of census data, NDIS administrative data and Department of Social Services data.¹²

In addition to estimating need for support services, as part of their work estimating the initial cost of the NDIS, the Australian Productivity Commission (2011) also make a brief calculation of unmet demand for specialist disability services using waiting lists. This is achieved by considering current expenditure on specialist support services in the state with the highest expenditure per capita on support, Victoria, and calculating the increase in expenditure required to extend support services to everyone on the waiting list. Assuming each state funds support services to the same level, it is calculated that expenditure would need to increase by 35 to 40 per cent to meet unmet demand for specialist disability support in Australia (Productivity Commission, 2011).

The Australian Productivity Commission (2011), however, acknowledges that this is only a crude estimate of 'expressed' unmet demand, as some individuals who require specialist support may not be on a waiting list. In addition, as pointed out by Working Group 1 (2018) in Ireland, estimating true unmet need is more elusive: 'Current unmet need would comprise both those who need a service and don't get one, and those who get a service, but with too few hours to meet their needs'. On the strength of the evidence considered here, it seems that Australia has made significant progress in identifying the extent of unmet need through establishing the collection of comprehensive, longitudinal data on NDIS users over time.

¹² The NDIS demand map is available at <https://blcw.dss.gov.au/demandmap/>.

6. COSTING MODELS OF SUPPORT SERVICE PROVISION

6.1. CONTEXT IN IRELAND

In Ireland, the Economic and Social Research Institute has developed a macro-simulation model for projecting future health and care service demand and expenditure, called the Hippocrates model (Brick, Keegan and Wren, 2020; 2019). This type of cell-based model groups service users in ‘cells’ by age and gender, and calculates expenditure for each cell by multiplying the number of individuals in the cell by a unit cost. Population projections can then be used to project demand and expenditure. As discussed in Section 5, while data of sufficient quality do not yet exist in Ireland to accurately estimate current use of some specialist disability supports, including personal assistance, it is expected that the development of the NASS database will improve this situation (Brick, Keegan and Wren, 2020; 2019).

Working Group 1 of the Transforming Lives programme has estimated the current and future levels of specialist disability service requirements by combining indicative cost figures of different support levels by present and future population estimates. Working Group 1 produced a range of estimates to account for uncertainties surrounding the data (Working Group 1, 2018). The Department of Health has updated and extended that work to produce estimates of the future capacity requirements for disability services covering the period to 2032 (Department of Health, forthcoming).

We are also cognisant of work undertaken by the NDA in evaluating the cost of different service models of disability supports, in particular the cost of transitioning from congregated models of care to person-centred support (NDA, forthcoming).

6.2. ANALYTICAL FRAMEWORK

6.2.1. Complexity in patterns of service provision

A starting point for costing different models of disability support provision is understanding patterns of service provision and use. Mansell et al. (2007) outline the potential complexity behind this. First, most disability support is provided by the ‘informal’ care sector, which consists of family, friends and neighbours. This support cannot be regarded as a free input when costing support models, as there are high opportunity costs associated with providing such support, and indefinite supply of informal support cannot be guaranteed. They state: ‘The availability of informal care heavily influences the level and nature of need for “formal” care for which, by definition, funding must be raised in order to employ staff’ (Mansell et al., 2007). Measuring informal support is hindered by difficulty in distinguishing between support and regular household tasks among the wide range of activities

performed by informal assistants. Furthermore, applying a monetary value to this support is problematic in the absence of market prices (Curtis, 2012).

A second source of complexity arises from the needs of users often requiring support from multiple providers. Support needs may simultaneously require health care, social care, and support from housing or education systems. Moreover, there may be unclear boundaries between these services, and different eligibility criteria or underlying cultures between agencies. This complexity can be further exacerbated if service provision is spread across public, private and voluntary sectors (Mansell et al., 2007). Altering the structure of support services may affect both the overall cost of support and the distribution of this cost among different parties. Therefore, to avoid incorrect conclusions, it is important to be comprehensive when costing models of service provision (Felce, 2017).

6.2.2. Conceptualising cost

Based on this complexity, it is helpful to consider the notion of cost in more detail. Mansell et al. (2007) outline a conceptual framework, which they call the ‘production of welfare’ framework, in which the costs of long-term support, including specialist disability services, can be located. This framework views the overall provision of support as a production process, and encompasses the links between resource ‘inputs’, intermediate service ‘outputs’, and final outcomes:

The success of a care system in improving health and quality of life depends on the mix, volume and deployment of resource inputs and the services they deliver, which in turn are dependent on the finances made available through various funding or commissioning routes (Mansell et al., 2007).

This framework includes several different dimensions to cost encountered at various stages of this process, which we summarise in Table 6.1.

TABLE 6.1 DIMENSIONS TO THE COST OF DISABILITY SUPPORT

Direct costs	Costs of the lead agency’s services, such as costs to the health system.
Indirect costs	Costs of the services of other agencies, such as costs to the social welfare system.
‘Hidden’ costs	Costs, including opportunity costs, of support from informal support networks, such as family, friends and neighbours.
Intangible costs	Other costs that can be identified but not quantified. These may include costs stemming from providing support, such as stress arising from unmet need.

Source: Mansell et al., 2007.

In addition, it is argued in the literature that instead of simply focusing on the cost

of disability support, the cost-effectiveness of service provision must be considered (Felce, 2017). This also situates costs in a production process, and involves identifying and measuring the use of resources, or costs, in relation to the production of outputs, or outcomes, such as the person-centred outcome measurements discussed in Section 2. Cost-effectiveness could thus be expressed as a ratio, such as the cost per unit of outcome (Felce, 2017). For example, when comparing two different models of service provision, focusing on cost alone would suggest simply favouring the least expensive model, whereas considering cost-effectiveness also accounts for the different levels of service outcomes provided, such as quality of life.

6.2.3. Unit costs

A key element of costing models of service provision is calculating the unit cost of a service. A unit cost is defined as the ‘total expenditure incurred to produce one unit of output’, for example the cost of one hour of personal assistance (Curtis and Burns, 2019). In this example, the ‘unit of activity’, or unit of intermediate output, is an hour of support.¹³ There are two main approaches to calculating unit costs, as described by Whyte et al. (2018). First, a ‘top-down’ approach targets the unit of activity from the highest level of data aggregation, dividing all relevant expenditure by the unit of activity. This relatively simple method can be employed to calculate an average cost per patient and can monitor changes in output, but it ignores variation in costs that stem from user characteristics. Second, a ‘bottom-up’ approach conversely targets the unit of activity from the lowest level of aggregation. This method attaches a cost to each component resource, requiring a much higher level of data availability but generally giving more precise unit costs (Whyte et al., 2018).

The UK’s PSSRU points out that there are complex differences in organisation between service providers, and therefore prescriptive guidelines on calculating unit costs for health and social care cannot be established. The PSSRU instead suggests four overarching principles: unit costs need to include the financial implications of all service components, match the service actually received, consider long-run marginal opportunity costs, and be up to date (Beecham and Bonin, 2016). The ‘marginal cost’ is the cost of supporting one additional person, while the opportunity cost accounts for ‘the resource implications of opportunities forgone rather than just the amounts spent’. Focusing on short run costs alone may underestimate this marginal cost, so long run costs should be considered (Beecham and Bonin, 2016).

One particular issue in relation to calculating unit costs using a bottom-up approach is the estimation of overhead costs (Whyte et al., 2018; Beecham and Bonin, 2016). Overhead costs include capital overheads associated with resources

¹³ It is important to distinguish an intermediate *output* from its associated final *outcome*, as not all units of output will necessarily result in the same level of outcome.

such as buildings, and non-capital overheads associated with ‘back-room tasks’ such as managing and supporting professionals or service interventions. They are separate from direct costs such as salary, and difficulties can arise in determining the amount of overhead costs attributable to the unit of activity of a particular service. Calculating capital overhead costs can involve estimating how much a resource is worth through a rebuild cost or market valuation, estimating how long the resource will last, and estimating a return on investment associated with the resource (Beecham and Bonin, 2016). In the case of services that do not include buildings, such as personal assistance, capital costs may include a transport vehicle. Non-capital overheads may be costed in a provider’s service-level agreements or through the use of recharges as a flat rate or percentage of revenue costs associated with a service (Beecham and Bonin, 2016). In the absence of this information for a particular service, a common approach is to include overhead costs as a percentage of staff costs (Whyte et al., 2018).

6.3. APPROACHES IN ACADEMIC LITERATURE

In comparing various models of specialist disability service provision – for example, weighing up different forms of community living or contrasting institutional and community-based settings – two broad approaches are evident in the literature. First, many studies conduct cross-sectional surveys of two or more support models, collecting detailed data on service characteristics and costs through survey questionnaires (Unwin, Deb and Deb, 2017; Cronin and Bourke, 2017; Larson et al., 2013; Chou et al., 2008; Knapp et al., 2005; Hallam et al., 2002; Stancliffe and Keane, 2000; Hatton et al., 1995). While this method can account for differences in user characteristics between support models to some extent, it is ultimately limited to comparing support for two different groups of users at a single point in time. Second, some studies conduct longitudinal surveys that follow users as they transition from one support model to another; for example, from an institutional or hospital setting to a community-based setting (May et al., 2019; Hallam et al., 2005). The longitudinal approach has the advantage of being able to compare the costs, as well as outcomes if such data are collected, of different support models for the same users. Both approaches rely on survey data, employing established questionnaires to gather detailed data on various aspects of service use and cost from users, carers or assistants, and administrative or managerial staff.

Approaches to measuring and valuing informal support in monetary terms are reviewed in Curtis (2012). Methods for measuring time spent giving support include time diaries, recall surveys, experience sampling and direct observation. Economic methods are then employed to estimate the monetary value of this time, including revealed preference and stated preference approaches (Curtis, 2012).

Whyte et al. (2018) review literature that calculates unit costs for health and social care services and find that most studies employ a bottom-up approach. In general,

they find that the bottom-up approach appears to be more common where precision is particularly important, as when assessing the impact of a particular technology, or when the data burden of such an approach is not overly taxing, as in setting-specific studies. Meanwhile, top-down approaches are found to be favoured when unit costs across a wide range of services are required, as in projection models, or when the data burden of a bottom-up approach is too high (Whyte et al., 2018).

6.4. INTERNATIONAL PRACTICE

6.4.1. UK

The PSSRU projection model discussed in Section 5 is also used to project the overall cost associated with meeting projected demand for long-term support in the UK, including community and residential support (Wittenberg, Hu and Hancock, 2018). However, the PSSRU acknowledges that these projections should not be considered estimates of the total costs to society of long-term care, as a full range of services and users is not considered and opportunity costs of informal care are not accounted for (Wittenberg et al., 2008).

Much of the academic literature calculating unit costs for health and social care services relies on those calculated, or the methodology used, by the PSSRU in the UK (Whyte et al., 2018). The PSSRU publishes annual estimates of unit costs for a wide range of services across health and social care in the UK; the first volume of unit costs was published in 1992 (Curtis and Burns, 2019).^{14,15} A bottom-up approach is employed by the PSSRU, including the financial implications of all service components, including overhead costs. This comprehensive approach is in line with the accounting principle of ‘full cost recovery’, which emphasises the need to include overhead costs of any output (Beecham and Bonin, 2016). The long-run marginal opportunity cost is considered the unit cost for a given service. This information is gathered using guidance from an advisory group, findings from academic literature, secondary data sources, consultations with individual organisations to estimate costs for specific services, and occasionally some primary research (Curtis and Burns, 2019). We summarise in Table 6.2 the unit costs published by the PSSRU in 2019 for various specialist disability services for adults aged under 65 years, although it should be noted that these unit costs are based on support services in the UK and should be interpreted in this country-specific context. While a unit cost is not calculated for personal assistance, unit costs are included for social workers, social work assistants and home care workers.

¹⁴ The PSSRU’s approach to estimating unit costs is summarised in a video, available at <https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2018/>.

¹⁵ The PSSRU has also developed a tool for individual service providers in the UK to calculate the unit cost of their support service, called the ‘Preventonomics Unit Cost Calculator’ (Beecham and Bonin, 2016). This tool is available at <https://www.pssru.ac.uk/project-pages/unit-costs/pucc/>.

The UK is clearly at an advantage in relation to costing different models of disability support service provision given the establishment of the PSSRU, a dedicated research unit for costing health and social care services. Ireland currently lacks such a resource, and would be in a better position to calculate the costs of support service models if such a capacity existed. Brick et al. (2015) is an example of a study that adapts PSSRU unit cost methodologies to an Irish setting in relation to palliative care.

TABLE 6.2 PSSRU UNIT COSTS FOR DISABILITY SUPPORT SERVICES IN THE UK

Support service	Unit cost (£)	Unit of activity
Services for persons requiring learning disability support		
Residential care home (4-bed)	1,770	Per person per week
Residential care home (8-bed)	1,394	Per person per week
Supported living (2-bed)	960	Per person per week
Supported living (3-bed)	967	Per person per week
Services for persons with autism and complex needs		
Residential care home	2,371	Per person per week
Supported living	1,552	Per person per week
Services for persons requiring physical support		
Local authority care home	969	Per person per week
Voluntary/private sector care home	967	Per person per week
Community-based social care		
Social worker	51	Per hour
Social work assistant	33	Per hour
Home care worker	28	Per hour

Source: Curtis and Burns, 2019; Curtis and Burns, 2018.

Note: The PSSRU did not publish unit cost data for persons with intellectual disabilities in 2019 as the data were over ten years old. The unit cost data summarised here for persons with intellectual disabilities were last published by the PSSRU in 2018.

6.4.2. Australia

The Australian Productivity Commission (2011) comprehensively estimates the total initial cost of establishing the NDIS, based on its projections of demand for specialist support services, discussed in Section 5. This exercise is an example of costing an overall model of specialist support provision for a country. The commission's approach involves dividing eligible persons with disabilities into groups with similar support needs and estimating an average cost per person for each group. This average cost is the annual average cost of an overall support package assumed to be appropriate for a given level of disability; individual support services are not costed separately. No single data source contains exact information on the costs of various forms of support in Australia, so the analysis relies on various data sources. Unit cost data are sourced for some forms of support from a previous National Disability Agreement, and for other supports from individual schemes and organisations. It is estimated that the overall cost of the NDIS when fully rolled out would be around four per cent of existing tax revenue (Productivity Commission, 2011). It should be noted that, as with unit cost

data from the PSSRU in the UK, this figure should be interpreted as specific to the Australian context. In addition to improving demand estimations for the NDIS, it is expected that the development of a longitudinal database, including information on individuals' support needs and use of services, will improve these cost estimates over time:

Accurate cost estimates for the NDIS could be prepared if a longitudinal database existed that included information on individuals' functional support needs, health conditions and use of formal and informal support. The current absence of such a database hampers the ability to prepare cost estimates of the NDIS (Productivity Commission, 2011).

7. CONCLUSIONS

This report examines international literature on the provision of specialist support for persons with disabilities living in the community. Several core themes are considered, including the wider transition to person-centred disability support, personal assistance services, individualised funding, measuring unmet need for support services and costing models of service provision. Overall, it is evident that, despite the widespread ratification of the Convention on the Rights of Persons with Disabilities (CRPD), there is considerable variation across countries in how community living is supported in practice. This variation appears to stem both from the policy origins in different legacy welfare-state models and their underlying ideologies, and from varying trends in the development of service provision over time. Of course, it is possible that the COVID-19 pandemic will lead to further shifts in the provision of specialist disability support, and the literature comparing different support settings could benefit from accounting for additional factors such as risk of infection.

The review of international literature in this area has revealed several key issues that are relevant to specialist disability service provision in Ireland. First, there is a need to continuously monitor evolving service provision at a local level in the context of the under-funding of some specialist supports, coupled with a lack of individual legal rights to community-living support. One approach suggested in the literature is to establish the statutory provision of a transparent assessment of needs in order to make unmet need for support services a matter of public record (Slasberg and Beresford, 2019). A comprehensive and standardised tool to assess needs would also help to ensure that inequalities in service provision – for example, by region or by the extent of skilled advocacy and negotiation – do not arise over time.

Personal assistance services can facilitate independent living at home by assisting with activities of daily living, in the workplace or in education. An important distinction between personal assistance and more traditional home care services, such as the Home Support Service in Ireland, is that personal assistance offers greater user control and extends beyond basic personal care to support independent living. A central challenge in establishing and facilitating personal assistance services is ensuring that user control is adequately promoted and supported. There is evidence that the focus of personal assistance services can gradually narrow to basic healthcare, with the erosion of support for other elements of community living, and thus user control, particularly as demand for personal assistance increases.

Individualised funding, or personal budgeting, is considered an alternative to more traditional funding routes for support services that have been characterised as

inefficient. The literature indicates that this should be complemented by a central government ensuring service quality and policy coherence, as well as independent support brokerage and clear eligibility criteria. In addition to a focus on service users, it is important to consider the implications of individualised funding schemes on support workers and assistants. For example, research suggests that relationships between service users and their assistants are more sustainable in an individualised funding system where the user acts as the assistant's manager rather than their employer, with the role of employer delegated to a third-party non-profit organisation (Christensen, 2012).

A trade-off is identified in the literature between the generosity and the coverage of individualised funding schemes in the context of budgetary constraints, with countries opting for different strategies in this regard. In terms of financing disability support services, some countries have adopted a social insurance model, such as the NDIS in Australia, which estimates an aggregated expected cost of claims instead of employing incremental budgeting.

Closely related to this, of course, is the importance of systematic and comprehensive data collection, including data on anyone provided with a needs assessment and longitudinal data on service users. This is required for monitoring and evaluating service outcomes as well as for estimating future needs from a life-cycle perspective. The development of the NASS is expected to improve the data landscape for specialist disability services in Ireland. Systematic and longitudinal data collection is also required to accurately cost models of support service provision and project future expenditure. The establishment of a dedicated research unit similar to the PSSRU in the UK would improve Ireland's capacity to calculate unit costs for support services. A theme that arises across most countries is the notable dearth of published data measuring unmet need for, and unit costs of, specialist disability supports. This gap can only serve to hinder efforts to make the achievement of individualisation, as set out in Article 19 of the CRPD, a reality.

This exploratory review of international literature is an initial step in a wider programme of research that examines the provision of specialist community living and personal assistance supports in Ireland, and in particular the extent of need and supply for these services. Future steps in this research will involve structured interviews with staff in selected CHOs in Ireland, as well as an assessment of how existing administrative data could be employed to quantify need and supply for services nationwide.

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