

Moving In, Moving On: Literature review

An evaluation of the outcomes and costs of congregated and community models of service in the disability sector



NDA

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**Transforming
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Abbreviations

ADLs	Activities of Daily Living
AFS	Audited Financial Statements
ASC-FR	Adult Social Care Finance
ASCOT	Adult Social Care Outcomes Toolkit
CHOs	Community Health Organisations
DPER	Department of Public Expenditure and Reform
DSW	Disability Support Worker
FACE	Functional Analysis of Care Environments
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IADLs	Instrumental Activities of Daily Living
IDS-TILDA	Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
IGEES	Irish Government Economic and Evaluation Service
IHRC	Irish Human Rights Commission
KPIs	Key Performance Indicators
NDA	National Disability Authority
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NESC	National Economic and Social Council
OECD	Organisation for Economic Co-operation and Development
PA	Personal Assistant
PSS Ex1	Personal Social Services Expenditure Returns
PSSRU	Personal Social Services Research Unit
QoL	Quality of Life
RoC	Roster of Care
SIL	Supported Independent Living
UK	United Kingdom
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VFM	Value for Money

I. Background to the study

I.1 Context for evaluation

In 2007, a Working Group on congregated settings was established by the Primary, Community and Community Care Directorate of the HSE to develop a national plan and implementation programme for moving people from congregated settings to homes in the community. In 2011, the report of the Working Group was published. The report pointed out that congregated provision is in breach of Ireland's obligations under UN Conventions and is not congruent with the policy of mainstreaming that underpins the National Disability Strategy. It asserted that accommodation in congregated settings contravenes the state policy of inclusion and full citizenship. It set no boundaries on community living and recommended that all those living in congregated settings, regardless of the severity of their disability, move to community settings. It further advised that no new congregated settings be developed and that no further admissions to congregated settings be permitted (HSE 2011). The report advised that a seven-year timeframe for the overall national closure programme for congregated settings should be set. It stipulated that community residences should support a maximum of four residents "who choose to share their accommodation".

Concerns regarding the quality, efficiency and financial sustainability of public spending on disability services prompted a major review of policies and practices which were reported in 2012 (Department of Health 2012). The monies allocated to disability services grew rapidly in the period prior to the review. This was of particular concern given that demographic projections indicated the likelihood of substantial increases in demand in future years (HSE 2011). The review was also prompted by concerns that the large number of agencies providing services was liable to result in the duplication of administrative and management costs and structures and had the potential for geographical and sectoral inequalities. There was also an awareness that there was undue reliance on self-regulation with a resulting variation in the quality of care delivered.

The Value for Money and Policy Review of Disability Services in Ireland (VFM) concluded that the model of service in operation at that time was not providing "a sufficient quality and quantity of services at an affordable price" (Department of Health 2012, p9). The review acknowledged that while some existing services promoted client choice, control and independence, flexible services responsive to individual needs were not generally available, particularly for people with intellectual disabilities. In common with the earlier report on congregated settings the VFM review highlighted that there was a failure to align the delivery of disability services with government policy (NESC 2012) and established the

need for fundamental and transformative change in the delivery of disability services in Ireland.

The “Transforming Lives” Programme, was established to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland (Department of Health 2012) and the policy set out in Time to Move on from Congregated Settings (HSE 2011). The programme was developed to bring about fundamental reform in the delivery of disability services in Ireland.

The overall objective of the Transforming Lives Programme is “to ensure full inclusion and self-determination for people with disabilities” (HSE 2017a, p.17).

The Health Act 2007 provides the statutory basis for the regulation, registration and inspection of residential services provided to people with disabilities, to children under the Child Care Acts, and to other dependent persons. The sections of the 2007 Act relating to the registration and inspection of designated centres for persons with disabilities were not commenced until the Minister for Health made the requisite order on the 1st of November 2013. Prior to commencement of the relevant sections of the 2007 Act, the Health Information and Quality Authority (HIQA) consulted extensively with service providers before publishing National Standards for Residential Services for Children and Adults with Disabilities (HIQA 2013; NDA 2015). The system of registration, regulation and monitoring that was ushered in addressed recommendations in previous inquiries into disability services (IHREC 2010; McCoy 2007) and was aligned with the commitment to delivering quality services set out in both the VFM review and Time to Move on.

The United Nations Convention on the Rights of People with Disabilities (UNCRPD) has been very influential in shaping the programme of reform (UN 2006). The UNCRPD, which came into force in the UN in May 2008, is an international legally binding treaty which seeks to ensure that people with a disability have full and equal access to all their human rights and freedoms. It is underpinned by a social model of disability and established human rights principles which guide rights based approaches to disability policies and programmes (Lang et al. 2011). The UNCRPD was signed by Ireland in 2007 and ratified in 2018. By early 2018 when Ireland ratified the UNCRPD the three elements necessary to promote the implementation of a rights based approach to disability had been put in place. The necessary elements are effective national policies which provide an appropriate mechanism for implementation, governance arrangements which are sufficiently robust to avoid dissonance between policies and practice and a commitment on the part of government and civil society to drive implementation (Lang et al. 2011).

1.2 Structure of Irish disability sector

In Ireland disability services are delivered by multiple service providers. Services are provided directly by the funding agency, the Health Service Executive, by not-for-profit or voluntary agencies (who can be divided into two principal categories based on their contractual relationship with the HSE), and by a small number of for-profit agencies. Many long-standing service providers were established by religious orders while others emerged on foot of efforts by family members. For-profit service providers are a more recent presence in the sector.

A small number of organisations receive a significant proportion of all HSE funding. The top 2% of providers receive more than a quarter of all funding whereas just 0.4% of total expenditure is shared by over one third of all providers (Department of Health 2012). More than half (58%) of disability funding to Section 38 agencies is allocated to four large faith-based service providers (Day, et al. 2019, p.23).

In the past the sector was largely unregulated and service providers were free to deliver services in accordance with their particular ethos and values. While some services put in place externally accredited quality assurance systems, others had no quality assurance system. This resulted in the emergence of a variety of service models and unevenness in the quality of the services delivered (Department of Health 2012; NESCC 2012). Following a major review of disability services, it was recognised that the vision of services set out in various government policies was not being consistently realised (Department of Health 2012; NESCC 2012).

In recent years, several factors have resulted in major and ongoing reform of Irish disability services. A series of policy and legislative initiatives were introduced in advance of the ratification of the UNCRPD. Additionally, since 2013, residential disability services have been subject to regulation by a statutory body, the Health Information and Quality Authority (HIQA) which has reported a marked improvement in services since regulation commenced (HIQA 2019, 2020; NDA 2016). The inspection of services, and perhaps especially the public reporting of such monitoring, has been an important driver of change.

The disability sector experienced repeated cuts in funding from 2009 to 2014 prompted by general budgetary constraints (Campbell et al. 2017). Since 2014 funding for disability services has increased and in 2016 funding levels exceeded those of 2009 (Campbell et al. 2017).

The combined effect of these changes has meant that most service providers have had to review and reform their approach to service delivery. A central element of government policy is that persons with a disability living in

congregated settings should transition to a home in the community and share their home with no more than three other persons of their choosing (HSE 2011; NDA 2010). The process of transitioning supports from congregated to community settings is ongoing.

Provision of services within the disability sector is largely by not-for-profit providers. Disability service providers rely largely or wholly on funding from the Health Service Executive (HSE) and other State bodies. The State, through the HSE, directly provides around one in eight residential care places and one in thirteen day places. However, HSE provision is not evenly distributed across regions. The organisation and structure of service provision vary by region and by disability type. Providers differ by size, geographical sphere of services, type of contractual arrangement with the HSE, culture and ethos, and the type of disability supports offered. Regional tiers of management and contracting within the HSE and within larger disability providers add to the complexity of the sector. Many organisations, particularly larger organisations, deliver supports via a variety of service models. While, private for-profit providers play a minor but growing role in the delivery of disability supports. The fragmented structure of the disability sector adds to the difficulty of implementing sector-wide reform.

The process of reform is, therefore, ongoing. Providers are seeking to align supports with the personal goals and preferences of clients, while embracing positive risk-taking and positioning supports within, rather than at the periphery of, communities continues to challenge long-established work practices and organisational structures. Elements of older models of service delivery still persist within some organisations, however. The process of re-configuring services towards a rights-based person-centred model of support is especially challenging for organisations that provide care in congregated settings and for those that have had a long-standing orientation towards a medical model of care. The absence of a unified approach to service provision, the multiplicity of service providers the challenges and resistance to transitioning residential supports from congregated settings to the community and ongoing budgetary constraints have meant that implementation of reform has proved difficult.

The literature below is presented in three sections and primarily relates to the key areas of the research tools used. First, the literature relevant to some key domains associated with the FACE tool are considered. Specifically, this includes literature on mental health, behaviours that challenge, medication, morbidity, activities of daily living and instrumental activities of daily living, family support, employment, nursing homes, and personal assistant services. The next section considers issues related to quality of life and the Adult Social Care Outcomes Toolkit (ASCOT). Finally, literature relating to the costs of disability services is considered.

2. Literature relevant to FACE data

2.1 Mental health

It is not possible to indicate an accurate prevalence rate of mental ill health in adults with intellectual disabilities due to the wide variation in the prevalence rates reported (Buckles et al. 2013; Deb et al. 2001). Variations in reported prevalence rates are attributed to a range of factors including inconsistencies in the definition of mental ill health; difficulties in the diagnosis of mental illness in people with intellectual disability; sampling bias and other methodological errors (Buckles et al. 2013). However, research indicates that adults with intellectual disabilities are significantly more likely to have a mental health condition, and twice as likely to have more than one mental health condition, as adults with no intellectual disability (Cooper et al. 2015). An Irish longitudinal study of older (i.e. over 40 years of age) adults with intellectual disability found that 47.5% of adults had emotional, nervous or psychiatric conditions (McCarron et al. 2011). This prevalence rate is high when compared to findings of other prevalence studies carried out in the UK, Australia and Canada (McCarron et al. 2011). The research found that women, people living in residential settings, and people with severe intellectual disabilities were more likely to have been diagnosed with mental ill health (McCarron et al. 2011).

More recently, a large-scale study, based on a 2011 Census of the Scottish population, reported a 23.4% prevalence rate of mental health conditions among individuals with intellectual disabilities (Hughes-McCormack et al. 2017). When compared with the population without intellectual disabilities, the study found that, at all ages, individuals with intellectual disabilities had a substantially higher prevalence of mental health conditions. The study also found that while females in the population without intellectual disabilities were more likely to have a mental health condition, this pattern was reversed in adults with an intellectual disability, as males with an intellectual disability were more likely to have mental health conditions than females. Among individuals with an intellectual disability, the odds of having a mental health condition increased up to the age of 64. After this age the likelihood of a mental disorder did not increase. The study also found that poor physical health increased the odds of a mental health condition for individuals with and without an intellectual disability.

The body of literature on physical disability and comorbid mental illness is limited. While research has suggested that mental ill health may be more commonly experienced by adults with physical disabilities compared to the general population (Dicianno et al. 2015; Leeper et al. 1985), the divergence in the type and severity of physical disabilities make meaningful generalisations difficult.

The estimated prevalence of mental illness in the Irish population is 18.5% (OECD 2018, pp.21-22). This places Ireland among the countries with the highest reported prevalence of mental illness in Europe. However, as attitudes to mental illness may impact reporting rates, and access to mental health services may vary from country to country, reported variations in prevalence rates between countries may not be true reflections of variations in the rate of mental illness.

2.2 Behaviours of concern

Behaviours of concern have been defined as “behaviours that indicate a risk to the safety or wellbeing of the people who exhibit them or to others” (Chan et al. 2012). The terms behaviours of concern and challenging behaviours are often used synonymously but Chan and colleagues suggest that ‘challenging behaviour’ is associated with negative connotations whereas ‘behaviour of concern’ places an emphasis on support staff adopting the right response rather than the challenge they must overcome (Chan et al. 2012). Behaviours of concern may be indicative of mental illness but may also arise in the absence of mental illness in response to environmental triggers, pain, boredom, or communication difficulties (Nankervis et al. 2020; Emerson, 2001; de Winter et al. 2011; Forster et al. 2011).

Several risk markers are linked to each of these different forms of behaviours of concern. Severe/profound intellectual disability, a diagnosis of autism and communication deficits appear to be predictors of self-injurious and aggressive behaviours (Borthwick-Duffy 1994; Cooper et al. 2009; Kiernan and Qureshi 1993; McClintock et al. 2003; Moseley et al. 2019; Summers et al. 2017). While destruction of property may be more common in persons with a diagnosis of autism (McClintock et al. 2003). Due to the limited evidence base, these predictors are presented as tentative rather than definitive findings. As the various predictive traits can overlap, researchers have pointed to the need for further study to isolate the relative importance of each trait (McClintock et al 2003, pp.414-415).

Several reviews of the literature have found mixed results regarding the effect that transition to the community has on behaviours of concern (Emerson and Hatton 1994; Kim 2001; Kozma, et al 2009; Lemay 2009; Lakin et al. 2011). A small number of studies have pointed to dis-improvements or no change in challenging behaviours following transition to the community (MacLeod et al. 2002; Stancliffe et al. 2002). Community settings may be more stimulating and demanding than institutional settings. While this may provide clients with more opportunities for choice and self-determination, it may also promote anxiety and stress in others. It must be noted, however, that some of these studies had very small sample sizes (MacLeod et al. 2002). Further, some authors have pointed to the relationship between staff attention and behaviours of concern; staff often respond more to challenging rather than adaptive behaviour and, thus, the lack of

improvement in challenging behaviours may be more related to staff working practices than the residential setting per se. Transitions have also been associated with improvements in behaviours of concern (Kim et al. 2001; Kozma et al. 2009). Bhaumik et al. (2009) found a reduction in aggressive behaviours in 80% of participants following their move to various community settings from a long-stay hospital in the UK. The improvements were sustained twelve months after the move. The authors suggest that careful advanced planning and the person-centred approach adopted by staff contributed to the improvements observed and point to the need to examine how environmental settings affect aggressive behaviours.

2.3 Psychotropic medication

Adults with intellectual disability are more commonly prescribed psychotropic medication than the general population (Robertson et al. 2000a; Sheehan et al. 2015; NHS England 2016). Reported rates of prescription of psychotropic medication have varied in accordance with different living arrangements of research participants, with those living in congregated settings being more likely to be prescribed psychotropic medications than those living in other types of residential settings (Robertson et al. 2000a; Lunskey et al. 2018). For example, a rate of 9%-10% has been reported for people living in family homes compared to rates of 20-50% 19-32% for those living in community settings (Branford et al. 1994; Clarke et al. 1990; Kiernan et al. 1995). A more recent study of residential settings for people with severe behaviours of concern reported rates of prescription of anti-psychotic drugs as 56% in non-congregate and 80% in congregate settings (Robertson et al. 2005). This variation may arise from the use of psychotropic drugs to control disruptive or aggressive behaviours (Clarke 1997; Emerson et al. 1997; Fleming et al. 1996; Kiernan et al. 1995; Robertson et al. 2005). The differences could also reflect selection bias, in that individuals with more behaviours of concern were potentially more likely to be directed towards congregated setting for their care.

In addition to being more likely to be prescribed psychotropic medication compared to others, adults with intellectual disability are more likely to be taking multiple medications (Cooper et al. 2015; O'Dwyer et al. 2017; Lunskey et al. 2018) Robertson and colleagues (2000a) found that adults with intellectual disabilities living in residential campuses were more likely to be receiving more than one type of antipsychotic drug on a regular basis compared to people living in village communities or in dispersed housing. These findings were supported in a study of older Irish adults with intellectual disabilities which found that those living in supported residential settings were 'significantly more likely to be exposed to psychotropic use and polypharmacy' than individuals not living in supported residential settings (O'Dwyer et al. 2017, p.978). The side effects of medication and drug interactions may be a contributory factor in respect of some conditions.

Although the rate of psychotropic medication prescription tends to be higher in congregated settings, there is also evidence of over prescription of psychotropic drugs in community settings. Research has indicated that psychotropic medication is commonly overused in community settings because appropriate systems are not in place to respond to behaviours that challenge (Kozma, et al. 2009). A growing body of research has highlighted that many people with intellectual disabilities who are prescribed psychotropic medications do not have a diagnosis of a psychiatric disorder (Lunsky et al. 2018). Thus, the over-reliance on psychotropic medication is not inevitable and indeed, if the appropriate clinical and environmental conditions are put in place, reductions in medication can be achieved (Ahmed et al. 2000).

2.4 Morbidity

Research indicates higher levels of morbidity (i.e. the presence of a disease or medical condition) and multi-morbidity (i.e. the presence of multiple medical conditions) in the population with intellectual disabilities than in the general population. The health risks of people with intellectual disability vary for a number of reasons. Specific syndromes are associated with an elevated risk of particular physical and mental health conditions. For example, an array of physical conditions, such as heart conditions, are more common in people with Down Syndrome than the general population of people with intellectual disability (Dobosz et al. 2019). People with Down syndrome also have a lower life expectancy than the general population of people with intellectual disabilities (Bittles et al. 2007; Baban et al. 2020; Wu and Morris 2013). Developmental disorders, such as autism, are often associated with a cascade of health conditions. A large study in the USA found that persons on the autism spectrum¹ were more likely to be diagnosed with almost all medical and major psychiatric conditions (e.g. autoimmune disorders, cardiovascular conditions, mood disorders, Obsessive Compulsive Disorder) compared to age and sex matched controls from the general population (Croen et al. 2015). Adults and children with intellectual disability and Cerebral Palsy may have impairments that affect their mobility, speech, vision and bladder function. They are also prone to gastrointestinal disorders and pneumonia (Evenhuis et al. 2000).

Multi-morbidity is common in all age groups for adults with intellectual disability but is mostly associated with older adults in the general population (Cooper et al. 2015). Irish research has confirmed higher rates of multi-morbidity in adults with intellectual disability aged 40 compared to adults aged 65 and older in the general population (McCarron et al. 2013). The pattern of multi-morbidity in older adults

¹ Almost a fifth (19.2%) of the sample had a co-occurring intellectual disability

with intellectual disability differed from that in the general population, however. Compared to older adults in the general population, older adults with intellectual disability had lower rates of conditions such as cardiovascular and liver disease and higher rates of gastrointestinal and joint disease. Overall, women with intellectual disabilities were found to be almost twice as likely as men to have multiple co-occurring conditions. Being over 65 years of age was found to be the strongest predictor of multi-morbidity, while level of intellectual disability was not found to be a significant predictor of multi-morbidity (McCarron et al. 2013).

Research indicates that lifestyle factors, such as poor diet, obesity and physical inactivity, can contribute to poor health in adults living in residential settings (Robertson et al. 2000b; Emerson 2004; Dairo et al. 2016). Robertson and colleagues (2000b) found a mixed pattern of risk factors with regard to participant and service characteristics. Poor diet, smoking and obesity, were more common in adults with greater ability and in less restrictive residential settings, whereas physical inactivity was more common in adults with lower ability and those living in more restrictive settings.

Compared to the general population, people with intellectual disability have a higher risk of experiencing pain and of having more frequent/severe pain due to higher levels of comorbidity (Doody and Bailey 2017). In an Irish study of adults with intellectual disability, one third of participants reported that they were often troubled by pain. Of those who reported pain 39.3% reported that the pain was moderate and a further 20.1% reported that the pain was severe (McCarron et al. 2011, p.81). Pain in people with intellectual disability is often unrecognised and poorly treated. Many people with intellectual disability have communication difficulties that hamper or prevent them from reporting their pain. Self-reporting is generally considered to be the best measure of pain but this may not be possible for people with intellectual disability and especially for those with severe/profound intellectual disability. Third party reports of pain may not be reliable, however (McGuire et al. 2010; McGuire and Kennedy 2013). Thus, accurate pain assessment may require a combination of approaches (Doody and Bailey 2017).

The prevalence of epilepsy is also much higher in the population of people with intellectual disabilities compared to the general population, although, estimates of population wide prevalence rates of epilepsy vary. Estimates of prevalence rates include a range from 0.5% to 2.0% (Ding et al. 2016) and a narrower range of 0.6-1.0% (Robertson et al. 2015). Amongst people with intellectual disability, the prevalence rate of epilepsy is estimated to be 22% (Robertson et al. 2015). The prevalence of epilepsy is related to the level of intellectual disability. Rates of epilepsy are lowest in people with mild intellectual disability and highest in those with profound intellectual disability (Robertson et al. 2015). A UK study that

assessed aggressive behaviour in adults with intellectual disability before and after their move to community settings reported that 65% (n=32) of participants had epilepsy (Bhaumik et al. 2009). Most (91%) participants in this UK study had severe/profound intellectual disability (Bhaumik et al. 2009). The prevalence of epilepsy is also higher in individuals with acquired brain injuries than in the wider population (Ding et al. 2016).

Epilepsy is further associated with a higher risk of fracture, aspiration episodes and pneumonia and can lead to increased cognitive impairment. In addition, epilepsy in adults with intellectual disability is associated with higher mortality rates (Evenhuis et al. 2000). As part of the IDS-TILDA study, the bone health of older (40 years or older) Irish adults with intellectual disability was explored. Over 30% (30.5%) of participants reported epilepsy and 38.2% were taking prescribed anti-epilepsy medications. The study found epilepsy and anti-epileptic medication were strong predictors of bone fractures (Burke et al. 2017).

2.5 Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)

Research in respect of older adults with intellectual disabilities indicates that the ability to undertake ADLs is often determined by mobility (Hilgenkamp et al. 2011). Mobility is not the only factor to be considered, however. An Irish study of older (aged 40 years and over) adults with intellectual disabilities has pointed to variations in the ability to undertake ADLs by living arrangements. People living independently and in community settings had greater ability to undertake ADLs than those living in congregate residential settings (King et al. 2017). However, the higher proportions of people with severe and profound intellectual disability and of older age living in congregate residential settings compared to those with other living arrangements may explain these findings at least in part.

The ability to perform instrumental activities of daily living is important for an individual's independence (Oppewal et al. 2015). Research in respect of older adults with intellectual disabilities has indicated that the level of intellectual disability is the main determinant of this population's ability to undertake IADLs (Hilgenkamp et al. 2011). More recently, physical fitness has also been found to be an important determinant of ability to undertake IADLs (Oppewal et al. 2015). These findings suggest that, although the level of intellectual disability is an important determinant, the enhancement of physical fitness may serve as a protective factor against decline in one's ability to undertake IADLs.

2.6 Family support

Previous research has interpreted the change in the size and strength of social networks as a proxy for change in quality of life following a move from an

institutional setting to the community (Bigby 2008; Kilroy et al. 2015; Sheerin et al. 2015). The findings suggest that improvements in family contact and social integration following transition to the community are uncertain. Bigby analysed the informal social networks of 24 adults with intellectual disability who moved from a large institutional setting to small homes in the community. Social networks were measured before the transition and one, three and five years after the transition. Bigby found that family contact increased at year one but by year five it was below the pre transition level. Reasons for decreases in family contact included, but were not limited to, declining parental health, geographical locations, high staff turnover and families being unfamiliar with their relative's daily routines. Research has also pointed to deinstitutionalisation resulting in an increased community presence without increased community integration (Chowdhury and Benson 2011; Kilroy et al. 2015). Thus, it is important to note that increased family support should not be considered a definite outcome of transitioning to the community. As Sheerin et al. point out:

Placing people with an intellectual disability in community housing should therefore not come with an expectation of close and frequent contact with neighbours and other locals. Policymaking as well as future research efforts should take this aspect into account and incorporate reflection and comparison with developments within the general population (2015, p.279).

2.7 Employment

In 2015, the Irish Government published its cross-governmental “Comprehensive Employment Strategy for People with Disabilities” for the period 2014-2024. The objective of this strategy is to support persons with disabilities to access employment. Despite such policy reforms, persons with disabilities in Ireland continue to face difficulties accessing employment compared to people without disabilities (OECD 2021). Census 2016 indicated that just one third (36.5%) of individuals aged 20-64 years with a disability were in employment. This compares to an employment rate of 72.8% for individuals aged 20-64 without a disability.²

The National Disability Authority recently commissioned the Economic and Social Research Institute (ESRI) to undertake research examining the workplace skills and abilities of persons with disabilities (ESRI 2021). The report found that, Ireland has the fourth lowest rate of employment of persons with disabilities in

² <http://nda.ie/Resources/Factsheets/NDA-Factsheet-2-Employment/NDA-Factsheet-2-Employment.pdf> (Last accessed December 2021)

Europe at just 36%. Further, Ireland has the lowest rate of persons with disabilities working full time and has one of the largest employment gaps between people with and without disabilities. Interestingly, the report did not find strong associations between disability severity and employment status suggesting that other barriers may exist for persons with disabilities trying to gain access to employment in Ireland.

The report also found variation in the percentages of people with disabilities in employment by disability type. Specifically, just 14.7% of those with an intellectual disability were in employment in 2016 compared to 45.7% of people who reported having “deafness or a serious hearing impairment” and 34% of those who reported experiencing “blindness or a serious vision impairment”. Moreover, individuals with intellectual disabilities are less likely to be in senior positions compared to people with deafness or a serious hearing impairment or with blindness or a serious vision impairment.

2.8 Nursing homes

Individuals with disabilities may also receive residential services within nursing homes, even when they are under 65 years of age. Most state funding for nursing home care is funnelled through the Nursing Home Support Scheme, a core component of spending on older people’s services. However, nursing home care may also be funded from the disability funding stream. The Health Information and Quality Authority (HIQA) is responsible for regulating and monitoring nursing homes, but applies different standards to nursing homes compared to designated centres within the disability sector. There has been criticism of the placement of individuals with disabilities younger than 65 years in nursing homes (Dwyer et al. 2019; Farrell 2013). Previous research indicates that many younger individuals with disabilities living in nursing homes are placed there following their discharge from acute hospital settings (Pierce et al. 2018). Nursing home placements for younger people have also been linked to a funding system that is ‘biased in favour of residential care’ (Pierce et al. 2018, p.6). This finding has been supported by a recent investigation conducted by the Office of the Ombudsman into the situation of some 1,300 people aged under 65 who are described as being ‘inappropriately placed in nursing home care’.³

2.9 Personal assistant services

There have been calls for a clear definition of personal assistant (PA) services (Buchanan 2014). In May 2018 at a Joint Oireachtas Committee on Public

³ <https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf> (Last accessed October 2021)

Petitions the role of a PA was described by an official from the Department of Health as:

To assist a person with a disability to maximise his or her independence through supporting him or her to live in integrated settings and access community facilities. The personal assistant works on a one to one basis in the home and/or in the community with a person with a physical or sensory disability. A vital element of this personalised support is the full involvement of the individual service user in planning and agreeing the type of support and the times it is provided for him or her (Committee on Public Petitions, 2018, p.3).

The report of the Joint Oireachtas Committee on Homecare describes Homecare Services as “the provision of additional health or care assistance to a person which allows them to remain living independently in their own home” (Joint Committee on Health 2019). It is considered that this description can also be applied to Home Support services for adults with disabilities. The introduction of a statutory home care scheme is planned (Day et al. 2019; Committee on the Future of Healthcare 2017).

3. Literature relating to Quality of Life and Outcomes

3.1 Quality of life

Quality of life (QOL) is a multi-dimensional phenomenon determined by personal characteristics and choices, environmental and structural factors and life course events and enhanced by self-determination. It is generally evaluated across a number of domains which are viewed as interdependent and which represent in aggregate the quality of life construct. It has subjective and objective components that are considered to be universal (Cummins 2005).

The concept of quality of life has attracted a great deal of academic interest that has generated multiple definitions and conceptualisations. This has resulted in a large body of measurement tools to assess quality of life, with very little agreement on a 'gold standard' measure (Bowling 2014). Without this 'gold standard' the selection of a quality of life measure is difficult.

Cummins points out that a series of large scale surveys have established the remarkable stability at population level of subjective wellbeing, the subjective dimension of quality of life. At the individual level, subjective wellbeing will normally fluctuate within a narrow range. Persistent subjective wellbeing below this range is associated with a high probability of experiencing depression. Behavioural, external and internal buffers combine to defend and maintain our normal level of subjective wellbeing. Objective measures of quality of life such as health or financial resources will vary over the life-course and from person to person. Resources (such as money, health or social care) can confer increased resilience and thus enable individuals to maintain subjective wellbeing. But resources alone cannot shift an individual's normal range of subjective wellbeing (Cummins 2013).

3.2 Social care and quality of life

The characteristics of social care make the quality of care difficult to define and to measure. Care services are described as 'performances' which are 'experienced' (Malley and Fernandez 2010). This means that the quality of the service is evident in the main as care is delivered and post hoc evaluations of care may be unreliable. It also implies that subjective evaluations are central to assessing the experience or quality of care. Efforts to assess quality of care through observational methods are likely to disturb the ecology of care and may result in modifications in the behaviour of either the caregiver or the care recipient. Covert observations of social care avoid this disturbance (and have revealed shocking instances of abusive and indeed criminal behaviour) but are ethically unsound.

Quality of life measures are used as a means of comparing the quality of care by different service providers and at different points in time. Quality of life is a concept which has attracted a great deal of interest in disability studies and literature in recent decades and for some years has been advocated as an indicator of the quality or effectiveness of social care (e.g. NDA 2007). However, both care-related and non-care related variables can influence quality of life so, differences in quality of life should be assessed with caution.

Given the multiplicity of factors that can influence quality of life scores it may be more useful to think in terms of factors that can contribute to quality of life rather than seek to attribute changes in quality of life to specific variables. Rand and Malley (2017) suggest that, while quality of life measures are likely to play an increasing role in evaluation of services, a greater understanding of all of the factors which influence quality of life is required before quality of life metrics are adopted as legitimate drivers of systems or organisational change.

Quality of life measures, therefore, have the potential to be useful outcome indicators and part of a quality assurance framework for care services but we should be careful not to overstate their importance.

3.3 From concept to outcome measure

Quality of life is now operationalised from an abstract concept to a measurable outcome for many different types of services and interventions. The support for quality of life measures is consistent with a trend towards incorporating user-perceived outcomes in the management of public services (Heinrich 2002; Wiesel et al. 2011). Despite the difficulty of translating an abstract concept into a reliable and easily administered tool there are now many instruments that are used to measure quality of life – some are generic (e.g. WHO 1998) and some are targeted at particular cohorts of people, such as adults with particular types of cancer (e.g. Avis et al. 2005) or people who have had a specific type of surgery (e.g. Vickrey et al. 1992). It is notable however that only a small number of instruments have been developed to measure social care.

3.4 Quality of life of people with disabilities

It is argued that measuring the quality of life of people with disabilities is consistent with the promotion and advancement of their human rights in accordance with the Convention on the Rights of People with Disabilities (United Nations 2006). The UNCRPD brings with it an expectation that the quality of life of people with disabilities should be comparable to that of other people in society (Bigby and Beadle-Brown 2018). Townsend-White and colleagues (2012) point to the many different ways quality of life measures can contribute to quality improvement strategies at individual, service provider, country and international

level; they claim that such measures have the potential to contribute to impact studies; inter-country comparisons; frameworks for service principles and service design; policy development and reform.

Developing an appropriate quality of life measure suitable for people with intellectual disability is especially difficult (McConkey et al. 2018; Davidson et al. 2017). Subjective measurement of quality of life relies on care recipients' ability to assess their wellbeing in a variety of domains. Measurement is normally undertaken using a questionnaire comprised of closed questions. Respondents therefore choose from a list of possible answers. Completion of such questionnaires imposes a cognitive burden on respondents, a burden that is especially heavy for respondents with an intellectual disability (McGillivray et al. 2009). Some research highlights that people with intellectual disability may be more inclined to acquiescence (providing the answer they think is desired) and recency (providing the last answer mentioned) bias (Morrison et al. 2019). Questionnaires may be designed in Easy Read format and include visual images and prompts such as smiley faces in an effort to ease the burden on respondents who may have difficulties engaging with the tool and to limit response bias. Assessing the quality of life of persons with severe/profound intellectual disability is especially difficult as subjective measurement may not be possible and the validity of proxy responses is contested.⁴ As yet, there is no generally accepted reliable means of measuring quality of life for this cohort.

3.5 Outcomes

Although the process of deinstitutionalisation has been ongoing for more than 50 years, only a slim body of methodologically sound literature is available regarding outcomes that flow from deinstitutionalisation (McCarron et al. 2018). The variation in the size and nature of both institutional and community settings and the methodological approaches hamper the evaluation of the available literature (McCarron et al. 2018). However, in their evidence review of high quality papers, McCarron et al. (2018) found that the majority of studies showed that moving to community settings was associated with improved quality of life, both overall and in most subdomains as compared to living in institutional settings. McCarron et al. (2018) conclude that more efforts are required to produce high quality research measuring the quality of life outcomes associated with moving to community settings. With these caveats in mind we set out below a brief

⁴ See Ouellette-Kuntz et al. 1994 for arguments in support of proxy responses and Green and Reid 1996; Hartnett et al. 2008; Verdugo et al. 2014 regarding the potential drawbacks of relying on proxy responses. Differences between proxy and self-assessed QOL are explored in Cummins 2002; McConkey et al. 2018.

summary of evidence regarding changes in behaviours and outcomes following transition to the community.

Research on post-congregation outcomes has focused, in the main, on aspects of life that can be objectively measured using standardised instruments (Kozma et al. 2009). The outcomes evaluated have included adaptive behaviours and behaviours that challenge, psychotropic drug use, lifestyle-related risk factors, community participation, choice/self-determination, family contact and social networks (Kozma et al. 2009). In general, research has found that people experience better outcomes across most domains in smaller scale community settings than in large congregated settings (NDA 2007; McCarron et al. 2019; Sheerin et al. 2015; Mansell and Beadle-Brown, 2008). However, better outcomes are not an inevitable outcome of decongregation (Sheerin et al. 2015). Variations in outcomes are often associated with characteristics of the clients or characteristics of the services (Robertson et al. 2000b). Positive outcomes from decongregation are most uncertain for people with high or complex needs (Kozma et al. 2009).

Chowdhury and Benson (2011) conducted a review of 15 studies that examined quality of life indicators of over 1200 participants following deinstitutionalisation. Positive outcomes commonly reported included increased opportunities to exercise choice, increased participation in a variety of leisure activities and outings, increased interaction with staff and other residents, improvements in material wellbeing, and increased levels of dignity (Chowdhury and Benson 2011, p261). Only three of the 15 studies used standardised tools to measure quality of life. Indicators of quality of life varied and included activity patterns of participants; time spent in inappropriate or neutral activities (looking, sitting passively); personal appearance; frequency of use of community facilities; trips outside home; and assessment of home environment. The authors questioned whether indicators such as a change in the amount of time spent in 'inappropriate activities' provided a valid measure of a change in quality of life and also pointed to the absence of other indicators (such as indicators related to emotional wellbeing and employment status). They noted that: "In the absence of validity estimates of the outcome measures used, it is unclear how well they assessed the construct of quality of life" (2011, p.262).

McCarron et al.'s evidence review of quality of life outcomes and costs following a move from institutional to community settings provided tentative evidence that deinstitutionalisation is associated with quality of life improvements. It should be noted however that only thirteen studies met the eligibility criteria and methodological threshold for inclusion in the evidence review. The studies largely focused on various objective measures of quality of life and differed in methodology and sample size. Quality of life subdomains assessed in the studies

included physical well-being, community access, routines, self-determination, residential well-being, and general life improvements. The authors conclude that 'the research highlights that a move from a large institution to a smaller residence is insufficient for achieving unambiguous quality of life improvements' (McCarron et al. 2018, p.70).

Research evidence suggests that a move from congregated settings to community settings often results in improvements in adaptive functioning for adults with intellectual disabilities (Lemay 2009). However, simply moving people does not guarantee improvements will be achieved. Factors associated with improvements in adaptive functioning include attractiveness and stimulation of the physical environment, opportunities for autonomy and making choices and implementation of active support (Heller et al. 1999; Heller et al. 2002; Stancliffe et al. 2002; Young 2006; Young and Ashman 2004). Improvements are dependent on the teaching of skills and opportunities to engage in domestic tasks (Lerman et al. 2005). People with intellectual disability transitioning from congregated settings to the community may also require input from occupational therapists to achieve improvements in their adaptive skills (King et al. 2017).

4. Literature relating to costs

4.1 Research on costing disability services

Research on disability services indicates that variation in support costs may be attributable to a wide range of factors including the level and complexity of the needs of individual clients, the quality and quantum of supports, the skills and skill mix of support staff, and the type and location of the support setting (Cronin and Bourke 2017; Hatton et al. 1995; McConkey et al. 2016; National Institute for Health and Care Excellence 2015). However, only a relatively slim body of literature is available and research findings have at times been inconsistent (McCarron et al. 2018).

The type of service provider and the contractual relationship with the relevant funding body may also influence the cost of service provision. Public sector provision is generally associated with higher costs and in many jurisdictions there has been a shift away from public service provision in favour of increased reliance upon the private and voluntary sectors (Humber 2016; Knapp et al. 2001; Pedlar and Hutchinson 2000). The increased marketisation of care services has resulted in funders of care in jurisdictions such as England and Australia setting prices for services.⁵ In other jurisdictions efforts to secure agreement on a pricing mechanism are ongoing.⁶ Such measures mean that the risk of cost over-runs are mainly borne by service providers and not funders. This can add to the attractiveness of shifting service provision away from the public sector, but can also result in an increased risk of instability in terms of the standard of care provided.

Variation in the cost of care has also been impacted by the legal status of agencies, the size of facilities and the profile of staff members. Costs were generally lower in Section 39 agencies⁷, while service units with 5-7 residents had lower costs per resident than units with 3-4 residents (Cronin and Bourke 2017). A recent Irish Government Economic and Evaluation Service (IGEES) report referred to high cost placements as one of the drivers of increased costs of residential services and noted “further analysis of the unit costs of residential

⁵ See: <https://www.ndis.gov.au/providers/price-guides-and-pricing#how-pricing-works> (Last accessed December 2021)

⁶ See: <https://www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/dss-pricing-programme> (Last accessed December 2021)

⁷ Section 39 organisations are Government grant-aided organisations which provide disability, mental health and community services.

service provision would be of benefit given the level of expenditure for these types of services” (Bruton et al. 2020, p.35).

Extant research indicates a consistently positive relationship between the level of need of disability residential services clients and the costs of providing services (Emerson et al. 1999; Hatton et al. 1995; Rhoades and Altman 2001). In general, higher levels of impairments and lower levels of functional ability are positively correlated with higher costs. Frequent and serious behaviours of concern are also positively correlated with higher costs. However, increased staffing levels and attendant higher costs may not result in a higher quality of service (Hatton et al. 1995). It is noteworthy that a number of studies have found that the time and attention offered by staff to persons with more severe disabilities was not always more than, and sometimes was even less than, that offered to their more able peers (Felce and Perry 1995; Felce and Perry 2004; Jones et al. 1999).

Past research has found that staffing levels and disability residential service clients’ level of support needs are often not optimally aligned. Felce and Perry have highlighted the absence of “a clear and consistent pattern of decline in staffing levels as residents’ adaptive behaviour increased” (2004, p.130) while suggesting that further research is needed to determine whether settings for people with higher adaptive behaviour are too intensively staffed.

Robertson and colleagues (2004) compared costs and outcomes for two groups of individuals with intellectual disability and behaviours that challenge. One group was supported in community based residential settings, while living alone or with housemates that did not have challenging behaviours. The other group lived in community based residences that were designated as ‘congregated’ because all the residents had challenging behaviours. Cost and quality of service data were compared for 25 residents in ‘congregated’ community-based settings with 25 matched residents in community-based settings where persons with intellectual disability either lived alone or with co-residents who did not present with challenging behaviour. The study found that support costs were higher in ‘congregated’ settings compared to other community residential settings (Robertson et al. 2004). Although congregated settings had on average higher staff-to-client ratios, quality of life outcomes were poorer for residents than in community based settings. The findings indicated that in general residents in congregated settings were more likely to be prescribed psychoactive medication, to be injured by fellow residents, to be subject to restrictive practices such as restraint, to experience a reduction in mental health and to have more restricted day activities than their counterparts in non-congregated settings. The authors comment on the unexpected absence of appropriate behaviour supports in ‘congregated’ settings and reach the conclusion that “specialist expertise in congregated facilities appears to be restricted to the use of medication specifically

to reduce challenging behaviour and use of physical restraint for the control of challenging behaviour” (2004, p.341). The findings highlight the negative consequences, in terms of both costs and outcomes, which can result from grouping people with challenging behaviour together in large institutional settings.

McGill and Poynter’s (2012) study looked at 70 high-cost placements in the Southeast of England. They found that in 2009 the mean placement cost was £172,000. Costs ranged from £88,000-£330,000, with the highest costs 3.75 times that of the lowest. Individuals in high-cost placements were predominantly male (73%), young (average age of 33, with 74% aged 39 or under) and living in a residential care home (61%). Individuals in high-cost placements were also characterised by a high prevalence of challenging behaviour and autistic spectrum disorder (McGill and Poynter 2012).

Research in Ireland has also looked at the cost of supporting adults with intellectual disabilities with high support needs (Cronin and Bourke 2017). The research focused on 68 high-cost residential placements in one county in Ireland. Like the earlier research by McGill and Poynter (2012), the study found that the mean age of 35 for high-cost clients was considerably younger than the average age of adults in residential care. The study also found that poorer levels of psychological well-being were linked to higher costs. However, it is notable that the study found no association between residents’ needs in relation to activities of daily living and the cost of supports, and no apparent relationship between staffing levels and clients’ level of need. This is consistent with the findings of Felce and Perry (2004) noted above.

4.2 Research on deinstitutionalisation and service costs

Available literature on the costs of disability services does not allow us to arrive at definitive conclusions regarding costs in different care settings. The small sample sizes included in many such studies has been noted as a limiting factor (Walsh et al. 2010). A recent review of the evidence regarding the costs of moving people with intellectual disability from congregated settings to community living arrangements was unable to present any conclusion regarding the pattern of costs following de-congregation, as the very limited evidence available presented inconclusive findings (McCarron et al. 2018). A wide-ranging literature review found limited evidence on costs associated with deinstitutionalisation⁸ for

⁸ Walsh et al. (2010) distinguish between deinstitutionalisation and post-deinstitutionalisation studies. Deinstitutionalisation studies seek to determine the impact of moving from larger institutional settings to community based settings. The focus of post-deinstitutionalisation studies is usually to compare costs and outcomes of different forms of community-based settings rather than to consider outcomes or costs following the relocation of people from one setting to another.

people with intellectual disabilities and noted significant gaps in the evidence base in relation to cohorts such as older people with serious health conditions and younger adults with challenging behaviours and complex support needs (May et al. 2019).

In the UK, deinstitutionalisation and post-deinstitutionalisation studies have, in general, linked smaller community based residences with higher costs (Emerson et al. 2000; Felce 2000; Emerson and Hatton, 1996). Higher costs in smaller settings are attributed to the loss of the economies of scale that can be achieved in larger settings. However, such economies of scale have been found to be less evident in very large services and in those supporting people with less severe intellectual disabilities (Wright and Haycox 1985). It has also been pointed out that in circumstances where staffing levels in institutional care settings were inadequate, putting in place safe and appropriate staffing levels following a shift to community based care may result in increased costs that are largely attributable to improvements in the standard of care itself, rather than the change of care setting (Wright and Haycox 1985).

Several studies have indicated that, dependent on the level of support need and the model of service provision, diseconomies of scale can occur in very small settings (Felce et al. 2003; Raynes et al. 1994). These studies indicate that when a modest but constant staff presence is required, higher per person costs can be expected in very small facilities. Diseconomies of scale set in when a reduction in staff is not possible (staff cannot be reduced below one) and the number of residents is reduced. If a continuous staff presence is not required, diseconomies of scale do not arise as staff input can be adjusted and per-capita costs can be maintained (Felce and Emerson 2005; Lakin and Stancliffe 2005).

Evidence from the US actually suggests lower costs in smaller settings following deinstitutionalisation (Rhoades and Altman 2001; Stancliffe et al. 2005). The opposing findings have been attributed to greater investment in institutional reform in the US and variation between the two countries in the relationship between the wage rates of staff in community and institutional settings (Stancliffe et al. 2005).⁹ The higher costs of institutional settings reported in the US have also been linked to what has been termed the 'diseconomies of reduced scale' that are a product of institutions providing a reduced quantum of services. It is claimed that "the common practice of downsizing (i.e., size reduction but not closure) at a gradual pace not only deprives "residual" service recipients access

⁹ In the US the wage rates of staff in community settings are generally lower than those of their counterparts in institutional settings. Differential wage rates between residential settings are not reported in respect of the UK.

to more effective opportunities and better quality of life but also subjects taxpayers to prolonged periods of paying inordinately high prices for inferior outcomes” (Lakin and Stancliffe 2005, p.322).

Christine Bigby and colleagues compared the cost of supported living for 31 adults to the cost of care in group homes in Australia. They describe the costs they present as ‘indicative figures’ as some of the funding arrangements for participants did not reflect current rates. Costs were calculated based on the type and quantum of supports provided. Their report sets out a schedule of supports and related costs and the number of participants accessing each support. Weekly costs varied and ranged from A\$213 to A\$1,877 per week (annual: A\$11,000-A\$98,000). The authors assert that supported living is substantially cheaper than care in group homes which they estimate costs a minimum of A\$80,000 per year, with day services costing a further A\$19,000. Details regarding the calculation of the cost of group homes were not provided (Bigby et al. 2018).

Emerson and colleagues compared the quality of life and care costs of twenty adults with severe and complex disabilities living in newly built residential campuses with those of twenty adults with similar disabilities living in community based dispersed housing schemes. They found that quality of life and costs were significantly greater for the adults with disabilities living in the community (Emerson et al. 2000). However, the study did not find any statistically significant difference between observed levels of staff contact in community residential settings compared to campus settings. Although staffing ratios in dispersed housing settings were 115% higher than those provided within residential campuses, staff contact was just 35% higher in dispersed housing compared to campus settings. The authors conclude that there is only ‘a tenuous relation between staffing ratios and staff activity’ (Emerson et al. 2000, p.275). However, our research points to differences in the work undertaken by staff in community and campus settings. In our study moving away from campus settings resulted in nursing and care staff undertaking duties previously assigned to catering or domestic staff. Smaller units also result in an increased administrative and regulatory workload. The expansion in the duties undertaken by nursing and care staff may lessen the time available for staff contact with residents.

Felce et al. (2008) compared outcomes and costs in the UK for 35 adults with intellectual disabilities and low support needs living in fully staffed group homes to those of 35 adults with intellectual disabilities with similar support needs living semi-independently. The majority of lifestyle outcome measures did not vary between the two groups. Both settings delivered better outcomes in specific domains. Those living semi-independently had better outcomes in terms of choice and control while those living in fully staffed houses had better outcomes for

money management and for some health indicators. Costs were lower for those living semi-independently. The authors concluded the semi-independent living could offer cost effective lifestyle advantages if appropriate attention was given to financial and health supports (Felce et al. 2008).

Felce and Perry studied the activity level of residents and the attention received from staff in 51 community residential settings and found a wide variation. Community residences were divided into four groups. The group of residences with the lowest resident engagement in activity had the highest mean staff hours per resident per week. The higher staffing ratio is also likely to have resulted in higher costs in these residences. Felce and Perry concluded that “quality of care and quality of life experienced by people with intellectual disabilities in small community residences is subject to undue variation” (2004, p.130).

4.3 Value for Money review of the Irish disability sector

The 2012 VFM review of disability services in Ireland highlighted the wide variation in costs within and between different service providers. The review pointed to a system of resource allocation based “largely on a combination of historical factors and emergency demographic pressures” (Department of Health 2012, p.126). This resulted in considerable divergence between the notional cost and the actual cost of day and residential places. It concluded that there was no effective system of resource allocation in place. The review indicated that larger agencies have higher rather than lower average costs in most categories of service. However, the level of support required by disability residential service clients clearly affects costs, and the support needs of clients generally varies between agencies. Almost half (46%) of persons with the highest level of support needs are supported by the five largest agencies - Brothers of Charity Services, Saint John of God Community Services, Daughters of Charity Disability Support Services, St Michael’s House, and Cope Foundation (Campbell et al. 2017).¹⁰ As these agencies support around 40% of all persons with disabilities in residential care, they are likely to incur higher costs in light of the level of support needs among their clients.

The VFM review revealed that negotiations between the HSE and service providers sometimes resulted in funding for two notional places being allocated to one person. In other instances, the supports allocated to disability residential service clients exceeded their needs and the excess was used to cover the additional needs of other clients with higher support needs (Department of

¹⁰ The ‘Top 5’ agencies can change over time as a result of changes in the proportion of funding allocated to individual agencies. The agencies referenced were the agencies receiving the highest amount of funding during the VFM review.

Health 2012, p.119). This approach resulted in difficulties determining the actual number of people in receipt of supports. The review also highlighted the absence of any objective measures of effectiveness, which meant that it was not possible to correlate cost variations to differences in quality of services.

The VFM review pointed to significant regional variations in service cost and noted that “no clear pattern emerges that pinpoints one region as having higher costs across the board. Instead, a region that has the highest cost for one service type is lower or lowest for another” (Department of Health, 2012, p.99). For example, the Dublin Mid-Leinster region was found to have the lowest cost for 7-day High Support residential services while costs were highest for this type of service in the South. However, lower costs were reported in the South for other residential service types and the cost of 7-Day Minimum Support residential services in the South was substantially lower than in other regions. The support needs of residents were very similar across regions and did not explain the variability reported. Some of this variability may be attributable to differences in the approaches adopted to costing services.

Significant cost variations were also reported between the statutory and non-statutory sectors. However, as with regional variations no clear pattern emerged. The costs reported in each sector for different services varied and were not consistently higher or lower. Since the VFM report a series of Key Performance Indicators (KPIs), which will be discussed later in this chapter, have been developed by the HSE to measure the effectiveness of disability services. A recent Spending Review conducted by the Irish Government Economic and Evaluation Service (IGEES) pointed to the continued absence of a coherent and consistent link between outputs and the funding of disability services. The authors concluded that “there needs to be a renewed push for reform of resource allocation within the disability sector to ensure that resources are optimised” (Campbell et al. 2017, p.33).

4.4 International approaches to costing disability service reforms

Service reforms in other jurisdictions such as Australia and the UK have led to significant improvements in choice and control for residents, improved quality of service and greater efficiencies. Australia has put in place transparent pricing models and measures to promote the supply of disability services. The transition from block-funding to individualised funding for disability supports was made possible as a result of general societal consensus that fundamental reform of the sector was necessary. It was also supported by a substantial increase in the funding provided for disability supports.

In the UK, the market in social care has expanded due to local councils reducing their role as providers of care. Local councils have struggled to achieve the dual

goals of maintaining market stability and achieving cost effectiveness. Assessing true costs of disability supports is considered to be central to achieving both these goals. In both of these jurisdictions the system of commissioning and funding supports for persons with disabilities explicitly recognises the importance of establishing and reimbursing the true costs of care. New Zealand is also seeking to put in place a pricing tool for residential services. This is being progressed in consultation with service providers.¹¹ Service reforms in these jurisdictions present a range of policy options that could be adopted to reform the disability sector in Ireland. In particular, further attention should be given to the budgetary and service quality implications of international reforms (See Appendix I).

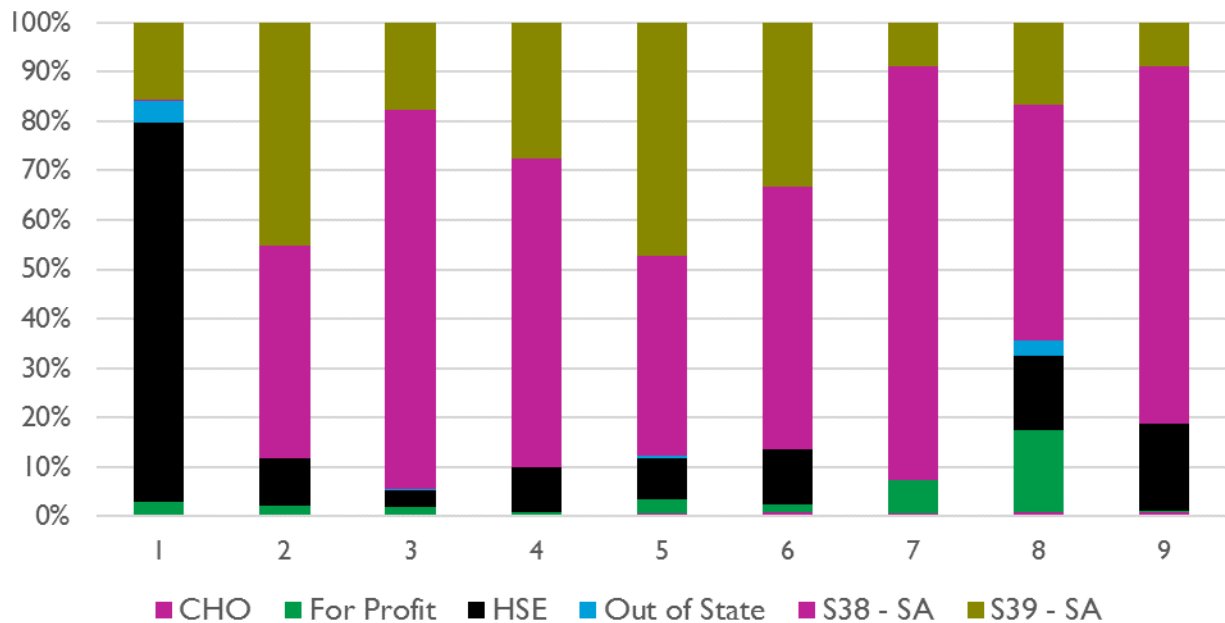
4.5 Funding arrangements in the Irish disability services sector

In Ireland the majority of residential care places are provided by non-statutory organisations. The dominant role of Section 38 and 39 agencies reflects the historical origins of service provision and the State's continued substantial reliance on the not-for-profit sector for the provision of disability services. A pivotal determinant of the funding arrangements between the HSE and non-statutory agencies is the designation of the agency as either a Section 38 or a Section 39 agency. Section 38 agencies provide a defined level of service on behalf of the HSE. In contrast, the HSE provides Section 39 agencies with grant-aid for services. Employees of Section 38 agencies are public servants. They are paid the same rates of pay as persons employed directly by the HSE and most enjoy the same access to public service pension schemes. Employees of Section 39 agencies are not public servants and are not necessarily in receipt of the same pay rates and conditions as public servants. Private providers of disability services are Section 39 bodies. The share of services provided by Section 39 bodies has remained minor and disability service provision continues to be largely the domain of voluntary not-for-profit agencies. However, the for-profit sector is the fastest growing sector. An analysis of places in designated centres registered with HIQA indicates that the HSE directly provides 12.3% of places in designated centres, Section 39 organisations provide 31.3% and Section 38 organisations provide 56.4% (HIQA 2020).

However, all available places in designated centres may not be occupied. An analysis of residential placements for 2018 indicates that the HSE directly provided 15.4% of all residential placements. As Figure 3.1 below highlights the pattern of provision within CHOs areas differed markedly.

¹¹ <https://www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/dss-pricing-programme> (Last Accessed December 2021)

Figure 3.1: Residential placements by provider type and CHO



Source: HSE

While there are approximately 200 non-statutory agencies providing disability services, funding is concentrated in a relatively small number of service providers (Department of Health, 2012, p.37). The VFM review of spending on disability services indicated that 86% of spending was absorbed by the 17% of providers that received funding of more than €10 million in 2009. The 2% of agencies that received funding of more than €50 million accounted for 27% of spending (Department of Health 2012, p.37). Analysis by the HSE Service Improvement Team indicated that in 2016 funding allocated to the ‘Top 5’ agencies amounted to €557m. This was equivalent to 35.8% of all HSE funding for disability services in 2016 (HSE 2017b). This contrasts to the position in the UK where, as noted previously, the largest four providers account for just 7% of the total value of the market. The recent independent review of the role of voluntary organisations in providing health and personal social services in the UK pointed to the requirement that local councils identify “difficult to replace” providers whose failure might destabilise the market. The review recommended that a similar list be compiled in Ireland and that the HSE put in place plans to ensure the continuity of such services (Day et al. 2019).

In Ireland, the HSE advises non-statutory agencies that a breakeven position is mandatory and that it cannot commit to covering cost overruns or deficits (HSE 2019a). However, in recent years many agencies have highlighted the inadequacy

of established funding levels to cover their service delivery costs.¹² Ireland's major service providers often report significant operating deficits. When agencies incur deficits, they typically seek to negotiate additional funding from the HSE.¹³ As additional funding has generally been secured through such negotiations, it appears that the HSE carries much of the risk of cost over-runs in the sector.¹⁴ Catherine Day, the Chair of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services, has argued that funding to service providers should represent the full cost of delivering services (Joint Committee on Health 2019). However, it is important, and indeed imperative, that the need to fund costs in full is not interpreted as an obligation to fund deficits incurred by wasteful, uncontrolled or inappropriate expenditure of service providers.

4.6 Factors affecting the cost of service delivery

There are a broad range of factors that can significantly impact upon the operating costs of disability service providers. Such factors may differ across service providers on the basis of their own particular structural or organisational characteristics, or may change over time simultaneously for all service providers on the basis of changes to the regulatory environment or fluctuating market conditions. Other factors affecting variation in service delivery costs are differences in employee wages and employer pension contributions. All agencies are required by the HSE to disclose the number of employees paid in excess of €60,000 in bands of €10,000 (DPER 2014). The disclosures reveal generally disparate employee structures and salary implications across the Top 5 agencies. In some cases such differences are reflective of the fact that the mix of services provided may differ, leading to the need to hire specific personnel and resulting salary cost implications. Employer pension costs are, for the most part, absent from the audited financial statements (AFS) of the Top 5 agencies. Superannuation benefits for employees of these and other Section 38 agencies

¹² See: <https://www.iwa.ie/disability-organisations-warn-health-committee-of-funding-crisis/>
<https://www.irishtimes.com/news/ireland/irish-news/unacceptable-use-of-client-funds-at-stewarts-care-focus-of-review-1.3963286>;
<https://www.independent.ie/regionals/goreyguardian/news/st-aidans-services-on-brink-of-closure-37471393.html> (All last accessed December 2021)

¹³ Saint John of God Community Services CLG 2019, p.14; Brothers of Charity Services Ireland CLG 2018, p.6

¹⁴ <https://www.independent.ie/irish-news/health/government-secures-2m-in-funding-to-fund-rehab-after-fears-services-would-shut-38134641.html> (Last accessed December 2021)

are largely provided by State pension schemes.¹⁵ By contrast, it is likely that most Section 39 agencies pay an employer's contribution towards employee pensions. The absence of the cost of employers' pension contribution in the audited financial accounts of most providers in the sector results in an understatement of the costs of disability services if looking at the AFS alone.

Another factor leading to differences in the financial outcomes of agencies is that of their clients' financial contributions. Contributions in respect of the cost of residential care provided by the HSE and Section 38 agencies are standardised (HSE 2019b).¹⁶ Charges vary according to the income of the individual care recipient and the amount of medical or nursing care provided on site. The upper limit of charges is equivalent to 80% of the maximum non-contributory state pension. A waiver of charges to avoid financial hardship can be applied for. The AFS of the Top 5 agencies include details on income from their clients. The level of income from client contributions disclosed in the accounts of each agency can vary considerably.

The insurance costs included in the AFS of the Top 5 agencies and in the accounts of other Section 38 bodies can also vary significantly, and often do not reflect the total cost of insurance that prevails in the market more broadly. Section 38 agencies are indemnified by the State Claims Agency in respect of certain risks. The claims covered by the State Claims Agency include:

- Injury to employees
- Injury to a member of the public
- Clinical negligence
- Third-party property damage

As a result of this indemnity, the insurance costs borne by Section 38 agencies are considerably reduced. In contrast, Section 39 agencies pay insurance costs in respect of all risks and must have the level of cover stipulated in Service Level Agreements with the HSE. A recent escalation in the cost of insurance for agencies not within the remit of the State Claims Agency has been an issue of discussion in recent Dáil debates.¹⁷

¹⁵ Government departments operate the State pension schemes and the agencies consider that they operate as agents for the relevant departments and have no obligation to contribute financially to the schemes.

¹⁶ Further details regarding the Residential Support Services Maintenance and Accommodation Contributions (RSSMACs) are set out in Appendix Six.

¹⁷ <https://www.kildarestreet.com/debates/?id=2019-11-27a.469>

4.7 Cost implications of decongregation

In comparing costs before and after decongregation, consideration should be given to the fact that the quality of support provided pre and post decongregation is likely to differ, with higher quality service outcomes generally anticipated in community based models of care. On the basis of a review of relevant literature the Working Group on Congregated settings concluded that “there is no evidence that community-based models of care are inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and comparable quality of care” (HSE 2011, p.64). It pointed to the need to compare equivalent costs of care in assessing support costs in congregated and community settings. The report noted that “the costs being incurred are based on the existing service model in these settings, and are not directly comparable to the community-based approach being proposed by the Working Group” (HSE 2011, p.110).

Using cost data for 2006 in respect of 70 of the 72 congregated settings, the Working Group reported that the average annual per capita cost of supporting a resident in a congregated setting was €106,000. Per capita costs varied from approx. €37,000 to €232,000 (HSE 2011, p.47). On average, pay costs accounted for 83% of total running cost. The average annual cost per staff member was €54,000.¹⁸

The Working Group on Congregated Settings also found that the ratio of staff to residents in congregated settings was 1.65:1. This was based on data from 69 centres that accommodated 81% of all residents. A total of 5,368 staff were employed within the centres, including 414 management and administration staff, along with 87 medical or therapeutic staff (HSE 2011, p. 46). While the Working Group report includes many findings of interest, the relevant 2006 field research data is now too dated to inform a cost assessment seeking to compare the current cost of service provision pre and post decongregation. The introduction of new HIQA standards for residential care from late 2013 onwards has led to increased staffing requirements, including the need for adequate night staffing for safe evacuation in the event of fire being highlighted in many inspection reports.¹⁹

¹⁸ This average was based on all staff (including medical, clinical and management staff) in 66 of the 72 congregated settings. The report of the Working Group on Congregated Settings indicates that almost 40% of staff in congregated settings were nursing staff and a further 39% were care staff or social care workers. The remainder of the staff were housekeeping/catering (11%) management and administration (8%) and medical/therapeutic (2%).

¹⁹ Staffing levels may also be the outcome of a negotiation process with staff around the transition, rather than based on assessing levels of support need.

General staffing pay levels and working arrangements have also changed following several rounds of public service pay agreements in the period since 2006.

Appendix I: International approaches to funding and costing disability services

Many developed countries have introduced reforms in commissioning, funding and delivery of disability supports. Reforms have been variously associated with promoting choice and control, improving quality and delivering cost efficiencies. This section focuses on recent developments and approaches adopted in Australia and the UK, as the information available regarding costing models for services is especially relevant to this study.

Australia

Australia is of particular interest as prior to the recent major reforms the system of funding long-term care was very similar to that in Ireland (Davidson et al. 2012). In Australia, a report of a public inquiry became a catalyst for major reform of the disability sector. In 2011, the public inquiry into the National Disability Long-Term Care and Support Scheme reported that:

The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports (Australian Government, Productivity Commission 2011 p.2).

The inquiry, in conjunction with a coordinated public campaign supported by an alliance of disability service providers, advocacy and family carer organisations, generated widespread political and public support for fundamental reform. Olney and Dickinson contend that framing reform as a human rights issue ensured cross party political support (2019, p.277). In 2013, legislation to establish the National Disability Insurance Scheme (NDIS) was enacted. The gradual rollout of the scheme began in 2016 with the national rollout initially scheduled to be completed by 2019-2020. This target has since been recognised as overly ambitious and unachievable (Australian Government, Productivity Commission 2017, p12).

Eligibility for the NDIS requires that a person has a permanent impairment that adversely affects their daily functioning. The term “permanent” implies there is no available treatment to remedy the impairment. NDIS funds “reasonable and necessary supports”. These are defined as “those that help participants live as ordinary a life as possible, including care and support to build their skills and capabilities, so they can engage in education, employment and community activities” (Australian Government, Productivity Commission 2017, p.3). The scheme is designed to provide supports in conjunction with informal, community and mainstream supports. In 2017, the number of NDIS participants was

projected to reach 475,000 by 2020. This level of coverage would constitute 11% of the population of persons with a disability and 1.9% of the total Australian population (Australian Government, Productivity Commission 2017, p.4). In an Irish context, an equivalent level of coverage would result in 71,000 participants.²⁰ As of 30 June 2019, approx. 300,000 persons with disabilities, or 1.2% of the total Australian population were being supported by the NDIS (NDIS 2019a, p.5).

NDIS is premised on the belief that disability is largely unforeseeable, unavoidable and indiscriminate, and the cost of supporting those with disabilities should be borne by society as a whole. The corollary of this premise is that costs that are not disability-related should not be shared. This provides the rationale for excluding from the scheme costs that are not disability-related.

The scheme involves a shift away from a block-funded welfare model of support, to a fee-for-service market-based approach. Its introduction resulted in greatly increased funding for the disability sector.²¹ An annual financial sustainability review is conducted and reviewed by an independent actuary (NDIS 2019a) but the test of the financial sustainability of the scheme has been summed up as “taxpayers’ continuing willingness to pay for it” (Australian Government, Productivity Commission 2017, p.7).

The success of NDIS is dependent on the ability of disability support providers to adapt, grow and respond to the needs and choices of participants. Its ambition and the scale of the planned change is remarkable. The Productivity Commission notes that:

Disruption of the disability supports market is designed to maximise the choice and control of participants, while also giving providers incentives to efficiently and effectively deliver the supports that participants want and need. While the scheme will drive efficiencies, the increase in funding and considerable unmet need in the disability support sector means that the number of workers and providers will need to grow quickly over the transition period. For example,

²⁰ This estimate is based on 11% of the population of persons with a disability as indicated by Census 2016. Compared to the Irish population a higher percentage of Australians report a disability (13.5% versus 18%).

²¹ In 2017 funding was projected to increase from A\$8bn to A\$22bn in 2019-2020 (Australian Government, Productivity Commission 2017). While the gross cost of the NDIS is estimated to be A\$22bn at full scheme commencement, the scheme is expected to reduce the funding required for a range of government programs. A review by the Australian Government Actuary in 2011 estimated that these offsets were about A\$11bn (Australian Government, Productivity Commission 2017, p.15).

the NDIS workforce will need to more than double from 2014/15 to 2019/20 (2017, p.32).

The scale of the reforms and the speed of implementation has inevitably resulted in criticisms and failures. The interpretation of “choice and control” and “reasonable and necessary supports” has resulted in some participants feeling that the scheme has not delivered on its promises. The administrative burden of the scheme has also been criticised, although participants that lack the capacity or simply do not want to manage their funding can opt to engage a plan manager to take on administrative tasks. Sourcing services has also proved difficult for some participants, especially those living in more isolated regions (Olney and Dickinson 2019). The scheme is described as “stretching the capacity of government, its agents, public and private service providers, community partners, people with disabilities and their support networks” and providing ongoing challenges to those tasked with realising its lofty aims (Olney and Dickinson 2019, p.287).

The operation of the Australian NDIS

Individuals with disabilities who wish to participate in the NDIS must submit a request to access the scheme. This involves establishing that they have a disability that adversely affects their functioning as defined by the scheme. If this request is successful, a personal plan is drawn up that considers current supports and any unmet needs and identifies specific goals. Applicants are encouraged to seek the support of the Local Area Coordinator or a planner appointed by the National Disability Insurance Scheme Launch Transition Agency to draw up their support plan. The National Disability Insurance Agency (NDIA) is an independent statutory agency, whose role is to implement the National Disability Insurance Scheme. Personal plans must be approved by the NDIA. When the plan is approved, participants must choose the services and supports that meet their needs and help them to achieve their goals.

The types of supports that NDIS may fund for participants include:²²

- daily personal activities
- transport to enable participation in community, social, economic and daily life activities
- workplace help to allow a participant to successfully get or keep employment in the open or supported labour market
- therapeutic supports including behaviour support

²² See: <https://www.ndis.gov.au/understanding/supports-funded-ndis>

- help with household tasks to allow the participant to maintain their home environment
- help to a participant by skilled personnel in aids or equipment assessment, set up and training
- home modification design and construction
- mobility equipment
- vehicle modifications

NDIS does not provide funding for supports that:

- are the responsibility of another government system or community service
- are not related to a person's disability
- relate to day-to-day living costs that are not related to a participant's support needs
- are likely to cause harm to the participant or pose a risk to others

Funding is also provided for Specialist Disability Accommodation for persons with extreme functional impairment or very high support needs. Such funding relates to the cost of the dwelling. This funding is viewed as an important means of stimulating the supply of specialist accommodation for persons with disability and thus providing more choice for those who require housing modifications. It is hoped that it will reduce the inappropriate admission of younger people with disabilities to aged care facilities.²³

The NDIS has involved the development of a National Costing and Pricing Framework for Disability Services to assist disability providers to adopt management accounting processes necessary for the unit cost approach that underpins NDIS (Gilchrist 2014). The prices set, which are stipulated by the NDIA, seek to deliver value for money while also encouraging the market supply of disability supports. It is anticipated that the price levels set to promote supply will reduce in time as the market expands (NDIA 2019, p.28). An Annual Price Review is undertaken by the NDIA to ensure that prices are aligned to market trends and changes in costs. A review conducted by a firm of consultants recommended 22 changes to the pricing structures in place (McKinsey & Company 2018). The recommendations were all accepted by the NDIA.

²³ See: <https://www.ndis.gov.au/news/1448-governments-take-action-increase-specialist-disability-accommodation> (Last accessed December 2021)

Fixed prices are set by the NDIA. The prices set seek to deliver value for money while also encouraging the market supply of disability supports. It is anticipated that the price levels set to promote supply will reduce in time as the market expands (NDIA 2019, p.28). An Annual Price Review is undertaken by the NDIA to ensure that prices are aligned to market trends and changes in costs. A review conducted by a consultancy firm recommended 22 changes to the pricing structures in place (McKinsey & Company 2018). The recommendations were all accepted by the NDIA.

The cost model specifies three different grades of support workers:

- Standard or Level 1 DSWs;
- High Intensity or Level 2 DSWs;
- And Very High intensity or Level 3 DSWs

The pay rates used for each of the three different grades of support workers are based on agreed rates for selected levels of social and community services employees. Eight levels of social and community services employees are specified with 3-4 different pay rates at each level. The rates used are based on level 2 and level 3 employees. By contrast, in HSE and Section 38 services that use the HSE's Consolidated Pay Scales, the incremental pay system means a large number of separate pay rates in each grade. Thirteen different pay rates are in place for both intellectual disability staff nurses and care assistants. Twelve pay rates are in place for social care workers with a qualification and eleven for those without a qualification (HSE 2019c).

The NDIA also issue 'Market Position Statements' to enable providers to respond to areas of expected demand growth and to inform them regarding geographical variations in the market for disability supports. The aim is to promote choice and control for participants by encouraging a range of providers and to encourage links with other pillars of support and services.²⁴

Assistance provided in Shared Living Arrangements is not subject to fixed prices. Until 1 July 2020 Providers quote for the specific Supported Independent Living (SIL) service they offer each participant. Providers bear any costs that arise from vacancies in a household. A providers' SIL pack that includes a number of templates assists providers to prepare quotations. Provider quotes identify separately supports planned for individual participants, and supports that ensure

²⁴ See: <https://www.ndis.gov.au/providers/working-provider/market-information/market-position-statements> (Last accessed December 2021)

the smooth and efficient management of the household. Individual supports are required to focus on maximising the person's capacity to be as independent as possible with household decision making, personal care and domestic tasks. Provider quotes are analysed by the NDIA to make sure that they represent value for money. The NDIA may enter into negotiation with providers to agree appropriate prices for SIL.

From 1 July 2020, providers will no longer need to submit a quote for SIL pricing. Instead providers will be required to develop a roster of care (ROC) and submit it to the NDIA for approval. The NDIA is currently conducting a review of SIL price controls. Until this review is complete, the price limits for assistance with daily living will apply to SIL supports. Existing plans containing agreed SIL quotes will continue until the end of their 12 month term, at which point the new SIL price limit will apply. Set price limits for SIL supports will replace the current quoting and negotiation process. The changes are being introduced to make the process of agreeing a price for SIL more streamlined.

NDIS does not cover living expenses such as cost of groceries, rent, utilities, or expenses related to holidays. Specific supports such as assistive technology, personal care while in the workplace, financial intermediary supports and specialist disability accommodation costs are considered independently of funding for SIL.

New Policy Directions in the United Kingdom

Shifts in the commissioning, funding and provision of disability services in the UK have resulted in major changes in the disability sector in recent years.²⁵ These changes stem largely from the increased prominence of individualised funding and person centred supports. They also result from efforts to deliver cost-effective services. While there are major differences between the Irish and UK disability sectors, it is instructive to explore the effect on costs brought about by the changes in the UK.

The responsibility for social care lies with UK local authorities who are required to provide services based on assessed need and means. Although funding has increased in recent years, the increase has not been sufficient to address the funding gap that developed as a result of several years of underfunding. As a result of funding pressures, local authorities are providing care and support to fewer people and concentrating it on those with the highest levels of need. A recent report concluded that the combination of needs and means testing results

²⁵ As a unified approach is not adopted within the UK, this section largely focuses on policy and practice in England.

in local authority funding only being available “to people with the lowest means and highest care needs” (Idriss et al. 2020 p.11). Many commentators have expressed concerns regarding the sustainability and stability of current care arrangements (House of Commons Health and Social Care and Housing, Communities and Local Government Committees 2018; Idriss et al. 2020).

In recent years direct provision of services by local authorities has reduced considerably, largely due to the much higher costs associated with such services. Independent providers include for-profit and not-for-profit providers. In England, disability services for younger adults (18-64) are now largely (around 90%) provided by independent providers.²⁶ UK providers of ‘adult specialist care’ are increasingly for-profit organisations. A corollary of the increased role played by for-profit providers in the UK care market is the increased relevance and importance of analysis and data about this market generated by private consultants. The provision of care for adults with disabilities in the UK is more fragmented than in Ireland. The largest four providers account for just 7% of the total value of the market (LaingBuisson 2018). In the UK, the monopsony²⁷ position of local authorities, the collapse of a growing number of care providers and a trend towards providers withdrawing from contracts for social care services has led to concerns regarding the stability of the care market (Cunningham et al. 2019). However, the market for adult specialist care is considered to be more stable than the market for the care of older people. This is partially because of the “stickiness” of clients who tend not to seek to change provider, and partially because of the higher levels of fees.

Instability in the market can stem from the withdrawal of providers due to negative or insufficient financial returns. Precipitous downturns in the financial position of providers can be triggered by care failings - particularly when these are highlighted in the public arena. The UK Care Act 2014 includes provisions designed to promote the stability of the care market. Market stability is promoted by enabling new entrants to join the market and by managing exits from the market, especially the exit of large providers from the market. Local authorities are required to identify ‘difficult to replace’ providers that could destabilise the care market if they were to fail. These providers are the subject of greater regulatory scrutiny than other providers. If a risk of failure is identified, contingency plans are drawn up with a view to minimising disturbance to clients. Despite these measures, the market is still considered to be described as “fragile” or “broken” (House of Commons Health and Social Care and Housing,

²⁶ See: <https://www.laingbuissonevents.com/wp-content/uploads/2017/05/WAL-ASC.pdf>

²⁷ Single buyer

Communities and Local Government Committees 2018, p.13; Idriss et al. 2020, p.2).

Price is also recognised as a key factor in maintaining market stability. Statutory guidance on the implementation of the UK Care Act 2014 states that:

“Local authorities should not undertake any actions which may threaten the sustainability of the market as a whole – for example, setting standard fee levels below an amount which is sustainable for providers in the long-term” (UK Department of Health 2014)

Local authorities have sought the input of external analysts to ensure that their fee structure does not undermine the long-term sustainability of providers. Profit, or a margin in addition to costs, is considered essential to long-term sustainability. This is regardless of whether the provider is a for-profit or not-for-profit organisation. The need to provide for a margin over costs is also echoed in the Australian National Costing and Pricing Framework for Disability Services (Gilchrist 2014). In Australia, disability service providers are advised to price their services based on the comprehensive cost and a mark-up. The message is clear: ‘it is necessary for disability service providers to recover all their costs and generate a profit to remain sustainable’ (Gilchrist 2014, p.4).

The broad mix of supports provided in the UK have changed in recent years. There has been a shift away from residential care and an increase in the proportion of adults accessing supported living arrangements in combination with a personalised budget. Demand for residential care remains strong among younger adults with complex needs and/or behaviours that challenge (Institute of Public Care 2014).

Approaches to costing services in the UK

The costing methodology for residential care developed by Beecham and Knapp more than a quarter of a century ago continues to be highly influential in the UK. In essence, the methodology determines costs of care by taking account of all relevant costs, including central overheads and capital costs. Detailed information on staffing levels, costs and clients’ use of services is compiled from information provided by care facilities. The composite information provides estimates of average costs (Beecham and Knapp 1992; Knapp 1995).

The approach developed by Beecham and Knapp broadly aligns with the methodology adopted by LaingBuisson in conducting costing surveys for health and social care. LaingBuisson are influential providers of ‘healthcare business intelligence’. Their services reflect the marketization of health and care services, in the UK and internationally, and the demand for data and analytics specifically tailored for markets, and indeed sub-markets, of health and social care.

LaingBuisson produce regular market briefings. A recent briefing highlights that providers of adult specialist care are earning significantly higher margins than providers of care for older adults (Laing 2019). An earlier briefing warned that providers relying on a single council and “low-intensity residential services” were highly vulnerable and contrasted that with the much less vulnerable position of “services catering for high-intensity, specialised demand drawing on a regional or even national catchment area” (Laing 2017).

In addition to being a resource for private investors, LaingBuisson reports are widely referenced within UK government reports and those of policy advocates. Various LaingBuisson reports are referenced throughout the Personal Social Services Research Unit (PSSRU) annual reports on unit costs of health and social care. We reviewed two publicly available LaingBuisson studies (LaingBuisson 2013, 2016). We focus in particular on the 2013 study that set out to determine the true costs of care incurred by providers of residential care and supported living services in Surrey to people with learning disabilities.²⁸ The methodology used was a costing survey. Responses were received from 20 residential care and 12 supported living arrangements. The 20 residential care settings ranged from 3-bed units (4) to 10-bed units (1).

The findings indicate a wide divergence of unit cost levels. Divergence in salary costs was a key factor and was an important contributor to variation in overall unit costs. The report notes that “in many instances, staffing mix can become top heavy and overly costly over time, as promoted staff are sometimes not re-deployed and staffing structures not fully adjusted to achieve the most cost-effective mix of experience” (LaingBuisson 2013, p.5). High salary rates were also typically accompanied by higher than average holidays, pensions and paid sickness. These ancillary benefits increased the basic pay differentials. The study notes that, typically, central overheads account for 8-9% of total costs but also points to significant variations in these costs.

The median size of residential care units in the Surrey cost survey was six beds. The report notes that because of the small number of responses from homes of other sizes it was difficult to arrive at “fully differentiated cost models” (LaingBuisson 2013, p.30) which could capture the relative unit costs of supporting individuals in different housing settings. It pointed out that while there was some evidence of economies of scale, there were also anomalies that were not consistent with the expected pattern.

²⁸ Learning Disabilities is the term used for Intellectual Disabilities in the UK.

The survey indicates that the cost of supporting a person with low, moderate and high needs in a three-bed home was higher than the cost of supporting that person in a six-bed home. However, it did not find any material difference between the cost of supporting an individual with low, moderate or high support needs in a six-bed home compared to an eight-bed home. Low need was defined as requiring 30 hours support per week, moderate need was defined as 65 hours of support per week and high need as 100 hours of support per week. The report also notes that it was not possible to link differences in hourly staff costs for individuals with different levels of support need. It states:

We would expect that staff working with those with higher needs would need to be more experienced and higher paid individuals, but this cannot be identified from the data, due to differences in levels of costs between providers - (LaingBuisson 2013, p.10).

Additionally, expected higher levels of management supervision, behaviour management support and individual expenses for clients with higher support needs, were not discernible from the available data. The study suggests that many providers were not recouping the total cost of care. It found that not-for-profit providers were especially likely to have negative margins. This was attributed to “high inherited staffing costs” (LaingBuisson 2013, p.16). The study points to the difficulty of allocating overheads fairly and points out that using a standard hourly rate that incorporates variable and fixed costs can result in the under-recovery or over-recovery of fixed overheads, as these may not vary with the amount of support provided, but rather with the number of people supported. Client mix can have significant implications in terms of cost recovery. This issue is illustrated by comparing the fixed overheads recouped from clients with low needs compared to that recouped when supporting clients with high needs. The report concludes that:

“high needs individuals tend to end up subsidising lower needs individuals, in terms of the fees received, based on standard hourly rates, and lower needs clients can be unprofitable to support” (LaingBuisson 2013, p.17).

Annual UK report on unit costs of health and social care

The Personal Social Services Research Unit (PSSRU) report on health and social care costs is an annual report that is funded by the UK National Institute for Health Research. In the preface to the report the authors contend that “how much a service costs is an important pre-requisite of evaluating how effective and efficiently care is being delivered” (Curtis and Burns 2018, p.1). The report is very wide-ranging and includes costs of various categories of community and hospital-based staff, services for older people and people with mental health

problems, hospital services, services for children and families and services for people with learning disabilities and those who require physical supports.

Section 4 of the report, which deals with services for adults requiring learning disability support (age 18-64), is of particular interest for our purposes. Unit costs include those for local authority day care, residential care homes, homes for adults on the autism spectrum and complex needs, and positive behavioural supports. The costs presented draw on a range of databases including Adult Social Care Finance Return (ASC-FR) and the Personal Social Services Expenditure Returns (PSS Ex1). Other data sources include previous research by PSSRU and other academics. The ASC-FR is populated with returns from local authorities in England. The databases ensure that the average unit costs calculated are representative of actual costs. They also promote the transparency of health and social care costs.

The primary reason for support among most adults aged 18-64 in receipt of residential care is intellectual disability. The average weekly cost of supporting a working aged adult with an intellectual disability in residential care is higher than for any other category of clients. As a result, while almost twice as many older adults receive residential care compared to adults aged 18-64, total spending on residential care for the two groups is roughly the same.²⁹

In 2018-19 the median cost per person of long-term residential care for adults (18-64) with learning disabilities was £1,520 per week (around £79,000 a year), an increase of 4.5% from the median cost for 2017-18 (Curtis and Burns 2019, p.56; 2018, p.55). The report provides models that set out the estimated average weekly cost under various cost categories per person receiving low (30 hours per week), moderate (60 hours per week) and high support (100 hours per week) while living in a residential care home or a supported living arrangement. The model is based on the LaingBuisson Surrey cost survey (2013) with updated costs. The model for calculating the cost of care for adults with autism and complex needs was drawn up in collaboration with three members of the Autism Alliance. The average cost of care was calculated by combining the average costs from each of the three participating agencies. In 2018-2019 the average weekly cost of supporting an adult with autism or complex needs was £1,866 before day care costs and £2,371 including day care costs (Curtis and Burns 2019, p.60). These are annual amounts of around £79,000 and £123,000 respectively. In 2018-19 the median weekly cost of residential care in local authority care homes for persons with a physical disability was £944 stg per week (£49,000 annually). The

²⁹ See: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2018-19/4.-long-term-care#long-term-care> (Last accessed December 2021)

median weekly cost excluding capital costs of land and buildings was £757, or around £39,000 a year (Curtis and Burns 2019, p.64).

Appendix 2: The financial position of major Irish service providers

As part of our evaluation of disability costs in different settings and using different service models we examined the Audited Financial Statements (AFS) of a number of disability providers. We focused in particular on the AFS of five³⁰ of the largest agencies for the years ended 31st December 2017 and 31st December 2018.³¹ Each of these five agencies are Section 38 agencies. The AFS of a number of other smaller agencies were also examined. Four of the five largest agencies reported a financial deficit in 2017, three did so in 2018 and four did so in 2019.³²

Table A2.1: Surplus/Deficit reported by Top 5 agencies in 2017 and 2018

	Brothers of Charity	Saint John of God CS	Daughters of Charity	St. Michaels House	Cope Foundation
	€	€	€	€	€
2017	(2,434,107)	(8,985,584)	(388,698)	472,141	(1,593,998)
2018	(3,987,096)	(6,525,570)	312,314	821,813	(1,372,831)
2019	(1,562,310)	(5,600,000)	654,655	(431,234)	(1,815,600)

Source: AFS of Agencies

Several factors need to be taken into consideration when examining the financial positions of these major service providers. While some agencies may report operational deficits for their disability services, many exist within larger parent organisations with complex legal and financial structures involving multiple distinct legal entities and balance sheets, not all of which are loss-making. In particular cases, the parent organisation may own significant asset portfolios, or

³⁰ Brothers of Charity Services Ireland CLG 2018, 2019; Saint John of God Community Services CLG 2018; Daughters of Charity Disability Support Services 2018, 2019; St Michael's House 2018, 2019 and Cope Foundation 2018, 2019.

³¹ Much of the analysis presented in this section focuses on 2017. Agencies in receipt of grants/funding from public bodies are required to provide AFS 'without delay' after the end of the financial year (see Circular 2014/13: <https://circulars.gov.ie/pdf/circular/per/2014/13.pdf> (Last accessed December 2021)). The HSE also stipulates that Financial Statements for all agencies managed by service level agreements are available on agency websites (see HSE 2019a). We encountered some difficulties finding Financial Statements on the websites of certain agencies.

³² Several other large agencies have also incurred recent deficits. For example in 2017 Stewarts Care Ltd incurred an operating deficit of over €3.5m.

own holding companies which own assets such as property or capital reserves. In cases where these assets are utilised by entities within the wider group, they use complex intra-group payments, structural transactions and asset transfers which significantly complicate any effort to assess the true financial position of these agencies in the context of disability services.

Comparison of the AFS of the five agencies is also complicated by the lack of a reliable standardised accounting format and differences in the mix of services provided by each.³³ All of the Top 5 agencies provide core (day, residential and respite) services for people with intellectual disability. However, the ancillary services provided by the agencies can differ. For example Saint John of God Community Services encompasses a range of mental health services including day hospital, outpatient clinics and acute in-patient beds, as well as operating private services. Similar services are not provided by the other four agencies.

³³ Agencies with a service arrangement are required to complete an Annual Financial Monitoring Return (AFMR). This return presents financial information in a standardised format and a reconciliation to the AFS.

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