

This is the accepted version of the following article:
FLEMING, P., MCGILLOWAY, S. & BARRY, S. 2016. Day Service Provision for People with Intellectual Disabilities: A Case Study Mapping 15-Year Trends in Ireland. *Journal of Applied Research in Intellectual Disabilities*, which has been published in final form at
<http://onlinelibrary.wiley.com/doi/10.1111/jar.12249/abstract;jsessionid=BD2A53470B73A0E69D4E1DDA3B77C70C.f03t03>
This article may be used for non-commercial purposes in accordance with the Wiley Self-Archiving Policy [http://olabout.wiley.com/WileyCDA/Section/id-828039.html].

Day service provision for people with intellectual disabilities: A case study mapping 15-year trends in Ireland

Abstract

Background

Day-services for people with intellectual disabilities are experiencing a global paradigm shift towards innovative person-centred models of care. This study maps changing trends in day-service utilisation to highlight how policy, emergent patterns and demographic trends influence service delivery.

Methods

National intellectual disability data (1998-2013) were analysed using WINPEPI software and mapped using QGIS Geographic Information System.

Results

Statistically significant changes indicated: fewer people availing of day-services as a proportion of the general population; more males; fewer people aged <35; a doubling in person-centred plans; and an emerging urban/rural divide. Day-services did not change substantially and often did not reflect demand.

Conclusions

Emergent trends can inform future direction of disability services. Government funds should support individualised

models, more adaptive to changing trends. National databases need flexibility to respond to policy and user demands. Future research should focus on day-service utilisation of younger people and the impact of rurality on service availability, utilisation, quality and migration.

Keywords

Intellectual disability, day-services, individualised support, personal budget, person-centred plan, implementation

Introduction

The future of day support services for persons with intellectual disabilities is of considerable international relevance, particularly for high income countries which tend to invest heavily in such services/supports, but often with questionable outcomes for service users (Whittaker and McIntosh, 2000, Health Service Executive, 2012). Despite recent (progressive) policy developments (Department of Health, 2012), Ireland is a prime example of a high income country which is lagging behind many of its European neighbours. For instance, it has yet to ratify the UN Convention on Human Rights of ~~of~~ Individuals with Disabilities which strives for true social inclusion for people with disabilities, including equal access to information, transport, education, employment and income support (Lee and Raley, 2015).

The European Association of Service Providers for Persons with Disabilities (EASPD)¹ identified six underperforming countries (Austria, France, Finland, Ireland, Hungary, Bulgaria and Romania) which were in need of capacity-building training (Ward, 2015). Amongst these, the process of de-institutionalisation in Ireland had stalled due to cuts in public expenditure, specifically a 66% reduction in the 'community

¹ EASPD is a European not-for-profit organisation representing over 10,000 social service provider organisations across Europe and disability. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.

employment scheme' - an essential source of funding for personal assistants required to facilitate independent living. This reportedly resulted in instances of re-institutionalisation, an austerity-related trend also seen in Bulgaria where spending allocated to institutional services far outweighed community-based services; likewise, in Portugal, the lack of new investment has seen an increasing number of people using more institutionalised forms of care (Hauben et al., 2012). Other areas identified as in need of essential policy change in improving the wellbeing of people with disabilities include: employment; health; independent living; and youth guarantee (Bignal, 2013).

The objectives of the current study, which was undertaken as the first stage of a larger multi-component evaluation of individualised funding, were to: (1) map any changing trends in day service provision in Ireland; (2) highlight where national policy changes, driven by international best practice, may be influencing service delivery; and (3) highlight potential future service needs and lessons for similar high income, underperforming countries in Europe and elsewhere, based on emergent patterns and changing demographic trends.

Historical context

From the late 19th century, the disability sector landscape in Ireland was dominated by large religious-run institutions. The subsequent Health Acts of 1953 and 1970 empowered the Department of Health to offer financial support to family and advocate-led organisations which eventually became the principal mechanism for providing activities, vocational training and sheltered work for people with disabilities. However, these developments were largely unsystematic and often unfit for purpose, with people remaining in child-orientated facilities well into adulthood. A segregated culture of ‘specialised’ services became embedded in service provision during the 1960s, with a range of specialised professions emerging to provide therapy and services to people with intellectual disabilities. (Health Service Executive, 2011, Health Service Executive, 2012)

In 1984, a landmark Green Paper on Services for Disabled People was published - seen by many as the start of more inclusive policies in Ireland to promote community integration of housing and services. The European Social Fund (ESF) (1970 – 1994), and subsequently the European Regional Development Fund, provided funding and specialist infrastructural support for vocational skills training (Health Service Executive, 2012). In 1993, the UN Standard Rules on the Equalisation of Opportunity for People with Disability

influenced the development of the ‘Commission on the Status of People with Disabilities’ in Ireland, now the ‘National Disability Authority’, and the production of ‘A strategy for equality’ (Commission on the Status of People with Disabilities, 1996). A number of policy documents based on international best practice have since been developed (Health Service Executive, 2011, Health Service Executive, 2012, Department of Health, 2012). For example, the “Value for Money and Policy Review of Disability Services in Ireland” (2012) – which is currently used as the benchmark for achieving disability sector improvements - recommends, amongst other things, the provision of ‘supports’ rather than ‘services’ in supporting the transition from a largely institutionalised to a personalised model. To achieve this, person-centred plans, individualised supports and personal budgets were recommended to bring Ireland in line with the global paradigm shift in day services for people with intellectual disabilities.

This historical evolution led to a reliance on voluntary organisations to lead pioneering change within the sector.

Semi-autonomous ~~Autonomous~~ non-governmental-organisations (NGOs), funded largely by the Government, continue to deliver services within geographical designated areas, accounting for around 90% of services delivered to

people with intellectual disabilities (Health Service Executive, 2012). Furthermore, the registration and regulation of services is only beginning to happen. Whilst some individualised supports do exist, people are still limited to a range of centre-based group activities with limited individual choice. In 2013, 99.8% of people registered on the National Intellectual Disability Database availed of at least one day programme, representing the highest number since records began in 1996 (Kelly and O'Donohoe, 2014). Of these, 29% were also in receipt of full-time residential care services. While demand for day services continues to grow, expenditure on disability services steadily declined year-on-year after peaking at €1.68 billion (net) in 2009 and falling to €1.45 billion in 2011 and €1.31 billion in the 2015 budget (Inclusion Ireland, 2014, Department of Health, 2012).

Given the extensive national and international developments in disability service provision, this study sought to explore the changing trends in demand and uptake of day services for people with intellectual disabilities in Ireland, whilst also providing insights into how service providers have responded to the changing policy landscape.

Methods

The National Intellectual Disability Database (NIDD) collates a minimum set of information, for all people in Ireland who receive or are in need of intellectual disability services, inclusive of day, residential and multidisciplinary services. Individual data forms are used to gather three basic pieces of information: demographic details; current service provision; and future service requirements. Diagnostic or medical information is not gathered as the database is not intended as an epidemiological tool. Snapshot data are gathered at a specific point in time and are updated annually. The national database employs an ongoing validation system whereby gaps or inconsistencies in the data are identified and guidelines and protocols put in place to address these, thereby ensuring greater standardisation. (Kelly et al., 2009) An audit of the database in 2007, the focus of which was residential services rather than day services, showed an overall accuracy of 72.2%, with 19.3% of data considered to be inaccurate, and 8.5% of the sought audit data not returned (Dodd et al., 2010). Data relating to the future demand for services was found to be the most inaccurate (50.4%) (due to confusion around contingency and future needs) so it is possible that a similar level of inaccuracy may apply to day services.

For purposes of this study, a standard data request form was submitted to the NIDD which included a detailed rationale and

declaration of confidentiality. Due to national data protection regulations, individual level statistics were unavailable. Therefore, aggregate secondary data relating to current day service utilisation and future service needs was requested for adults aged 18 years and over, broken down by county of residence. Data were requested for six specific years between 1998 and 2013, covering a 15 year period at three yearly intervals. The 2013 data were the more recently available at the time of the study. Demographic summary statistics were also provided for each year based on: sex; age group; degree of disability; and receipt of a “person-centred-plan”. The data request was reviewed and approved by a national committee. For comparative purposes, general population statistics were sourced from the Central Statistics Office (CSO), Ireland’s national statistical office.

It should be noted that the NIDD supplied data for the main day service that was used in addition to the second and third day services used. For the purposes of this study, only primary day services were compared since every individual on the dataset had availed of a primary day service, whereas only 5%-18% of people had availed of a second day service between 1998 and 2013, with even fewer availing of a third. In addition to the breakdown by county of residence, data were broken down by local health office, but due to the shifting parameters of local

health authorities over the 15-year period, it was deemed more appropriate to map trends based on the unchanging geographical county borders.

The most popular day services were examined first in order to map general trends (i.e. those with 500 people or more attending or wishing to attend). The aggregation of data restricted the complexity and depth of statistical analysis. Upton's chi-square was used to test for statistically significant differences when comparing proportions of two independent samples, as recommended by Campbell (2007); the analysis was conducted using WINPEPI, a computer programme specifically developed for epidemiologists conducting health research (Abramson, 2011). The data were collated and mapped using QGIS Geographic Information System (QGIS Development Team, 2015) and various trend visualisation tools in Microsoft Excel (2010).

~~A potential limitation of this study relates to registration on the NIDD, which is voluntary whilst data are only captured for people who avail of specialised services. Therefore, the database may not capture all people with intellectual disabilities living in Ireland. This may be particularly true for those with a mild intellectual disability, since they tend to use more mainstream services and activities. Nonetheless, the~~

~~database contains the most accurate data available for people with an intellectual disability in Ireland. Furthermore, coverage and comprehensiveness are considered very good since service providers themselves return the information (Kelly et al., 2009).~~ It should be noted that when comparing the NIDD and general population data, the census year did not always directly correlate with the data provided by the NIDD; for example, census data are presented from 1996, while NIDD data for the study commenced in 1998. This is clearly indicated throughout the graphs.

Results

Demographic and background information

The total number of adults (18+) with an intellectual disability registered on the NIDD in 1998 was 14,897, increasing to 18,275 in 2013. Generally, more men than women availed of day services with the gap widening over time, increasing from 5.3% (n=785) in 1998 to 8.7% (n=1,585) in 2013 ($p < 0.001$). In contrast, the census data for a similar period showed significantly more women than men in the general population (1996 – 51.1% vs. 48.9%; 2011 - 51.0% vs. 49.0% $p < 0.001$). It might also be of interest to note here, that the overall population in Ireland increased during the 15 year period (1996-2011) by almost 1 million (21%), largely due to mass immigration (CSO, 2012b).

NIDD summary data were provided in five year age groups. These were further collapsed into five categories and CSO data were extracted within the same parameters for direct comparison. When presented by age group, the population growth pattern within the NIDD was consistent with the older general population during a similar time period, i.e. those aged 50 years and older (Figure 1). Whilst the general population showed a steady growth in the 35-49 age group, the NIDD data showed a levelling off and slight drop from 2010 to 2013. Even more marked, was the difference for the 18-34 category; the census showed a steady growth up to 2006 where it then began to decline slightly, whereas the NIDD population showed a steady decline over a similar time period, levelling off between 2010 and 2013.

< Please insert Figure 1 about here >

The NIDD categorises intellectual disability using the International Statistical Classification of Diseases, 10th Revision, (ICD-10) criteria which describe the degree of disability as ‘mild’, ‘moderate’, ‘severe’ or ‘profound’ (Kelly et al., 2009). Comparable data are available from 2001 to 2013 when all three categories showed an increase, with the ‘moderate’ category accounting for 62.2% of the growth

(increasing from 6,495 to 8,296). Over 45% of people on the NIDD had a moderate intellectual disability in 2013, whilst the smallest proportion of people had a severe/profound disability (21.5%). These trends were seen, by and large, throughout the country.

Use of day services

Counties containing the largest urban centres (in the east, south and west of the country) had the largest proportion of people using day services in 2013 including: Dublin (23%, n = 4,200 or a 235:1 ratio with the general population); Cork (11.5%, n = 2,092 / 187:1); Galway, (5.8%, n = 1,066 / 178:1); and Limerick, (5.2%, n = 945 / 154:1) (Figure 2). These were followed closely by the suburban county of Kildare with 901 individuals (4.9% / 167:1). The lowest numbers of people availing of day services were in Longford (1.0%, n = 182 / 156:1) and Leitrim in the midlands and north-west of the country respectively (0.53%, n = 96 / 247:1) (Figure 2).

< Please insert Figure 2 about here >

Interestingly, the ratio for the least populated county in Ireland (Leitrim), exceeds the most highly populated county of Dublin, suggesting that there are very few people with intellectual disabilities in this area availing of day services when compared to the general population. The neighbouring county (Sligo) had

the lowest ratio in the country with only 95 people in the general population for every one person availing of intellectual disability day services. This pattern suggests a possible migration of people in need of services to larger urban centres where services are available (in this case from Leitrim to Sligo). This pattern was also seen in other rural counties (e.g. Meath, a neighbouring county of Dublin, which had the largest ratio of 256:1, suggesting a similar migration towards the nearest urban centre).

While the number of adults with intellectual disabilities availing of day services increased by over 20% from 14,861 to 18,249, a proportional decrease occurred when compared to the general adult population between 1998 and 2013 (0.58% to 0.53% ($p < 0.001$)). The ratio shifted from 172:1 in 1998 to 188:1 in 2013. At a county level, there was almost a 50:50 split between increases and decreases. Three groupings of counties experienced a statistically significant change in the proportion of people with an intellectual disability availing of day services when compared to all people with an intellectual disability on the national database. County Limerick experienced the largest change in the proportion of people availing of day services with a drop of -2.03% ($p < 0.001$). The southern and western regions of Cork and Sligo also experienced a significant decrease (-0.81%; -0.51% $p < 0.05$). Three counties experienced a

significant increase: Donegal, 0.74%; Meath, 0.79%; and Wicklow, 0.80% ($p < 0.001$). No other statistically significant changes were observed (Figure 2).

Type of day service

In all, 31 distinct types of day services were recorded, 23 (74%) of which have been in place since 1998; the remaining were added to the data collection form over the 15 year period in response to changing demands. The most popular, according to uptake figures, were ‘Sheltered work centres’ and ‘Activation centres’ (Table 1) (62% in 1998; 55% in 2013). In 1998, these two types of provision accounted for 4,724 (32%) and 4,491 (30%) respectively of all services. Over the 15 year period, ‘Sheltered work centres’ declined, almost in parallel, by 16.5%, while ‘Activation centres’ increased by 10%, to account for 40.2% (Figure 3(a) – top right quadrant). Sheltered work centres often consist of contract work for which trainees are paid a minimal wage with an accompanying risk of exploitation by service providers.

< Please insert Table 1 about here >

An additional seven day services attracted 500 or more people at some point over the 15 year period (Figure 3(a)). Of these, ‘rehabilitative training’ was the most popular in 1998 (12.7%, n

= 1,886), although this showed a steady decline over a decade before peaking again in 2010, followed by another decline to 8.6 % (n = 1,562) in 2013. Such rehabilitative training comprises mostly time-limited programmes aimed at school leavers and funded by European Social Fund monies. This service appears to have been largely replaced by 'Multidisciplinary support services' (which is categorised as a day service within the NIDD) which rose from 1.1% (n =163) in 2001 to 8.8% (n = 1,601) in 2013. 'Special high support day services' and 'Programme for the older person' (Table 1) also increased steadily over the 15 year period, peaking at 4.0% (n = 735) and 3.6% (n = 657) respectively. An overall reduction in uptake was experienced in 'Other day programme' (5.4% to 2.8%); and 'Special school' (3.5% to 2.0%). 'Supported employment' experienced a general increase (3.5% to 4.2%) but the pattern fluctuated (Figure 3(a)).

<Please insert Figure 3 about here >

A number of services experienced similar trends (when comparing uptake in relation to demand, Figure 3). However, these did not necessarily mean that needs were being met. For example, 'Multidisciplinary support services' showed a similar upward trend while actual numbers were considerably different, with uptake well below demand. 'Rehabilitative training' also

experienced a similar downward trend, dropping by 4% for uptake and demand. However, almost one in ten people (8.6%, n=1562) were availing of the service in 2013 (Figure 3(a)) whereas fewer than three per cent (2.7%, n=409) were demanding the service in 2013 (Figure 3(b)). Furthermore, uptake and demand were sometimes on opposite trajectories. 'Special high support day services', for example, demonstrated a similar upward trend until 2007 when demand started to decline, falling from 4.2% (n = 628) to 2.9% (n = 447). Uptake on the other hand continued to increase.

Personal Care Plan

Personal care plan (PCP) data were available from 2004 onwards. During the next decade, those in receipt of a PCP more than doubled, increasing by over 40% from 37.1% (n=6,237) to 78.7% (n=14,374). Figure 4 demonstrates how each county in Ireland was performing in terms of provision of PCPs in 2004 and again in 2013, with the change highlighted over the ten year period. The more rural counties (e.g. Cavan, Offaly, Longford, Meath, Mayo, Kerry and Leitrim) were below the 25th percentile of people in receipt of a PCP in 2004. Of these, Leitrim and Longford (moving north-west of the country) remained below the 25th percentile in 2013, while Meath reached the 75th percentile in 2013, with Cavan approaching same. By contrast, three counties (Kilkenny,

Dublin and Louth) dropped below the 75th percentile between 2004 and 2013. Only two counties remained within the 75th percentile for both periods (Monaghan and Wicklow).

< Please insert Figure 4 about here >

Discussion

This study was undertaken to map the changing trends - during a 15-year period - of day services for people with intellectual disabilities in Ireland in order to: gain insights into the service response to policy recommendations, particularly around personalised supports (facilitated partly by individualised funding); and to determine (insofar as possible) future service needs based on emerging demographic trends.

By and large, day service trends in Ireland suggest little change to the limited menu of services that dictate the lifestyles of people with disabilities, nor do they suggest a move away from centre-based activities. When examining the two most popular day services – use of the more traditional sheltered workshops declined over time in contrast to an increase in the use of activation centres. The lack of clear definitions around ‘activation programmes’ and the co-facilitation of both activities within the same service, often in the same premises, would suggest that this change was perhaps a re-branding

exercise, whereby service providers were seen to make changes in line with policy goals, but with little changing in reality; indeed, evidence suggests that a similar situation has materialised in Australia (Chapman and Soldatic, 2010).

Regardless of the labels used, group-orientated activities within centres continue, which many would argue is exploitative, closed, paternalistic and preventive of proper community integration (Kirby 1986; Murphy and Rogan 1995; Parent et al. 1989; Neufeldt 1990; Schuster 1990 as cited in Lemon and Lemon, 2003). Others claim, by contrast, that rather than simply being physically integrated within the general community, service provision should be concerned with connectedness and that such connectedness is actually more achievable within a community of people with an intellectual disability (Cummins and Lau, 2003). Nonetheless, this study suggests that, whilst a limited number of new services were introduced during the latter part of the 15-year period, the demand for services was generally not met by service providers; in addition, the places provided and the subsequent uptake, were inconsistent with the pattern of demand for supports such as ‘special high support day services’, ‘supported employment’, and ‘rehabilitative training’.

On a more positive note, the changes that have occurred in Ireland since the 1950s reflect, to some extent, the general paradigm-shift experienced internationally in the delivery of intellectual disability services (Bigby and Frawley, 2010). Taylor and Taylor (2013) describe this shift as an evolution from formal and professionally- led treatment interventions toward an emphasis on the individual and individualised support. For Ireland, person-centred planning remains the most innovative approach for achieving current policy goals related to individualisation of services (Health Service Executive, 2012). This is reflected in the considerable increase in those with a person-centred plan during the 15-year period, indicating progress. Claes et al (2010), in their systematic review of person-centred planning, report a moderately positive impact on personal outcomes, whilst also acknowledging implementation weaknesses, specifically the lack of external systematic support, such as prospective employers, limitation in residential opportunities, overcrowding in available services, and the limited natural supports within the community. These kinds of challenges in translating policy into action are consistent with the UK experience of disability services and of the wider health and social care services (Dowling et al., 2006). They also reflect the Irish experience where views on effectiveness have been mixed, whilst almost 3,000 of those

who use day services have no such individualised plans in place (Health Service Executive, 2012).

It is difficult to make international comparisons in relation to degree of disability due to varying definitions and categorisations (Mont, 2007, McDermott and Turk, 2011). However, the proportion of people with moderate disabilities in Ireland is considerably higher than that seen in other countries such as Canada and Western Australia where around 25% of people have a moderate disability (Statistics Canada, 2004, Bittles et al., 2002). In terms of age, the youngest cohort of people in the current study appears to be deviating from the expected population trends. While it is unlikely that the proportion of people being diagnosed with an intellectual disability has decreased significantly, this would suggest that fewer young people are availing of day services. A recent systematic review by Foley, Dyke, Girdler, Bourke and Leonard (2012) concluded that changes to policy and legislation have had very little effect on improving the experiences of school leavers with intellectual disabilities. The same is true for transition programmes and the development of resources despite a number of recommendations to the contrary (Hay and Winn, 2009). However, Foley et al (2012) acknowledge that there are major gaps and weaknesses in the literature; people with disabilities themselves have rarely been

involved in the research and when they have, the focus has been on those with mild intellectual disabilities. Research identified in this review highlights a need for service providers to understand the belief systems of families which, in turn, is key to the development and implementation of effective services across the world (Schneider et al., 2006, King et al., 2008).

Perhaps the overall trends in Ireland suggest that people are ‘voting with their feet’, by avoiding services that may not meet their needs, as seen with residential settings in the past (Kinsella, 1993). Alternatively, perhaps this cohort of people, the first to have attended mainstream second level education, have already attained the life skills being offered in traditional programmes. For example, some evidence suggests that a person’s capacity to manage activities of daily living is the best predictor of future capacity for work or alternatively, the need for transition-to-work programmes (Eagar et al., 2006).

The changing geographical patterns in the uptake of day services are also notable. Although the ratios observed suggest a possible urban migration of people wishing to avail of day services, the 15 year trends suggest otherwise. Aside from the capital, Dublin, which did not experience a significant change in the proportion of people availing of day services - an

urban/rural divide is evident. For example, the county of Limerick (with the third largest city in Ireland) experienced the biggest decrease nationally. This was followed by county Cork, with the second largest city. Sligo, the largest town in the western province, also experienced a significant decrease. (CSO, 2012a) Conversely, Donegal, which is one of the most geographically isolated and poorest counties in Ireland, had one of the highest increases in the proportion of people availing of day services. This was followed by two more rural, although considerably less isolated, counties of Meath and Wicklow in the east of the country. This trend is unusual considering that 62% of Ireland is now urbanised; in fact, the urban population has increased by 10.6% when compared to a rural growth of 4.6% between 2006 and 2011 (CSO, 2012b). International evidence is mixed on the impact of such urban/rural divides. For example, Gething (1997) argues that people with disabilities living in rural areas are doubly disadvantaged across a wide spectrum of areas; conversely, Nicholson and Cooper (2013) report better opportunities and less deprivation for rural dwellers when compared to urbanites. In the case of Ireland, these patterns of increased use in rural areas may point toward the lack of alternative (and more innovative) forms of service provision in more isolated areas, but a need for further research is indicated.

Finally, the findings show that a disproportionate and growing amount of men avail of day services when compared to the expected general population. A similar trend is being experienced in the United States where, according to statistics from the Employment and Disability Institute (2015), the proportion of women with cognitive disabilities exceeded men significantly in 2008 (2.42% female vs. 2.40% male ($p < 0.001$)) but in 2012, the trend was reversed in favour of men (2.44% female vs. 2.49% male ($p < 0.001$)). Higher rates of intellectual disabilities amongst men have also been seen in population-based figures from Western Australia (Bittles et al., 2002) and for people with learning and developmental disabilities in Canada (Statistics Canada, 2004). Interestingly however, previous studies in Ireland have shown no differences in lifespan between men and women with an intellectual disability, while Australian and Finnish studies suggest a lower life expectancy for men with intellectual disabilities (Lavin et al., 2006, Bittles et al., 2002, Patja et al., 2000). Furthermore, life expectancy in one study diminished as degree of disability increased, while people with mild intellectual disabilities experienced similar life expectancies as the general population (Patja et al., 2000).

| Study limitations

A potential limitation of this study relates to registration on the NIDD, which is voluntary whilst data are only captured for people who avail of specialised services. Therefore, the database may not capture all people with intellectual disabilities living in Ireland. This may be particularly true for those with a mild intellectual disability, since they tend to use more mainstream services and activities. Nonetheless, the database contains the most accurate data available for people with an intellectual disability in Ireland. Furthermore, coverage and comprehensiveness are considered very good since service providers themselves return the information (Kelly et al., 2009).

~~This study was limited in a number of ways. Firstly,~~

Another potential limitation relates to the fact that over half of data pertaining to ‘future demand for residential services’ was found to be inaccurate on the national database (Dodd et al., 2010). Although Dodd et al did not focus on day services in their audit, the authors of this study acknowledge the potential for similar inaccuracies regarding ‘future demand for day services’ data. Furthermore, the database only records needs in terms of existing service options. ~~whilst some inaccuracies may also be present.~~ For these reasons, Dodd et al (2010) argue that the NIDD is no longer useful in providing information for the kind of planning and development of intellectual disabilities

that would place the sector ahead of other care groups in terms of competing for limited resources. These authors further contend that low user involvement in the completion of NIDD data forms is not person-centred, nor does it reflect the ethos of policy recommendations for individualised service delivery. The findings of this study would support this view.

Conclusion

As individualisation continues to be at the forefront of innovative change in disability services, a number of key lessons may be identified from the current study. National databases, such as the NIDD, must conduct regular reviews and updating of data capture forms to ensure that their remit is broad enough to include new and innovative models of service delivery. Any emerging urban/rural divides need to be monitored closely and further large-scale studies are required to clarify the experiences of rural dwellers in this respect. Service developments in Ireland and in other developed countries must also be responsive to these kinds of trends within their individual jurisdictions and not become overly focussed on urban centres. It is also important that future services incorporate appropriate gender-focused activities because, in the case of the current study, the proportion of men availing of services continue to grow; it is important, therefore, that, for example, 'Arts and Crafts' - historically the most popular

activity in the UK - is meeting their needs (Felce et al., 1999). This may be facilitated by ensuring that individualised developments are led by the ‘voices’ of individuals with a disability and their natural supports. However, this must move beyond the simple provision of personal-care-plans, to ensure that the resources and skills are in place to realise them.

A lack of skills has been reported elsewhere as one of the challenges associated with self-directed support, which is compounded by a low rate of training beyond a general skillset (Bogenschutz et al., 2010). In Ireland, a non-profit funding organisation called Genio (whose mission is to develop, test, and scale, cost-effective ways of supporting people who are disadvantaged to live full lives in their communities), has already provided ‘Endeavour for Excellence’ training, based on the ‘Social Role Valorisation’ model. This programme was delivered to front-line personnel from approximately 50 service providing organisations over an 8-month period (Genio, 2016). Similar educational programmes could be incorporated into essential staff training both in Ireland and elsewhere.

Finally more in-depth research should be conducted on younger people with intellectual disabilities (e.g. 18–25 year-olds), to determine what services are being used by those who are no longer *formally* reporting service utilisation. Perhaps they are

involved in innovative activities such as the personal budgeting initiatives that are currently being evaluated (Fleming et al., 2015) and which are omitted from the national database; more worryingly, this cohort may not be in receipt of any support and are therefore, invisible within the current service delivery system.

The findings of this study suggest that government funding, both in Ireland and other countries with similar patterns of service limitations (e.g. Austria, Finland, France, Romania and Bulgaria), should aim to promote individualised supports by redistributing funds from traditional, congregated service delivery to individualised models. Personalised budgeting has been at the forefront of change in this regard throughout Canada, the US, Australia and Britain, yet there is no mention of such initiatives on the Irish NIDD, despite specific policy recommendations to the contrary. The findings of our larger evaluation of individualised funding pilot schemes in Ireland should help to address some of the key issues (also commonly reported in other countries) related to resource allocation, operational processes, administration, governance, quality assurance, management and organisation. However, these should not hamper progress for the majority of people with intellectual disabilities; for instance, the smallest proportion of people in Ireland have a severe or profound disability - the

group most likely to face challenges with self-directed support (Harkes et al., 2014). In addition, the learning from the on-the-ground implementation of such new services and initiatives should help to inform future policy goals in order to take account of the ‘lived experience’ and everyday lives of people with disabilities (Graham, 2010). Without widespread implementation, however, these learnings are not possible.

References

- ABRAMSON, J. H. 2011. WINPEPI updated: computer programs for epidemiologists, and their teaching potential. *Epidemiologic Perspectives & Innovations : EP+I*, 8, 1-1.
- BIGBY, C. & FRAWLEY, P. 2010. *Social Work Practice and Intellectual Disability*, Basingstoke, Palgrave Macmillan.
- BIGNAL, T. 2013. Europe 2020 and the European Semester: Bringing Wellbeing to All? Brussels: EASPD.
- BITTLES, A. H., PETTERSON, B. A., SULLIVAN, S. G., HUSSAIN, R., GLASSON, E. J. & MONTGOMERY, P. D. 2002. The Influence of Intellectual Disability on Life Expectancy. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57, M470-M472.
- BOGENSCHUTZ, M., HEWITT, A., HALL-LANDE, J. & LALIBERTE, T. 2010. Status and Trends in the Direct Support Workforce in Self-Directed Supports. *Intellectual and Developmental Disabilities*, 48, 345-360.
- CAMPBELL, I. 2007. Chi-squared and Fisher–Irwin tests of two-by-two tables with small sample recommendations. *Statistics in Medicine*, 26, 3661-3675.
- CHAPMAN, A. & SOLDATIC, K. 2010. Surviving the Assault? The Australian Disability Movement and the Neoliberal Workfare State. *Social Movement Studies*, 9, 139-154.
- CLAES, C., VAN HOVE, G., VANDEVELDE, S., VAN LOON, J. & SCHALOCK, R. L. 2010. Person-centered planning: Analysis of research and effectiveness. *Intellectual and Developmental Disabilities*, 48, 432-453.
- COMMISSION ON THE STATUS OF PEOPLE WITH DISABILITIES 1996. A strategy for equality: summary of the report of the Commission on the Status of People with Disabilities. Dublin, Ireland: Commission on the Status of People with Disabilities.
- CSO. 2012a. Profile 1 Town and County. Available: http://www.cso.ie/en/media/csoie/census/documents/census2011vol1andprofile1/Profile1_Town_and_Country_Entire_doc.pdf [Accessed 28 July 2015].
- CSO. 2012b. This is Ireland: Highlights from Census 2011, Part 1. Available: <http://www.cso.ie/en/media/csoie/census/documents/census2011pdr/Census,2011,Highlights,Part,1,web,72dpi.pdf> [Accessed 28 July 2015].
- CUMMINS, R. A. & LAU, A. L. D. 2003. Community Integration or Community Exposure? A Review and

- Discussion in Relation to People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 16, 145-157.
- DEPARTMENT OF HEALTH 2012. Value for Money and Policy Review of Disability Services in Ireland. In: HEALTH, D. O. (ed.). Dublin, Ireland: Department of Health.
- DODD, P., CRAIG, S., KELLY, F. & GUERIN, S. 2010. An audit of the Irish National Intellectual Disability Database. *Research in Developmental Disabilities*, 31, 446-451.
- DOWLING, S., MANTHORPE, J., COWLEY, S., KING, S., RAYMOND, V., PEREZ, W. & WEINSTEIN, P. 2006. *Person-centred planning in social care: a scoping review*, York, York Publishing Services Ltd.
- EAGAR, K., GREEN, J., GORDON, R., OWEN, A., MASSO, M. & WILLIAMS, K. 2006. Functional Assessment to Predict Capacity for Work in a Population of School-leavers with Disabilities. *International Journal of Disability, Development and Education*, 53, 331-349.
- EMPLOYMENT AND DISABILITY INSTITUTE 2015. Disability Statistics: Online Resource for U.S. Disability Statistics. 2015 ed. USA: Cornell University.
- FELCE, D., LOWE, K., PERRY, J., JONES, E., BAXTER, H. & BOWLEY, C. 1999. The Quality of Residential and Day Services for Adults with Intellectual Disabilities in Eight Local Authorities in England: Objective Data Gained in Support of a Social Services Inspectorate Inspection. *Journal of Applied Research in Intellectual Disabilities*, 12, 273-293.
- FLEMING, P., MCGILLOWAY, S. & BARRY, S. 2015. An Evaluation of the Development and Implementation of Personal Budgets for People with a Disability in Ireland. *12th Annual Psychology, Health and Medicine Conference - Improving health and well-being: Better futures for all*. Stranmillis University, Belfast: The British Psychological Society Division of Health Psychology Northern Ireland Branch and the Psychological Society of Ireland.
- FOLEY, K. R., DYKE, P., GIRDLER, S., BOURKE, J. & LEONARD, H. 2012. Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation*, 34, 1747-1764.
- GENIO. 2016. *Learning and skills* [Online]. Genio. Available: <http://www.genio.ie/learning-skills> [Accessed 10th June].
- GETHING, L. 1997. Sources of Double Disadvantage for People with Disabilities Living in Remote and Rural

- Areas of New South Wales, Australia. *Disability & Society*, 12, 513-531.
- GRAHAM, H. 2010. How the tea is made; or, the scoping and scaling of 'everyday life' in changing services for 'people with learning disabilities'. *British Journal of Learning Disabilities*, 38, 133-143.
- HARKES, M. A., BROWN, M. & HORSBURGH, D. 2014. Self Directed Support and people with learning disabilities: a review of the published research evidence. *British Journal of Learning Disabilities*, 42, 87-101.
- HAUBEN, H., COUCHEIR, M., SPOOREN, J., MCANANEY, D. & DELFOSSE, C. 2012. Assessing the impact of European governments' austerity plans on the rights of people with disabilities. Brussels, Belgium: European Foundation Centre.
- HAY, I. & WINN, S. 2009. Transition from school for youths with a disability: issues and challenges. *Disability & Society*, 24, 103-115.
- HEALTH SERVICE EXECUTIVE 2011. Time to Move on from Congregated Settings A Strategy for Community Inclusion. Dublin, Ireland: Health Service Executive.
- HEALTH SERVICE EXECUTIVE 2012. New Directions - Personal Support Services for Adults with Disabilities: Review of HSE day service and implementation plan 2012 - 2016. Dublin, Ireland: Health Service Executive.
- INCLUSION IRELAND. 2014. Budget 2015 offers little hope to people with an intellectual disability. Available: <http://www.inclusionireland.ie/content/page/budget-2015-offers-little-hope-people-intellectual-disability> [Accessed 30 June 2015].
- KELLY, C., KELLY, F. & CRAIG, S. 2009. Trends in demand for services among those aged 50 years and over with an intellectual disability, 2003-2007. *HRB Trend Series*. Dublin, Ireland: Health Research Board.
- KELLY, C. & O'DONOHUE, A. 2014. Annual Report of the National Intellectual Disability Database Committee 2013 Main Findings *HRB Statistics Series 24*. Dublin, Ireland: Health Research Board.
- KING, G., CURRIE, M., SMITH, L., SERVAIS, M. & MCDOUGALL, J. 2008. A framework of operating models for interdisciplinary research programs in clinical service organizations. *Evaluation and program planning*, 31, 160.
- KINSELLA, P. 1993. 'Supported Living' A New Paradigm - From control to freedom. Available: <http://www.supportedliving.org.au/site/wp-content/uploads/From-control-to-freedom-Peter-Kinsella1.pdf> [Accessed 28 July 2015].
- LAVIN, K. E., MCGUIRE, B. E. & HOGAN, M. J. 2006. Age at death of people with an intellectual disability in

- Ireland. *Journal of Intellectual Disabilities*, 10, 155-164.
- LEE, G. & RALEY, M. 2015. Ireland must ratify UN Convention on Rights of People with Disabilities. *The Irish Times* [Online]. Available: <http://www.irishtimes.com/opinion/ireland-must-ratify-un-convention-on-rights-of-people-with-disabilities-1.2157963> [Accessed 02 July 2015].
- LEMON, C. & LEMON, J. 2003. Community-based cooperative ventures for adults with intellectual disabilities. *Canadian Geographer*, 47, 414-428.
- MCDERMOTT, S. & TURK, M. A. 2011. The myth and reality of disability prevalence: measuring disability for research and service. *Disability and Health Journal*, 4, 1-5.
- MICROSOFT 2010. Microsoft Excel. Redmond, Washington: Microsoft.
- MONT, D. 2007. Measuring disability prevalence. *World Bank Social Protection Discussion Paper*, 706.
- NICHOLSON, L. & COOPER, S. A. 2013. Social exclusion and people with intellectual disabilities: a rural-urban comparison. *Journal of Intellectual Disability Research*, 57, 333-346.
- PATJA, K., IIVANAINEN, M., VESALA, H., OKSANEN, H. & RUOPPILA, I. 2000. Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of intellectual disability research*, 44, 591-599.
- QGIS DEVELOPMENT TEAM 2015. QGIS Geographic Information System. Open Source Geospatial Foundation Project.
- SCHNEIDER, J., WEDGEWOOD, N., LLEWELLYN, G. & MCCONNELL, D. 2006. Families challenged by and accommodating to the adolescent years. *Journal of Intellectual Disability Research*, 50, 926-936.
- STATISTICS CANADA. 2004. Profile of disability in 2001. *Canadian Social Trends* [Online]. Available: <http://www.statcan.gc.ca/pub/11-008-x/2003004/article/6804-eng.pdf> [Accessed 02 July 2015].
- TAYLOR, J. E. & TAYLOR, J. A. 2013. Person-Centered Planning: Evidence-Based Practice, Challenges, and Potential for the 21st Century. *Journal of Social Work in Disability and Rehabilitation*, 12, 213-235.
- WARD, K. 2015. EASPD Annual Report: Reaching out in 2014. Brussels, Belgium: EASPD 2015 - European Association of Service Providers for Persons with Disabilities
- WHITTAKER, A. & MCINTOSH, B. 2000. Changing days. *British Journal of Learning Disabilities*, 28, 3-8.

Table 1 – Description of Day Services

Figure 1 – Changes in Age Groups

Figure 2 – Changing Trends in Uptake of Day Services

Figure 3 – Change in Uptake / Demand in Day Services over 15
year period

Figure 4 – Percentage of people with Person-centred Plan in
2013