Moving From Family Care to Residential and Supported Accommodation: National, Longitudinal Study of People With Intellectual Disabilities

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Abstract
A cohort of nearly 11,000 persons was traced over 8 years to determine those who had moved from family care and those who had remained. The majority (85%) continued to live with families, and, for two thirds (67%), no future move was deemed necessary. The 2 main predictors of moving were as follows: A need had been previously recorded and the family had used out-of-home respite services during the 8 years. However, just one quarter of those identified as needing to move had done so in the 8 years. Conversely, no prior indication of need had been recorded for two thirds of people who had moved in this period. The complexities of assessing need and equitably meeting demands are discussed.

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The long-term care of dependent people outside of families is a pressing problem in many countries (Feder, Komisar, & Niefield, 2000). Although the focus of this debate has been mainly on the care of the individuals who are elderly, another large group is people with long-term disabilities, such as intellectual disability, who may enter care at a younger age and, thus, incur higher lifetime costs. To date, sparse consideration has been given internationally to planning for these individuals’ needs.

In Ireland, as in many other countries, families typically care for their relatives with intellectual disabilities well into their adult years (Barron, McConkey, & Mulvany, 2006). Often, this is the wish of both parties (Gilbert, Lankshear, & Petersen, 2008; McConkey, Sowney, Milligan, & Barr, 2005), and many parents expect the care of their son or daughter to be continued by other family members (Hogg & Lambe, 1998). However, this is not always possible or even desirable (Power, 2008).

In general, past research has focused on futures planning within families and on their preferences for alternative accommodation (McConkey, McConagherie, Barr, & Roberts, 2006; Seltzer et al., 1995). Yet the option of moving out of the family home is not solely dependent on the wishes and needs of the family and the person for whom they care; it is also determined by the overall demand for places as well as the availability of resources to pay for substitute care (Kang & Harrington, 2008).
However, a survey in England highlighted the dearth of planning that local authorities had undertaken in relation to alternative placements for people living with family caregivers (Mencap, 2002). In addition, there has been little research on the supply of residential accommodations for persons with intellectual disability even though living costs form a substantial proportion of the funds expended by health and social care services in Western economies (e.g., Braddock, 2002) and are the area with the greatest cost pressures (Parrott, 2005). Moreover, few studies have identified the characteristics of adult persons who move from family care (an exception being the 18-year follow up of 54 persons in Aberdeen, Scotland, which showed that over half remained in the same location, but with passing years an increasing number entered community rather than institutional accommodations; May & Hogg, 2000). In addition, some research has been done with children but, again, with small samples and a focus only on those persons who had moved (e.g., Baker & Blacher, 2002).

When economic constraints are present, it is likely that more people are denied the opportunity to move even though they are judged to require it. This raises two questions. First, to what extent is it possible to anticipate the demand for residential accommodation outside of the family? This information would enable forward planning and at least provide the data on which to base funding bids, albeit in the context of competing demands. Second, who are the people most likely to receive this form of service? Knowing this would validate the criteria used to assess the allocation of resources and provide a more equitable and transparent basis for so doing, particularly when demand exceeds supply.

The National Intellectual Disability Database in the Republic of Ireland (population = 4.2 million in 2006) was set up in part to address the first question. It records both the services that people already receive as well as those that are required (Kelly, Kelly, Maguire, & Craig, 2009). The database has been instrumental in planning for and achieving increased governmental funding for extra service provision to meet the growing numbers of Irish persons requiring services. For example, in the 4-year period between 1999 and 2003, a time of unprecedented economic prosperity in Ireland, the noncapital health and social service expenditure on intellectual disability services nearly doubled from $550 million to $1,050 million and extra investment continued up to 2007 (Department of Health and Children, 2005). Indeed, Ireland’s expenditure on disability services as a proportion of gross domestic product was second highest in the European Union (Timonen, 2003).

In addition, a regularly updated, national database enables longitudinal research to be undertaken that can address the second question: the characteristics of persons with intellectual disabilities who move from family care to residential accommodation and the type of accommodation to which they moved. In the present study, we also compared, over an 8-year period, the characteristics of people who were recorded as needing a transition from family care to residential accommodation and the extent to which these needs were met over that period.

Although such information has particular relevance to Ireland, the experiences of gathering this form of data and being able to track changes over time for a sizeable national sample should inform the development of similar systems in other countries with comparable services to those provided in Ireland.

In summary then the goals of study were as follows:

1. To identify the number and characteristics of persons with intellectual disability who moved from family care into residential accommodation over an 8-year period;
2. To identify the need for residential accommodation, as recorded in the database, and how this related to the provision of such services; and
3. To examine the type of accommodation to which people moved and how it compared with that which had been requested.

**Method**

**Data Source**

Data for the National Intellectual Disability Database is returned to 10 health service areas (formerly health boards) that have responsibility for service provision, either directly or, more typically, through funding of nongovernmental agencies. In each area, a coordinator is responsible for identifying the service personnel who either complete or update a database pro forma for each child or adult with an intellectual disability.
known to him/her. This data set forms part of a regional database. Data on individuals are updated annually. Information from the regional databases (excluding personal details) is available to the Disability Databases Unit of the Health Research Board, which manages the database on behalf of the Department of Health and Children and undertakes analysis of the data at a national level. An annual report is produced that provides details of the characteristics of persons with an intellectual disability within the country, the services they receive, and the services they will require in the future (see Kelly et al., 2009, for the latest example).

These data represent all children and adults throughout Ireland who have a known mild, moderate, severe, or profound intellectual disability (using International Classification of Diseases-10 [ICD-10] criteria) and/or receive or need a specialist intellectual disability service. In all, 25,613 persons were recorded in 2007, representing a prevalence rate of 6.04 per 1,000 persons. Of these, 64.2% lived with family caregivers.

To detect trends in people moving from family care to residential accommodation over an 8-year period, a cohort of persons was identified, namely those living since 1999 with family caregivers in 2007 (n = 9,146) plus those who had previously lived with family caregivers from 1999 to 2006 but had moved and were now living (or had lived) in some form of residential accommodation (n = 1,678). The characteristics of the cohort are noted in Table 1 (excluded from this cohort were persons who were recorded on the database in 1997 but who had been removed from it in the intervening years [e.g., through death] and those persons who had entered the database from 1998 onwards [e.g., children born after 1997]).


<table>
<thead>
<tr>
<th>Variable</th>
<th>Living with family caregivers (2007)</th>
<th>Moved to residential accommodation</th>
<th>N/n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>9,146</td>
<td>1,678</td>
<td>10,824</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5,183 (57%)</td>
<td>885 (53%)</td>
<td>6,068 (56%)</td>
</tr>
<tr>
<td>Female</td>
<td>3,963 (43%)</td>
<td>793 (47%)</td>
<td>4,756 (44%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–19 years</td>
<td>2,769 (30%)</td>
<td>136 (8%)</td>
<td>2,905 (27%)</td>
</tr>
<tr>
<td>20–39 years</td>
<td>4,588 (51%)</td>
<td>819 (49%)</td>
<td>5,407 (50%)</td>
</tr>
<tr>
<td>≥40 years</td>
<td>1,789 (19%)</td>
<td>723 (43%)</td>
<td>2,512 (23%)</td>
</tr>
<tr>
<td>Disability level&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild intellectual disabilities</td>
<td>3,206 (35%)</td>
<td>528 (32%)</td>
<td>3,734 (35%)</td>
</tr>
<tr>
<td>Moderate intellectual disabilities</td>
<td>4,400 (48%)</td>
<td>738 (44%)</td>
<td>5,138 (48%)</td>
</tr>
<tr>
<td>Severe–profound intellectual disabilities</td>
<td>1,221 (13%)</td>
<td>358 (21%)</td>
<td>1,579 (15%)</td>
</tr>
<tr>
<td>No. of caregivers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two parent&lt;sup&gt;b&lt;/sup&gt;</td>
<td>5,872 (64%)</td>
<td>883 (53%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Single parent&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2,297 (25%)</td>
<td>527 (31%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Other family&lt;sup&gt;b&lt;/sup&gt;</td>
<td>977 (11%)</td>
<td>268 (16%)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<sup>Note</sup>. N/A = not available, because a proportion of the cohort no longer lived with family and the availability of their previous family caregivers was not recorded for this group.

<sup>a</sup>The level of disability was missing for 373 persons. <sup>b</sup>The data on family caregivers for those who moved were as recorded in 1999.
Because each person has a unique identifier, it was possible to trace his/her records over an 8-year period, to 1999. Although the national database was started in 1995, it was not fully functional until 1999, the first year chosen for this study. This year also marked the beginning of a significant investment by government in intellectual disability services, driven in part by the evidence of unmet need that the database had identified in previous years.

The database records each person’s needs for future services, including residential accommodation outside of the family. These are determined through annual reviews and updates of the database completed by a designated worker and often in consultation with family members. An indication is also noted of the type of accommodation that the person is thought to require based on perceived support needs and/or family preferences.

The annual review of all the data held on the person is the main means of checking the validity of the information stored. In addition, regular audits are undertaken of randomly selected samples, the most recent from the 2007 data set. The 2007 audit showed an overall accuracy in excess of 85% in relation to people and where they lived (Dodd, Craig, Kelly, & Guerin, 2010).

**Accommodation Options Available to Families**

The range of accommodation options available to families can influence their decision to seek alternative care. In Ireland, until 2004, accommodation for persons with intellectual disability was mainly provided within residential centers, which typically were a cluster of houses, each for six to eight persons, in a campus setting. Recently, group homes have been developed using domestic-style housing in community settings for approximately six persons, and these are now the dominant form of residential accommodation. In addition, independent or semi-independent living arrangements have become available as has a range of “augmented accommodation” for persons with additional needs, such as challenging behaviors and complex, physical health care needs, who have extra support staff (see Kelly et al., 2009).

The type and amount of residential accommodation have changed in recent years. In 1999 a total of 7,412 persons were residents in some form of residential accommodation: 3,539 (48%) in campus settings; 2,835 (38%) in group homes; 673 (9%) in independent or semi-independent arrangements; and 365 (5%) in augmented accommodation. By 2007, the total number of people receiving residential services had risen to 8,526, of whom 3,178 (37%) were in residential centers; 3,750 (44%) in group homes; 903 (11%) in more independent living settings; and 695 (8%) in augmented accommodation. The reduction in numbers of individuals living in campus settings was balanced by increased numbers in the other three options. Over the 8-year period, there was a 15% increase in the number of persons in some form of residential accommodation, which reflects the increased funding made available by government over this period. However a greater number of persons had moved from family care, as some would have taken up residential places that had become vacant, largely through deaths.

**Results**

The findings are presented in two sections. In Section 1, we provide details on the number of people who moved from family care from 1999 to 2007 and the different types of accommodation to which they moved. We performed a regression analysis to compare the characteristics of people who had moved from family care with those who had stayed. Section 2 describes the recorded need for accommodation away from family care and compares those families for whom a need to move was recorded in 2007 with those who had no need recorded. We again used a regression analysis to identify the people recorded as requiring a move from family care. Details are also provided on the type of provision that families requested compared with that which was provided.

**Section 1: People Moving From Family Care**

From 1999 to 2007, 1,678 persons had moved from family care to some form of residential accommodation. Their mean age was 35 years (SD = 14.1 years) and additional details of their characteristics are given in Table 1.

Of these who moved, 890 (53%) had been relocated to group homes, 314 (19%) were living independently or semi-independently, 230 (14%) had moved to a residential center, and 242 (14%) were had received various augmented residential services, of which the most frequent were nursing home care (n = 79), intensive support placements for challenging behaviors (n = 73), intensive
support for profound and multiple disabilities ($n = 51$), and inpatient stays in a psychiatric hospital ($n = 34$). Two persons were recorded as having no fixed address.

These data represent a very different pattern of residential placements compared with the distribution of available accommodation options noted above in 1999, and even in 2007, which confirms the development of new styles of accommodation options that followed increased resources becoming available from the government.

**Predictors of moving from family care.** Stepwise binary logistic regression was used to identify the significant predictors of people who moved from family care compared with those who remained with families. The database contained a limited number of demographic variables that could be used in these analyses (see Table 1). Two additional predictor variables were also included: (a) whether a need to move to residential accommodation was recorded and (b) whether the family had used available out-of-home respite services. The results of these analyses were statistically significant for the model, as shown in Table 2.

Not surprisingly, people who had requested a move up to 8 years prior were over three times more likely to move than those families who had not requested a move. However, requesting a move in the preceding year also added significantly to the model. This suggests that the longer the need has been recorded, the greater is the likelihood that a move will occur, but a recent request will increase further the chances of a move occurring.

In addition, those persons who had used respite provision were over twice as likely to move. Adult persons, especially those aged 40 years and over, were more likely to transfer than were younger persons. People who lived with relatives and with single caregivers had a higher likelihood of moving.

Level of disability made a significant but small additional contribution to the model in that people with moderate levels of disability were somewhat less likely to move than those with mild disabilities. Gender was not a significant predictor in the overall model.

### Section 2: People Who Needed to Move

Each year, the national database recorded whether the person needed a residential placement. In 2007, 2,680 persons (29%) living with family caregivers had a need to move recorded. As before, stepwise binary logistic regression analysis was used to identify the characteristics of persons with a recorded need to move from

<table>
<thead>
<tr>
<th>Variable</th>
<th>$p$</th>
<th>Corrected odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recorded need for move in 1999</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No need recorded (reference)</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Move needed</td>
<td>.000</td>
<td>2.98</td>
</tr>
<tr>
<td>Recorded need to move in preceding year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No need (reference)</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Move needed</td>
<td>.001</td>
<td>1.24</td>
</tr>
<tr>
<td>Age group of person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–19 years (reference)</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>20–39 years</td>
<td>.000</td>
<td>1.96</td>
</tr>
<tr>
<td>$\geq 40$ years</td>
<td>.000</td>
<td>2.82</td>
</tr>
<tr>
<td>User of respite care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No use of respite</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Respite user</td>
<td>.000</td>
<td>2.36</td>
</tr>
<tr>
<td>Family caregivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two-parent caregivers (reference)</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Single caregivers</td>
<td>.000</td>
<td>1.68</td>
</tr>
<tr>
<td>Relatives</td>
<td>.000</td>
<td>1.91</td>
</tr>
<tr>
<td>Level of disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild (reference)</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Moderate</td>
<td>.000</td>
<td>0.75</td>
</tr>
<tr>
<td>Severe–profound</td>
<td>.896</td>
<td>0.99</td>
</tr>
<tr>
<td>Gender of person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (reference)</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Female</td>
<td>.104</td>
<td>1.10</td>
</tr>
</tbody>
</table>

Note. $N = 10,037$. Hosmer and Lemeshow Test = 49.10 ($df = 8$, $p < .001$); Nagelkerke $R^2 = 0.183$. $x^2(10, N = 10,037) = 1,143.7$, $p < .001$. 

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The family home compared with those with no recorded need. The resulting model is shown in Table 3.

Those individuals most likely to require a move were adult persons, especially those aged 40 years and over; those who had used overnight respite services; people with severe–profound levels of disability; and those living with relatives or single caregivers. This pattern was similar to that reported above for people who moved from family care, with the exception of severity of disability.

Met and unmet needs. The proportion of people recorded as needing to move had increased markedly over the 8-year period: 1,052 persons needed to move as far back as 1999; this number had risen to 1,968 by 2003 and to 2,680 by 2007. However, identification of a need did not mean that the need would be met. By 2007, 658 persons of those identified as having a need to move had actually moved, which is only about one quarter of those for whom a need to move had been identified.

Conversely, higher proportions of people who moved from family care had no need for a move recorded, even in the year prior to admission; specifically, 1,020 persons (61% of those who moved) had no need recorded in the preceding year. This suggests that the relocation of certain persons takes precedence over those whose needs for a move may have been recorded for up to 8 years. The most likely reason for the unforeseen moves would be breakdowns in family care arrangements.

Type of accommodation required. Comparisons were made over a 4-year period regarding the types of accommodation that persons were thought to require and those in which they were located. A subsample of persons who had a need recorded in 2003 were followed up in 2007 (n = 1,968), as this provided a larger sample than using the 1999 data. In 2003, a place in a group home was noted for approximately two thirds of the individuals (n = 1,339). In addition, 14% (n = 278) were deemed to require an augmented residential service (mostly due to challenging behaviors or complex physical needs), whereas for 10% (n = 194) independent or semi-independent living was noted, and for 8% (n = 157) a placement in a residential center. This pattern of preference contrasts to the availability of different accommodation options that have been historically available in Ireland, with more places formerly being available in residential centers than in community options, although this pattern had changed over the 8-period, as noted earlier.

It was also possible to track, for each type of accommodation, the proportions of individuals who were placed by 2007 in accordance with the type of accommodation identified as suitable for them. This ranged from 23% in group homes (i.e., those who had actually moved to this form of accommodation as a percentage of those recorded as needing group homes) to 11.5% with augmented residential services (i.e., those who moved to an augmented service as a proportion of those recorded as needing it). The lower proportion in the latter form of accommodation suggests that these placements were more difficult to find, with people having to be placed instead in other forms of accommodation. However, it should be noted that the majority of people living with families did not request a
move. Of the 9,146 people living with families in 2007, 67% anticipated a continuation of family care arrangements for the foreseeable future.

Discussion

The longitudinal information extracted from this national data set provides empirical data about trends that are not always apparent to, or appreciated by, service planners and providers.

Over an 8-year period, the majority of persons with an intellectual disability continued to be cared for by their families, and only a small proportion moved to other forms of supported accommodation. This equated to 2% per annum of those living with family caregivers, which is similar to the 2.5% figure reported by McConkey (2005) for those requiring an imminent move in Northern Ireland. Based on these data, we can predict that 1 in 20 persons living with family caregivers will present each year as urgently needing alternative placement.

However, this figure may underestimate the numbers of persons who may need to move. In this study, the total number of persons recorded as needing a place in 2007 \( (n = 2,680) \) equated to an extra 3% of people living with family caregivers who may need an alternative place per annum (calculated over an eight year period). This would give an overall planning estimate of 1 in 20 persons per annum needing to move from family care. If the demand for places equates with the vacancies that arise primarily through deaths in existing residential provision, significant funding problems may not arise. However, it is likely that additional funding will be required to achieve these targets, due to the increased longevity of persons with an intellectual disability. McConkey, Mulvany, and Barron (2006) estimated a 20% rise in this population in Britain and Ireland up until 2020. When demand outstrips vacancies, increased funding will be required, and in recent years this has not been adequate in the United Kingdom and in the United States (Braddock & Hemp, 2006; Parrott, 2005). Indeed, only the lower target of 2% of people per annum transferring from family care was achieved in Ireland \( (n = 1,678 \text{ over an } 8\text{-year period}) \) and that was during a period of unprecedented investment in new services, particularly in new community living options. When economic constraints are present, it becomes even more crucial to ensure that available resources go to those who are most in need of them.

In this study, we show the complexities in anticipating a family's need for alternative placement (Freedman, Krauss, & Seltzer, 1997) and identify areas where additional investigation is needed, because the existing literature is scarce. For example, the need for a move had not been recorded, even in the previous year, for around two thirds of persons who had transferred from family care to other accommodations. This could reflect inadequate updating of information held on individuals, but this seems unlikely, given that the database was set up with the express purpose of identifying unmet needs and annual updates are a key feature of it. Rather, it is more likely that unforeseen breakdowns occurred in the family care arrangements, such as illness or sudden death of a main caregiver (Grant, Nolan, & Keady, 2003). Services are then placed under a great deal of stress in responding to crises, and the placements found may not be the most suitable for the person (Mencap, 2002). Subsequent studies could usefully explore the reasons for residential placements that had been unforeseen and unplanned using samples drawn from the database.

A favored solution to avoid crisis placements is to encourage family caregivers to formulate a futures or succession plan for their relative's care, with increased incentives offered to support continuing care by families (Bigby, 1996; Heller & Caldwell, 2006). Investment in these strategies could lead to more efficient use of scarce resources and avoid crisis responding.

In contrast to the unexpected placements, many more people were recorded as needing to move from family care, but they had not done so, even up to 8 years later. No reasons are recorded in the database for why a move was considered necessary. Additional research could elucidate this and confirm whether the family would accept a place if it were offered to them and any reasons for declining it (Essex, Seltzer, & Krauss, 1997).

Information was not available in the database as to whether these families had been offered a place but had refused it, for example, on the grounds that it was not needed at that time or they may have judged the placement as being unsuitable for their relative (Gilbert et al., 2008). Again, additional studies might explore these issues. Nonetheless, the most likely explanation for failing to obtain a place in residential accommodation despite families having indicated a need
for one, is that there were not enough places available and other families were given greater priority.

In this respect, it is surprising that the severity of disability was not a strong predictor of a person moving to a residential placement, although this was associated with a recorded need to move in this study. In addition, McConkey et al. (2010) found that severity of disability was a significant predictor of a family’s use of respite services. That people with moderate disabilities were significantly less likely to move is puzzling but may reflect the fewer demands they place on family caregivers, either from challenging behaviors or physical care needs. In any case, these findings further support the supposition that family factors represent stronger reasons in actually moving to a residential placement.

In this regard, the regression analyses identified two main predictors of placement: The people who were more likely to move were those who had waited for 4 years or more and those who currently used respite breaks. The former may be an indication of the length of time it can take to develop new accommodation options or in waiting for vacancies to arise in existing provision (Bowey & McLaughlin, 2007). Similar issues arise with other client groups, such as individuals who are elderly (Castle, 2001).

The use of short breaks may be an indication of caregivers’ greater needs as well as being a response by services to provide some form of assistance to caregivers while waiting for an alternative placement (McConkey et al., 2010). In addition, people over 40 years old and those living with relatives or single caregivers were also more likely to move, echoing results from a study in the United States (Essex, Seltzer, & Krauss, 1997). It should be noted though that it is difficult to disentangle the contribution of caregiver’s age as distinct from that of the person.

A considerable amount of the variance in predicting who would move to alternative accommodation was unaccounted for by these variables. One question to pursue in the future is whether the stress on families is due to a person’s severe challenging behaviors, which has been cited as a precursor of admission to residential facilities for children (Hanneman & Blacher, 1998). Consideration could be given to including information on this issue within this and similar data sets.

There may be other factors unique to the individual family, as well as the local opportunities for available placements, that are important determinants in deciding who moves. For example, a person who is judged suitable to fill a vacancy in an existing group home accommodating six persons may be preferred over another person with ostensibly greater needs but who is thought to be incompatible with the existing group. More detailed study of past placement decisions by services could help elucidate the various considerations involved in prioritizing allocation of places, which in turn could lead to refinement in assessing need for out-of-home placements for people with intellectual disabilities.

This study also confirmed a shift in the type of residential accommodation that caregivers preferred, notably a move from campus, congregated living toward community-based options. Although government services had invested new resources in these options over the 8-year period, there were indications that the provision of these options fell far short of the demand for them, particularly when augmented residential services were required. Consequently, people may have been placed in settings that were inappropriate to their needs. Indeed Irish services, as well as those elsewhere, are faced with the challenge of reconfiguring existing provision from congregated care to more individualized accommodation, especially for persons with more support needs (Department of Health, 2009). The failure to do so increases the risk that people, especially when a crisis arises, are moved into vacant places in existing facilities, despite their wish to live elsewhere, thereby perpetuating a style of service that is no longer fit for purpose and is not cost effective. Ongoing monitoring of inappropriate placements is necessary.

Last, the database failed to distinguish between the wishes of persons with the disability and those of their caregivers. It is likely that there was a proportion of caregivers who felt that a move was not required, whereas the person they cared for may have wished for this to happen. Indeed, both parties might have enjoyed a better quality of life as a result of moving to alternative accommodation (Werner, Edwards & Baum, 2009). Person-centered planning with individuals seems the best vehicle for ensuring the aspirations of the individuals with disabilities are included in futures planning (Robertson et al., 2008).

As this study has illustrated, a national database makes explicit significant trends in
service provision and can help to shape its future pattern. An additional advantage of having population data is that future studies can draw samples from the data to investigate other issues highlighted by this study, such as the caregiver's intention to accept offers of living accommodations for the person with disabilities. In addition, more qualitative information could be gained from selected samples to elaborate key questions: notably, does people's quality of life improve following a move? In our opinion, the main justification for all these efforts is to provide the evidence base to adequately plan nationally for the future care of persons with intellectual disabilities and to argue for the additional resources that will likely be needed.

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