

Predictors of access to healthcare professionals for people with intellectual disability in Ireland

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Abstract

The Irish National Intellectual Disability Database is updated annually and in 2017 contained records for nearly 22,000 persons aged 15 years and over. Information was extracted on the contacts each person had with one of eight health professionals in the years 2007, 2012 and 2017. Over these years, there was an increase in the number of people in contact with any professional or with four and more professionals. Nevertheless, the people less likely to have contact were those with milder forms of intellectual disability, persons living with family carers or independently and those linked to smaller provider agencies. By contrast, the odds of people with more severe disability in residential settings were up to eight times greater for having contact with four or more different professionals. As demand for healthcare grows due to increased longevity and service models shift to the community, redeployment of existing professional resources will be needed along with a review of the skill mix.

Keywords

intellectual disability, Ireland, health professionals, access, health services

Introduction

People with intellectual disability experience poorer physical and mental health. Among the more common conditions are respiratory problems, cardiovascular disease, certain cancers, diabetes as well as depression and anxiety (Taggart and Cousins, 2014). Consequently, they are likely to die earlier than their non-disabled peers. Heslop et al. (2013) reported that the median age of death for

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people with intellectual disability (65 years for men; 63 years for women) was significantly less than for the non-disabled UK population of 78 years for men and 83 years for women. In Ireland, comparable figures were 72 years for men and 79 years for women, whereas for people with intellectual disability, it was 53 years for males and 56 years for women (McCarron et al., 2015).

People with intellectual disability are also more likely to have additional physical and sensory impairments as well as other conditions such as epilepsy and challenging behaviours. McCarron et al. (2013) identified that 63% of individuals with intellectual disability had multi-morbidities in an Irish sample of over 700 people aged 40 years and over.

Some of the poorer health of this population results from the genetic or metabolic disorders associated with the person's intellectual disability. These are often compounded by other lifestyle factors, such as poor diet, lack of physical activity and inadequate living conditions (Emerson and Hatton, 2013). The impact of wider social determinants of health are as applicable to them as to the general population, such as poverty, prejudicial attitudes and discriminatory practices (World Health Organisation, 2008).

However, it is well recognised that some of the health disparities experienced by people with intellectual disability arise from a lack of timely access to effective healthcare and preventive actions (Krahn and Fox, 2014). There is accumulating evidence internationally of a failure in health systems to make reasonable adjustments to accommodate persons with intellectual disability and their specific health needs (Ali et al., 2013). A review in the UK found that avoidable deaths from causes amenable to change by good quality healthcare were more common in people with intellectual disability (37%) than in the general population of England and Wales (13%) (Heslop and Glover, 2015).

However, there is limited literature on access to healthcare by people with intellectual disability. Three main gaps are evident. Firstly, the focus to date has tended to be on care by medical professionals, especially in GP practices and acute hospitals, rather than the wider range of allied healthcare professionals such as nursing, therapies and psychology. Secondly, there is also limited information available on changes in access to these healthcare professionals over time, especially as the poorer health of persons with intellectual disability has become better known and guidance has been issued identifying health improvement strategies (National Institute for Health and Clinical Excellence (NICE), 2018). Is there a discernible improvement in access to healthcare in recent years?

Thirdly, past studies into service access have tended to use selected samples, which may not reflect the typical experience of people with intellectual disability across a country. Indeed, variations in the availability and type of service provision nationally may contribute to disparities in access to healthcare (Krahn and Fox, 2014). Nor do we know the characteristics of those persons who are more likely to gain access to healthcare professionals and more pertinently, who are at greater risk of not doing so.

The Republic of Ireland provides an opportunity to address these shortcomings in two ways. First, service provision in Ireland is centred on voluntary, not-for-profit organisations that are largely government funded. Certain services are funded to employ a range of health professionals to provide assessment and treatment specifically to persons with intellectual disability, although people may also avail of mainstream healthcare services. Moreover, the services cover designated urban and/or rural areas.

Second, uniquely in Europe, Ireland has a national database of persons with intellectual disability, which records those receiving specialist services or who could benefit from having them (Bakel et al., 2014). Set up in 1995 by the Department of Health, the Irish National Intellectual

Disability Database (NIDD) aims to gather information that will assist with the planning and provision of appropriate services in response to the changing needs of people with intellectual disability and their families. The database registers all persons who are receiving or assessed as being in need of specialist disability services for intellectual disability and anyone with a mild, moderate, severe or profound intellectual disability regardless of service use.

A core set of information is recorded for each person: namely their demographic details (gender, age, level of intellectual disability, present living arrangements) and the services they had received that year and those they may require in the immediate future. These include the services of the health professionals employed by the specialist providers or those accessed from mainstream primary care services (see Table 2). However, the database does not distinguish the employment status of the health professional.

Thus, Ireland provides a unique opportunity to examine the access that people with intellectual disability have to different healthcare professionals throughout the country, to monitor changes in access over a 10-year period and to identify the characteristic of persons who are more likely to access healthcare and those at risk of not doing so.

Ideally, this information should be matched with details of the healthcare workforce employed in intellectual disability services in particular, but this information is not readily available for Ireland (Department of Health, 2012), although an attempt was made to do this for specialist health services in Scotland (Smiley et al., 2002).

The aims of the study

The main research questions of this descriptive study were:

- How many persons with intellectual disability accessed one of the eight healthcare professionals and what changes occurred in their access over a 10-year period?
- What were the characteristics of people with intellectual disability who had contact with any health professional in the chosen years and also the characteristics of those persons who had contact with four or more professionals from different disciplines within the same year?
- Did the type of service provider and location within the country influence access to healthcare professionals?

The country context

The Republic of Ireland is classed as a high-income country by the World Bank (2019). In 2017, the estimated population was 4.792 million: 72.5% of whom were aged 20 years and over. Life expectancy at birth is around 81 years. Two-thirds of the population live in cities and towns.

Services in Ireland for adults with intellectual disability are mainly provided by non-statutory – ‘voluntary’ – not-for-profit organisations. They are long-established autonomous bodies with their own Boards of Management that are independent from government but mostly funded through block grants from the Department of Health. They provide services specifically for persons whose primary need is deemed to be due to an intellectual disability. Similar organisations provide services for persons with other forms of impairment.

Intellectual disability organisations can be grouped into four types on the basis of historically different funding arrangements with government and the different styles of services they provide. The type of agency could influence access to healthcare professionals.

Large organisations

There are 14 major providers operating across the country which cover the full age range of service users. They cover a specific geographical area and provide schools, day centres and residential services. They also employ a range of health professionals who work mainly with clients linked to their service or those who may be in need of a service.

These organisations can be further grouped into two categories. Ten of the longer established services – mostly religious orders – initially provided mainly residential services, similar to the institutions commonly provided in other countries such as United Kingdom, mainland Europe and the United States. Initially, the main professions employed were doctors and nurses, although in time psychologists and therapists were also recruited. From the 1960s onwards, four new organisations were formed with a focus on community, rather than institutional-based services, although they later added residential services, mainly in the form of group homes.

These 14 large organisations together provide services to the majority of persons with intellectual disability. Service contracts with the Health Services Executive on behalf of the government cover nearly all of their capital and revenue costs, but they retain their autonomy in terms of how services are staffed and function.

Small organisations

From the 1960s onwards, local parent and friends associations across Ireland initiated community-based services including preschools and day care, schools, day centres, training workshops and residences. Although these voluntary smaller scale services were initially funded through charitable donations, they are now almost totally dependent on government monies. They too remain autonomous agencies with around 40 organisations having service-level agreements with the Health Service Executive (HSE). However, they rarely employ health professionals directly and clients who require these services will do so mainly through mainstream community services.

Health Service Executive (HSE)

The HSE – a government agency – is the national provider of hospital and community health and social care services. In addition, to being a commissioner of services with the voluntary organisations as described above, the HSE is a direct provider of mostly residential services to around 10% of adult persons with intellectual disability. The HSE also provides medical and therapeutic services to the wider community as well as to their specialist intellectual disability services.

A small number of people with intellectual disability are linked with a variety of other agencies such as hospitals, private nursing homes and other voluntary organisations serving local communities.

All the government-funded services are provided free to individuals with intellectual disability as are mainstream health services.

The HSE commissions and provides community health and social care through nine Community Healthcare Organisations (CHOs) each covering a specific geographical region. Areas 1–4 cover the western part of the country (a mix of cities and rural areas); areas 5 and 8 are the midland areas that are mostly rural, with areas 6, 7 and 9 covering Dublin city and the greater Dublin conurbation which are largely urban. Often people living in more rural areas in Ireland have greater difficulties in accessing health services (Walsh et al., 2012). The present study would explore a possible impact of location on access to healthcare professionals.

A further system variable was included in the study. Social workers often act as ‘case managers’ for persons and family carers and may be involved in referrals to healthcare professionals for assessment and treatment. However, not every person with intellectual disability will have an allocated social worker. Many social workers continue to be employed by the larger voluntary providers as state-provided community and social care services were poorly developed until recently (Redmond and Jennings, 2005).

Method

National intellectual disability database

The data reported in this study were obtained from NIDD, which is a national case register of persons with intellectual disability. In addition to a core set of demographic information on each person registered, details are collected of services received including those provided by health professionals: namely, medical doctors (including GPs and hospital staff), nurses (employed mostly in residential services), psychiatrists, psychologists, speech and language therapists, physiotherapists, occupational therapists and dietitians. In addition, a current contact with a social worker is noted and they too can be employed in both the specialist services or from mainstream community teams. However, other professional services such as dentistry and chiropody/podiatry have not been provided by the intellectual disability services and are not recorded on the database.

An individual must have had four contacts with a health professional within the current year for this to be recorded on the database. This is intended to reflect treatment episodes and may underestimate the proportion of people with intellectual disability who have contact with the various health professionals in the year. However, no records are maintained of visits to Accident & Emergency (A&E) departments or hospital admissions.

The records for each individual are reviewed annually by the person’s key worker in the service or the professional with whom they have had contact. These reviews are usually done in consultation with the person and/or family carer to ensure accuracy. Periodic audits are also undertaken of the NIDD which have found over 85% accuracy in records (Dodd et al., 2010). Individual records are later collated anonymously at a national level by the Health Research Board. This is done annually and copies of annual reports of data held on the NIDD from 2004 onwards are available at: <http://www.hrb.ie/health-information-in-house-research/disability/nidd-publications/>.

For the purposes of this study, the focus was on persons aged 15 years and above. Information relating to their contact with healthcare professionals was obtained over a 10-year period using the 2007, 2012 and 2017 data sets. From 2007 to 2012, the Irish Government was forced to implement austerity measures due to the financial crash including cuts to health services, but from 2012 to 2017, the financial pressures started to ease (Hauben et al., 2012).

Participants

In 2007, 19,316 adults (aged 15 years and over) were recorded on the NIDD, which represents an overall prevalence rate of 5.55 per 1000. Although lower than the average international rates reported for high-income countries of 9.2 per 1000 (Maulik et al., 2011), the latter figure includes persons who are not in receipt of specialist services and those with mild intellectual disability.

The equivalent figures for 2012 were 20,692 persons (prevalence 5.57 per 1000) and for 2017 were 21,807 persons (prevalence 5.76).

Table 1. The number and percentages of people in the three cohorts: 2007, 2012 and 2017 grouped by predictor variables.

Predictors	2007	2012	2017
Gender			
Male	10,521 (54.5%)	11,419 (55.2%)	12,340 (56.6%)
Female	8795 (45.5%)	9273 (44.8%)	9467 (43.3%)
Level of disability			
Mild	6843 (35.4%)	7378 (35.7%)	7860 (36.0%)
Moderate	8173 (42.3%)	9061 (43.8%)	9802 (44.9%)
Severe/profound	4300 (22.2%)	4253 (20.6%)	4145 (19.0%)
Age group			
15–19 years	2845 (14.7%)	3123 (15.1%)	3261 (15.0%)
20–29 years	4382 (22.7%)	4207 (20.3%)	4686 (21.5%)
30–49 years	7946 (41.1%)	8108 (39.2%)	7657 (35.1%)
50 years+	4143 (21.4%)	5254 (25.4%)	6203 (28.4%)
Living arrangements			
Family home	10,262 (53.6%)	11,377 (55.5%)	12,967 (60.0%)
(Semi) independent	880 (4.6%)	1193 (5.8%)	1272 (5.9%)
Group home	3731 (19.5%)	4234 (20.6%)	4397 (20.4%)
Congregated setting	4279 (22.3%)	3700 (18.0%)	2969 (13.7%)
Location			
Urban area	6016 (31.9%)	6170 (30.5%)	6469 (30.4%)
Mixed urban rural	6573 (34.9%)	7008 (34.6%)	7403 (34.8%)
Mostly rural	6264 (33.2%)	7049 (34.8%)	7393 (34.8%)
Type of organisation			
Small agency	5128 (26.5%)	5975 (28.9%)	6630 (30.4%)
New large agency	2667 (13.8%)	2966 (14.3%)	3028 (13.9%)
Old large agency	6694 (34.7%)	6960 (33.6%)	7139 (32.7%)
HSE	3731 (19.3%)	3753 (18.1%)	3699 (17.0%)
Other	1096 (5.7%)	1038 (5.0%)	1307 (6.0%)
Social worker			
Contact	6711 (35.6%)	7974 (39.4%)	7981 (36.6%)
No contact	12,145 (64.4%)	12,253 (60.6%)	13,826 (63.4%)

HSE: Health Service Executive.

The demographic details of registered cases are given in Table 1.

The level of disability is recorded using International Classification of Diseases, 10th Revision (ICD-10) categories. Living arrangements are grouped into people living with family carers (either parents or relatives), those who live independently or semi-independently (with visiting support), people living in group homes (with up to six persons) and those living in ‘congregated settings’ (such as campus settings with 6–10 people living in dispersed units on the same site or in ward-like settings).

Access to health professionals may also be determined by the type of organisation to which the persons are linked as described previously but also in relation to the Community Health Organisations in which they lived. The three CHOs in the greater Dublin area were classed as Urban, those

in the western area which had a mixture of large towns and cities as well rural areas were classed as mixed urban/rural and those in the middle of the country were deemed as mostly rural.

As noted previously, having contact with a social worker may also facilitate access to health professionals and those who had contact with social workers in each of the years are noted in Table 1.

There are some noteworthy changes in the demographics of the three cohorts over the 10-year period. The proportion of persons aged 50 years and over rose from 21.4% in 2007 to 28.4% in 2017. There was an increase in the proportion of persons living with family carers from 53.6% in 2007 to 60.0% in 2017 with a conversely marked decrease in persons living in congregated settings from 22.3% to 13.7% which was in line with government policy (HSE, 2011). There was a smaller drop in the proportion of persons with severe and profound intellectual disability from 22.3% to 19.0%, which may be linked to the decrease of persons living in congregated settings.

Data analysis

A three-stage process was followed. First, the number of adult persons accessing each health professional was identified for the three chosen years. Comparisons could then be made across the different health professionals and over time but as each year represents a different cohort, inferential statistics could not be used to test the significance of the differences.

Secondly, bivariate analyses (Chi Square) were used to identify significant differences ($p < 0.01$) in accessing each healthcare professional that was associated with the person's demographic characteristics listed in Table 1. Nearly all of the predictors were significantly related to having contact with each of the eight professionals in the 3 years. A cluster analysis was undertaken to determine whether there were combinations of professionals that people were more likely to access but no significant clusters emerged. A count was then made of the number of different professionals seen by each person in each year ranging from none to eight. Three groupings were then created: people who had no contact with any professional, those who had been in contact with one to three professionals across the eight disciplines and those who had contacted four or more professionals. Any combination of professionals was counted in the contact groupings.

Thirdly, binary logistic multiple regression analyses were used to determine the probabilities associated with persons having any contact compared to no contact with a health professional and between those who had few contacts (one to three) and many contacts (four or more). The regressions were repeated for the 3 years to test the robustness of the relationships and any changes occurring. In each of the six regressions, the same set of predictors were included. This also controlled for the interrelationships among the predictors: for example, people with more severe disability were more likely to live in congregated settings.

Data were managed and analysed in SPSS, version 25.0 (IBM Corporation, 2013).

Ethical approval was not sought for the study as it was based on secondary analysis of anonymised data. Moreover, at registration on the NIDD, written consent was obtained for anonymised information to be used in service planning and for research purposes. All the data analyses were undertaken by Health Research Board staff.

Results

Table 2 summarises the percentage of persons with intellectual disability who had at least four contacts with each of the health professionals listed in each of the three selected years. Medical

Table 2. The percentage of persons with ID having at least four contacts with each of the disciplines listed in 2007, 2012, 2017.

Discipline	2007	2012	2017
	N = 19,152 (%)	N = 20,504 (%)	N = 21,605 (%)
Medical	33.4	36.9	38.
Psychiatry	29.6	33.2	30.9
Psychology	26.9	28.2	28.5
Nursing	25.3	31.4	30.9
Physiotherapy	15.4	19.1	20.9
SLT	13.3	22.9	29.4
OT	13.1	18.2	23.2
Dietitian	11.6	14.1	14.0
No contact with any of the above	32.6	25.1	25.8
One to three professionals	52.0	53.5	50.2
Four or more professionals	15.4	21.4	24.0

SLT: Speech and Language Therapy; OT: Occupational Therapy.

professionals were consistently the highest across the 3 years with the least number of people with intellectual disability seen by a dietician.

The high proportion seen by a psychiatrist is largely a historical legacy in that the large voluntary organisations and the HSE mostly appointed psychiatrists as the ‘medical director’ of their services who in turn tended to recruit junior doctors from that specialism. Psychiatric contacts were especially marked with people living in congregated settings in 2017 (70.9% compared to 13.5% of those living independently) which is perhaps reflective of the greater mental health needs and challenging behaviours of residents in such settings.

Over a quarter of persons had contact with a psychologist which also has its roots in history. The larger voluntary organisations pioneered the appointment of psychologists to services in Ireland (Carr, 2015) and this tradition has continued although unlike psychiatry, there is less variation across the people with whom psychologists have contact.

The proportion of persons in contact with nursing staff is highest with persons who have severe and profound disability. In 2017, 55.8% of these persons had contact with nurses compared to 18.1% of those with mild disability. Also, 66.4% of persons residing in congregated settings had nursing contact in 2017 compared to 12.3% who lived independently. This suggests that nurses are employed mainly as full-time staff in residential settings rather than as community-based nurses (Doody et al., 2012).

A smaller proportion of people in each year had contact with a therapeutic service, with speech and language therapists and occupational therapists seeing more people than physiotherapists by 2017. Dietitians were involved with the lowest percentage of people with ID in all 3 years. These four health professionals had higher levels of engagement with people who had severe and profound disability.

Over the period 2007 to 2017, the only professions to have a marked increase in the proportion of people seen by them was speech and language therapy (a 120% increase) and occupational therapist (a 77% increase). For the other professions, the increases ranged from 4% to 36%.

The increases were more marked in the period 2007–2012 than in 2012–2017, when for some professionals the percentages of people seen dropped slightly in recent years.

As Table 2 also presents, around one-third of persons had no contact with any of the listed professionals on four or more occasions in 2007, but this had fallen to around one-quarter in 2017. By contrast, there was an increase over the years in the numbers of people having contact with four or more different professionals.

Regression analyses

Binary logistic regressions were undertaken for each of the 3 years, contrasting people who had no contact with any of the professionals with those who had one or more contacts (Table 3). A second regression contrasted those who had four and more different contacts with those who had one to three contacts (Table 4). In the tables, the significance level of the predictor variable is given along with the odds ratio (Exp *B*) for that predictor (details of 95% confidence intervals are available from authors). Also the percentages for the subgroups within each predictor who had any, or four and more, contacts are given to clarify the differences among the subgroups, although due to interrelationships among the predictor variables some of these may show little difference on the single predictor. All the regressions were statistically significant and the resulting models accounted for up to 30% of the variance as indicated by R^2 .

As Table 3 presents, the persons who were most likely to have accessed at least one professional were those living in group homes or congregated settings (with an odds ratio over five times greater than those living with family carers). Likewise, the odds of people with severe and profound intellectual disability were up to four times greater to see a professional. Also the odds of seeing a professional were up to four times higher for people associated with the newer large organisations and over three times greater for those who had contact with a social worker. People aged 20 years and over were less likely than the 15–19 years age group or the 50 years and over to see a professional.

The other predictors although statistically significant did not increase the odds ratio to any great extent.

The regressions presented in Table 4 show a similar pattern of significant predictors. The odds of people living in congregated settings were up to eight times greater to see four or more professionals than those living with family carers or independently with those living in group homes up to three times more likely. The odds of those with severe and profound intellectual disability were up to five times greater to see four or more professionals than those with mild intellectual disability while the odds of those with moderate intellectual disability were twice as great. People aged 50 years and over had an increased likelihood of seeing four or more professionals as did those who had a social worker. Females rather than males also tended to see more professionals. However, the type of agency providing the service or the location of the service had less marked effects.

Alternatively, these results identify those persons who were most likely to have no contact with any health professional or see a fewer number of professionals: namely those living independently or with family carers; people with mild intellectual disability; younger adults, those linked with small agencies and not having an active contact with a social worker. Males and those living in urban areas were also less likely to have contact with a healthcare professional.

Table 3. Variables related to the receipt of any health professional input in 2007, 2012 and 2017.^a

Predictors	2007			2012			2017		
	Outcome		Model	Outcome		Model	Outcome		Model
	% Contact	Exp(B)	Significance	% Contact	Exp(B)	Significance	% Contact	Exp(B)	Significance
Male ^b	65.4	1.191	.000	74.3	1.036	.336	73.2	1.081	.030
Female	69.1	1.660	.000	75.7	1.550	.000	75.5	1.622	.000
Mild ^b	51.2	3.867	.000	63.1	4.853	.000	61.7	4.868	.000
Moderate	69.2	0.525	.000	76.0	0.507	.000	76.1	0.492	.000
Severe/profound	88.3	0.548	.000	93.0	0.479	.000	93.5	0.445	.000
15–19 years ^b	61.1	0.646	.000	76.1	0.636	.000	75.7	0.546	.000
20–29 years	59.1	1.136	.111	66.5	0.994	.931	65.1	1.041	.568
30–49 years	69.3	3.461	.000	73.9	4.444	.000	72.5	5.546	.000
50 years +	75.6	4.424	.000	82.6	4.400	.000	82.6	5.512	.000
Family home ^b	55.4	0.952	.286	66.1	0.918	.073	65.6	1.205	.000
(Semi) independent	51.0	1.199	.000	56.4	1.166	.003	57.8	1.772	.000
Group home	81.4	0.952	.286	89.3	0.918	.073	91.4	1.205	.000
Congregated setting	87.5	4.424	.000	91.7	4.400	.000	93.3	5.512	.000
Urban area ^b	69.7	0.952	.286	79.2	0.918	.073	74.4	1.205	.000
Mixed urban rural	67.1	1.199	.000	73.2	1.166	.003	73.2	1.772	.000
Mostly rural	64.5	1.396	.000	72.8	1.691	.000	75.0	1.772	.000
Other ^b	39.8	6.488	.000	71.3	4.002	.000	71.0	4.827	.013
Small agency	54.9	1.614	.000	64.5	1.013	.891	65.0	1.336	.000
New large agency	87.5	1.901	.000	92.4	1.013	.891	90.0	1.336	.000
Old large agency	72.3	3.391	.000	75.5	2.457	.000	75.1	3.002	.000
HSE	67.1	0.448	.000	77.5	1.822	.000	77.2	1.129	.126
No social worker ^b	58.5	3.391	.000	68.9	2.457	.000	67.3	3.002	.000
Social worker	82.9	0.448	.000	84.2	1.822	.000	86.1	1.129	.126
Constant									

HSE: Health Service Executive.

^a2007: $n = 19,038$; $\chi^2 = 4763.6$, $df = 16$; $p < 0.001$; Nagelkerke $R^2 = .309$; 2012: $n = 20,479$; $\chi^2 = 4143.2$, $df = 16$; $p < 0.001$; Nagelkerke $R^2 = .271$; 2017: $n = 21,605$; $\chi^2 = 4769.2$; $df = 16$; $p < 0.001$; Nagelkerke $R^2 = .291$.

^bReference group used in the regression.

Table 4. Variables related to having seen four or more health professionals in 2007, 2012 and 2017.^a

Predictors	2007			2012			2017		
	Outcome		Model	Outcome		Model	Outcome		Model
	% Contact	Exp(B)	Significance	% Contact	Exp(B)	Significance	% contact	Exp(B)	Significance
Male ^b	19.7			26.4			30.5		
Female	25.9	1.716	.000	31.2	1.337	.000	34.7	1.235	.000
Mild ^b	9.0			13.9			15.9		
Moderate	17.4	1.778	.000	24.7	1.650	.000	28.7	1.732	.000
Severe/profound	42.9	4.685	.000	52.7	4.160	.000	60.0	4.830	.000
15–19 years ^b	21.6			27.4			31.5		
20–29 years	21.2	0.440	.000	23.0	0.517	.000	23.0	0.441	.000
30–49 years	22.4	0.272	.000	28.9	0.370	.000	31.1	0.321	.000
50 years+	24.8	0.307	.000	32.5	0.369	.000	39.8	0.345	.000
Family home ^b	12.5			17.3			19.9		
(Semi) independent	3.6	0.655	.113	7.0	0.793	.154	8.8	0.839	.214
Group home	19.1	2.680	.000	32.2	3.270	.000	40.8	3.759	.000
Congregated setting	43.4	7.609	.000	53.8	6.611	.000	64.6	8.256	.000
Urban area ^b	24.7			33.9			35.6		
Mixed urban rural	22.0	1.013	.827	27.4	0.878	.009	32.7	1.071	.158
Mostly rural	21.1	1.236	.002	24.7	1.049	.402	29.1	1.270	.000
Other ^b	13.0			25.6			30.5		
Small agency	11.5	0.884	.488	16.5	0.583	.000	20.5	0.621	.000
New large agency	31.5	2.971	.000	37.2	1.517	.000	38.4	1.523	.000
Old large agency	25.2	0.900	.546	35.2	0.716	.002	40.1	0.833	.050
HSE	23.3	1.153	.425	25.3	0.621	.000	30.6	0.773	.007
No social worker ^b	18.8			24.0			25.3		
Social worker	27.6	2.124	.000	34.3	1.791	.000	41.9	2.355	.000
Constant		0.054	.000		0.173	.000		0.166	.000

HSE: Health Service Executive.

^a2007: $n = 12,828$; $\chi^2 = 2719.1$; $df = 16$; $p < 0.001$; Nagelkerke $R^2 = .291$; 2012: $n = 15,350$; $\chi^2 = 3198.1$; $df = 16$; $p < 0.001$; Nagelkerke $R^2 = .269$; 2017: $n = 16,031$; $\chi^2 = 4119.5$; $df = 16$; $p < 0.001$; Nagelkerke $R^2 = .316$.

^bReference group used in the regression.

Discussion

The unique strengths of this study are its coverage of a national population of people with intellectual disability, the opportunity provided to monitor changes in access to healthcare professionals over a 10-year time span and the inclusion of therapists in addition to medical and nursing staff on which previous studies have focussed. Although there are shortcomings noted below, a number of clear conclusions emerge from the analyses undertaken that clearly identify the persons most likely to access healthcare professionals and the influence that service systems have on access.

The majority of Irish persons with intellectual disability were in contact with at least one or more health professionals from 2007 through 2017. Indeed, over this time period, the numbers of people who had not accessed any health professional dropped and those seeing four or more professionals had increased. The change was particularly evident for contacts with speech and language therapists and occupational therapists. Moreover, these changes took place during a period of economic austerity and at a time when other services for this client group were reduced, notably a reduction in respite and residential places (McConkey et al., 2018) and a refocussing on day-care centres (McConkey et al., 2019). A greater awareness of the unmet health needs among people with intellectual disability may have contributed to the change which was supported by lobbying from advocacy groups as well as by health professionals.

Unfortunately, no comparable data on people's access to health professionals from other countries were found especially from those countries where healthcare to people with intellectual disability is largely provided through mainstream services. The employment of dedicated healthcare professionals by Irish disability services may result in greater access to healthcare than is available in other jurisdictions. Further comparative studies would help to elucidate this issue. But better access does not necessarily result in better outcomes as Irish persons seem to die at a younger age than their English counterparts (McCarron et al., 2015)

The Irish data also identify people with intellectual disability who are at greater risk of having no or limited access to healthcare professionals: notably those with milder forms of intellectual disability, persons living with family carers or independently and those linked to smaller provider agencies who do not employ any healthcare professionals. Emerson et al. (2016) noted a similar pattern. As Table 1 presents, this grouping forms the majority of persons with intellectual disability and yet the main focus of healthcare professionals in Ireland remains on people with more severe disability in residential settings. This may reflect the historical origins of the large voluntary providers notwithstanding that the persons with more severe disability are likely to have greater healthcare needs. But the numbers living in congregated settings are declining and yet the danger is that healthcare professionals maintain old precedents and priorities in their practices while overlooking the unmet healthcare needs of others who are living in community settings (McCarron et al., 2018). The recruitment of extra staff is a favoured solution to addressing unmet needs and one that was successful in Ireland even at times of financial stringencies. Yet redeployment of existing resources must also be considered and not only in terms of the clients having priority but also the skill mix among healthcare professionals involved with people with intellectual disability and the training they receive (Lennox et al., 2015). In future years, these issues will need to be tackled as the population of people with intellectual disability continues to increase due to longer life expectancy and consequently increasing numbers of older persons (World Health Organisation, 2011). Yet the extra funding demands on health and social care services for the general population

will likely make it more difficult to obtain extra resources for people with intellectual disability when they already incur greater costs (Lunsky et al., 2019).

Arguably the present study, like many similar ones, failed to address the outcomes for people with intellectual disability from their contact with healthcare professionals. Put simply, does their health improve: do they live longer? A Cochrane review by Balogh et al. (2016) found no well-designed studies that had investigated the organisation of health services for persons with an intellectual disability and concurrent physical disabilities, although there were seven studies that had focused on mental health problems with some evidence that community-based behaviour therapy might decrease behavioural problems.

Given the large amount of monies spent annually on the provision of healthcare services for people with intellectual disability in Ireland and presumably many other European countries, the failure to monitor outcomes is particularly surprising. The ‘cost-benefit’ debate not only applies to spending among the different health professionals but also how this spending compares to the funding of other supports that might also improve a person’s health such as supported living, paid work and access to sports and leisure (Simões and Santos, 2017).

The Irish database illustrates the value of obtaining national data on an annual basis. However, there are some notable shortcoming in relation to people’s health that should be addressed in further studies. No details were available of the health problems or comorbidities experienced by individuals. People with intellectual disability who have no contact with specialist intellectual disability services were not included and it is likely that they are at a greater disadvantage in accessing mainstream healthcare services (Emerson et al., 2016). No details were available of the total number of contacts each person had with the individual health professional in the course of the year or of the treatments provided and the outcomes achieved. Also, it was not possible to align the case data with the number of professionals employed across all the different services so information on caseloads could not be determined.

Steps are being taken to revise the Irish database to address some of the gaps. However, a bigger challenge is to improve existing administrative data sets used by healthcare professionals across different services – primary care, hospital and specialist services – and combining them so that a fuller picture can be obtained of the health needs of people with intellectual disability, the treatments provided and the outcomes achieved.

Invariably the findings reported here are specific to Ireland and the way in which health services are delivered to people with intellectual disability but the insights gained could have wider applicability especially in countries with similar models of service provision. Arguably the main lesson from the study is not so much the findings but highlighting the information about access to healthcare that is lacking and the priorities for future research that all countries need to address.


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