



HRB Statistics Series 28

Annual Report of the National Intellectual Disability
Database Committee 2014

Main Findings

Caraíosa Kelly

design by Clickworks



*'Surge of Colour' by Carmel Curran,
NIDD Cover Design Winner 2014*

Carmel Curran is from Kilmacathomas, Co. Waterford. She lives with her Dad and Mum, Ned & Bridget Curran.

Once a week, Carmel attends an integrated art class with a group of transition year students from the Ard Scoil in Dungarvan. She really enjoys meeting and chatting to all the students and the teacher Claire Cahill. Carmel has worked on many arts and crafts projects, which she proudly displayed at the school's recent art exhibition.

Carmel has also achieved another personal goal- to be a model. She braved the catwalk at the Ard Scoil Fashion Show to model clothes that she and her student friends made from recycled materials.

She is a lady of many talents such as music, singing and dancing, she has performed in concerts and shows in front of large audiences. She loves swimming and horse riding too.

Carriglea Cairde Services are privileged to support Carmel achieve her personal goals and wishes in life.

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Health Research Board
An Bord Taighde Sláinte
Grattan House
67–72 Lower Mount Street
Dublin 2
Ireland

t 353 1 234 5000

f 353 1 661 2335

e disability@hrb.ie

w www.hrb.ie

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Disability Databases Team

e disability@hrb.ie

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About the HRB

The Health Research Board (HRB) is the lead agency supporting and funding health research in Ireland. We also have a core role in maintaining health information systems and conducting research linked to these systems. Our aim is to improve people's health, build health research capacity, underpin developments in service delivery and make a significant contribution to Ireland's knowledge economy.

Our information systems

The HRB is responsible for managing five national information systems. These systems ensure that valid and reliable data are available for analysis, dissemination and service planning. Data from these systems are used to inform policy and practice in the areas of alcohol and drug use, disability and mental health.

The **HRB Statistics Series** (published 2007 to present) compiles data on problem alcohol and drug use, disability and mental health from a single point or period in time. Previous reports associated with this series are:

- Activities of Irish Psychiatric Units and Hospitals (1965–2006)
- National Physical and Sensory Disability Database Committee Annual Reports (2004–2006)
- National Intellectual Disability Database Committee Annual Reports (1996–2006)

The **Disability Databases Team** manages two national service-planning databases for people with disabilities on behalf of the Department of Health: the National Intellectual Disability Database (NIDD), established in 1995, and the National Physical and Sensory Disability Database (NPSDD), established in 2002. These databases inform decision-making in relation to the planning of specialised health and personal social services for people with intellectual, physical or sensory disabilities.



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Tedstone Doherty D, Walsh D, Moran R and Bannon F (2007) *High support community residences census 2006*. HRB Statistics Series 1. Dublin: Health Research Board.

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- Disability Unit, Department of Health;
- the Health Service Executive, in particular the database co-ordinators and the database administrators/managers;
- the National Federation of Voluntary Bodies providing services to people with intellectual disability;
- the parents and families of people with intellectual disability and their representative bodies; and
- all service users throughout Ireland.



Members of the National Intellectual Disability Database Committee 2014

Ms Gráinne Duffy

Disability Unit, Department of Health

Ms Jacqueline Grogan

Disability Federation Ireland

Ms Margaret Dorney, (Secretary)

Disability Unit, Department of Health

Mr Harry Harris

Disability Unit, Department of Health

Dr Máirín Boland

Department of Public Health

Health Service Executive

Mr Dharragh Hunt¹

National Disability Authority

Mr Gerard Tully²

National Disability Unit,

Health Service Executive

Ms Fionnuala O'Donovan

Chief Executive

Enable Ireland

Ms Sarah Craig

Health Research Board

Ms Mary O'Gorman

Health Research Board

Ms Anne O'Donohoe

Health Research Board

Ms Caraíosa Kelly

Health Research Board

Mr Declan Ryan

St Michael's House

Representing the National Federation of Voluntary Bodies

Mr James Roche

Western Care Association

Representing the National Federation of Voluntary Bodies

¹ Replaced Ms Eithne Fitzgerald on committee in June 2014

² Replaced Mr William Ebbitt on committee in June 2014



Chairperson's statement

It gives me great pleasure to introduce the 2014 Annual Report of the National Intellectual Disability Database. The year 2014 marks the fortieth anniversary since the first "Census of Mental Handicap" was undertaken by the Health Research Board in 1974. In 1974, information was collected on 4,863 people with an intellectual disability.

The 2014 report provides:

- a profile of people with a disability registered on the databases in 2014;
- details of the specialised health and personal social services provided; and
- an outline of the future need for those services.

One of the fundamental goals of Government in providing public services for people with a disability is the right to live in the community. The databases show that most people with disabilities in Ireland live independently, or with their families. The Government, and the non-statutory agencies who provide services to people with disabilities on behalf of the Government, have been working towards the goal of enabling our disabled citizens to live as independently as possible with appropriate social, housing and employment supports from the State. However, over 3,000 people, many with complex support needs, still live in larger, isolated institutional settings. The Department of Health is working with its many partners in the health and wider public sector to close down these institutions, and to support these people in the community.

A set of standards for all disability residential centres, including the institutional settings mentioned earlier, were developed. Compliance with the standards is a requirement under the Service Level Arrangements between the Health Service Executive and the non-statutory service providers who currently provide the bulk of disability services and supports. The statutory inspection process has now been up and running for approaching two years. The process of inspection has highlighted many areas where much work needs to be done and areas of good practice. The Health Service Executive is implementing a comprehensive programme of measures to improve the quality and safety of residential services and much work remains to be carried out to ensure all facilities comply with the standards.

The disability databases have recorded the changes in service provision over the past decades. The database committee looks forward to working with the implementation framework of the Value for Money Review in the development of a new management and information system that will meet the future information requirements of the disability programme in the HSE.

Sincere thanks are due to all those involved in the maintenance of the database at service provider, Health Service Executive and Health Research Board level. The contribution of my colleagues on the National Disability Databases Committee, especially the HRB, in steering the operation of the database is also much appreciated.

Gráinne Duffy

Chair, National Disability Databases Committee



Introduction

This report is a summary of the main findings of the analysis of the seventeenth annual extract of data from the National Intellectual Disability Database (NIDD). The report is based on validated data extracted from the NIDD in December 2014. The 2014 dataset consists of information relating to 27,887 individuals. Of these registrations, 92% (25,648 records) were updated following the 2014 annual review of NIDD information; the remaining 2,239 registrations contain the last-known data in each case³. Prevalence rates per thousand of population are based on data from the 2011 Census of Population⁴. Comparative data for 1996 and 2013 used in this report are from published NIDD data for these years.

In addition to this report, a complete set of tables and figures, mirroring data in reports from 2013 and previous years, is available in user-friendly MS Excel versions on the HRB website.

³ The majority of those not reviewed were due to resource issues in two HSE areas.

⁴ Central Statistics Office (2012) Census of Population, 2011: Principal demographic results. Dublin: Stationery Office.



Main findings

There were 27,887 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2014. Based on 2011 census figures, this represents a prevalence rate of 6.08 per 1,000 population. The prevalence rate for mild intellectual disability (which traditionally has been under-reported) was 1.99 per 1,000, and the rate for moderate, severe or profound intellectual disability was 3.58 per 1,000. Figure 1 presents the number of registrations by county of residence and shows that Sligo (10.6/1,000) had the highest prevalence rate while Leitrim (4.7/1,000) had the lowest.

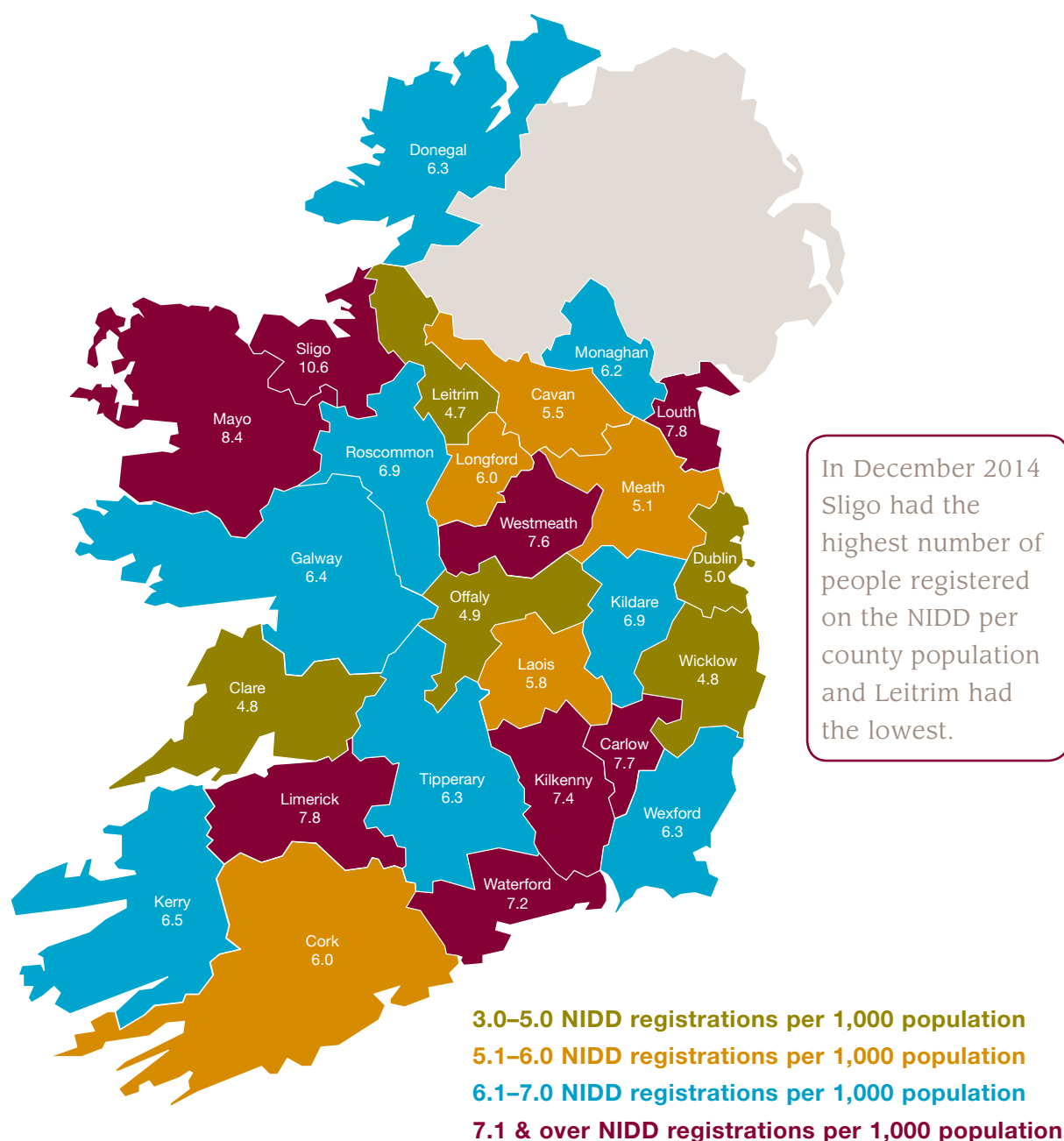


Figure 1. NIDD registrations per 1,000 of the general population, by county of residence, 2014

Figure 2 below displays a summary profile of the number of people registered on the NIDD in 2014 by gender, age group and CHO of residence.

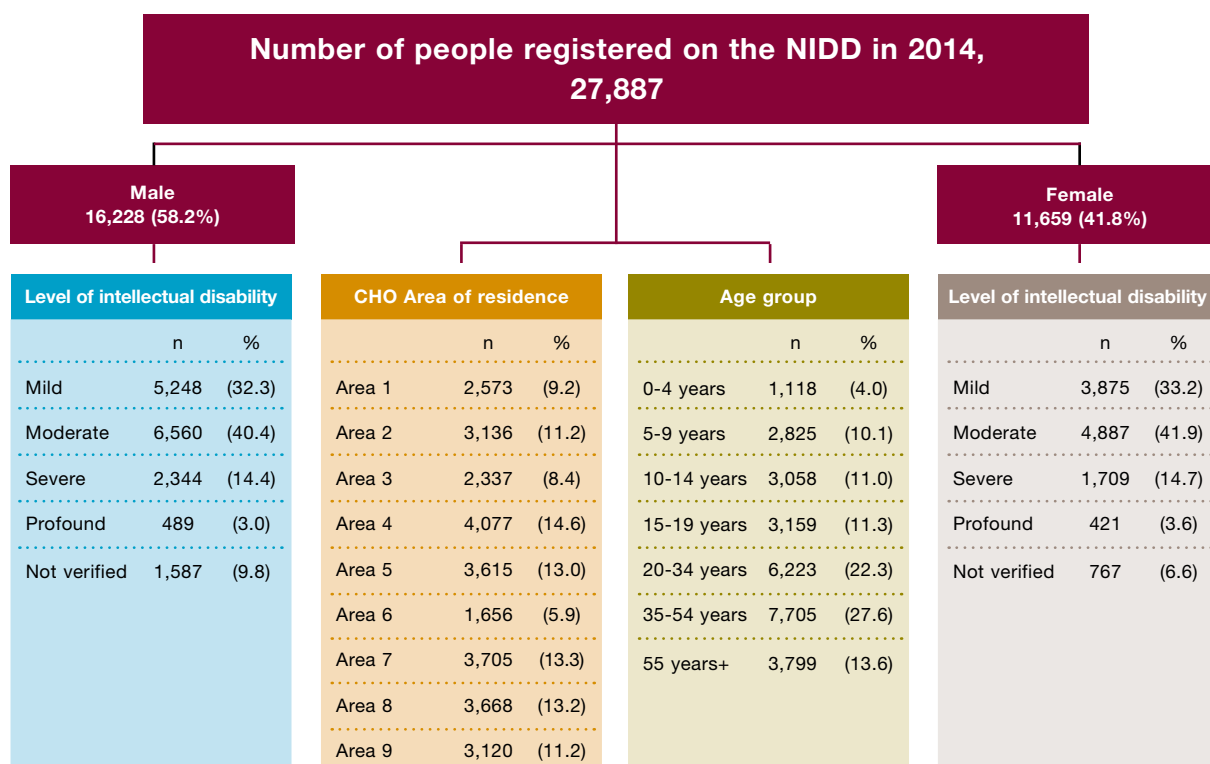


Figure 2. Profile of the population registered on the NIDD, 2014

The 9 Community Healthcare Organisations (CHO) are:

- Area 1: Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan
- Area 2: Galway, Roscommon, Mayo
- Area 3: Clare, Limerick, North Tipperary/East Limerick
- Area 4: Kerry, North Cork, North Lee, South Lee, West Cork
- Area 5: South Tipperary, Carlow/Kilkenny, Waterford, Wexford
- Area 6: Wicklow, Dun Laoghaire, Dublin South East
- Area 7: Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West
- Area 8: Laois/Offaly, Longford/West Meath, Louth/Meath
- Area 9: Dublin North, Dublin North Central, Dublin North West



There were more males than females registered with intellectual disability in all age groups except the 55-years-and-over age group, with an overall ratio of 1.39 to 1 (Figure 3).

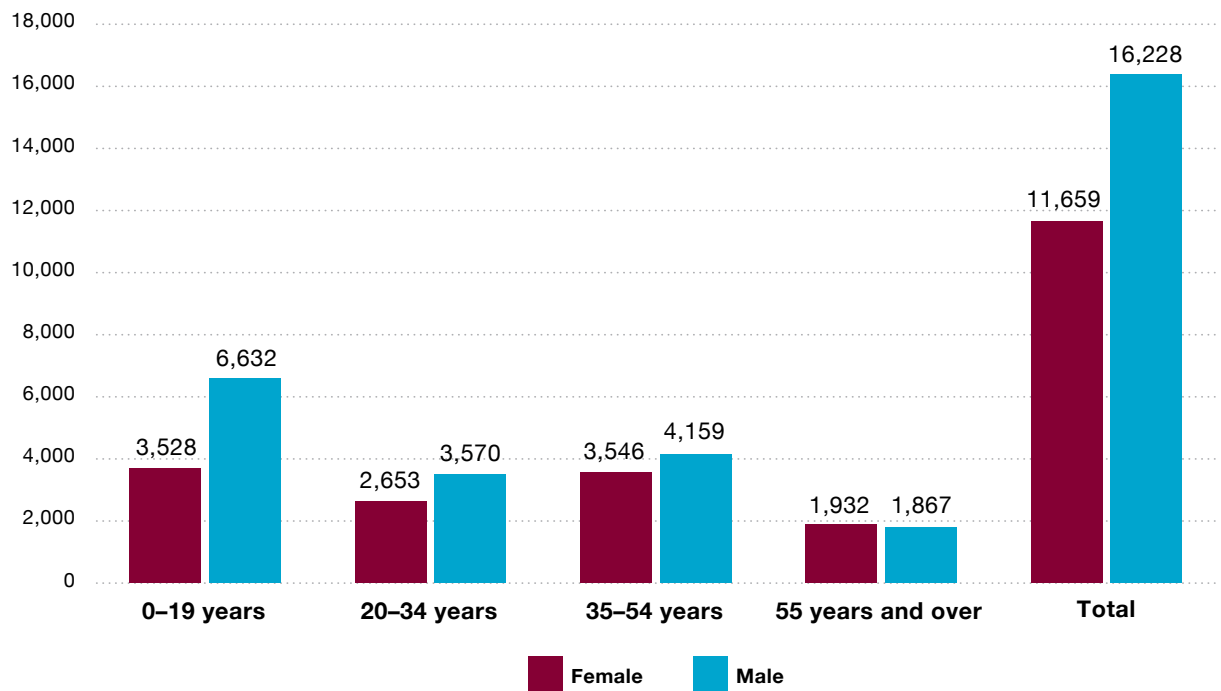


Figure 3. Number of people registered on the NIDD, by age group and gender, 2014

The total number of individuals recorded as having moderate, severe or profound intellectual disability has increased by 46% since the first Irish Census of Mental Handicap⁵ – as it was referred to then – was carried out forty years ago in 1974. One of the factors contributing to this increase in numbers is the growth in the general population over the period, resulting from increased births, a reduction in the number of deaths and an increase in net migration. Of the people with moderate, severe or profound intellectual disability, the percentage aged 35 years or over increased from 29% in 1974 to 38% in 1996 when NIDD data were first reported, and to 49% in 2014 (Figure 4). These figures reflect a steady increase in the lifespan of people with intellectual disability. This changing age profile, observed in the data over the past four decades, has implications for service planning; as there is a continuing high level of demand for services designed to meet the needs of older people with intellectual disability, in addition to support services for ageing care givers.

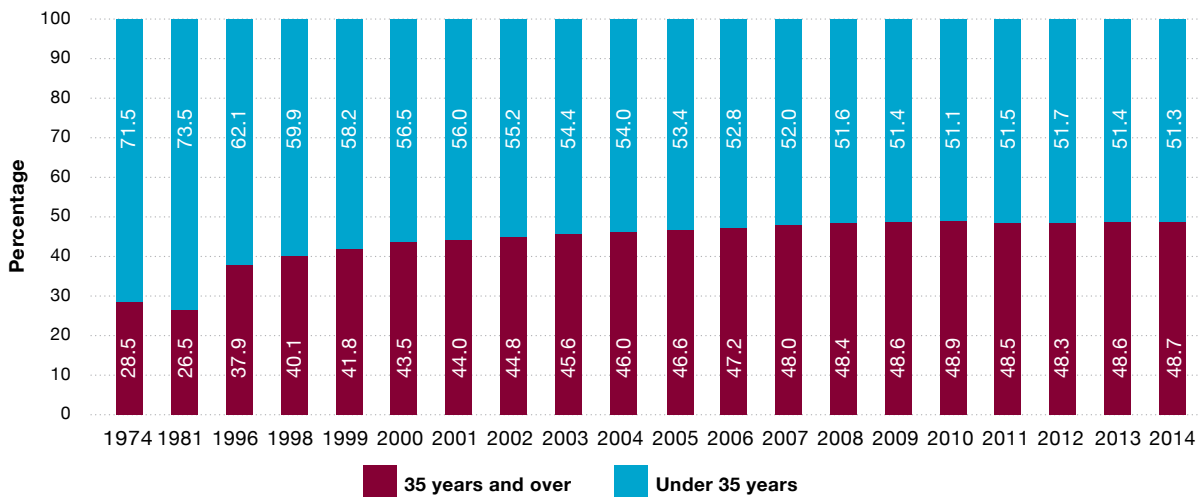


Figure 4. Percentage of people with moderate, severe, or profound intellectual disability (combined), by age group, 1974–2014

⁵ Mulcahy M (1976) Census of the mentally handicapped in the Republic of Ireland 1974: non-residential. Dublin: Medico-Social Research Board.



Service provision in 2014

The numbers registered on the NIDD in December 2014 were as follows:

- 27,515 people with intellectual disability were in receipt of services, representing 98.7% of the total population registered on the NIDD. This was the highest number of people in receipt of services since the database was established in 1995.
- 229 people (0.8% of those registered) were without services in 2014 and were identified as requiring appropriate services in the period 2015–2019.
- 143 people (0.5%) were not availing of services and had no identified requirement for services during the planning period 2015–2019.

Of the 27,515 people who were in receipt of services in 2014:

- 7,886 (28.7%) were in receipt of full-time residential services, a decrease of 1.1% on the 2013 figure. This is the eleventh consecutive year in which the data indicate that more people live in community group homes than in residential centres (Figure 5). The majority (82%) of full-time residents had a moderate, severe or profound level of intellectual disability, were aged 35 years or over (84%), and lived in a community group home (54%) or residential centre (30%). It is recognised that this group may require greater residential supports and have increased medical needs as they age.

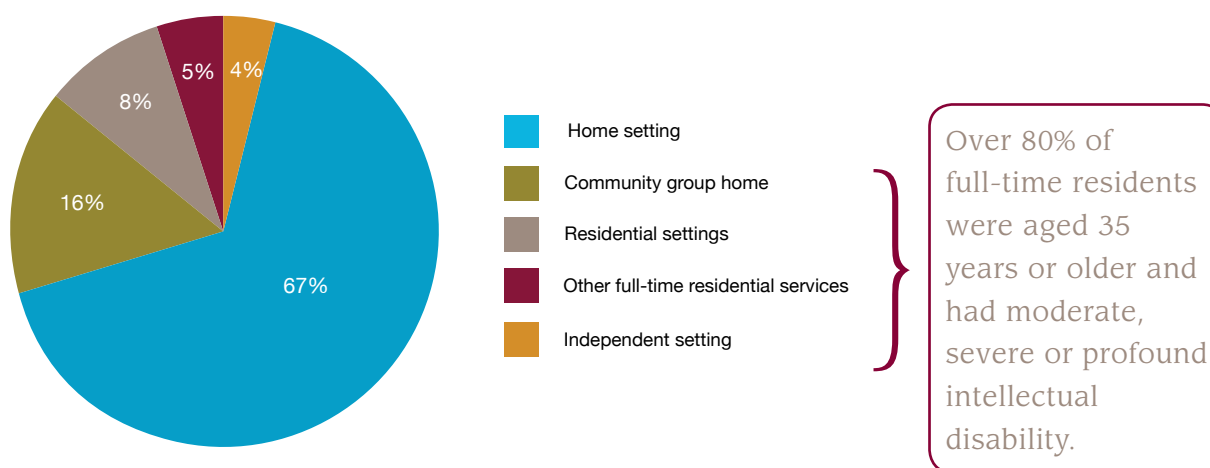


Figure 5. Main residential circumstance, NIDD 2014

- 27,467(98.5%) people availed of at least one day programme in 2014. This is the highest number registered as receiving such services since NIDD data were first reported in 1996. Of this group, 7,858 were in full-time residential care.
- 23,430 (84.0%) people availed of one or more multidisciplinary support (Figure 11) – this varies by CHO area. The services most commonly availed of by adults were social work, medical services and psychiatry. The services most commonly availed of by children were speech and language therapy, occupational therapy and medical services.
- Sixty seven per cent of those registered on the NIDD (18,794 individuals) lived at home with parents, siblings, relatives or foster parents in 2014. Almost one third (30%) of people aged 35 years or over with moderate, severe or profound intellectual disability lived at home in 2014. Because people with intellectual disability are living longer, the likelihood of them outliving their caregivers has increased substantially in recent years, which has implications for planning of support services.
- The number of people with intellectual disability accommodated in psychiatric hospitals decreased by 10 (5.7%), from 175 in 2013 to 165 in 2014. Almost three quarters (72%) were residing in CHO area 9; and over one third (38%) required a transfer to an alternative residential facility in the period 2015-2019 (see Future service requirements for more details).



Future service requirements 2015–2019

The NIDD facilitates an assessment of the needs of people with intellectual disability. Figure 6 provides summary data on four distinct categories of requirements for the five-year period, 2015–2019, and these are described in more detail below.

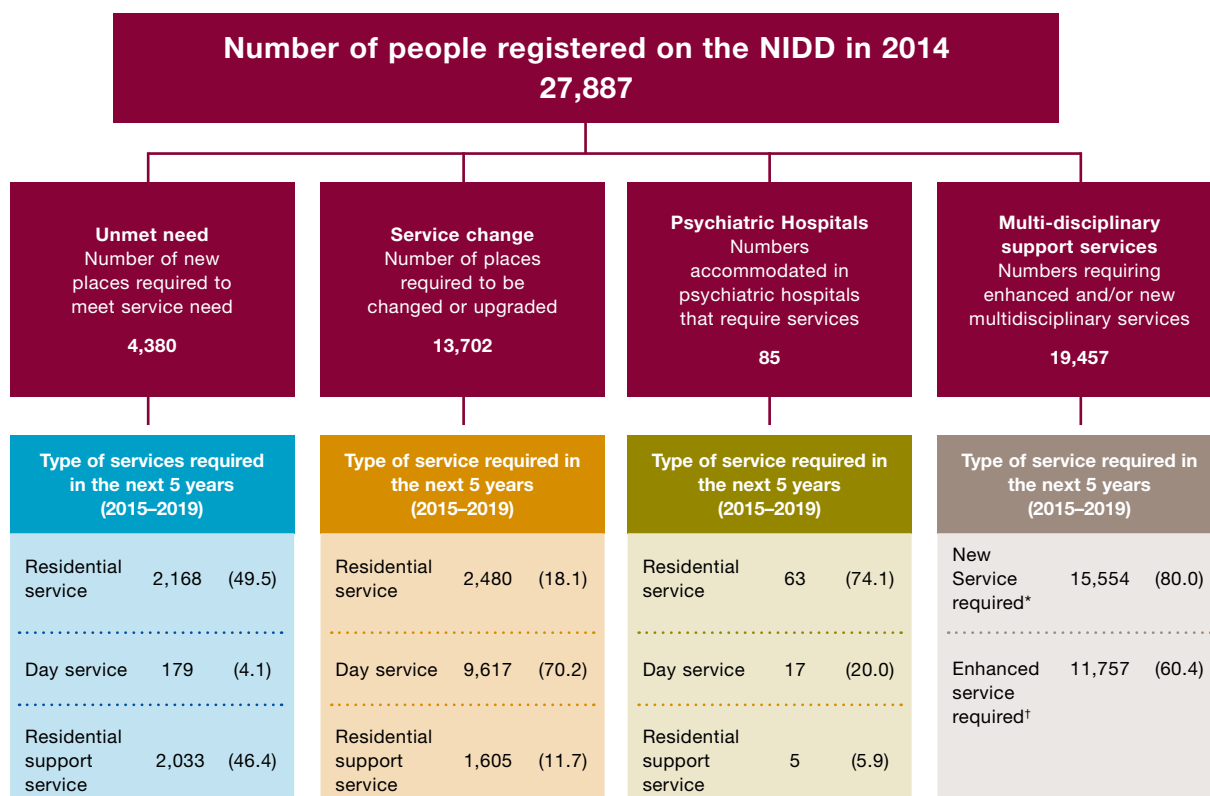


Figure 6. Summary of service requirements of those registered on the NIDD, 2014

* 'New service required' refers to a new type of therapeutic input that the individual does not currently receive.

† 'Enhanced service required' refers to a change in the delivery of a therapeutic input that the individual currently receives. There are 7,854 individuals whose multidisciplinary support service change involves both a new service and an enhanced service, therefore the actual number of people requiring a new and/or enhanced service is $(15,554 + 11,757) - 7,854 = 19,457$

Unmet Need

The 2014 data indicate that 4,380 new residential, day and residential support places will be needed to meet service requirements of those who do not currently avail of these services. The following services will be needed in the period 2015–2019 (most service needs were recorded as being immediate):

- 2,168 new full-time residential placements (Figure 7), a decrease of 47, or 2.1%, on the projected number required in 2013. Almost three quarters (71%) of this group had a moderate, severe or profound level of intellectual disability and 57% were aged 35 years and over. The majority (86%) require placements in community group homes.
- 2,033 residential support services, a decrease of 10 on the projected number required in 2013. The majority of this group (90%) live at home or independently in the community. A high level of need for these services still exists (Figure 7), even though there were over 5,000 people availing of residential support services in 2014 (Figure 13).

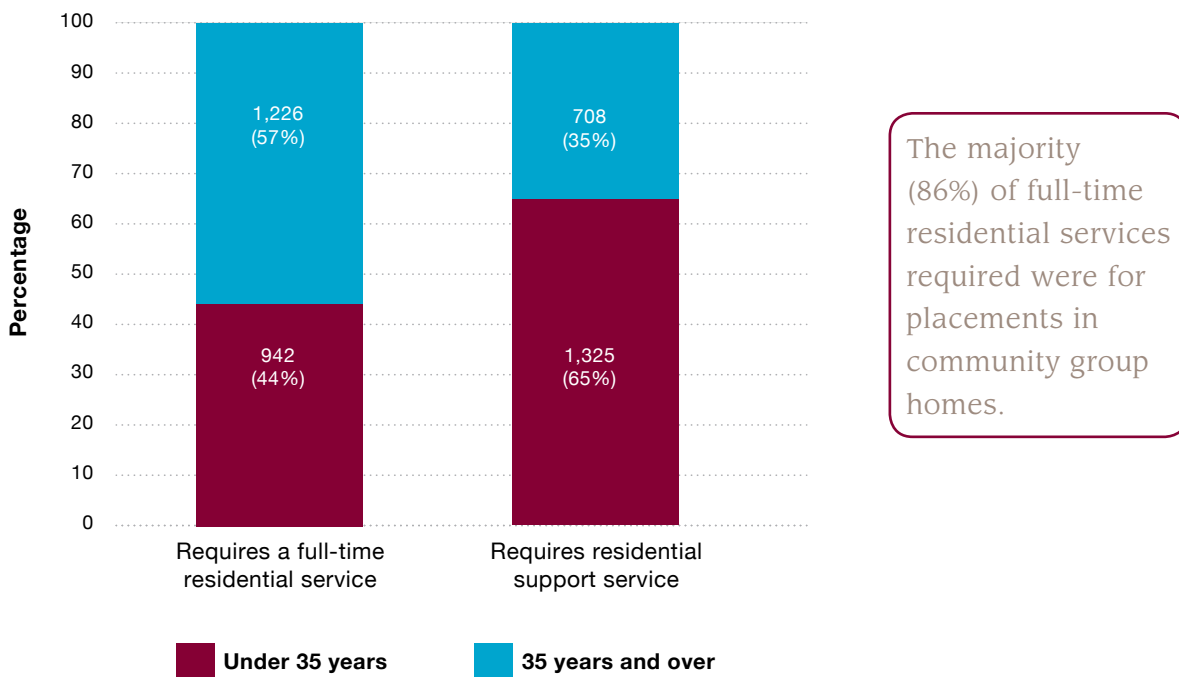


Figure 7. Unmet need – number of people requiring residential service or residential support service by age group, NIDD 2015–2019

- 179 day programmes (this figure excludes multidisciplinary support services (Figure 11) and services provided by early intervention teams). This number is in addition to the services required by 842 young adults who, as they approach the age of 18, are preparing to leave the education system to take up a range of training and supported employment opportunities, which traditionally have been funded by the health sector.
- 63 individuals who were living in psychiatric hospitals in 2014 have been identified as needing to transfer from these locations to more appropriate accommodation such as community group homes or intensive placements for profound/multiple disabilities and/or challenging behaviour. The majority of those requiring a transfer were registered in the CHO Area 9*.

Service Change

Of those in receipt of services in 2014, 11,155 people require alternative, additional, or enhanced services in the period 2015–2019 (resulting in a total number of 13,702 required place changes), a decrease of 364, or 3.2%, since 2013. This group includes people who required an increased level of service provision, additional support within their existing services, transfer to more appropriate placements, or a service change to coincide with a transition period in their lives, such as a move from child to adult services, or from education to training and/or employment placements. To address the required service changes over the next five years:

- 9,617 day places will require changes or enhancements (Figure 8). The majority are for health-funded services which are required by 6,560 individuals (68.2%). Education services are required by 1,223 individuals (12.7%), employment services are required by 1,254 individuals (13.0%), and generic services are required by 580 individuals (6.0%).

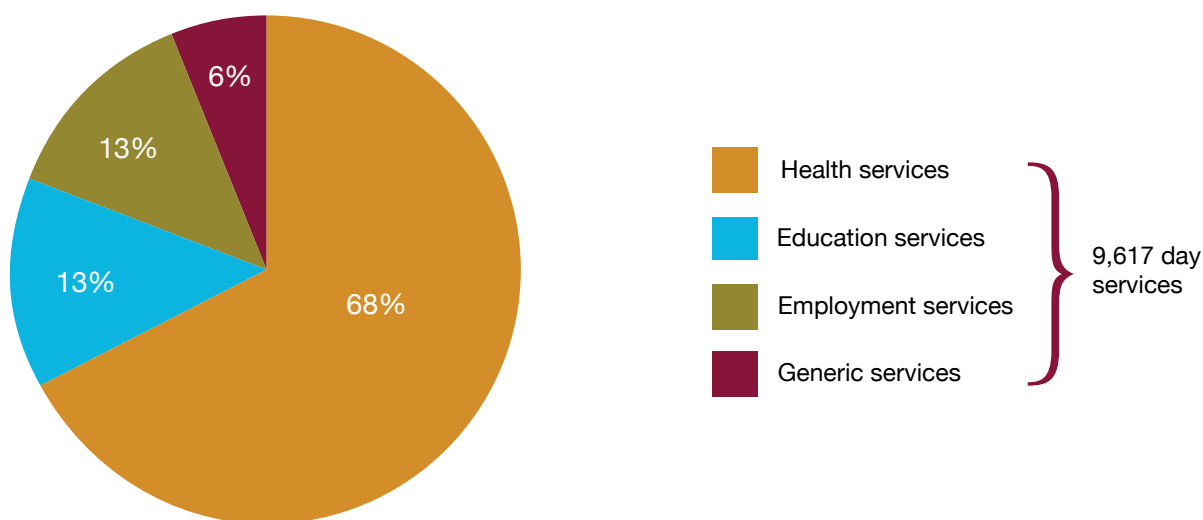


Figure 8. Number and type of day services requiring change or enhancement, NIDD 2015–2019

*Further analysis by CHO area is available in the full set of NIDDC tables and figures 2014

- Of the 842 young people (aged 16–19 years) who were in an education setting in 2014, one third (282 individuals) require rehabilitative training, 213 (25.3%) require vocational training and 149 (17.7%) require activation programmes in the next 5 years 2015–2019 (Figure 9).

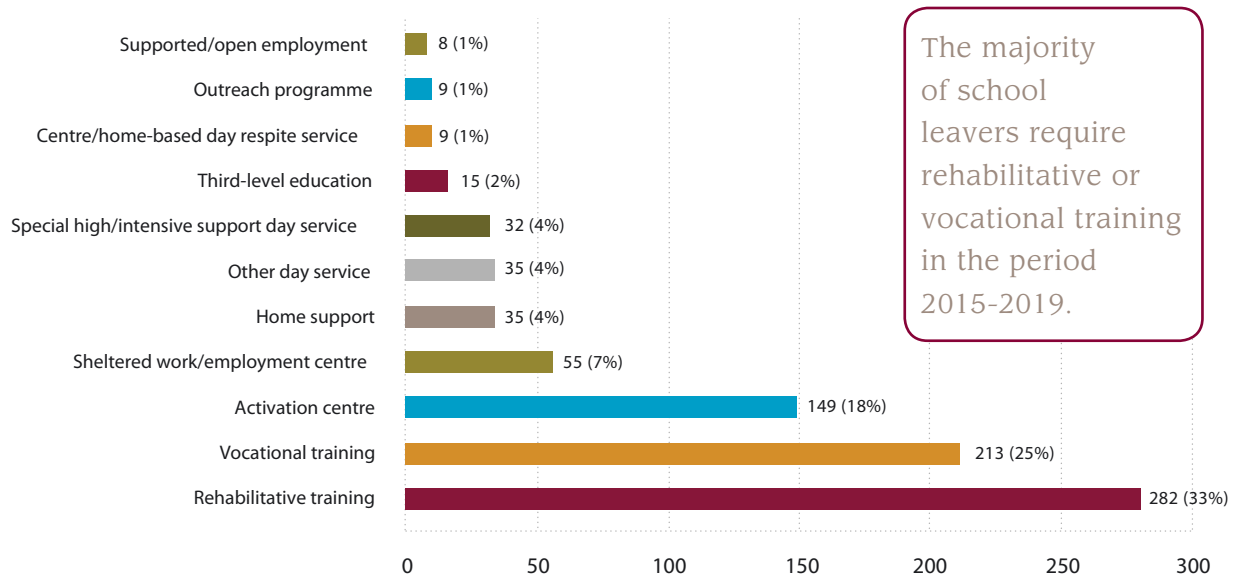


Figure 9. Future day service requirements of individuals aged 16–19 years and in an education setting, NIDD 2015–2019

- 2,480 individuals in residential places require changes or enhancements to their service. The majority (90%) of this group had moderate, severe or profound intellectual disability and were aged 35 years or older (85%) (Figure 10). Almost two thirds (59%) require a move to an alternative residential service, of which 62% require a move to a community group home and 31% to an intensive placement, for either challenging behaviour or multiple disabilities.
- 1,605 individuals require changes or enhancements to their residential support places (Figure 10). Most of this need was for more frequent centre-based crisis or planned respite breaks for people already availing of this service (1,117 Individuals).



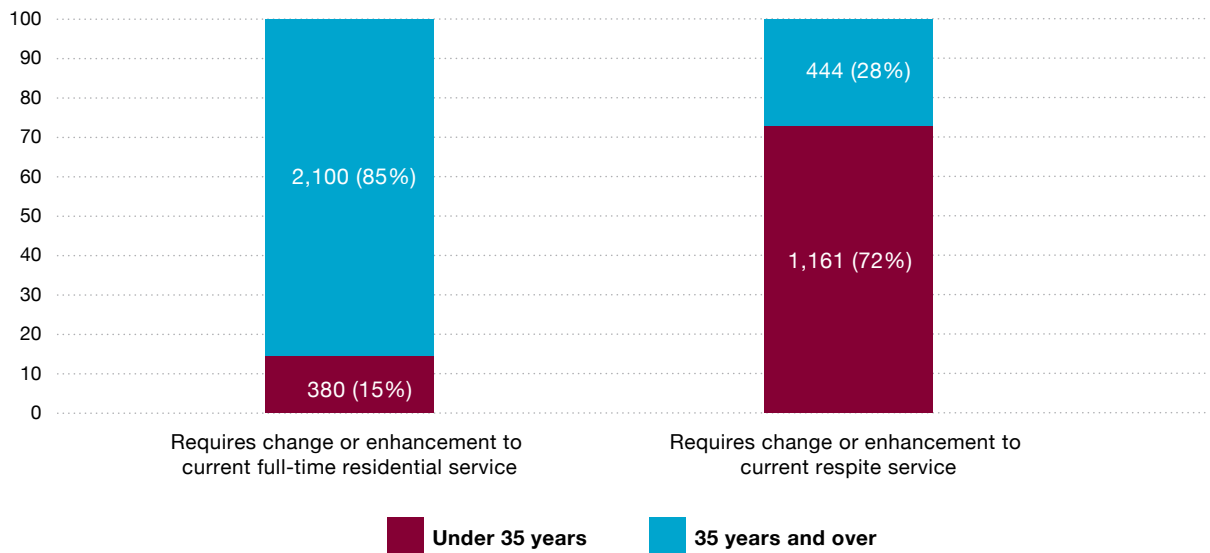


Figure 10. Service change – number of people requiring a change to, or enhancement of, their current service by age group, NIDD 2015–2019

Despite high levels of service provision in 2014, there remains a significant demand for new and enhanced multidisciplinary support services. Seventy percent (19,457 individuals) of the population registered on the NIDD require a new or enhanced multidisciplinary support service in the period 2015–2019. There was substantial demand for all the therapeutic inputs, in particular, psychology, occupational and speech and language therapies (Figure 11).

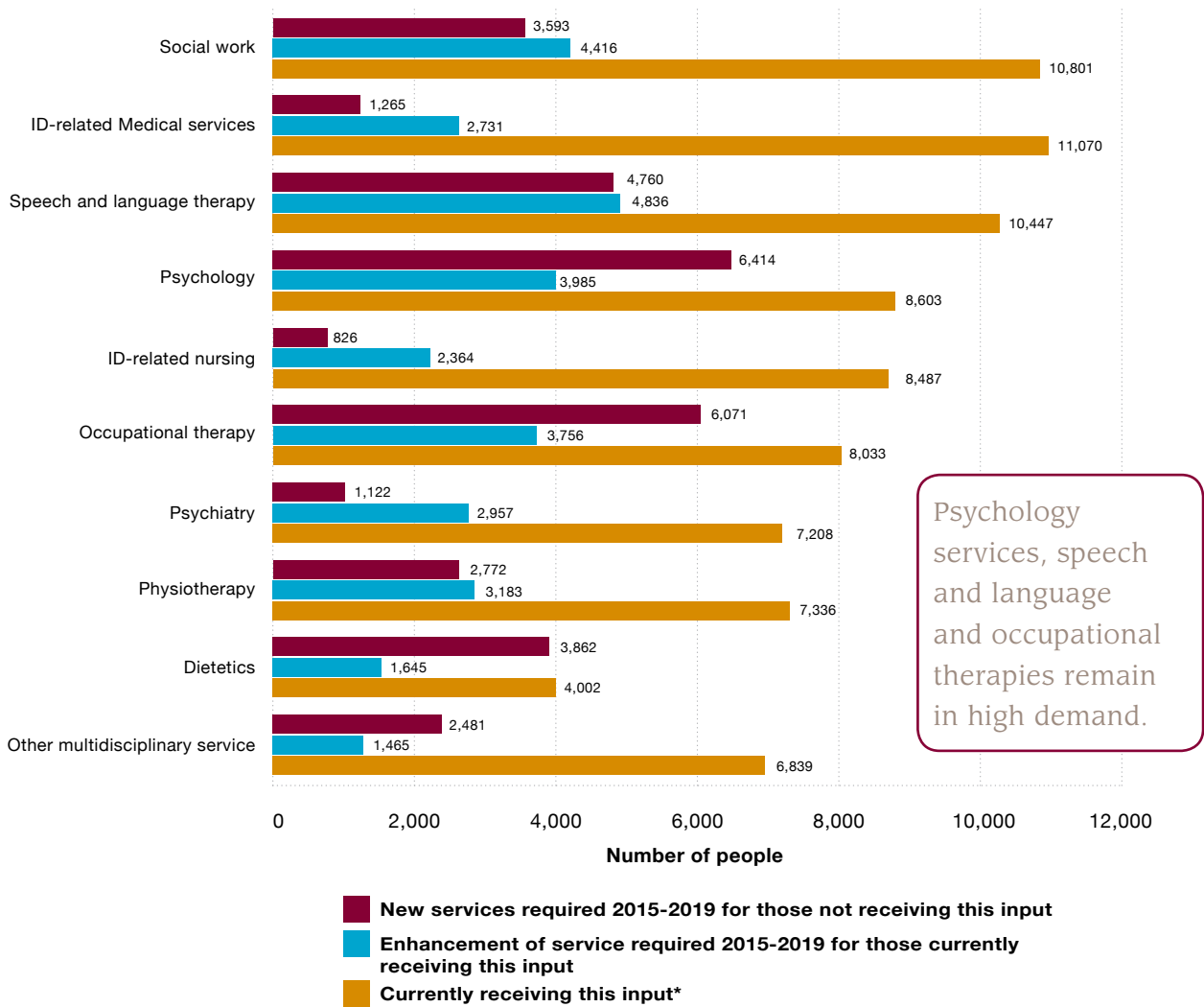


Figure 11. Multidisciplinary support services received in 2014, and required in the period 2015–2019, NIDD 2014

* Further analysis on current services is available by CHO area in the full set of NIDDC tables and figures 2014.



Key trends since 1974

The year 2014 is significant as it marks the fortieth year since the first Census of Mental Handicap was undertaken by the HRB, then the Medico-Social Research Board in 1974. In that year, information was collected on 4,863 people with intellectual disability; in 2014 the number of NIDD registrations had risen to almost 28,000 people. Since 1974, there has been a consistent year-on-year increase in the number of people registered on the NIDD with moderate, severe or profound intellectual disability who are aged 35 years and over; in 1974 this age cohort made up 28.5% of total registrations, whereas in 2014 almost half of all of those registered on the NIDD (48.7%) were aged 35 years and over. In 1974, 3,016 (62%) had co-morbid physical incapacities; in 2014 this proportion was 44%. These trends have implications for the type and level of service provision required.

Over the past 40 years, the range and type of services that are provided for people with intellectual disability have changed considerably. There has been significant growth in the level of provision of full-time residential services, residential support services, and day services. For example, in 1974 only 25 (1.7%) of the 1,444 people aged 25 years or older with a moderate level of intellectual disability, attended sheltered work centres. This figure rose to 1,449 (20.5%) in 2014 or 2,276 individuals (32.1%) if we include supported and open employment placements, which may not have been available to people in this cohort forty years ago.

In the 18-year period since the NIDD was set up (1996), there have been a number of key developments (Figure 12):

- An increase of 79% (from 2,393 in 1996 to 4,281 in 2014) in the number of people with intellectual disability living full-time in community group homes, whilst the numbers accommodated in residential centres decreased by 39% in the same period. This trend looks set to continue with the growing policy focus on de-congregation gaining momentum.
- The trend in reducing numbers of people with intellectual disability accommodated in psychiatric hospitals continues; with an 83% reduction in the 18 year period (from 970 in 1996 to 165 in 2014).



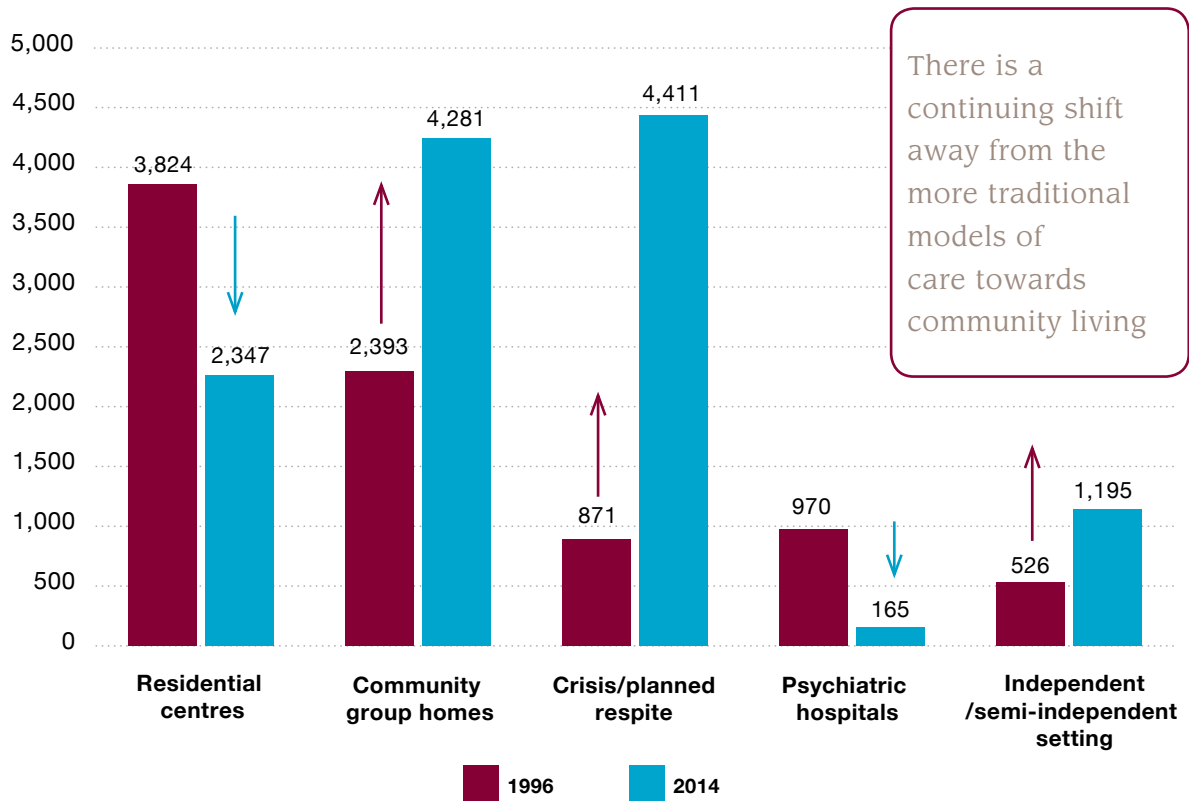


Figure 12. Residential circumstance, NIDD 1996 and 2014

- Despite a substantial expansion in the provision of crisis/planned respite services (406%) in the period 1996-2014 (Figure 12) there was a slight decline (7%) in the provision of these services from 2013 to 2014. The data continue to show marked differences between CHO Areas in the total number of people receiving respite and in the median number of nights received (Figure 13).





Figure 13. Use of respite nights, by CHO area of residence, 2014

- Since the establishment of the NIDD in 1996 there has been increased provision of almost all types of adult day services and in the level of support services delivered as part of a package of day services to both children and adults (Figures 14 & 15). Marked increases were observed in the number of supported employment, rehabilitative training, special high support day placements, and day support services such as respite over the 18-year period (Figure 14).

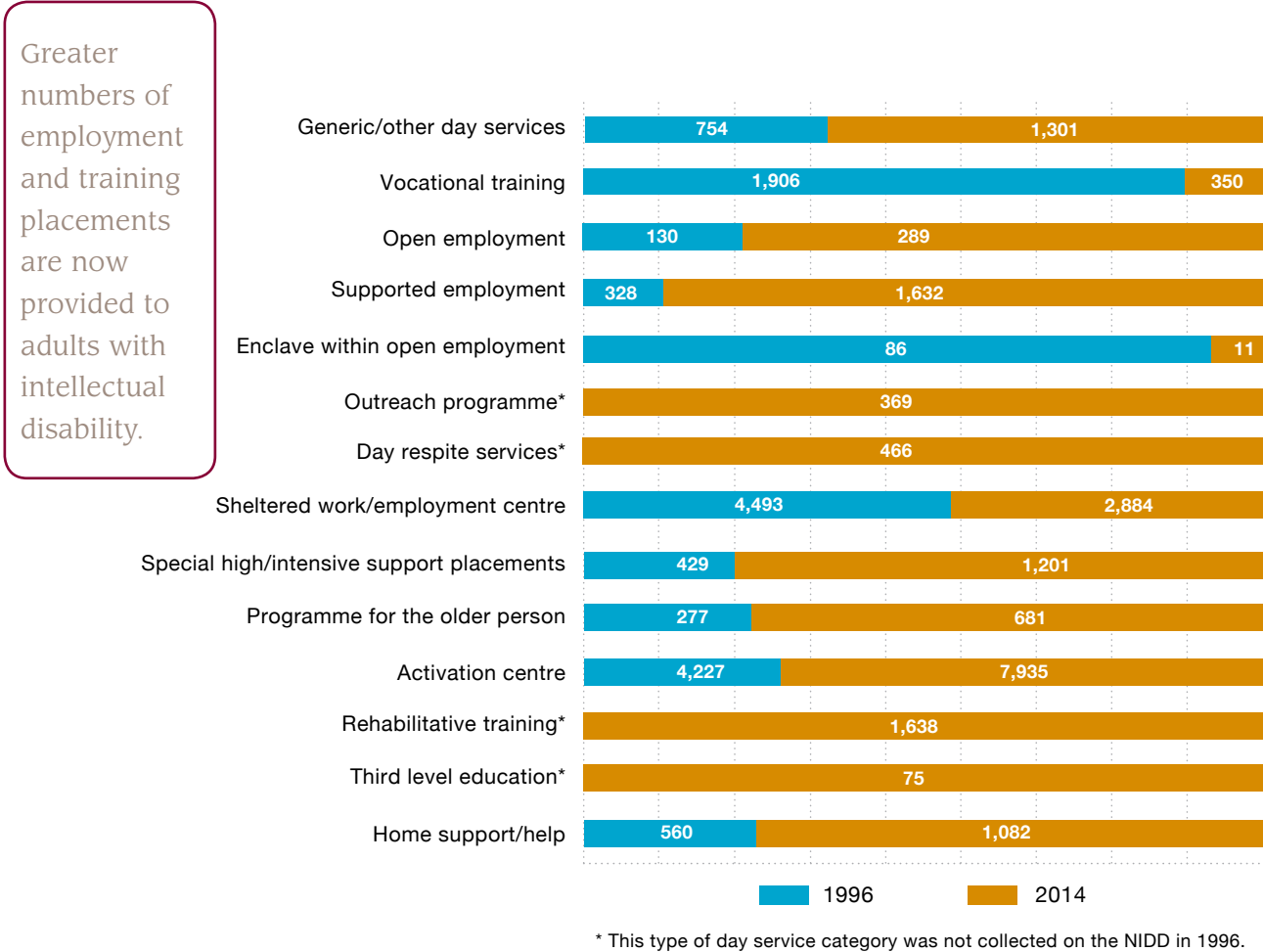
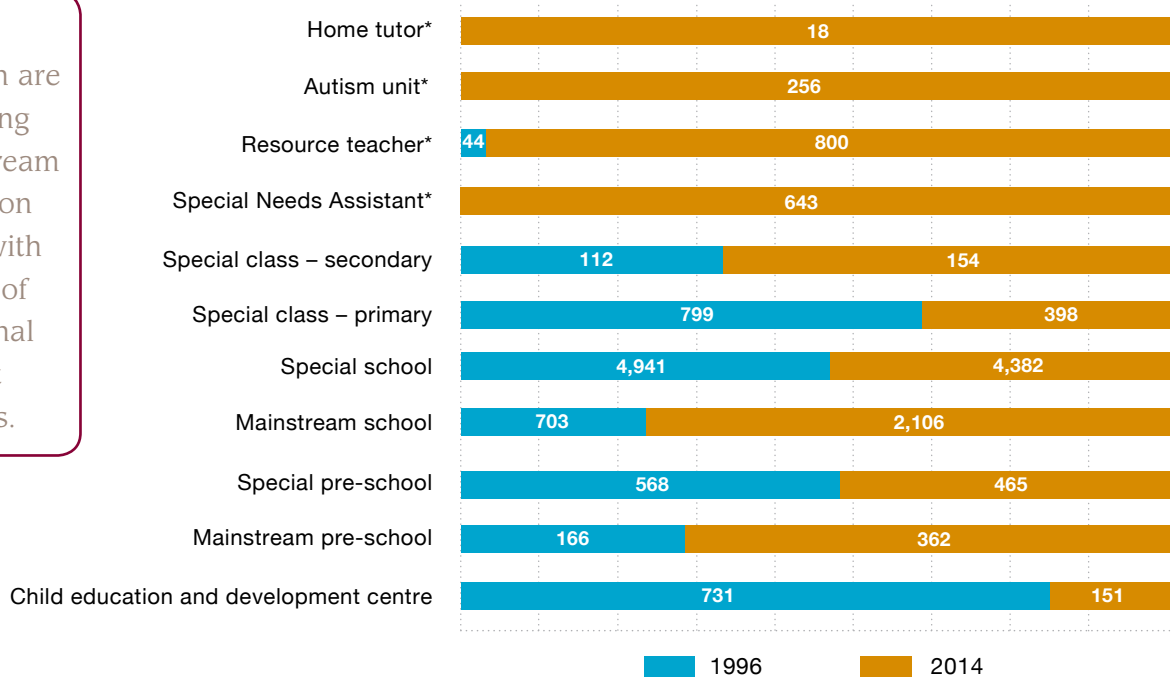


Figure 14. Day services for adults with intellectual disability, NIDD 1996 and 2014

- A continuing trend in children’s day services from 1996 to 2014 is the increasing number of individuals who availed of mainstream schooling, resource teachers and special needs assistants (Figure 15). In 2014, there was a reduction in the number of younger children registered on the NIDD. This may be due to their information being recorded elsewhere following the establishment of the HSE’s ‘Progressing Services for Children and Young People’ initiative and the setting up of Early Intervention Teams.



More children are accessing mainstream education today with the aid of additional support services.



* This type of day service category was not collected on the NIDD in 1996.

Figure 15. Education services for children with intellectual disability, NIDD 1996 and 2014

Summary

As a national health information system collecting data about service provision and requirements in the intellectual disability area, the NIDD continues to assist health service managers and policy makers in planning these services. This Main Findings report, based on information collected from over 27,800 individuals registered on the database at the end of December 2014, represents the cumulative service use and needs of this group of people. Notable points from this report include:

- The majority of adults with intellectual disability continue to live with their families with the aid of additional support services. As their caregivers age, a wide range of additional services is required for people who wish to continue to live as independently as possible.
- The improvement in life expectancy among adults with severe intellectual disability has placed an increased demand on full-time residential services as fewer places are becoming free over time. Older service users availing of day and residential services also require a higher degree of support within these services, including increased medical services to cater for their specific needs.
- There is a continuing shift away from the more traditional institutional models of care towards community-based living arrangements for those requiring residential services.
- The proportion of those registered who are in receipt of day services continues to increase. Many of those in receipt of day services are also benefiting from additional supports, such as home support, home help and respite services.
- The demand for services for young people in transition from the education system to HSE-funded day services, particularly in the areas of training and employment, remains high.



- The level of provision of multidisciplinary support services in 2014 was high and future demand for these services remains high in the five-year period 2015–2019. Provision of multidisciplinary support services varies by CHO Area of residence.
- There was a slight decline in respite service provision between 2013 and 2014. This also varied by CHO Area of residence.
- Over the past 40 years the range and type of services that are provided for people with intellectual disability have changed considerably, with a shift away from special schooling and the more traditional institutional models of care.
- There remain high levels of unmet need among a critical number of individuals who are registered on the NIDD, particularly those who are aged over 35 years and require a full-time residential place in the next 5 years.
- The NIDD continues to be a key source of data on services for people with Intellectual disability.



Notes



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