

Trends in demand for services among children aged 0–5 years with an intellectual disability, 2003–2007

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National Intellectual
Disability Database

Contents

Summary	1
Introduction	3
Methods	4
Analysis	4
Conclusion	14
References	15
Acknowledgements	15

Summary

This paper sets out trend data from the National Intellectual Disability Database (NIDD) on the specialised health services that are provided for and required by children with an intellectual disability in the 0–5 years age group. The data used are derived from returns by service provider agencies and the Health Service Executive (HSE) to the Health Research Board (HRB) for inclusion on the NIDD. The aim of the paper is to assist policy makers and service planners to develop services that are specific to the needs of young children.

The NIDD is a national level information system which is used by the Department of Health and Children (DOHC) for service planning purposes. Intellectual Disability on the NIDD is defined using the criteria set out in the International Classification of Diseases, Tenth Edition (ICD-10), where disability is estimated by standardised intelligence tests on a scale ranging from mild to moderate to severe to profound (WHO 1996). The paper includes data on demographics, service use and future need for children aged 0–5 years for the period 2003–2007. The paper has been prepared to outline key issues with regard to the service use and service needs of children in this age category over the last five years with a view to informing developments into the future. The paper presents a brief outline of recent legislative and policy developments and presents the data from the NIDD. It then draws some conclusions from the data about the ongoing need for service planning for this age group.

There are a number of limitations to the data that should be noted. First, registration on the NIDD is voluntary and so the data do not capture the needs of *all* children with intellectual disability in the 0-5 years age group. In addition, this age group has always been under-represented on the NIDD, due in part to parents' wishes not to register their child on a disability database and due to a lack of a full diagnosis at the earlier stages of the child's life. Finally, the NIDD has an under-representation of those with a mild intellectual disability who tend to be in mainstream settings and not using specialised services as such.

The main findings are:

- The total number of children aged 0–5 years registered on the NIDD increased by 8% over the five-year period.
- The number of children on the Database who did not have their level of intellectual disability confirmed increased by 37% between 2003 and 2007. This category represents a particularly vulnerable group of children that require close monitoring so that appropriate services can be provided to meet their specific needs.
- As expected, most of the cohort lived at home with one or both parents (98%) and were in receipt of day services (95%).
- Key services provided to this age group in 2007 included special pre-school (452, 29%), early intervention services (436, 28%) and mainstream pre-school (252, 16%). The figures show a shift, in line with policy, away from specialised settings to more mainstream provision.
- With regard to future needs, the demand for residential places for this age group is low but there is considerable demand for residential support services such as respite care and home support.
- Within the next five years, 971 children will require a change, enhancement or upgrade of their day service, the majority relating to the school in which they attend.
- The vast majority of children were in receipt of multidisciplinary support services such as speech and language therapy and physiotherapy.
- Over the five year period, there has been considerable growth in multidisciplinary services such as occupational therapy. Notwithstanding this growth, there is still considerable demand for multidisciplinary support services in the period 2008–2012; for example 912 children received occupational therapy in 2007, 474 of whom need an enhancement of this service and a further 326 children who did not receive occupational therapy in 2007 require it.

The findings suggest that:

- Continued investment in and expansion of services for this age group is needed, particularly with regard to the level and range of multidisciplinary support services that are provided.
- Highest levels of unmet service need relate to the provision of respite and home support services while for those already receiving services, high numbers require a change to the day service they currently access. This suggests that more individualised service planning will be required, based on the needs of each child.
- There is a shift, in accordance with policy, in the number of children accessing more mainstream provision. This will have implications for the way in which services continue to develop in the future.

Introduction

The NIDD was established in 1995 to ensure that information is available to enable the DOHC, the HSE and the non-statutory agencies in Ireland to provide appropriate services designed to meet the changing needs of people with intellectual disability and their families. The Database is intended to provide a comprehensive and accurate information base for decision making in relation to the planning, funding and management of services for people with an intellectual disability. The Database is a service planning tool and, as such, is an innovative development internationally, as few other countries have national level disability registers.

The HSE is responsible for the local administration of the Database. This includes the implementation and maintenance of structures for the identification of individuals and the collection, review and updating of data. Responsibility for providing this information to the HSE lies primarily with local service providers, HSE personnel and school principals. Consent is sought before the individual is entered on the Database. The HRB manages the data at national level on behalf of the DOHC. While registration on the Database is voluntary, comprehensiveness and coverage of the NIDD is generally regarded as very good given the direct involvement of service providers in the return of information.

The Database collects information on the individual service user and his or her family. It also gathers data on current service usage and future service need in relation to day services, residential circumstance and residential support and multi-disciplinary services. Future service need is based on the data supplied by the providers of intellectual disability services which is reviewed each year for its relevance to the individual. Updating of information can take place at any time as the system operates in real time.

Policy and legislative context

In the last number of years there has been a greater degree of interest in the rights of children in their early years. The National Children's Strategy (Government of Ireland 2000) set out Government objectives and principles to guide children's policy over the next 10 years. One of the national goals of the Strategy is that 'children will receive quality supports and services to promote all aspects of their development' (p.23). The Strategy recognises that children with a disability have additional needs and that they require services to be able to achieve their full potential.

In relation to disability, the issue of improved service delivery has underpinned recent legislative developments. The National Disability Strategy has two constituent pieces of legislation; the Disability Act 2005 and the Education for Persons with Special Educational Needs (EPSEN) Act 2004. The aim of the Strategy is that both pieces of legislation will be implemented in a co-ordinated manner and that, together, the health and education sectors will work to improve the delivery of services to people with disabilities. Sectoral Plans have been developed by the five key Departments involved in the implementation of the Disability Act 2005 and the Department of Education and Science is considering a Report of the National Council for Special Education (NCSE) which sets out how EPSEN will be implemented over the next five years (NCSE 2006).

With regard to the specific needs of children with a disability, the Sectoral Plan of the Department of Health and Children (DOHC 2006) sets out the provisions of the Disability Act 2005 and the manner in which Part 2 of the Act, which relates to an independent assessment of need, will be implemented. The Sectoral Plan makes provision for the implementation of this part of the Act for children up to five years of age. Irish research reports (e.g. NESF 2005; McGough 2006) have continually emphasised the need for policies on early intervention and personalised responses to the needs of children with disabilities.

Methods

Data for the paper were taken from the NIDD archive for the period 2003 to 2007. As noted earlier, the NIDD records three basic elements of information: demographic details, current service provision, and future service requirements. The objective is to obtain this information for every individual known to have an intellectual disability and assessed as being in receipt of, or in need of, an intellectual disability service. The record is updated whenever there are changes in the person's circumstances or during an annual review process.

The HSE is responsible for the administration of the database. This includes the implementation and maintenance of structures for the identification of individuals and the collection, review and updating of data. The initial step in the generation of the national dataset is the completion of a data form for each identified individual.

Information (excluding personal details such as name and address), is extracted at the end of the annual review and update period of NIDD information. This information forms the national data set for that year. The HRB, on behalf of the DOHC, manages the national data set. The data for this paper are based on the national data sets for each of the years 2003 to 2007.

Analysis

Profile of the population

Table 1 sets out the population profile of those aged 0-5 years on the NIDD for the period 2003-2007. The total number of children aged 0-5 years registered on the NIDD increased by 11% from 1,429 in 2003 to 1,588 in 2006, and decreased slightly to 1,542 in 2007. From 2005 onwards there was a steady decline in the number and proportion of children classified as having a mild, moderate, severe or profound intellectual disability. Each year, there was, however, an increase in the number and proportion of children in the 'not verified' category, i.e. those whose degree of intellectual disability had not been confirmed, increasing from 860 (60%) in 2003 to 1,181 (77%) in 2007.

Table 1 Number of children aged 0-5 years registered on the NIDD by degree of intellectual disability, 2003 to 2007

Degree of intellectual disability	2003		2004		2005		2006		2007	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Not verified	860	(60.2)	913	(61.2)	1006	(64.8)	1111	(70.0)	1181	(76.6)
Mild	220	(15.4)	233	(15.6)	218	(14.0)	213	(13.4)	156	(10.1)
Moderate	226	(15.8)	218	(14.6)	199	(12.8)	159	(10.0)	138	(8.9)
Severe	96	(6.7)	109	(7.3)	109	(7.0)	87	(5.5)	52	(3.4)
Profound	27	(1.9)	18	(1.2)	21	(1.4)	18	(1.1)	15	(1.0)
Total	1429	(100.0)	1491	(100.0)	1553	(100.0)	1588	(100.0)	1542	(100.0)

As noted earlier, traditionally, the number of children in the 0–5 years age group on the NIDD has been under-representative of the total number in this cohort. This can be attributed to a number of factors including parental attitudes to registration of young children on a national disability database. The absence of a diagnosis at an early stage in the child’s development can also influence levels of registration; in the early stages a definitive diagnosis is often absent as it is unclear what degree of disability can be attributed to developmental delay. This is clear from the numbers on the Database in the ‘not verified’ category; as noted above this figure has increased over time. This may, in part, be due to reluctance on the part of clinicians to diagnose a specific condition early in a child’s life. Notwithstanding this trend, those in the ‘not verified’ category represent a particularly vulnerable group of children that require close monitoring so that appropriate services can be provided to meet their specific needs.

The number, proportion and prevalence of males exceeded the number of females in all five years (Figures 1 and 2). The number of males increased by 10% between 2003 and 2007, while in the same period the number of females increased by just 5%. The average male to female ratio over the 5 year period was 1.6:1 which represents an average prevalence rate of 5.0 per 1000 males to 3.4 per 1000 females. This is consistent with international trends (see, for example, National Centre on Birth Defects and Developmental Disabilities 1996; Australian Institute of Health and Welfare 2004).

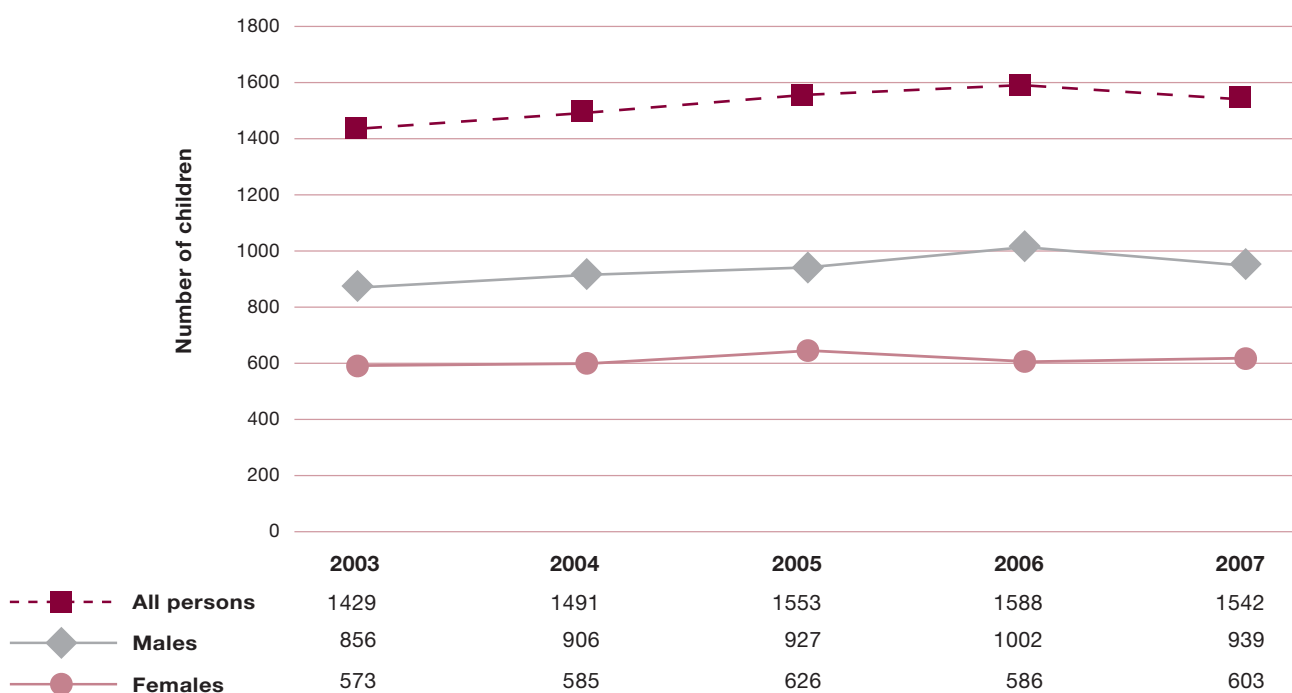


Figure 1 Number of children aged 0–5 years registered on the NIDD by gender, 2003 to 2007

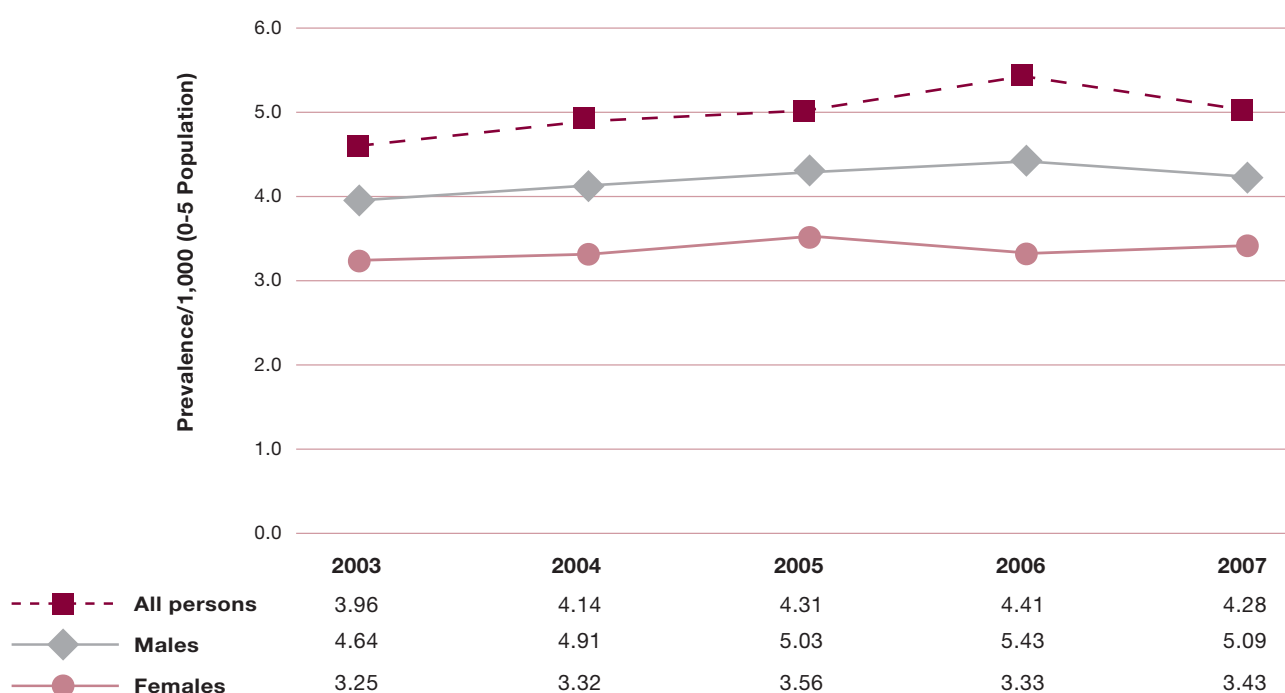


Figure 2 Prevalence of children aged 0–5 years registered on the NIDD by gender, 2003 to 2007

Table 2 presents the number of children aged 0–5 years registered in each of the four HSE areas. For the period 2004–2007, the largest number and proportion of children were registered within the HSE Dublin/Mid-Leinster area, with this area also experiencing the largest percentage increase over the period, increasing by 15%. The numbers registered in the HSE South area increased by 8% over the same period, while in the HSE West and Dublin/North-East areas, the numbers decreased by 7% and 10% respectively.

Table 2 Number of children aged 0–5 years registered within the Regional Health Areas of the Health Service Executive based on returns to the NIDD, 2004 to 2007

	2004		2005		2006		2007	
	n	(%)	n	(%)	n	(%)	n	(%)
Dublin/Mid-Leinster	480	(32.2)	501	(32.3)	602	(37.9)	552	(35.8)
South	359	(24.1)	404	(26.0)	411	(25.9)	389	(25.2)
West	395	(26.5)	392	(25.2)	365	(23.0)	369	(23.9)
Dublin/North-East	257	(17.2)	256	(16.5)	210	(13.2)	232	(15.0)
Total	1491	(100.0)	1553	(100.0)	1588	(100.0)	1542	(100.0)

No data are available for 2003 as the new Health Service Executive areas did not come into effect until 2004.

Service provision

With regard to service provision (Table 3), as expected, in 2007 the vast majority of children (1,504, 98%) live at home with one or both parents and attend services on a day basis (1,471, 95%).

Table 3 Main residential circumstances and service provision of children aged 0–5 years registered on the NIDD, 2003 to 2007

	2003		2004		2005		2006		2007	
	n	(%)	N	(%)	n	(%)	n	(%)	n	(%)
At home with both parents	1180	82.6	1236	82.9	1278	82.3	1318	83.0	1292	83.8
Attending services on a day basis	1163	81.4	1212	81.3	1242	80.0	1254	79.0	1242	80.5
Receiving residential support services only	2	0.1	0	0.0	1	0.1	2	0.1	2	0.1
Receiving no service – on waiting list	7	0.5	16	1.1	9	0.6	4	0.3	18	1.2
No current service requirements	8	0.6	8	0.5	26	1.7	58	3.7	30	1.9
At home with one parent	213	14.9	216	14.5	235	15.1	216	13.6	212	13.7
Attending services on a day basis	209	14.6	211	14.2	231	14.9	212	13.4	204	13.2
Receiving residential support services only	0	0.0	0	0.0	1	0.1	1	0.1	1	0.1
Receiving no service – on waiting list	3	0.2	4	0.3	3	0.2	2	0.1	6	0.4
No current service requirements	1	0.1	1	0.1	0	0.0	1	0.1	1	0.1
Foster care and boarding out arrangements	24	1.7	20	1.3	26	1.7	14	0.9	20	1.3
Attending services on a day basis	24	1.7	20	1.3	26	1.7	14	0.9	20	1.3
Residential centre or community group home	7	0.5	7	0.5	6	0.4	6	0.4	7	0.5
Receiving 5 or 7 day residential services	7	0.5	7	0.5	6	0.4	6	0.4	7	0.5
Other residential service	4	0.3	8	0.5	8	0.5	8	0.5	10	0.6
Attending services on a day basis	2	0.1	4	0.3	4	0.3	6	0.4	5	0.3
Receiving 5 or 7 day residential services	2	0.1	3	0.2	3	0.2	1	0.1	4	0.3
Receiving no service – on waiting list	0	0.0	1	0.1	1	0.1	1	0.1	1	0.1
Insufficient information	1	0.1	4	0.3	0	0.0	26	1.6	1	0.1
All cases	1429	100.0	1491	100.0	1553	100.0	1588	100.0	1542	100.0

In 2003, 10 children (0.7%) were without services but had identified service needs; this figure increased to 25 children (1.6%) in 2007. Similarly, in 2003, 9 children (0.6%) were without services but had no identified requirement for services; this number more than trebled to 31 (2%) in 2007. One explanation for this increase is that the number of children whose level of intellectual disability had not been verified (Table 1) did not have their service needs adequately identified.

Table 4 shows a breakdown of the main day services that are accessed by children aged 0-5 years and registered on the NIDD for the period 2003-2007. The table shows that the key services in 2007 were special pre-school (452, 29%), early intervention services (436, 28%) and mainstream pre-school (252, 16%).

Table 4 Principal day service accessed by children aged 0–5 years registered on the NIDD, 2003 to 2007

	2003		2004		2005		2006		2007	
	n	(%)	N	(%)	n	(%)	n	(%)	N	(%)
Special pre-school	490	34.3	504	33.8	475	30.6	499	31.4	452	29.3
Early intervention services	437	30.6	446	29.9	476	30.7	466	29.3	436	28.3
Mainstream pre-school	189	13.2	169	11.3	205	13.2	236	14.9	252	16.3
Home support	103	7.2	127	8.5	96	6.2	67	4.2	62	4.0
Special school	58	4.1	76	5.1	73	4.7	76	4.8	74	4.8
Mainstream school	29	2.0	17	1.1	32	2.1	32	2.0	32	2.1
Child education and development centre	25	1.7	21	1.4	33	2.1	22	1.4	15	1.0
Resource teacher	28	2.0	61	4.1	81	5.2	54	3.4	84	5.4
Multidisciplinary support services	18	1.3	17	1.1	16	1.0	8	0.5	16	1.0
Special class – primary	16	1.1	9	0.6	12	0.8	15	0.9	29	1.9
Other day service	13	0.9	10	0.7	12	0.8	17	1.1	29	1.9
No day service	23	1.6	34	2.3	42	2.7	96	6.0	61	4.0
Total	1429	100.0	1491	100.0	1553	100.0	1588	100.0	1542	100.0

Over the period 2003-2007, there had been a number of changes which reflect policy developments over that time. The introduction, for example, of legislation like the EPSEN Act 2004 and its focus on mainstream educational provision for children with special needs has resulted in a small reduction in the number of children in special pre-schools from 490 in 2003 to 452 in 2007 and a consequent rise in the numbers attending mainstream pre-schools, increasing by one third from 189 in 2003 to 252 in 2007. This trend is likely to continue as the Act is implemented over the next five years.

The number of children in Child Education and Development Centres (i.e. day facilities for those with severe and profound disability) has declined by 40% in the period 2003-2007, while the number who had access to a resource teacher more than trebled over the same period. Again, this trend reflects the shift towards mainstream education in line with inclusive education as set out in the EPSEN Act 2004.

Multidisciplinary support services

The total number of children aged 0–5 years that were in receipt of at least one multidisciplinary support service, increased by 13% from 1,278 in 2003 to 1,438 in 2007. The large difference in numbers receiving multidisciplinary support services (the difference between Table 4 and Figure 3) arises because multidisciplinary services are only recorded as a principal day service if they are the only day services that an individual receives. In each of the five years, speech and language therapy was the most common multidisciplinary support service accessed by children, followed by physiotherapy and social work (Table 3). Nutritional services and occupational therapy experienced the highest percentage increase over the five year period, increasing by 79% and 69% respectively. The increase in both of these services is sizeable. It should be noted that nutrition services were provided to only a small proportion of children in 2004. The figures reflect changes in practice and policy with regard to the type of support services that are required by young children.

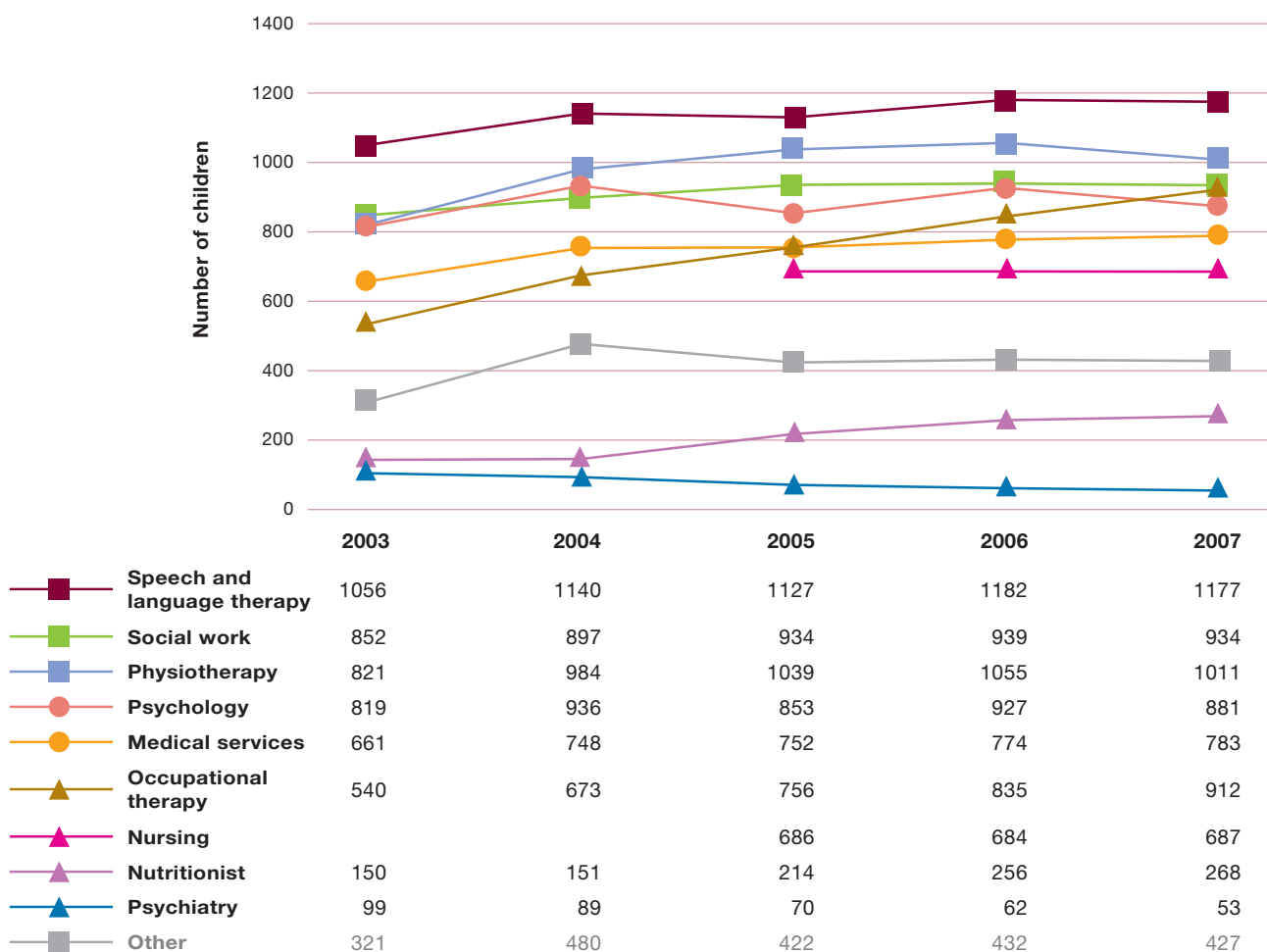


Figure 3 Number of children aged 0–5 years registered on the NIDD and in receipt of multidisciplinary support services, 2003 to 2007

With the exception of psychiatric services which declined by 46% between 2003 and 2007, all of the other multidisciplinary support services experienced a percentage increase. The decline in psychiatry may be accounted for by the scarcity of child psychiatry services in the intellectual disability area.

In the period 2003–2007 there has been a growth in the range of ‘other’ multidisciplinary services. These services include education services and therapeutic services like music therapy, play therapy and hydrotherapy. The number accessing these services is displayed in Figure 4.

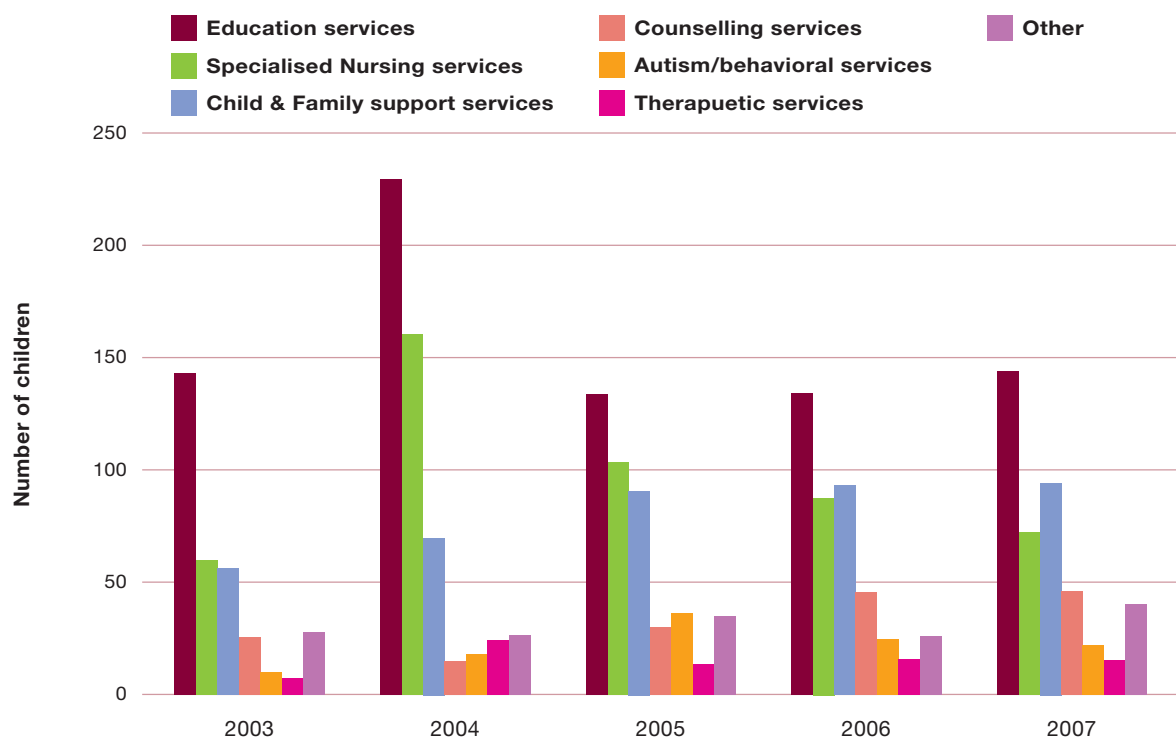


Figure 4 Number of children aged 0–5 years registered on the NIDD and in receipt of ‘other multidisciplinary support services’, 2003–2007

Unmet need

The number of new residential, day and residential support places required in the period 2008–2012 to provide children with services is identified in Table 5 and is categorised by each HSE administrative area. This information refers to those already on the NIDD and who require a new service or a change to their existing service. The data are based on information supplied by service provider staff and the HSE. As one would expect, the demand for residential places among this age group is relatively low (4 places, 4%). The need for new day places is also low in each HSE administrative area, with the exception of the West, where 16 children require a day place. This represents more than half (57%) of those who need a new place. The need for residential support places (i.e. respite and home support services) among the 0–5 years age group is high; 84 new residential support places are required to meet the needs of children aged 0–5 years which is 79% of all new places.

Table 5 Number of new places required to meet the needs of children aged 0–5 between 2008 and 2012 by Regional Health Area of the Health Service Executive

	Residential	Day	Residential support	Total
Dublin/Mid-Leinster	1	3	24	28
HSE Midland Area	0	0	14	14
HSE South Western Area	0	0	2	2
HSE East Coast Area	1	3	8	12
South	1	0	20	21
HSE South-Eastern Area	1	0	11	12
HSE Southern Area	0	0	9	9
West	0	16	12	28
HSE Mid-Western Area	0	0	3	3
HSE North-Western Area	0	0	5	5
HSE Western Area	0	16	4	20
Dublin/North-East	2	0	28	30
HSE North-Eastern Area	0	0	9	9
HSE Northern Area	2	0	19	21
Total	4	19	84	107

Table 6 indicates that 976 children who received services in 2007 will require a change to these services in the period 2008–2012. Of those who require a change, 971 (99%) will require a change to their day services (of whom 24 will also require a change to their residential support services). Children in the Dublin/Mid-Leinster region account for 363 (37%) of the service change, while children in the South and West account for 272 (28%) and 249 (26%) respectively. Ninety-two (9%) of the service changes are required by children from the Dublin/North-East area.

Table 6 Category of service change required for children aged 0–5 years between 2008 and 2012 by Regional Health Area of the Health Service Executive

	Residential only	Day only	Day and residential support	Residential support only	Total requiring service changes
Dublin/Mid-Leinster	1	354	7	1	363
HSE Midland Area	0	71	4	1	76
HSE South Western Area	0	225	0	0	225
HSE East Coast Area	1	58	3	0	62
South	0	265	7	0	272
HSE South-Eastern Area	0	108	5	0	113
HSE Southern Area	0	157	2	0	159
West	0	237	10	2	249
HSE Mid-Western Area	0	22	3	1	26
HSE North-Western Area	0	58	6	1	65
HSE Western Area	0	157	1	0	158
Dublin/North-East	0	91	0	1	92
HSE North-Eastern Area	0	32	0	0	32
HSE Northern Area	0	59	0	1	60
Total	1	947	24	4	976

The number of places needed to address the required service changes is summarised in Table 7. Day services are described under two headings: health and educational (see Table 8 for a breakdown of health and education services). The number of places required to be changed exceeds the number of people requiring service change because some people require changes in both their residential and day services.

Health funded services are required for 523 children (52% of all changes or enhancements), while educational services are required in 448 cases (45% of all changes or enhancements). Residential (1 child, 0.1%) and residential support services (28, 2.8%) make up the remaining service changes or enhancements required in the next five years.

Table 7 Number of places requiring change for children aged 0–5 years by service type and Regional Health Area of the Health Service Executive, 2008–2012

	Residential	Residential Support Services	Day Services		Total requiring service changes
			Health	Educational	
Dublin/Mid-Leinster	1	8	173	188	370
HSE Midland Area	0	5	41	34	80
HSE South Western Area	0	0	102	123	225
HSE East Coast Area	1	3	30	31	65
South	0	7	127	145	279
HSE South-Eastern Area	0	5	28	85	118
HSE Southern Area	0	2	99	60	161
West	0	12	172	75	259
HSE Mid-Western Area	0	4	24	1	29
HSE North-Western Area	0	7	32	32	71
HSE Western Area	0	1	116	42	159
Dublin/North-East	0	1	51	40	92
HSE North-Eastern Area	0	0	13	19	32
HSE Northern Area	0	1	38	21	60
Total	1	28	523	448	1000

Of the 523 service changes required in the next five years within health-funded services (see Table 8), almost half (255) are within mainstream pre-schools, one third (172) are within special pre-schools for intellectual disability and more than one in ten (58) are related to home support. Similarly, of the 448 service changes required within education, almost half (221) are within mainstream schools, more than one third (155) are within special schools and 15% (65) are within special classes in primary or secondary schools.

Table 8 Number of day places requiring change for children aged 0–5 years by health and education services and Regional Health Area of the Health Service Executive, 2008–2012

	Dublin/Mid-Leinster		Southern		Western		Dublin/North-East		Total	
Health Services	173	(33.1)	127	(24.3)	172	(32.9)	51	(9.8)	523	(100.0)
Home support	5	(8.6)	23	(39.7)	19	(32.8)	11	(19.00)	58	(100.0)
Home help	0	(0.0)	0	(0.0)	1	(100.0)	0	(0.0)	1	(100.0)
Mainstream pre-school	108	(42.4)	39	(15.3)	85	(33.3)	23	(9.0)	255	(100.0)
Special pre-school	57	(33.1)	58	(33.7)	42	(24.4)	15	(8.7)	172	(100.0)
Child education and development centre	0	(0.0)	2	(14.3)	10	(71.4)	2	(14.3)	14	(100.0)
Centre-based day respite service	0	(0.0)	0	(0.0)	14	(100.0)	0	(0.0)	14	(100.0)
Day respite in the home	0	(0.0)	2	(100.0)	0	(0.0)	0	(0.0)	2	(100.0)
Other day service	3	(42.9)	3	(42.9)	1	(14.3)	0	(0.0)	7	(100.0)
Education Services	188	(42.0)	145	(32.4)	75	(16.7)	40	(8.9)	448	(100.0)
Mainstream school	78	(35.3)	70	(31.7)	52	(23.5)	21	(9.5)	221	(100.0)
Resource teacher	2	(28.6)	0	(0.0)	3	(42.9)	2	(28.6)	7	(100.0)
Special class - primary	29	(53.7)	8	(14.8)	13	(24.1)	4	(7.4)	54	(100.0)
Special class - secondary	8	(72.7)	0	(0.0)	0	(0.0)	3	(27.3)	11	(100.0)
Special school	71	(45.8)	67	(43.2)	7	(4.5)	10	(6.5)	155	(100.0)
Total	361	(37.2)	272	(28.0)	247	(25.4)	91	(9.4)	971	(100.0)

Demand for multidisciplinary support services

The demand for multidisciplinary support services for those in the 0–5 years age group is reported in Figure 5. A ‘requirement’ refers to a new type of therapeutic input that the individual does not currently receive and an ‘enhancement’ refers to a change in the delivery of a therapeutic input that the child currently receives (e.g. an increase in the provision of the specific service or a change in service provider).

Despite high levels of service provision, there is substantial demand for new services and enhanced services relating to all the therapeutic inputs, in particular speech and language therapy, occupational therapy and psychology. For example, 912 individuals received occupational therapy in 2007, 474 of whom need an enhancement of their service, and a further 326 children who did not receive occupational therapy require it.

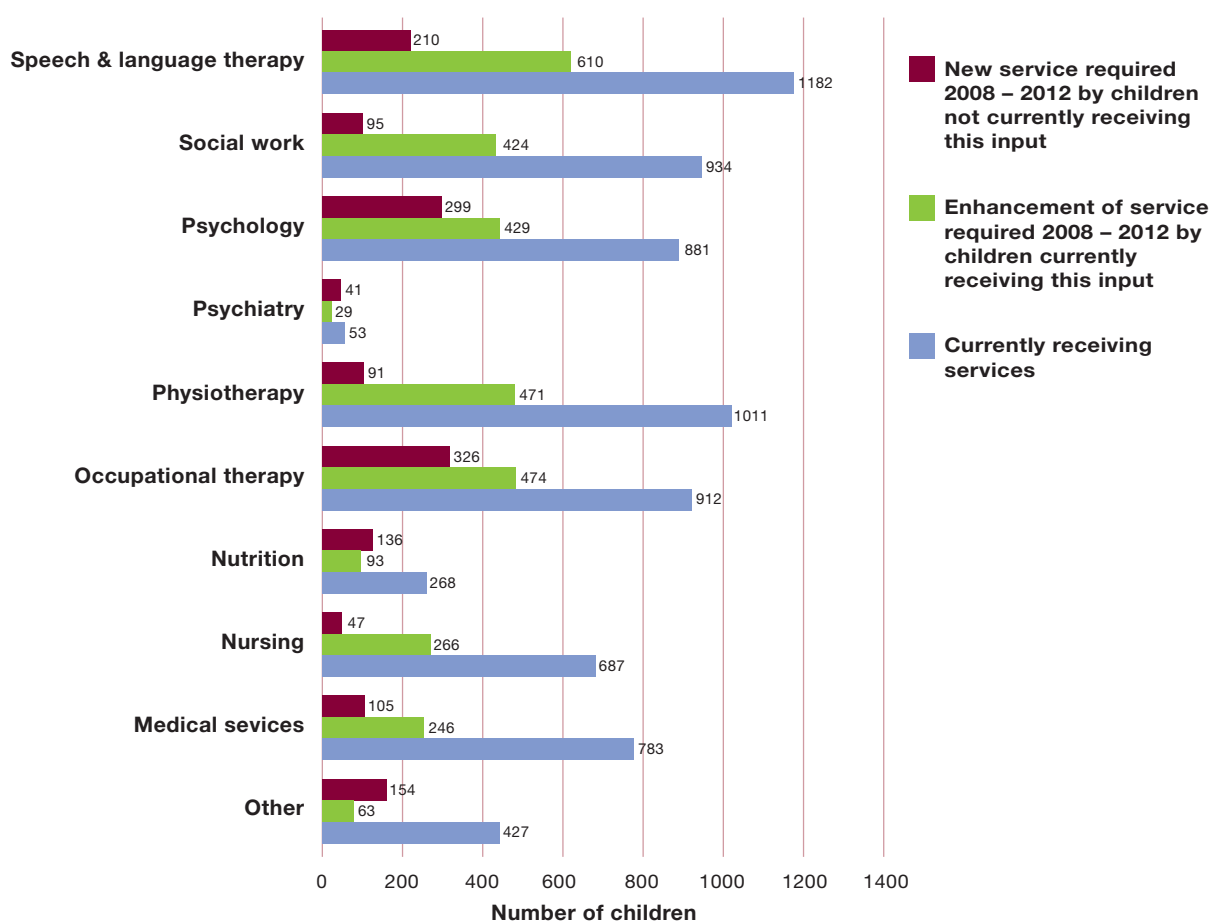


Figure 5 Current and future multidisciplinary support services for children aged 0–5 years registered on the NIDD in 2007

Conclusion

The main findings from the data show that the total number of children aged 0–5 years registered on the NIDD increased by 8% over the 5 year period. The data also show an increase of 37% in the number of children on the Database who do not have a confirmed diagnosis.

With regard to service provision in 2007, as expected, most of the cohort were living at home with one or both parents (98%) and were in receipt of day services (95%). Key services provided to this age group in 2007 included special pre-school (452, 29%), early intervention services (436, 28%) and mainstream pre-school (252, 16%). The figures show a shift, in line with policy, away from specialised settings to more mainstream provision.

With regard to future needs, the demand for residential places for this age cohort is low but there is considerable demand for residential support services such as respite and home supports.

High numbers of children are in receipt of multidisciplinary support services. Notwithstanding this high level of service, the data show that there is still considerable demand for multidisciplinary services in the period 2008-2012.

Overall, the focus on the specific needs of young children shows that their service usage and need is different from that of the NIDD overall and that trend analysis of groups such as the 0–5s can give a clear picture of the specific interventions that may be required into the future for this age group.

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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 national health priorities. 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.

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