Northern Ireland
Assembly

Research and Information Service
Briefing Paper

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International Methods of Gathering Learning Disability Prevalence Statistics

1   Introduction

This paper will identify and discuss methods of data collection on people with Learning Disabilities (LD) used by countries outside Northern Ireland. It forms part of a series of papers on LD by RaISe for the Committee for Employment and Learnings inquiry into post-secondary support for people with learning disabilities. This paper should be considered a companion paper to NIAR 259-2014 which discussed statistics on people with learning disabilities in Northern Ireland.

It should be noted that different nations use a variety of terms when referring to learning disabilities. Definitions may also vary, so for the purposes of this paper the term used in each nation is applied.

The paper will discuss data collection methods that have been identified as part of RaISe research for the Inquiry. The research discussed is:

- eSAY dataset, SCLD, Scotland
- NIDD, Republic of Ireland; and

■ New Zealand Disability Survey, New Zealand.

The paper also discusses studies carried out by the OECD and Inclusion Europe.

2   eSAY dataset, SCLD, Scotland

The Scottish Consortium for Learning Disability (SCLD) was established following the "Same as you?" review in 2000.

Funded by the Scottish Government, the SCLD operates as a centre of excellence to support people with learning disabilities and related organisations.

As part of the role of the SCLD, the eSAY dataset was developed in order to monitor progress in achieving the goals of the "Same as you?" policy. In broad terms, eSAY collects data from local authorities' about the number of adults with learning disabilities or diagnoses on the autism spectrum.

It costs approximately £90,000 per year to produce the dataset.[1]

The database can be used to accurately provide statistical/research evidence around:[2]

■ Monitoring the progress of the recommendations of "The same as you?" and other policies;

■ Making sure they are being implemented on time, and in the right way;

■ Helping to plan services;

■ Identifying where there are unmet needs; and

■ Comparing information across local authority areas and to evidence what is happening nationally.

Prior to the establishment of the eSAY dataset, no national or local data was gathered on people with learning disabilities with data based on a prevalence figure.

The eSAY statistical collection has achieved Official Statistics Status and is subject to scrutiny and assessment by the UK Statistics Authority.

2.1 Data Collection

The data gathered for the eSAY dataset is local administrative data (rather than, for example, survey data) held by local authorities. It is collected only on those aged 16 and above and not in full-time school education.

The data is held by local authorities in their Management Information Systems and may be supplemented with information from other sources such as local area coordination teams or colleges.

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[1] http://www.statisticsauthority.gov.uk/assessment/assessment/assessment-reports/new-component.pdf
[2] http://www.scld.org.uk/sites/default/files/eSAY_statistical_return_data_methodology_paper_august_2013.pdf

The SCLD works closely with local authorities in the gathering of data. Local authorities gather and submit the data to a dedicated secure data upload system, using guidance documents produced by the SCLD each year.

There is a minimum set of variables on which data is gathered. These are:

- ID number;
- Learning Disability (Y/N);
- Autism Spectrum Disorder;
- Local authority code/health board code;
- Person current gender;
- Person year of birth;
- Ethnic group;
- Accommodation type;
- Lives with family carer;
- Number of people with a learning disability living in the same accommodation;
- Advocacy;
- Personal life plan;
- Further education;
- Employment opportunities;
- Day opportunities; and
- Local Area Co-ordination.

As stated in the eSAY statistical return methodology:[3]

> *any data local authorities wish to provide over and above the minimum will be gratefully received and will contribute greatly to the development of the national dataset.*

2.2 Potential Issues with the eSAY dataset

The guidance on the dataset acknowledges a number of issues that must be taken into consideration when using statistics from eSAY[4]. These are:

- **The data is skewed towards people with learning disabilities:** As the data is derived from learning disability service data there is a bias towards individuals with a learning disability. This creates an under-estimate in the population of people on the autism spectrum;
- **eSAY is a count of adults with LD known to social services:** There will be a proportion of people with learning disabilities who are not in contact with learning disability services and as such they do not appear in the eSAY dataset. As such it

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[3] Ibid
[4] Ibid

does not provide a count of the population with learning disabilities but rather a subset of this population (people with learning disabilities who accessed learning disability services); and

- **Data errors:** eSAY has, to date, a 100% response rate from local authorities. However, not all of these responses provide a complete return on the minimum variables required by the dataset.

2.3   Example of eSAY Data

The three tables below provide examples of some of the data made available by the eSAY dataset.[5]

The data is available on the SCLD website and provides both national and local authority level information.

Table 1: Number adults with learning disabilities known to local authorities by age and gender in Scotland, 2012

	Male	Female	Total	Rate per 1,000 population*	Rate in 2011
16-17	439	148	587	4.6	5.7
18-20	1,457	754	2,211	10.2	10.9
21-34	5,155	3,206	8,361	8.7	8.2
35-44	2,398	1,789	4,187	5.7	6.2
45-54	2,716	2,137	4,853	6.2	6.3
55-64	1,871	1,465	3,336	5.0	5.0
65 and over	1,262	1,294	2,556	2.9	2.7
Not known	17	9	26	-	-
Total	**15,315**	**10,802**	**26,117**		**6.0**

Table 2: Employment opportunities* of adults with learning disabilities known to local authorities in Scotland, 2012

Employment status	Number of adults	Total as a % of all adults
In employment	2,102	8.0
In T.F.E., but not in employment	1,291	4.9
Not in employment or T.F.E.	14,254	54.6
Not recorded	8,470	32.4
Total	**26,117**	**100.0**

*Employment opportunities include: open/non-open employment; employment, type not specified; self-employment; in training for employment (TFE) but not in employment.

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[5] SCLD, Statistics Releases, http://www.scld.org.uk/scld-projects/esay/publications-and-resources/statistics-releases

Table 3: Further education course enrolment and time spent attending courses for adults with learning disabilities known to local authorities in Scotland, 2012

	In education, 2.5 days or fewer	In education, 3 or more days	In education, amount of time not specified	Not currently in education	Not recorded	Total
16-17	38	133	6	104	306	587
18-20	135	388	56	612	1,020	2,211
21-34	544	304	93	3,640	3,780	8,361
35-44	203	27	17	2,115	1,825	4,187
45-54	223	36	24	2,370	2,200	4,853
55-64	96	19	12	1,746	1,463	3,336
65+	32	7	5	1,319	1,193	2,556
Not recorded	8	0	1	4	13	26
Total	**1,279**	**914**	**214**	**11,910**	**11,800**	**26,117**

3   National Intellectual Disability Database, the Republic of Ireland

In the ROI there is an established database that tracks the prevalence of intellectual disabilities.

Established in 1995, it has the aim of:[6]

> …providing 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 National Intellectual Disability Database (NIDD) gathers three types of data:

- Demographic details;
- Current service provision; and
- Future service requirements.

The objective of the NIDD is to:[7]

> …record 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 NIDD is owned by the Department for Health and managed by the Health Research Board.

Statistical releases are also made as part of the Annual Report of the National Intellectual Disability Database Committee as published by the Health Research Board.

The information from the database is used to:

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[6] NIDD, Annual Report 2012, http://www.hrb.ie/health-information-in-house-research/disability/nidd-publications/
[7] Ibid

- Monitor current services;
- Assess future service needs;
- Prioritise service needs;
- Support the planning of services; and
- Help research.

3.1   Data Collection

The Health Service Executive (HSE) collects the data which is provided by service providers, HSE personnel and school principals.

Information is collected for each (voluntarily) registered person. Once an individual registers with the NIDD they are asked to complete a data form. This form asks 96 questions gathering data on four types of information:[8]

- Personal and demographic details such as date of birth, gender and level of intellectual disability;
- The residential, day, and support services that are currently received;
- What residential, day, and support services are required and when; and
- Additional information to assist with the administration of the Database.

The data is updated whenever there is a change in their individual circumstances or following the annual review process in which service provider agencies must assess an individual's current and future needs.

Information is collected from people who meet the following criteria:[9]

- Individuals who have a moderate, severe, or profound intellectual disability;
- Individuals who have a mild intellectual disability and who are in receipt of a specialised health service;
- Individuals who have a mild intellectual disability and who have been assessed as requiring a specialised health service immediately, within the next five years, or has contingency requirements for such services;
- Individuals (whether or not they have any level of intellectual disability) who are in receipt of specialised health services from an intellectual disability service;
- Anyone who is in a psychiatric hospital who has been assessed as having an intellectual disability; and
- Individuals who have a syndrome of which intellectual disability is usually a feature such as Down Syndrome.

The statistical information gathered by the HSE is accessible only to:[10]

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[8] Health Research Board, NIDD: What information is collected, http://www.hrb.ie/health-information-in-house-research/disability/nidd/what-information-is-collected/

[9] Health Research Board, NIDD: Information for participants, http://www.hrb.ie/health-information-in-house-research/disability/nidd/information-for-participants/

- The Department for Health and Children;
- The Health Service Executive;
- The Health Research Board; and
- Approved researchers.

In regards accuracy of the data, the NIDD Committee states that:[11]

> *The nature of service provision in the intellectual disability area in Ireland ensures that an almost complete capture of data on all individuals with a moderate, severe or profound intellectual disability is possible and expected.*

3.2 Potential Issues with the NIDD data

Whilst not necessary a major issue, it is worthwhile noting that:[12]

> *The NIDD registers data only on individuals with an intellectual disability for whom specialised health services are being provided or who, following a needs assessment, are considered to require specialised services in the next five years.*

As such, it does not take into consideration those who have not been in contact with authorities. It should not, therefore, be considered a definitive measure of the number people in the ROI with an intellectual disability.

In addition to this, the number of people on the NIDD with a mild intellectual disability may be underestimated as they are less likely to require specialised intellectual disability services.[13]

3.3 Example of NIDD data

The figures and table below provide examples of the statistical information provided by the NIDD.

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[10] NIDD Committee, Planning Services for People with Disabilities: A guide to the Intellectual Disability Database, http://www.hrb.ie/fileadmin/Staging/Documents/In_House_Research_Info_Systems/DDU/Other_PDF_docs/4._b__NIDD_Info_Leaflet_2008_Eng.pdf
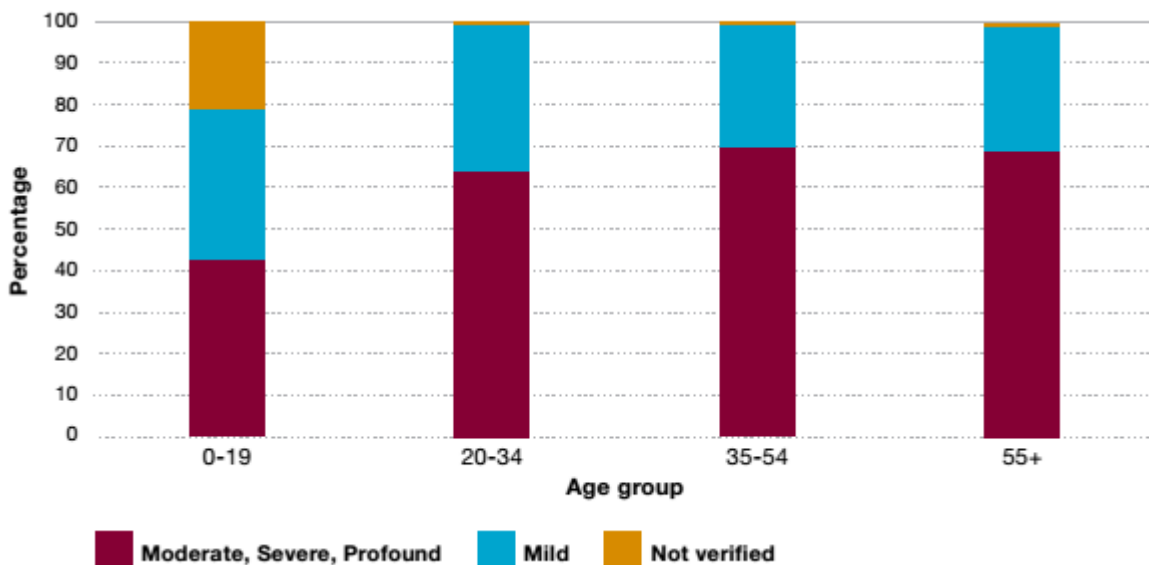
[11] NIDD Committee, Annual Report 2012, http://www.hrb.ie/health-information-in-house-research/disability/nidd-publications/

[12] NIDD, Annual Report 2012, http://www.hrb.ie/health-information-in-house-research/disability/nidd-publications/

[13] Ibid.

Number of people registered on the NIDD in 2012
27622

Male
15952 (57.8%)

Female
11670 (42.2%)

Level of intellectual disability		
	n	%
Mild	5213	(32.7)
Moderate	6283	(39.4)
Severe	2349	(14.7)
Profound	526	(3.3)
Not verified	1581	(9.9)

HSE region of registration		
	n	%
Dublin/ Mid-Leinster	7004	(25.4)
South	7832	(28.4)
West	7185	(26.0)
Dublin/ North-East	5601	(20.3)

Age group		
	n	%
0-4 years	1328	(4.8)
5-9 years	2755	(10.0)
10-14 years	3086	(11.2)
15-19 years	3052	(11.0)
20-34 years	6186	(22.4)
35-54 years	7677	(27.8)
55 years and over	3538	(12.8)

Level of intellectual disability		
	n	%
Mild	3913	(33.5)
Moderate	4774	(40.9)
Severe	1733	(14.9)
Profound	438	(3.8)
Not verified	812	(7.0)

Figure 1: Profile of the population registered on the NIDD, 2012

Figure 2: Individuals registered on the NIDD, by degree of intellectual disability and by age group, 2012

| Number of people registered on the NIDD in 2012 |
| 27622 |

| Under 18 | 18 or over |
| 9123 (33.0%) | 18499 (67.0%) |

Main residential circumstances		Main day service grouping		Main residential circumstances		Main day service grouping	
	n %		n %		n %		n %
Home setting	8970 (98.3)	Health	1836 (20.1)	Home setting	9360 (50.6)	Health	15916 (86.0)
Independent setting	0 (0.0)	Education	7258 (79.6)	Independent setting	1157 (6.3)	Education	458 (2.5)
Community group homes	79 (0.9)	Employment	0 (0.0)	Community group homes	4147 (22.4)	Employment	997 (5.4)
Residential centres	25 (0.3)	Generic	5 (0.1)	Residential centres	2536 (13.7)	Generic	721 (3.9)
Other full time services	42 (0.5)	No day service	24 (0.3)	Other full time services	1269 (6.9)	No day service	407 (2.2)
No fixed abode	0 (0.0)			No fixed abode	13 (0.1)		
Insufficient information	7 (0.1)			Insufficient information	17 (0.1)		

Figure 3: Summary of service provision, by age group, 2012

4   New Zealand Disability Survey, New Zealand

The New Zealand Disability survey is carried out after each census, with the previous survey conducted in 2006. The first survey was carried out in 1996. Surveys are generally carried out every five years. However, following the Canterbury earthquake, the census was delayed for one year.

The survey:

> …*provides detailed information on the needs of disabled people, and is currently the most comprehensive source of data on disabled people living in New Zealand.*

It collects information on a number of variables including:

- How many disabled people live in New Zealand;
- The nature and cause of their impairment; and
- Employment and education.

This information is used by the New Zealand government to evaluate and develop policies and legislation on issues affecting disabled people. The data is also used by disabled people's organisations, community groups and other organisations.[14]

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[14] Statistics New Zealand, Disability Survey, http://www.stats.govt.nz/survey-participants/a-z-of-our-surveys/disability-survey.aspx

The survey gathers data on a variety of disability groups including those with intellectual and learning disabilities.

4.1   Data collection

The survey is carried out by Statistics NZ. It is mainly carried out via telephone interviews, although in some cases face-to-face interviews can be conducted such as when a respondent has hearing difficulties.

The data is collected through:[15]

- A household survey of disabled and non-disabled children and adults;
- A survey of adults living in residential facilities, such as rest homes.

Telephone interviews take between twenty to thirty minutes and ask a variety of questions covering areas such as those discussed above. Census data is added to respondent's answers in order to bolster the data and reduce the interview times. Information used from the census includes ethnicity, education and occupation.

Under New Zealand legislation, if an individual is selected to take part in the survey, they must participate. If, for reasons due to a medical condition for example, an individual is unable to complete the survey, a caregiver or family member can be asked to complete it on their behalf.

The survey data can be used for a variety of purposes, including:[16]

- Helps government to evaluate and develop policies and legislation on issues that affect disabled people in New Zealand;
- Reporting against the New Zealand Disability Strategy; and
- Meeting obligations for reporting and monitoring under the UN Convention on the Rights of Persons with Disabilities.

The 2013 survey ran from July to October, with results to be published in June 2014.

4.2   Potential Issues with the New Zealand Disability Survey

Surveys include a number of inherent issues, including:

- Researchers are reliant on participants providing accurate responses. For example, some participants, especially those with mild intellectual disabilities, may not be aware they have a disability. In other cases, a participant may be embarrassed by a condition and omit it from the survey response; and
- Whilst surveys have an advantage in being able to identify trends within a population, the data can be subject to sampling errors in which the actual proportion

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[15] Statistics New Zealand, 2013 Disability New Zealand, http://www.stats.govt.nz/~/media/Statistics/browse-categories/health/disabilities/2013-disability-survey/04100_7827_Stats_Disability_Brochure_WEB_FA2.pdf
[16] Ibid

of the population in a household with a particular characteristic may differ from the proportion of the survey sample with that characteristic – effectively the larger the group the more precise the estimate is, with the smaller the sample, the greater the potential for errors.

4.3   Examples of Disability Survey Data

As the 2013 survey is yet to publish any results, examples from the previous survey (2006) are provided below.
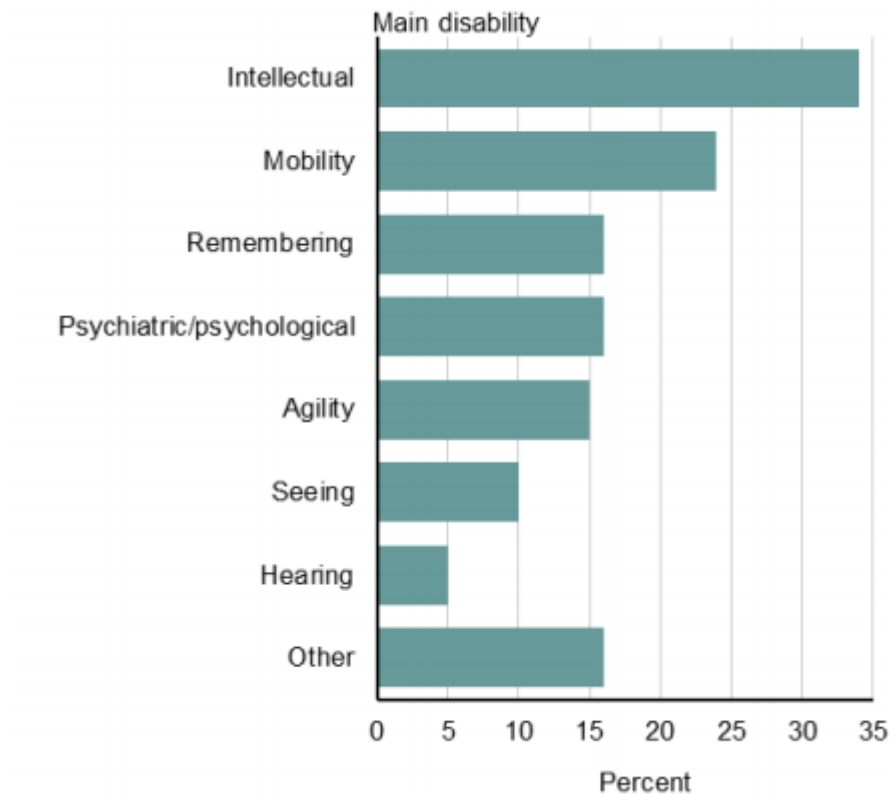
Table 4: Disabled adults enrolled in formal education and training, New Zealand 2006[17]

Disability type	Enrolled		Not enrolled		Not elsewhere included		Total	
	No.	%	No.	%	No.	%	No.	%
Mobility	14,000	5	264,500	93	6,500	2	285,000	100
Agility	11,900	5	237,100	93	7,200	3	256,100	100
Hearing	6,600	4	170,700	94	3,700	2	181,000	100
Seeing	3,600	6	53,200	89	2,900	5	59,700	100
Intellectual	3,700	12	23,900	75	4,100	13	31,700	100
Psychiatric or psychological	10,800	13	68,100	82	4,200	5	83,000	100
Speaking	3,500	9	30,700	83	2,900	8	37,100	100
Remembering	6,000	7	74,700	88	3,800	5	84,600	100
Learning	10,100	15	51,200	78	4,400	7	65,600	100
Other	9,100	10	81,100	89	--S	--S	91,500	100
Total	37,800	7	490,600	91	10,800	2	539,200	100
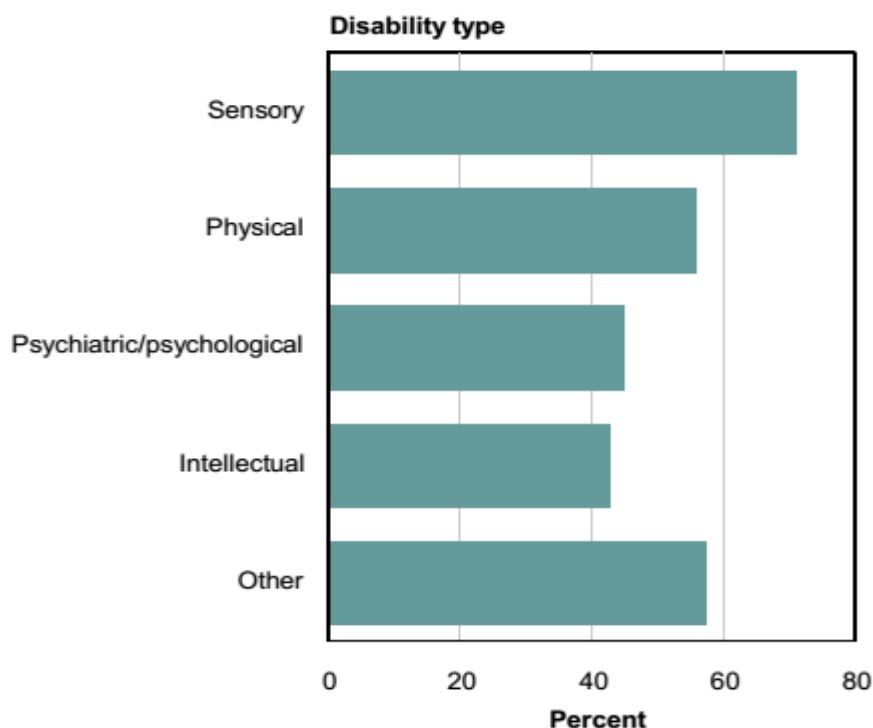
Figure 4: Labour force participation by disabled people, New Zealand, 2006[18]

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[17] Statistics New Zealand, Disability and Education in New Zealand, 2006,
http://www.stats.govt.nz/browse_for_stats/health/disabilities/disability-and-education-in-nz-2006.aspx

Figure 5 bar chart: Main disability

Main disability	Percent (approx.)
Intellectual	34
Mobility	24
Remembering	16
Psychiatric/psychological	16
Agility	15
Seeing	10
Hearing	5
Other	16

Figure 5: Disabled adults who received a needs assessment, 2006[19]

5   Reports

In addition to the larger, national statistics produced on learning disabilities, there is also data produced by research organisations.

A number of international organisations gather statistics and provide prevalence and data analysis on people with learning disabilities. The Academic Network of European Disability Experts (ANED) identified a number of these studies in its 2009 report "European Comparative Data on the Situation of Disabled People: an annotated review."

Two reports identified by the ANED are discussed below.

5.1   Inclusion Europe - Poverty and intellectual disability in Europe:

This was a study into identifying the causes of poverty and social exclusions for people with intellectual disabilities and their families carried out by Inclusion Europe.

[18] Statistics New Zealand, Disability and the Labour Market in New Zealand 2006,
http://www.stats.govt.nz/browse_for_stats/health/disabilities/disability-and-the-labour-market-in-nz-2006.aspx
[19] Statistics New Zealand, Disability and formal supports in New Zealand in 2006,
http://www.stats.govt.nz/browse_for_stats/health/disabilities/disability-and-formal-supports-2006.aspx

Inclusion Europe is a European wide association, with 36 national member organisations. It was started in 1988 to:[20]

> *Represent[s] the voice of people with intellectual disabilities and their families throughout Europe.*

Its report on poverty and intellectual disability was part of a three year global initiative (working with Inclusion International and the Norwegian Association for Persons with Developmental Disabilities).

The study gathered data in three ways:

- Via questionnaires on poverty and intellectual disability provided by member associations of Inclusion Europe;
- A literature review of existing research; and
- Focus groups carried out by Inclusion Romania.

The study also reviewed existing EU statistical data on intellectual disabilities and found that:[21]

> *There is a clear lack of understanding and information about the scope and dimension of disability in Europe. Eurostat and national census data from Member States make it difficult to get a clear picture of the number of persons with intellectual disabilities, but also to identify household data where there is a person with an intellectual disability.*

It should be noted, however, that this is based on Census data from the 2000s and as such subsequent censuses may have taken the need for further clarification of data into consideration.

Below can be found two examples of the data provided in the study. Figure 6 shows the percentage of people with Intellectual Disabilities.

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[20] Inclusion Europe, About Us, http://inclusion-europe.org/en/about-us
[21] Inclusion Europe, Poverty and Intellectual Disability in Europe, http://inclusion-europe.org/images/stories/documents/policies/SocInc_EUPovertyRreport.pdf

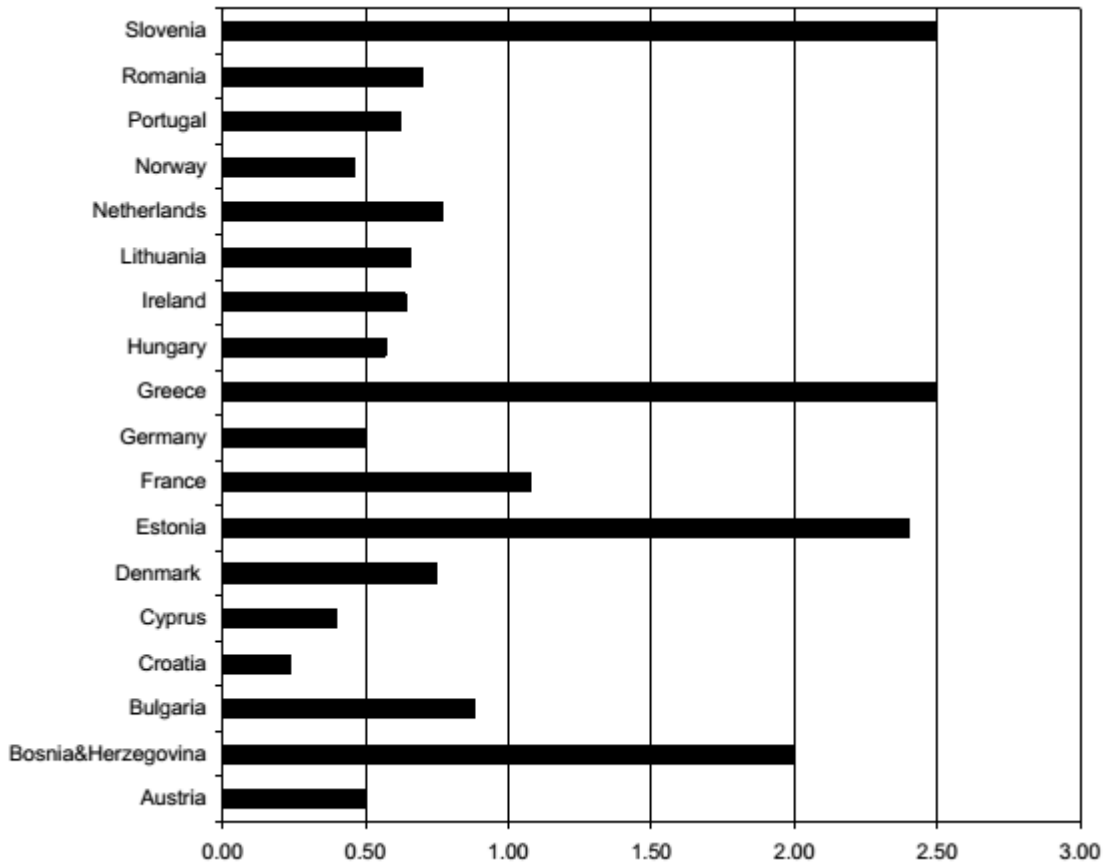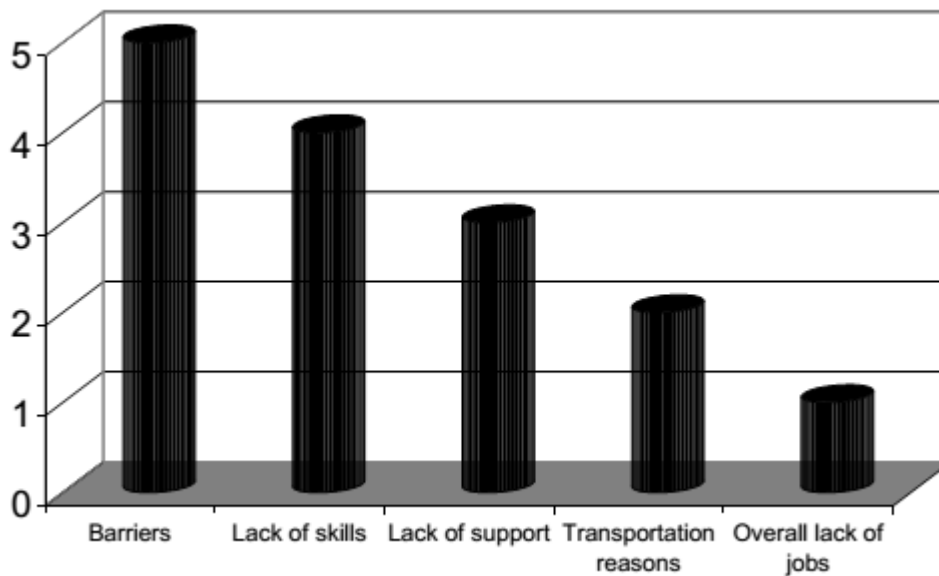**Figure 6:** Percentage of people with Intellectual Disabilities

Figure 7, on the page following, identifies reasons for unemployment amongst people with learning disabilities:

Figure 7: Reasons for unemployment of people with intellectual disabilities

It should be noted that Inclusion Europe highlights that there is an issue regarding the variations in definitions regarding Intellectual Disabilities. In other cases, some countries gather data for policy and planning purposes and others estimate ID prevalence.

5.2   OECD – Students with disabilities, learning difficulties and disadvantages

The Organisation for Economic Co-operation and Development (OECD) works to promote policies that will improve the economic and social well-being of people around the world.

The study provides:

> *…an internationally comparable set of indicators on educational provision for students with disabilities, learning difficulties and disadvantages.*[22]

Member states were issued an electronic questionnaire which was used to gather data. Data gathering was broken into six tables and requested information including:

- Information on the number of students with special educational needs in special schools, on the institutions (public and private), numbers of classes and on the teaching staff;
- Information on the number of students with special needs in special classes, on the institutions (public and private), numbers of classes and on the teaching staff; and
- Information on the number of students with special needs in regular classes, on the institutions (public and private), and numbers of classes.

The data from the questionnaire was used to develop a database which was designed to take account of the wide variety of national systems in use in order to ensure comparability between countries. The compiled information was then used in the production of a report.

A large number of figures were produced, including those provided on the page following.

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[22] OECD, Students with disabilities, learning difficulties and disadvantages, http://www.oecd.org/edu/innovation-education/studentswithdisabilitieslearningdifficultiesanddisadvantagesstatisticsandindicators.htm#SC
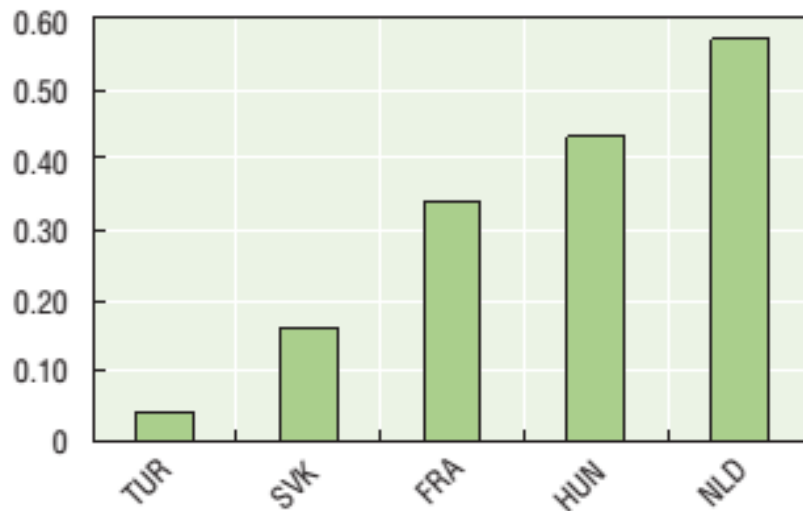
Figure 8: Percentage of students receiving additional resources by nationally classified categories of disability, difficulty and disadvantage by country as a percentage of all students in primary and lower secondary education (2001).
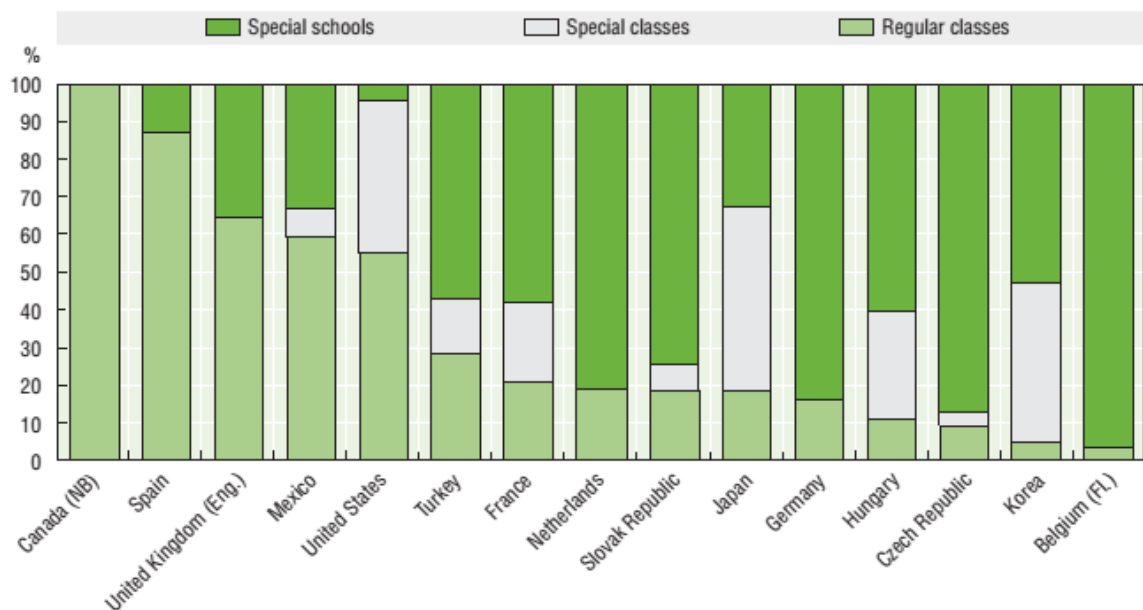
Figure 9: Percentage of students receiving additional resources over the period of compulsory education by location.

6   Conclusion

A variety of research methods can be employed to provide information on people with learning disabilities. In this paper a number of methods have been discussed such as using surveys, administrative data and questionnaires.

Each of these methods comes with advantages and disadvantages. Surveys can provide broad, snapshots of a population but the data becomes less applicable to the population at large the smaller the sample size becomes.

Questionnaires can also be highly beneficial. Relatively cheap to produce and easily distributed (especially with the advent of services such as Survey Monkey and the wide spread use of email). However, there can be difficulties in getting people to respond.

No one data collection method is better than another and should be defined, in part, by what the objectives of the research is.