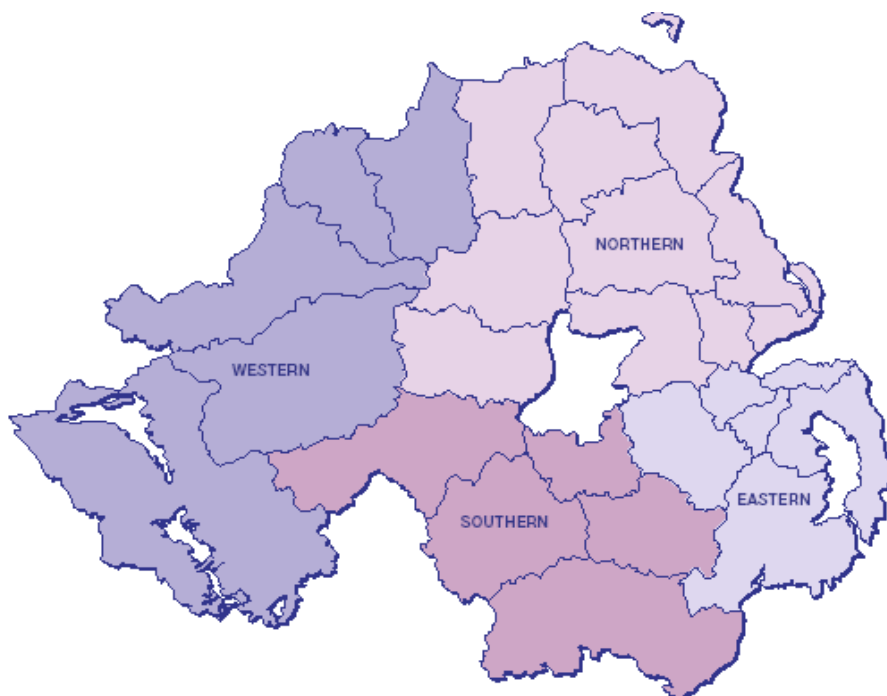


# **Administrative Prevalence of Learning Disability in Northern Ireland**



**Roy McConkey,**  
*University of Ulster*

**Martin Spollen,**  
*MSA-Ferndale Secta,*

**Jim Jamison**  
*Consultant.*

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## Summary

This study into the administrative prevalence of learning disability is the first to cover all of Northern Ireland. The main aim was to determine from existing datasets the administrative prevalence of learning disability across Northern Ireland and in particular to estimate the numbers of people in long-stay hospitals, in registered residential accommodation and those living in ordinary housing and cared for in the main by family carers.

A total of 16,366 persons with moderate, severe and profound learning disabilities in Northern Ireland were recorded on Soscare and Child Health Systems and 7,439 on Social Security systems. Additional data sources were accessed as cross-checks. This gives a prevalence rate of 9.7 persons per 1,000 population which is higher than that reported in previous studies in Northern Ireland and for the Republic of Ireland.

However the increased rates are mostly for children and young people under 20 years. This may have resulted from children being recorded on the Child Health System as possibly having a learning disability rather than with a confirmed diagnosis of a learning disability.

Three sub-populations are then considered:

- An estimated 440 – 470 people resident in long-stay Hospitals
- Around 1,900 people living in residential care and nursing homes, or supported living accommodation.
- Around 14,000 people living in community settings, either with family carers, in their own accommodation or in supported housing.

For each sub-population details are given of the breakdown by two levels of disability, by HSS Trusts, by age and gender.

Recommendations are made as to how existing datasets could be improved or developed in order to provide more accurate information that could be used by HPSS commissioners to inform future resource allocations.

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# 1. Introduction

This study into the administrative prevalence of learning disability is the first to cover all of Northern Ireland. Previous studies, most recently by McDonald and Mackay (1996), have focussed on one particular Board. They reported variations in the prevalence rates (per 1,000) across the Trust areas: namely Newry & Mourne 9.04; Armagh & Dungannon 6.72; Craigavon & Banbridge 5.85. Likewise in the Republic of Ireland, prevalence rates have consistently varied across Health Boards.

Given these findings, it would be unwise to extrapolate from data gathered in particular localities to estimate the numbers in other Boards or regions.

The main alternatives then are two fold.

1. To conduct a census of all persons with a learning disability throughout Northern Ireland on a particular date. This would require extensive resources and full co-operation from a wide range of agencies. Moreover the time and effort entailed in this approach would be better rewarded if a register of such persons was created and that could be updated regularly. (This approach has been adopted in the Republic of Ireland and in certain local authorities in Great Britain.)
2. Existing databases could be used to obtain a reasonable estimate of the population presently known to services. This approach would be less costly and would also provide an insight as to how existing datasets might be improved to provide a more accurate indication of the people served by the learning disability programme of care.

Although the initial scoping study commissioned by the Regional Capitation Formula Review Group (McConkey, Carr-Hill, Jamison and Donnelly, 1998) concluded that option 1 was preferable, the CFRG considered that there were sufficient datasets available for this population (unlike other client populations) that the second approach would be worth trying and the present study was then commissioned. The main aims were:

1. to determine from existing datasets the administrative prevalence of learning disability across Northern Ireland and in particular to estimate the numbers of people in long-stay hospitals, in registered residential accommodation and those living in ordinary housing and cared for in the main by family carers.
2. to explore how this data could inform a new resource allocation formula for this Programme of Care.
3. to recommend how existing datasets could be improved or developed in order to provide more accurate information that could be used by HPSS commissioners to inform future resource allocations.

Ethical approval for the study was granted by the University of Ulster Ethics Committee.

## 2. Methods

This study undertook to identify the people who were recorded as having a 'learning disability' on existing databases commonly used in Northern Ireland. Two main sources of data were accessed for this study.

### 1. Information systems held by HSS Trusts.

Data held on Soscare and the Child Health System (Module V) in the period October 2002 to April 2003 were merged to produce a common data file after duplicates had been eliminated<sup>1</sup>. These two systems were used because:

- They are registers of persons unlike other systems, such as L-CID, which was developed to record professional activities.
- They have been developed for use throughout Northern Ireland with definitions agreed across all the Boards and trusts.
- Soscare is used by all 11 community HSS Trusts and Child Health System – Module V is presently maintained by 10 of the 11 Trusts.
- The two systems complement each other in that adult persons tend to be recorded on Soscare with children recorded on the Child Health System.

However Ulster Community and Hospital Trust could not supply CHS data from Module V and projections were made of their likely numbers based on CHS data from the other Trusts in EHSSB. This resulted in an extra 519 persons being added to UCHT.

### 2. Social Security Data

A listing was obtained of all persons in Northern Ireland with a primary diagnosis of 'learning disabilities' in receipt of disability living allowances/attendance allowances as at 11 November 2002. This data was analysed separately from Trust data due to Data Protection concerns.

#### *Additional data sources*

In order to cross-check information data was also obtained from:

- The Hospital In-patient Census of people resident in Learning Disability Hospitals on 17 February 2002.
- Data held in June 2003 in the Trojan Finance systems of people in residential accommodation (NB this was not available for Craigavon & Banbridge Trust as they use a manual recording system).

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<sup>1</sup> Named data had to be used to enable duplicate records to be detected. Only Trust Information staff or their nominees had access to the named data. Thereafter all personal identifiers were removed from the data files.

- Data from four studies into housing and support needs in Northern Ireland involving all four Boards and their community Trusts (McConkey et al, 2000, 2002, 2003). Data was obtained from Trusts on the number of registered places in care homes and nursing homes for people with learning disabilities and service staff also completed pro formas on people in residential accommodation, those in hospitals requiring to be resettled and on representative samples of people in community settings. The latter were drawn in the main from Soscare databases.

Note: Consideration was given to accessing from Education and Library Boards, the names of children who had statements of special educational needs that included 'moderate or severe learning difficulties'. Legal advice to the Boards advised that this required permission from individual parents for this to happen. It was felt that only a minority of parents would agree to this.

## **Sub-groupings**

The data obtained from the trust and social security systems was then grouped into three populations and cross-checked with other data sources. (Financial information from the Trusts is similarly grouped).

### *1. Those with an address in a long-stay Hospital.*

These are likely to be people who have no other address and who have been resident in the Hospital for some time. Most are awaiting resettlement in line with current Departmental policy but a proportion of long-stay patients are likely to be receiving on-going treatment. This group does NOT include people who are admitted for short-term assessment and treatment and who have an address to which they can be discharged.

Other studies by McConkey et al (2002) of treatment admissions to Muckamore Abbey Hospital over a two-year period can provide estimates of these numbers. In addition the Hospital Inpatient census identifies people by length of stay and those recently admitted – in last 12 months – are most likely to be people on short-term admissions.

The Hospital subpopulation on Soscare records may be incomplete because people were resident in the Hospitals before Trust data systems were set up or Trust records may not have been updated when the person moved into Hospital and likewise on discharge. However as named information was available for 10 of the 11 Trusts it was possible to check for duplicate records within and across trusts and Boards. The level of duplication was highest in the SHSSB because the 'owning' Trust recorded the person as well as the Hospital Trust.

The Hospital in-patient record is likely to be a more complete record of people but it does not distinguish those who are a short-term assessment and treatment admission from those who have no other place to live. Nor does it assign people by Trusts and Boards. However this information was provided via the Trusts representatives on the Project Steering Group.

An accurate count of the numbers of people resident within Hospitals (that is they had no address to which they could be discharged) could be obtained directly from the three main long-stay Hospitals in Northern Ireland. This fell outside the scope of the present project.

## *2. Those with an address in a registered residential care home or nursing home.*

Although recent studies (McConkey et al, 2000, 2002, 2003) show that this form of accommodation is the most common in Northern Ireland, the residential sub-population does not include all those people who are living in 'ordinary housing arrangements such as small homes for around three people or in supported living arrangements. The latter two groups are included in the third grouping: people living in community settings (see below).

This data from Soscare was also checked for duplicates within and across Trusts and Boards although few instances were found.

However this dataset is also subject to error as the originating address may still be recorded for people who have moved more recently into residential care. (Estimates from previous studies in WHSSB suggests that this is true for around 4.5% of the community population while comparable figures for the NHSSB are 3% and for SHSSB 1%).

Also people in long-stay arrangements who have no contact with Trust staff are not likely to be recorded on Trust data systems.

Data was also obtained from Trojan information systems which records payments made for all persons in residential and nursing homes as well as a small proportion of people in supported living, all within the EHSSB and NHSSB areas.

## *3. Those living in community settings*

This includes people living with family carers, in their own accommodation with no support and in supported housing arrangements as noted above (the latter group probably consists of around 400 persons). Duplicates were checked within Trusts but not across Trust due to the size of the dataset (although this could be done). However it is likely to be minimal as most of the services are delivered locally.

The main cross-check for this population was between Trust data and Social Security information.

## **Sources of Error**

As with any data systems there are various sources of error in attempting to reflect the 'true' numbers of people with a learning disability; particularly those living in community settings rather than long-stay hospitals and specialist residential accommodation.

- Those people who have no contact with HSS services or who are not in receipt of social security payments are missed. However for the purposes of devising a capitation formula for service provision this is a less serious concern.
- The definition of 'learning disabilities' used by service personnel is imprecise and may be wrongly used to include some people in the learning disability programme and conversely to record people with a learning disability in another programme of care, e.g. child and family, mental health etc. (This issue was of particular concern to participants in the consultation seminar attended by Board and Trust personnel involved with the learning disability programme of care. The Regional User Advisory Group for the NI Child Health System also noted that a definition of children to be recorded on Module V had only recently been agreed.)

- The definitional issue is potentially even more serious with social security data as only the primary reason for the payment is given. Hence people with learning disabilities and additional disabilities - such as epilepsy or physical impairments - could be missed as these disabilities are recorded as the primary reason for their care needs. Secondary reasons are not recorded on DSD computer databases.
- People who are deceased may remain on the system as might those who move out of their area. (Estimates from previous studies in three HSS Boards suggests that this is the case for 1.8% to 2.4% of people recorded on Soscare with a community address.) Likewise people who are newly in contact with services may not appear on the system for some time although the downloads requested were for six months previously to help counter-act this.
- People with a learning disability may be recorded on other data systems because of the nature of the services and supports they are receiving, most notably L-CID which is used to monitor health activity in the Eastern and Northern HSS Board areas. However the Steering Group for the project decided these systems would not be included for the following reasons:
  1. They are not used throughout Northern Ireland.
  2. The systems are not registers of people but rather of professional activities with patients being allocated to a programme of care.
  3. Previous research in the NHSSB and WHSSB had shown that health activity systems tended to include many more cases than did Soscare of people who were not known to the personnel working in the learning disability programme of care (McConkey et al, 2000, 2002).

It is possible that the above sources of error apply equally across Trusts and Boards and hence should not affect the relativities within and between Trusts and Boards but it is hard to empirically test this.

## **Levels of disability**

People classed as having a learning disability embrace a wide range of needs and they have been traditionally grouped into sub-categories such as borderline, mild, moderate, severe and profound learning disabilities. Traditionally this classification has been based on IQ Test scores but the reliability and sensitivity of these measures is poor particularly with scores less than 50. To a large extent, the classification is made on professional judgements and with particular regard to the support needs of the person. Both the Child Health System and Soscare record levels of disability.

### *Child Health System*

Module V of the Child Health System allows for children to be grouped using this categorisation. Of the 10,166 children accessed for this study, level of disability was recorded for 86.3% of them. The numbers in each grouping were as follows:

**Table 1: Numbers of people recorded for each level of disability on the Child Health System**

<b>Grouping</b>	<b>N</b>	<b>%</b>
Borderline	163	1.9
Mild	2354	26.8
Moderate	4794	54.6
Severe	1303	14.9
Profound	155	1.8
<b>Total</b>	<b>8769</b>	<b>100.0</b>

However this categorisation does not appear to be uniformly applied across the nine Trusts which use Module V (see Appendix Table A1b). The WHSSB records much higher proportions of children as borderline/normal (52% in Sperrin Lakeland and 29% in Foyle) whereas in the other Trusts this ranged from 0% to 7%. Similarly the proportion of children with mild disabilities also varies 11.9% (Causeway) to 36% (Sperrin Lakeland); moderate disabilities from 8% (Sperrin Lakeland) to 63.7% (Causeway); severe disabilities from 3% (Sperrin Lakeland) to 22% (S&E Belfast) and profound disabilities from 0.2% (N&W Belfast) to 4% (Foyle). The Regional User Advisory Group for the NI Child Health System had noted this potential problem.

On the advice of the Steering group, children with borderline/normal ratings were excluded from the main sample as were those with mild learning disabilities. However this was not done for WHSSB. Following consultations with the Senior Community Medical Officer in Foyle Trust, children categorised as having a mild disability were included to compensate for a potential undercount of those with moderate to severe disabilities as noted above. The Regional User Advisory Group for the CHS would be a suitable forum for reviewing this issue.

However details of the total numbers of cases with mild, moderate, severe and profound disabilities are given in Appendix 4.

#### *Soscare records*

A total of 8,928 persons were recorded on Soscare in community settings. This system records two main levels of disability and this information was available for 7,323 persons (82.0%) recorded on this system. The breakdown is shown in Table 2.

#### **Combining data on levels of disability in Soscare and Child Health**

When the information from the two systems is combined, level of disability information is available for 12,227 persons (86%).

For most people, this information came from only one system (see earlier) however there is a set of 1,292 cases where information is available from both systems. The level of concurrence is NOT perfect especially on ratings of severe/profound disabilities on the Child Health System (see

Table 3 below). This again highlights the need for common definitions across systems.

**Table 2: Numbers of people recorded for each level of disability on Soscare**

<b>Grouping</b>	<b>Number</b>	<b>Percent</b>
Learning Disability	4869	54.5
Severe Learning Disability	2358	26.4
Severe Mental Impairment^	96	1.1
Unclassified*	251	2.8
Statementing by ELB*	335	3.8
Missing	1019	11.4
<b>Total</b>	<b>8928</b>	<b>100.0</b>

*^ regrouped with severe learning disabilities \* included as missing.*

**Table 3: Numbers of people recorded across systems by level of disability**

	<b>Soscare LD</b>	<b>Soscare Severe LD</b>	<b>Total (Column percentages)</b>
CHS Moderate	437 (85%)	76 (15%)	513 (40%)
CHS Severe/Profound	405 (52%)	374 (48%)	779 (60%)
<b>Total</b>	<b>842 (65%)</b>	<b>450 (35%)</b>	<b>1,292 (100%)</b>

*Chi Sq = 150; df 1; p<0.001*

For the purposes of this study, it is proposed that the person is rated as having the more severe of the disabilities noted on the two systems. This could mean an over-count of people with more marked disabilities and hence an over-estimation of potential service costs (see Part 2 of the report).

Two broad groupings of people living in community settings can therefore be proposed as follows: (NB Data from National Intellectual Disability Database in the Republic of Ireland: Annual Report 2001 - is given as a comparator.)

- 9,147 persons (74.5% valid cases) have mild/moderate learning disabilities (79.8% of verified cases in RoI)
- 3,126 persons (25.5% valid cases) have severe/profound learning disabilities. (20.2% of verified cases in RoI).

More children (under 19) are rated as mild/moderate (79%) whereas fewer adults aged 35-49 years (65%) are in this category. *Chi Sq = 150; df 3; p<0.001.*

### **Levels of Disability and Social Security Data**

Of the 6,422 persons in receipt of social security benefits and resident in community settings, 99.3% were in receipt of DLA and 0.7% (N=48)

Attendance Allowance (AA). In all 89.5% (N=5,752) were receiving the mobility component of DLA.

AA and the care component of DLA are paid at a high, medium and low tariff depending on the persons' assessed needs for care. The mobility component of DLA is at a high and low rate. The numbers and percentages of each benefits are given in Table 4 below.

**Table 4: Numbers of people recorded on Social Security Data for each type of benefit**

<b>Benefit</b>	<b>Number</b>	<b>Percent</b>
<b>DLA CARE/AA</b>		
High	2805	43.7
Medium	3097	48.2
Low	467	7.3
Not known	53	0.8
<b>DLA MOBILITY</b>		
High	1563	24.3%
Low	4189	65.2%
Not Known/not awarded	670	10.4%

The proportion of people in receipt of the higher rate of the DLA mobility component (27% of known cases) compares well with the proportion of people having severe/profound disabilities in the Soscare and CHS systems (25%). However a greater proportion receive the highest rate of the care component (43.7%).

It is likely that the criteria used for assessing differential rates of care needs is not directly related to a categorisation of level of disability. Once again more information is required about the definitions used to categorise persons within and across systems.

### 3. Overall Numbers

Table 5 gives the overall numbers of people with a moderate, severe or profound learning disability recorded on the two data sources plus the added numbers to account for missing CHS data in one trusts.

**Table 5: Count of persons recorded on the main information systems**

Location	Trust Systems		Social Security	
	N	%	N	%
Hospital*	390*	2.4%	192	2.6%
Residential+	1,703+	10.4%	825	11.1%
Community – Soscare only	5,474		-	-
Community – CHS only	7,050^		-	
Community – Both systems	1,749		-	-
Total Community	14,273~	87.2%	6422	86.3%
<b>Total</b>	<b>16,366~</b>	<b>100%</b>	<b>7439</b>	<b>100%</b>

\* This number rises by 60 -80 if data from the Hospital in-patient survey is used along with data supplied by Boards (see later.) Thus between 440 and 470 persons are likely to be long-stay Hospital patients (see Section 4)

+ Information on people in residential provision held on 'Trojan databases' gives a total figure of 1,884 persons. However this includes people being supported in ordinary housing and who may be counted in the community sub-population (see Section 5).

^ 6,531 persons were recorded only on CHS but this rises to 7,050 when 519 cases are added to compensate for the missing CHS data in UCHT (see Section 6).

~The WHSSB report a possible undercounting of an estimated 175 persons (see Appendix 1).

NB The proposed adjustments for Hospital and WHSSB would bring the total to 16,601 (rate 9.85 per 1,000).

This gives an overall prevalence rate based on Trust data of 9.69 persons per 1,000 and 4.41 per 1,000 using Social Security information.

Figures from the Intellectual Disability Database in the Republic of Ireland (2003) which is a register based system, report an overall prevalence of 7.35 per 1,000. A previous study by MacDonald and Mackey in SHSSB (1996) identified a total of 2251 persons; an overall prevalence rate of 7.76 persons. These studies also include a proportion of people classed as having 'mild' learning disabilities.

This suggests that in Northern Ireland more people are recorded by services as having a moderate, severe or profound learning disability. Again the definitions used could be a factor in this.

Table 5b gives the number of people by age and severity levels as recorded on the Trust systems (see earlier). (NB The total in this table is less than the total reported in Table 5 because of missing data on age and/or level of severity.)

**Table 5b: The number and percentages by age group and severity of disability**

<b>Age Bands</b>	<b>Moderate</b>	<b>Severe/Profound</b>	<b>Total</b>
0-19	5365	1432	6797
	39.3%	10.5%	49.8%
20-34	2087	878	2965
	15.3%	6.4%	21.7%
35-49	1246	790	2036
	9.1%	5.8%	14.9%
50+	1228	623	1851
	9.0%	4.6%	13.6%
<b>Totals</b>	<b>9926</b>	<b>3723</b>	<b>13,649</b>
	<b>72.7%</b>	<b>27.3%</b>	<b>100%</b>

The percentages within each cell could then be applied to the estimated total population of 16,226 to give an estimate of the number of people within each cell and the associated prevalence figures. The results are shown in Table 5c.

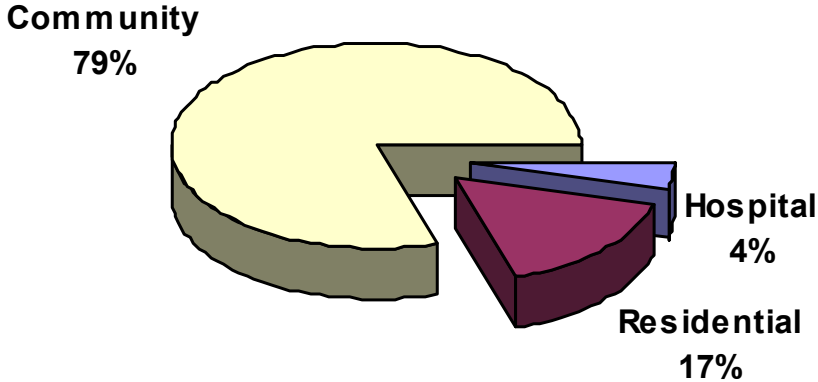
This data suggests that the increased prevalence in Northern Ireland compared to the Republic of Ireland stems mainly from the 0-19 years age group. Hence the Child health System is recording children who *may have* a learning disability whereas the Register in the Republic of Ireland most likely records children with a confirmed diagnosis.

**Table 5c: The estimated number and percentages by age group and severity of disability**

<b>Age Bands</b>	<b>Moderate</b>	<b>Severe/Profound</b>	<b>Total</b>	<b>Overall Prevalence</b>	<b>Rol Prevalence</b>
0-19	6432	1718	8150	16.30	7.69
	39.3%	10.5%	49.8%		
20-34	2504	1047	3551	10.16	9.59
	15.3%	6.4%	21.7%		
35-49	1489	949	2438	7.04	7.81
	9.1%	5.8%	14.9%		(35-54 yrs)
50+	1473	753	2226	4.54	3.62
	9.0%	4.6%	13.6%		(55+ yrs)
<b>Totals</b>	<b>11,898</b>	<b>4468</b>	<b>16,366</b>	<b>9.71</b>	<b>7.35</b>
	<b>72.7%</b>	<b>27.3%</b>	<b>100%</b>		

The remainder of the report provides further details of people within the three sub-populations of Hospitals, Residential Care and Community.

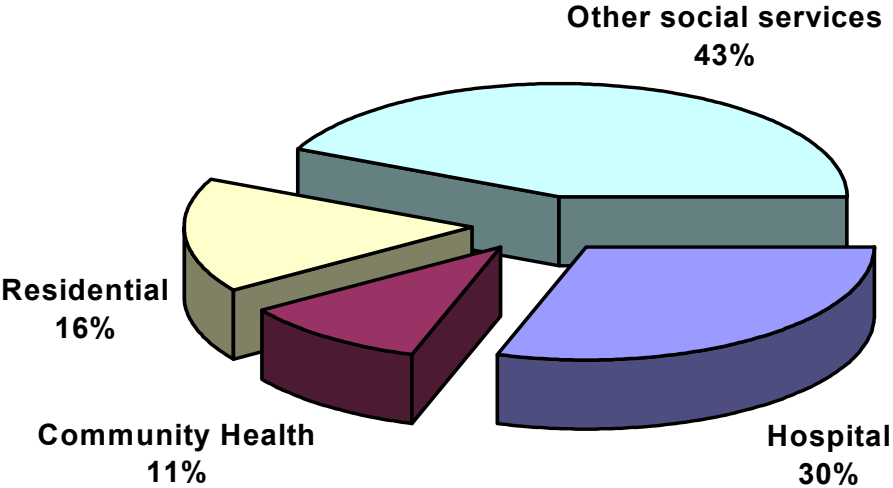
Nearly all those under 20 years of age recorded on Trust systems were living with family carers. However of the 7,970 persons aged 20 years and over, the distribution of people in the three forms of provision are shown in Figure 1.



**Figure 1a: The proportions of people aged 20 years and over living in different settings**

Comparable figures for the Republic of Ireland (2001) are: Hospitals (4%); Residential services - 5 day and 7 day (39%); Community (57%). This suggests that over twice as many people are in residential provision in the Republic than in Northern Ireland.

The proportions of revenue monies spent in the learning programme of care as at 31<sup>st</sup> March 2002 is shown in Figure 1b.



**Figure 1b: The proportions of monies spent in the Learning Disability Programme of Care – year end 31 March 2002 (Total £105.122 million).**

## **4. People in Learning Disability Hospitals.**

Three datasets were available to the project.

### **1. Soscare records**

These were checked for a Hospital address (these cases are not flagged separately in the system. Checks were made to remove duplicates within and across Trusts and Boards. Of the final total of 390 people with a Hospital address, 344 people were recorded once on Soscare, 42 people had been recorded by two trusts within the same board, and 4 people had been recorded in different boards.

Soscare should flag if the person is in residential care but of the total (390) identified, 5 persons (1.3%) had the residential flag; 288 (73.8%) were flagged as 'no' and for 97 persons (24.9%) the flag was absent.

As noted earlier, there are also concerns that Soscare undercounts the number of people in Hospital.

### **2. Social Security data.**

There is a hospital code recorded for social security data but this dataset was checked for people with a hospital address and they were recoded accordingly. Checks were made to remove duplicates.

However only 192 persons were recorded on Social Security systems as having a Hospital address. This dataset was considered incomplete as not all patients attract/claim benefits and hence this dataset was not used in the study.

### **3. Hospital In-patient census (DHSSPS)**

Data for the most recent census date (17 February 2002) was made available to the study. This records people by their age and length of stay in the Hospital. Patients on home leave are included in the total even though they are not resident in the Hospital. This data is available by Hospital but not by the Trust from which the patient came.

A proportion of these patients will have been admitted for short-term assessment and treatment. However they are not identified as such in the Census. To avoid possible double-counting of persons who are ordinarily reside in residential homes or community settings, it was presumed that people who had been in Hospital for more than one year would be classed as 'long-stay' patients (see Appendix 2).

Additional information was also supplied by Boards regarding numbers in Hospital according to their own records. Adjustments were made to the Hospital In-patient census, most notably for Longstone Hospital. The census recorded 92 patients but data provided by the Trust recorded 118 long-stay patients as being in the Hospital on 31 March 2003. The latter

figure concurs with data reported by Slevin et al (2002) of a consensus undertaken in the Hospital in December 2001.

### **Numbers of people in Hospital by Trusts and Boards**

Table 6 shows the number of patients recorded by each Trust on Soscare and in the long-stay Hospital census. These numbers are also expressed as a ratio of 10,000 of the population of the Trust.

**Table 6: Number of patients per originating Trust and rate per 10,000 of population**

Trust	Soscare Records	Rate per 10,000	Long-stay In-patient Number	Rate per 10,000
A&D	74	7.26	N/a	N/a
C&B	42	3.34		
N&M	13	1.49		
<b>SHSSB</b>	<b>129</b>	<b>4.14</b>	<b>118<sup>^</sup></b> (Longstone)	<b>3.79</b>
Foyle	24	1.48	26	N/a
Sperrin Lakeland	17	1.43	9	
<b>WHSSB</b>	<b>41</b>	<b>1.42</b>	<b>39<sup>^</sup></b> (Stradreagh)	<b>1.30</b>
Homefirst	56	1.71	N/a	
Causeway	13	1.12		
<b>NHSSB</b>	<b>69</b>	<b>1.55</b>	<b>90*</b>	<b>2.11</b>
Down Lisburn	41	2.37	N/a	
NW Belfast	76	5.29		
SE Belfast	25	1.24		
UCHT	9	0.60		
<b>EHSSB</b>	<b>151</b>	<b>2.26</b>	<b>220*</b>	<b>3.30</b>
<b>Combined EHSSB &amp; NHSSB</b>	<b>220</b>	<b>2.01</b>	<b>310<sup>^</sup></b> (Muckamore)	<b>2.84</b>
<b>Total NI</b>	<b>390</b>	<b>2.35</b>	<b>467</b>	<b>2.77</b>

<sup>^</sup> Longstone total includes 5 patients from WHSSB; 5 from EHSSB and 2 from NHSSB; Stradreagh total includes 4 patients from other Boards and Muckamore total includes 9 patients from WHSSB. (Data supplied from WHSSB – July 2003).

\* The apportionment is based on data supplied by EHSSB as at 28<sup>th</sup> Feb. 2002

The total number of 467 long-stay patients from the Census data is greater than the Soscare total of 390. This discrepancy is most marked in the EHSSB. According to data supplied by the Board there are undercounts particularly of patients from S&E Belfast and Ulster CHT. This may arise because Soscare does not record all the patients from the Trusts who are in Hospital. It is also possible that Muckamore Abbey Hospital has more

patients who originated from other Boards and who are not recorded on their Soscare systems.

An accurate count of the numbers of people for whom the Hospital is their home could be obtained from each Hospital but this fell outside the scope of this study. (Note: this will NOT equate with the numbers identified for resettlement as a proportion of these people will require to remain in Hospital because they are considered by the medical consultants to be receiving active treatment.) However the housing studies undertaken by McConkey and colleagues (2000 – 2003) identified a total of 441 persons who need to be rehoused from hospital settings.

In summary, the various data sources suggest that between 440 and 470 persons are likely to be living in long-stay hospital settings. (NB The number may fluctuate as long-stay patients require active treatments at different time periods.)

### **Recommendation**

The Hospital In-patient Census offers the best estimate of the numbers of people living in long-stay Hospitals. Possible refinements to the gathering of this information would be to ask Hospitals to note on their returns to the Department:

- The originating Trust of the patient.
- Whether or not the person has an address to which they will be discharged.

### **Numbers by age and level of disability in Hospital**

The level of disability was available for 70% of patients recorded on Soscare (N=273). Of this figure, 34% were recorded as 'learning disabled' and 66% as severe learning disabilities/severe mental impairment' (using Soscare categories). This data is not recorded on the in-patient census.

Table 7 shows the age bands of hospital patients for Soscare data and the Hospital census. (NB: The datasets report different age bandings and data was missing for some patients). This shows a high degree of concordance.

The mean age of residents was 49 years, with ages ranging from 9 to 96 years. The EHSSB has a slightly older population, with a mean of 52 years, compared to the other boards where the mean is 47 years (One way Analysis of Variance;  $F=3.0$ :  $p<0.05$ ).

Given a normal life expectancy of 70 years, this data suggests that over the next ten years a maximum of around one quarter of these patients will die. (There should be no replacement of places if the resettlement policy is implemented.)

**Table 7: The number and percentage of patients by age bands**

Age Band	Soscare Number	Soscare Percent	Hospital Census	Census Percent
0-19	6	1.5	18	4.0
20-24	7	1.8	201	44.4
25-29	18	4.6		
30-44	133	34.1		
45-59	130	33.3	181	40.0
60-64	30	7.7	29	6.4
65-74	30	7.7		
75+	29	7.4		
Total	383	98.2	453	100
Missing	7	1.8	0	0
<b>Total</b>	<b>390</b>	<b>100</b>	<b>453</b>	<b>100</b>

Of the 390 persons on Soscare : 62% were male and 38% female. (The females had a significantly higher mean age of 51.2 years compared to a mean of 47.0 years for males: One way ANOVA F=7.68 p<0.01).

The mean length of time these patients had been in Hospital ranged from 16 years in WHSSB to 24.5 years in SHSSB.

### **Breakdown by age and level of disability**

Table 8 shows the distribution of people within long-stay hospitals broken down by age and level of disability. This shows that almost half of the patients are aged over 35 years with severe/profound disabilities. Few patients aged under 35 years have moderate disabilities.

**Table 8: Proportions of people in each cell who are living in Long-stay Hospital settings (based on Inpatient Census but using Soscare ratings of severity) (n=453)**

Age Bands	Moderate	Severe/Profound
0-19	2%	4%
20-34	6%	13%
35-49	13%	25%
50+	13%	24%
<b>Total</b>	<b>34%</b>	<b>66%</b>

### **Assessment and Treatment Admissions to Hospital**

Information on the numbers of people admitted to Hospital for short-term assessment and treatment is not directly provided by any of the information systems accessed. However this can be imputed from the Hospital inpatient census data for those with admissions of less than one year. In addition, data was available from a study of admissions over a two-year

period to Muckamore Abbey Hospital (McConkey, Marriott, Cunningham et al, 2002).

Tables 9a and 9b show the breakdown by age and level of disability for these two sub-populations. This data suggests that people living in Hospital tend to be more severely disabled whereas those who are admitted for assessment and treatment are more able and many are classed as mildly handicapped (McConkey, Marriott et al, 2002).

The Muckamore Abbey Hospital admission data also found marked differences among the six community trusts in the Eastern and Northern Board areas in their admissions to the Hospital. Proportionately more people were admitted from North & West Belfast HSS Trust (3.91 per 10,000 of Trust population aged 16 years and over). The ratio for all the other Trusts was between 1.07 and 1.94 persons per 10,000 Trust population.

**Table 9a. Number and proportion of people in each cell in LD Hospitals on 17 Feb 2002 with an admission less than one year (N=143) (using estimates of levels of severity from the admissions study – see below).**

Age Bands	Moderate		Severe/Profound	
0-19	31	21%	4	3%
20-34	43	29%	6	4%
35-49	30	21%	4	3%
50+	24	17%	3	2%
<b>Total</b>	<b>128</b>	<b>88%</b>	<b>17</b>	<b>12%</b>

*NB This data may also include respite admissions (especially of children) which does not happen at Muckamore Abbey Hospital.*

**Table 9b. Numbers and Proportion of people in each cell admitted to Muckamore Abbey Hospital for short-term assessment and treatment over a two-year period (based on McConkey, Marriott, Cunningham et al, 2002). (N=154 people admitted: 187 admissions)**

Age Bands	Moderate		Severe/ Profound		Mean length stay	Total bed days*
0-19	17	11%	3	2%	184 days	4,241
20-34	54	35%	7	5%	172 days	13,097
35-49	37	24%	5	3%	120 days	6,492
50+	27	18%	4	2%	134 days	5,246
<b>Total</b>	<b>135</b>	<b>88%</b>	<b>19</b>	<b>12%</b>		<b>29,076<sup>^</sup></b>

\* Includes repeat admissions of the same person

<sup>^</sup> The admissions were tracked for a further six months into the third year. The admissions reported in the study used the equivalent of 40 bed days per annum (80% occupancy). The age effect is nearly significant but there is no effect of severity of disability.

Similar findings were also reported for study of admissions to Longstone Hospital, Armagh in that the 'owning Trust' Armagh & Dungannon had significantly more admissions (1.2 per 10,000) compared to the other two Trusts (Craigavon & Banbridge 0.6 per 10,000 and Newry & Mourne 0.3 per 10,000) (Slevin et al, 2002).

This could result from ex-Hospital patients being resettled close to the Hospital and being more prone to re-admissions.

Overall the admission rates to Longstone Hospital were lower than for admissions to Muckamore Abbey Hospital. Comparable data is not available for Stradreagh Hospital.

## **5. People in Residential Accommodation**

Information on people living in residential accommodation was available from three sources: Trust Soscare systems, from Social Security data and from Trojan financial systems. The latter was supplied for 10 of 11 Trusts but not for Craigavon & Banbridge as they do not maintain a computerised database. However this trust supplied data from care management returns (CC7).

The postcode of origin of the resident was not available on Soscare or Social Security datasets and this was recorded to a variable extent on the Trojan systems. (A postcode of origin was recorded by five community Trusts for 678 residents: 47% in all. However of these, 227 were the postcode of the home in which the person presently resided. Moreover the postcode of the residential facility was missing for 180 people but a postcode of origin given. Many of these appear to be a facility postcode. Also among those whose original postcode differed from that of the facility, there were people who had a postcode of a long-stay hospital or other residential facility recorded as their original postcode. Hence at best the actual family home of the person may be recorded in 450 cases: 31% but for the reasons given it is probably considerably lower than this).

### ***Soscare data***

In all 1703 persons were identified from Soscare records as likely being resident in a registered residential facility (i.e. nursing home; residential care home; hostel or group home). However this data may not be updated for people who have died or moved out of residential accommodation.

Soscare should flag if the person is in residential care but of the total identified, 462 persons (27%) had the residential flag; 964 (57%) were flagged as 'no' and for 279 persons (16%) the flag was absent (NB of this around 50% came mainly from one Trust who may have omitted it from their download).

There was wide variation in the percentages of people recorded by each Trust as being in residential care: from 89.0% to 1.4%.

### ***Social Security Data***

A total of 825 persons were identified by the address of their residence as being in a residential care home or nursing home (mostly registered homes for learning disabled persons but some were homes for the elderly or held dual registration.)

### ***Trojan Data***

A total of 1,441 persons with learning disability were identified on computerised records obtained from 10 HSS Trusts plus an additional 83 persons from care management records of Craigavon & Banbridge Trust. Of the 1,524 persons, 547 persons (37%) were in nursing homes, 812 (57%) in residential homes and 89 persons (6%) in supported living (mostly NHSSB and some in SHSSB).

However the Trojan data in the EHSSB does not include people residing in statutory homes in S&E Belfast and N&W Belfast Trusts. Figures supplied by the EHSSB have been used in the totals presented in Table 10 under Trojan data.

## Numbers of people by Trusts and Boards

Table 10 shows the number of residents recorded by each Trust on the three information systems and expressed as a ratio of 10,000 of the population of the Trust.

**Table 10: The numbers and percentage of people in residential accommodation recorded on Soscare, Social Security and Trojan Systems**

Trust	Soscare Records	Rate per 10,000	Social Sec *	Rate per 10,000	Trojan + Board updates	Rate per 10,000
A&D	81 <sup>^</sup>	7.94	93	9.12	132	12.94
C&B	120	9.83	29	2.38	83	6.80
N&M	152	17.46	82	9.43	113	12.99
<b>SHSSB</b>	<b>353</b>	<b>11.34</b>	<b>204</b>	<b>6.56</b>	<b>328~</b>	<b>10.54</b>
Foyle	113	6.97	44	2.72	134	8.27
Sperrin Lakeland	140	11.74	60	5.03	149	12.52
<b>WHSSB</b>	<b>253</b>	<b>9.00</b>	<b>104</b>	<b>3.70</b>	<b>283</b>	<b>10.07</b>
Homefirst	241	7.35	163	4.97	346	10.55
Causeway	141	12.25	50	4.35	104	10.51
<b>NHSSB</b>	<b>382</b>	<b>8.62</b>	<b>213</b>	<b>4.81</b>	<b>450</b>	<b>10.54</b>
Down Lisburn	129	7.47	71	4.11	206	11.94
NW Belfast	135	9.40	46	3.22	190	13.24
SE Belfast	267	13.32	40	2.00	248	12.38
UCHT	184	12.30	98	6.55	179	11.97
<b>EHSSB</b>	<b>715</b>	<b>10.73</b>	<b>255</b>	<b>3.82</b>	<b>823</b>	<b>12.36</b>
<b>Total NI</b>	<b>1703</b>	<b>10.10</b>	<b>825</b>	<b>4.90</b>	<b>1884*</b>	<b>11.18*</b>

<sup>^</sup> The Trust's Procure system records 132 people in residential accommodation; the same figure as per Trojan listing.

\* This total includes 359 persons reported to be in supported accommodation (258 EHSSB: 82 NHSSB: 7 SHSSB: 12 WHSSB). It is possible that some of these individuals are also counted in the community sub-population.

As the Table shows, social security information yielded the least number of persons.

The level of disability was available on Soscare records for 68% of residents (N=1162) . Of this figure, 62% were recorded as 'learning

disabled' and 38% as severe learning disabilities/severe mental impairment'.

The mean age of residents was 48 years (significantly higher in WHSSB – 52 years; compared to SHSSB mean of 47 years). The age varied significantly across Trusts with UCHT having the lowest average age (41 years) and Foyle Trust highest (55 years).

Table 11 shows the age bands of residents on the three information systems. Given a normal life expectancy this data suggests that over the next ten years only 25% of these residents pass away.

Of the 1703 residents on Soscare; 51% were male and 49% female and identical proportions were found for Trojan Data.

Previous research for NIHE and the four HSS Boards found an average length of stay in residential accommodation of 7.0 to 8.3 years.

**Table 11: The numbers and percent of residents by age groupings**

Age Band	Soscare Number	Soscare Percent	Social Sec. Number	Social Sec. Percent	Trojan	Trojan Percent
0-19	48	2.9	7	0.8	9	0.7
20-24	69	4.1	24	2.9	42	3.0
25-29	70	4.2	28	3.4	56	4.0
30-44	477	28.4	218	26.4	425	30.2
45-59	592	35.2	321	38.9	502	35.6
60-64	155	9.2	99	12.0	138	9.8
65-74	194	11.5	113	13.7	146	10.4
75+	77	4.6	15	1.8	91	6.5
<b>Total</b>	<b>1682</b>	<b>100.0</b>	<b>825</b>	<b>100</b>	<b>1409*</b>	<b>100</b>
Missing	21	-	0	-	32	-
<b>Total</b>	<b>1703</b>		<b>825</b>		<b>1441</b>	

*\* Information for Craigavon & Banbridge trust and the extra numbers supplied by EHSSB of people in statutory accommodation and supported living are not included as age data was not available.*

**Breakdown by age and level of disability**

Data on level of severity was available from Soscare records. Also in the Trojan database people residing in nursing homes could be deemed to have more severe disabilities than those in residential homes and supported living. In addition information was available from a census of people in residential accommodation undertaken as part of housing studies for the NIHE and the four HSS Boards.

Tables 12a, 12b and 12c presents the breakdown by age and level of severity for people in residential facilities from these three data sources.

The pattern is very similar across all three datasets. Compared to the Hospital population more people in residential settings tend to have moderate disabilities and about half are over 50 years of age.

**Table 12a. Proportion of people in each cell who are in registered residential accommodation (Soscare data) (N=1145)**

<b>Age Bands</b>	<b>Moderate</b>	<b>Severe/Profound</b>
0-19	1%	1%
20-34	9%	6%
35-49	19%	15%
50+	33%	16%
<b>Total</b>	<b>62%</b>	<b>38%</b>

**Table 12b. Proportion of people in each cell who are in registered residential accommodation\*(Trojan data) (N=1381)**

<b>Age Bands</b>	<b>Moderate*</b>	<b>Severe/Profound*</b>
0-19	0.6%	0.1%
20-34	10%	4%
35-49	20%	14%
50+	31%	20%
<b>Total</b>	<b>62%</b>	<b>38%</b>

*\* based on type of home*

**Table 12c: Data based on census returns from four HSS Board Housing Studies (2000-2003) (N=1,528) (Data missing for 2% of cases).**

<b>Age Bands</b>	<b>Moderate*</b>	<b>Severe/Profound*</b>
0-19	0.5%	0.5%
20-34	9%	7%
35-49	21%	10%
50+	36%	14%
<b>Totals</b>	<b>66.5%</b>	<b>31.5%</b>

*\*ratings used by key-workers*

## **Recommendation**

The Trojan financial system potentially offers the best register of people of people with learning disabilities in residential accommodation. It is also likely to be kept updated. All trusts should agree to record on a computerised database:

- People living in statutory accommodation;
- The Trust of origin of the resident;
- The postcode of the family home from which the resident was admitted.
- People living in supported housing arrangements.

## 6. People in Community Settings

A total of 14,273 persons with 'moderate, severe and profound disabilities' were identified from combining the data recorded on Soscare and Child Health System – Module V held by HSS trusts.

1,749 (12.7%) were on both Soscare and CHS

5,474 (39.8%) were only on Soscare.

6,531 (47.5%) were only on CHS (*but this rises to 7,050 when 519 cases are added to compensate for the missing CHS data in UCHT*).

This varied by ages as the following table shows.

Age Groups	% on Child Health	% on Soscare
0-19 years	6,723 (81.5%)	2,447 (34%)
20-34 years	1,531 (18.5%)	1865 (26%)
35-49 years	0	1605 (23%)
50+ years	0	1219 (17%)

### Social Security Data

Of the 6,422 persons in receipt of social security benefits and resident in community settings, 99.3% were in receipt of DLA and 0.7% (N=48) Attendance Allowance (AA). In all 89.5% (N=5,752) were receiving mobility allowances.

AA and the care component of DLA are paid at a high, medium and low tariff depending on the persons' assessed needs for care. The mobility component of DLA is at a high and low rate.

The numbers and percentages of each benefits are given in Table 13.

**Table 13: The number and percentages of people on Social Security benefits**

Benefit	Number	Percent
<b>DLA CARE/AA</b>		
High	2805	43.7
Medium	3097	48.2
Low	467	7.3
Not known	53	0.8
<b>DLA MOBILITY</b>		
High	1563	24.3%
Low	4189	65.2%
Not Known/not awarded	670	10.4%

The proportion of people in receipt of the higher rate of the mobility component compares well with the proportions of people having severe/profound disabilities in the Soscare and CHS systems.

In all 64% were male and 36% female. However the percentage of males varied significantly by Trust from 67.5% in Craigavon & Banbridge Trust to 54.8% in UCHT (Chi Sq 70.1 p<0.001).

## Numbers of people by Trust and Board

Table 14 shows the number of people with moderate to profound disabilities by Trust and the prevalence rate per 1,000 of the population. This data also includes the estimated extra number of people added to compensate for the lack of CHS data from UCHT.

**Table 14: Number and percentage of people with moderate, severe and profound disabilities by HSS Trust**

Trust	Trust Pop (2001 census)	Soscare/ CHS Records	Rate per 1,000~	Social Sec#	Rate per 1,000
Armagh & Dungannon	101,998	821	8.05	441	4.32
Craigavon & Banbridge	122,063	1,041	8.53	431	3.53
Newry & Mourne	87,058	812	9.33	353	4.06
<b>SHSSB</b>	<b>311,119</b>	<b>2674^</b>	<b>8.59</b>	<b>1225</b>	<b>3.94</b>
Foyle	162,039	1,276	7.88	701	4.33
Sperrin Lakeland	119,177	929	7.81	511	4.29
<b>WHSSB</b>	<b>281,216</b>	<b>2,205 (2,380)+</b>	<b>7.85 (8.46)+</b>	<b>1212</b>	<b>4.31</b>
Homefirst	327,823	2,813	8.58	1045	3.19
Causeway	99,142	927	9.35	374	3.25
<b>NHSSB</b>	<b>426,965</b>	<b>3,740</b>	<b>8.76</b>	<b>1419</b>	<b>3.20</b>
Down Lisburn	172,522	1,647	9.55	587	3.40
NW Belfast	143,534	1,487	10.36	640	4.46
SE Belfast	200,346	1,349	6.73	630	3.14
UCHT	149,567	1,171	7.83	426	2.84
<b>EHSSB</b>	<b>665,969</b>	<b>5,654</b>	<b>8.49</b>	<b>2283</b>	<b>3.42</b>
<b>Total NI</b>	<b>1,685K</b>	<b>14,273 (14,448)+</b>	<b>8.47 (8.57)+</b>	<b>6422</b>	<b>3.81</b>

~ Calculated on the population figures for the Trusts and Boards in 2001 Census

# Trust data was missing for 283 persons. They are included in NI Total.

^ MacDonal and Mackay report a total of 2,251 persons in SHSSB in the early 1990s

+ The WHSSB maintain an informal register. This is estimated to identify an extra 8% of persons aged 15 years and over (see Appendix 1)

Appendix 1 gives the prevalence information for each trust based on the Soscare systems and Child Health Systems independently. This shows that Soscare rates were between 3.05 to 6.13 per 1,000.

Rates on the Child Health System fall within a similar range (3.14 to 6.37) but with a different rank ordering by Trusts. It is not clear why this should be so but may result from the ways records are kept within Trusts. There is also wide variation across Trusts in the proportion of children assessed within each level of disability. This needs to be further explored by the Regional User Advisory group on the NI Child Health System (see Appendix A1b).

**Age breakdown**

The age breakdown of the community population is given in Table 15 (NB These figures also have been adjusted for the extra 695 cases to compensate for missing CHS data).

**Table 15: The numbers and percent of people by age groupings**

Age Band	Trust systems Number*	Trust systems Percent	Social Sec. Number	Social Sec. Percent
0-4	364	2.6	240	3.7
5-9	1721	12.2	707	11.0
10-14	2968	21.0	721	11.2
15-19	3178	22.4	674	10.5
20-24	1816	12.8	765	11.9
25-29	687	4.9	546	8.5
30-44	1778	12.6	1371	21.3
45-59	1175	8.3	932	14.5
60-64	218	1.5	200	3.1
65-74	205	1.4	236	3.7
75+	54	0.4	30	0.5
Total	14,164	100.0	6,422	100
Missing	109		0	
Total	14,273	100	6,422	

\* estimated figures included pro rata for the breakdown by age-groups)

As the Table shows, social security systems tend to record more people aged 25 years and over.

In all 56% of the population on trust systems were under 20 years of age. The small numbers of persons aged over 60 is a reflection of the early mortality that this client group experienced until recent years.

The peak prevalence rate occurs in the 15-19 years age band; representing 2.5% of the population in this age banding. This is close to the figure usually quoted for children with moderate and severe learning difficulties.

Appendix 3 gives the age breakdown by Boards and Trusts for people with moderate, severe and profound disabilities.

### Severity of disability

Table 16 presents the numbers of persons in four age bands by level of severity. (NB This data was missing for 2,076 persons.)

**Table 16: The numbers and percentages in each cell of age bands by degree of disability.**

	<i>Grouped by level of severity</i>		<i>Total</i>
	<i>Moderate</i>	<i>Severe/Profound</i>	
0-19	5,385 44.2%	1468 12.0%	<b>6853 56.2%</b>
20-34	1918 15.7%	894 6.6%	<b>2722 22.3%</b>
35-49	985 8.1%	522 4.3%	<b>1507 12.4%</b>
50+	788 6.5%	327 2.7%	<b>1115 9.1%</b>
<b>Total</b>	<b>9076 74.4%</b>	<b>3121 25.6%</b>	<b>12,197</b>

There tends to be more people with moderate disabilities under 20 years of age - 79% of total compared to 71% aged 20-34 years; 65% aged 35-49 and 71% of those aged 50 years and over (Chi Sq 158:df 3: p<0.001).

### Service data

The Soscare download should have provided information on various social services that a person received but this data was sparsely recorded by Trusts.

Information from the Housing studies in the four Boards, provided data for representative samples of people aged 14 years and over, living in community setting of their present service provision – day services, overnight respite breaks, domiciliary services – and their future need for such services and also for residential provision. This data was obtained through Trust staff completing a pro forma on each individual in the sample.

This data could be used to construct a matrix of the present extent of service provision by age and severity level. The following tables show the proportion of the total population within each of the eight cells in the matrix.

## **DAY CENTRES**

**Table 17: Percentage of people in each cell living in community who attended day centres in the four HSS Boards (N=2,036 random sample).**

<b>Age Bands</b>	<b>Severe/Profound</b>	<b>Moderate</b>
0-19	2.7%	4.3%
20-34	11.1%	19.4%
35-49	7.0%	16.0%
50+	2.5%	8.0%
<b>Totals</b>	<b>23.3%</b>	<b>47.7%</b>

As the Table indicates, over 70% of people attend day centres; mostly in 20-49 age range.

## **USE OF RESPITE**

**Table 18: Percentage of people in each cell living in community who receive respite in the four HSS Boards (N=2,087 random sample).**

<b>Age Bands</b>	<b>Severe/Profound</b>	<b>Moderate</b>
0-19	3.6%	8.2%
20-34	7.7%	8.7%
35-49	4.3%	8.0%
50+	2.0%	4.4%
<b>Totals</b>	<b>17.6%</b>	<b>29.3%</b>

These figures suggest that nearly half of the people receive some form of respite provision however the quantum of service is not known. More of those in the 20-34 age range appear to receive respite services.

## **DOMICILIARY SUPPORT**

**Table 19: Percentage of people in each cell living in community who receive domiciliary support in the four HSS Boards (N=1,993 random sample).**

<b>Age Bands</b>	<b>Severe/Profound</b>	<b>Moderate</b>
0-19	2.6%	1.5%
20-34	4.6%	2.9%
35-49	2.9%	4.0%
50+	1.7%	4.3%
<b>Totals</b>	<b>11.8%</b>	<b>12.7%</b>

Around one quarter of people were reported to have domiciliary support.

**PROFESSIONAL INPUTS**

Data from one HSS trust identified a total of 2,254 professional episodes delivered to people with learning disabilities in one year (N=883 persons) (McConkey and McAteer, 1999). This included social work, nursing and therapy inputs in the main. The number and percentage across the matrix is as follows (NB percentages add to 100%).

**Table 20: Percentage of people in each cell living in community who receive a episode of professional input in one HSS Trust (N=1,993 random sample).**

<b>Age Bands</b>	<b>Severe/Profound</b>		<b>Moderate</b>	
0-19	534	24%	426	19%
20-34	202	9%	375	17%
35-49	99	4%	314	14%
50+	0	0 %	304	13%
<b>Total</b>	<b>835</b>	<b>37%</b>	<b>1419</b>	<b>63%</b>

**Recommendations**

Soscare and Module V of the Child Health System have the potential to provide comprehensive information about the population of children and adults with learning disabilities living in ordinary community settings. The following improvements should be considered.

- ❑ The proposed Health Care Number should provide a common identifier for the persons recorded on both systems and this would make it easier to identify duplicate records.
- ❑ The definitions used for recording a person as having a learning disability need to be reviewed and ideally they should be consistently applied across Trusts and information systems. This will not be easy to achieve but the present study could serve as a trigger for further action as it provides for the first time an indication of the variations that result when comparisons are made across Trusts and different information systems. The Information Analysis Directorate of DHSS&PS and/or DIS might formulate proposals for doing this in respect of Soscare and the Child Health System – Module V. The ongoing Review of Learning Disability Services is also likely to provide guidance on definitions.
- ❑ Linked to this issue are the definitions used to categorise the level of severity of the disability. Again these should be uniformly applied across all trusts and systems. It may be that a dual classification as used in this study (rather than using three, four or five groupings) is the most feasible and would accord with the statements of special educational needs made by Education and Library Boards. However

the main criteria should be that the distinction between the groupings is aligned with likely service demands.

- ❑ Soscare has the capacity to record service usage and this could provide a rich source of information for allocating resources if these records were maintained and updated.

## 7. Conclusions

There is no register of people with a learning disability that covers all of Northern Ireland and it would be expensive and time-consuming to produce such a register. As an alternative, this study was able to access a variety of databases that recorded children and adults with a learning disability in Northern Ireland. These also yielded information about the age and severity level of the population.

The characteristics of three sub-populations were described; namely those living in long-stay hospitals; those in residential facilities and those living in community settings, mostly with family carers.

There was ample evidence that present service usage within the learning disability programme of care does vary according to the age of the person and their level of disability. This applied to those persons who were resident in hospital and residential homes as well as those availing of a range of community services. Further data analysis will explore possible linkages with deprivation indices.

However it is evident that existing data sources could be improved in order to provide a more accurate appraisal of the population of people who receive or who may require services from the learning disability programme of care. Recommendations for doing this are noted in the report.

This data presents a snap-shot in time. Given the changing nature of service provision for this client group, notably resettlement of long-stay patients from hospitals and the move towards supported living arrangements along with increased longevity of these clients, it is recommended that a comparable study be undertaken every five years. This would be relatively easy to undertake if the recommendations for improving existing datasets were implemented.

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## Appendix 1: People in community settings

The Table shows the number of people living in *community settings* who were recorded on the Soscare and Child Health Systems along with the prevalence rates for each system. (NB These are not additive as some people are recorded on both systems).

**Table A1: Number and prevalence rates of people with moderate, severe and profound disabilities recorded on Soscare and CHS by HSS Trust**

Trust	Trust Pop (2002 census)	Number on Soscare	Rate per 1,000	Number on CHS	Rate per 1,000
A&D	101,998	358	3.51	562	5.51
C&B	122,063	650	5.51	518	4.25
N&M	87,058	461	5.34	494	5.68
<b>SHSSB</b>	<b>311,119</b>	<b>1469</b>	<b>4.72</b>	<b>1574</b>	<b>5.06</b>
Foyle	162,039	721	4.45	726	4.48 <sup>^</sup>
Sperrin Lakeland	119,177	730	6.13	444	3.73 <sup>^</sup>
<b>WHSSB</b>	<b>281,216</b>	<b>1451</b>	<b>5.16</b>	<b>1170</b>	<b>4.16<sup>^</sup></b>
Homefirst	327,823	990	3.05	2092	6.37
Causeway	115,076	395	3.50	669	5.82
<b>NHSSB</b>	<b>442,899</b>	<b>1385</b>	<b>3.13</b>	<b>2761</b>	<b>6.25</b>
Down Lisburn	172,522	806	4.75	1046	6.08
NW Belfast	143,534	702	4.90	889	6.22
SE Belfast	200,346	758	3.83	840	4.20
UCHT	149,567	652	4.35	519 <sup>*</sup>	3.48 <sup>*</sup>
<b>EHSSB</b>	<b>665,969</b>	<b>2,918</b>	<b>4.38</b>	<b>3294</b>	<b>4.94</b>
<b>Total NI</b>	<b>1,685K</b>	<b>7255</b>	<b>4.31</b>	<b>8,796</b>	<b>5.22</b>

<sup>^</sup> These rates for WHSSB include people categorised as 'mild' as the ratings system in this Board makes greater use of this category which other Trusts may include in a higher rating.

<sup>\*</sup> An estimate has been made of the likely numbers in UCHT based on records from other Trusts within the Board. The Trust feels this is an underestimate of their likely numbers although this was not quantified by them.

As the Table shows, Soscare rates fall between 3.05 to 6.13 per 1,000 and they are generally similar within Boards. The lower rate for the NHSSB may arise because of that Board's policy to limit access to the learning disability programme to those persons who have been formally assessed as having a learning disability. This may also apply to Foyle Trust.

The WHSSB maintain an informal register of people "deemed clinically to have severe mental handicap". In a comparison of people aged 15 years and over living in community settings, more people were identified on the

Register than were recorded by Soscare (@16%). However an analysis comparing people recorded on different systems identified that the Register contributed around 8% extra persons who were not recorded on any other data system held by the Board (see Housing Report by McConkey et al, 2002).

Rates on the Child Health System fall within a similar range (3.14 to 6.37) but with a different rank ordering by Trusts. It is not clear why this should be so but may result from the ways records are kept within Trusts.

Table A1b. shows the proportion of children within each trust who are recorded for each level of disability on Module V of the Child Health System. Again this variation is also hard to explain.

**Table A1b: The proportion of children recorded on child health system Module V for each level of learning disability (NB omitting missing cases)**

Trust	% Borderline	% Mild	% Moderate	% Severe	% Profound
<b>SHSSB</b>					
A&D	1.8%	29.9%	51.4%	16.7%	0.1%
C&B	3.2%	35.4%	50.6%	9.7%	1.2%
N&M	1.6%	17.5%	63.2%	15.1%	2.6%
<b>WHSSB</b>					
Foyle	29.1%	29.1%	27.8%	10.3%	3.8%
Sperrin Lakeland	52.1%	36.2%	8.1%	2.6%	0.8%
<b>NHSSB</b>					
Homefirst	7.3%	17.4%	53.9%	19.4%	2.1%
Causeway	2.4%	11.9%	63.7%	19.5%	2.6%
<b>EHSSB*</b>					
Down Lisburn		29.6%	57.5%	12.0%	0.9%
NW Belfast		18.0%	73.0%	9.0%	0.2%
SE Belfast		20.8%	54.9%	22.1%	2.3%
UCHT	N/a				

*\* These trusts only supplied records for children with mild, moderate, severe and profound ratings.*

*N/a Not available*

## Appendix 2: Hospital In-patient census

The numbers of people who were classed as 'long-stay' patients as compared to those with a stay of less than 12 months is shown in the Table below.

**Table A2: The numbers of people recorded in LD Hospital in 2002 Census who had been resident for greater than one year,**

Hospital	Numbers less than 12 months	Numbers greater than 12 months	Board Pop	Long-stay Ratio per 10,000
Muckamore (EHSSB & NHSSB)	54 (15% of total in this Hospital)	310 (68% total)	1,093,000	2.84
Longstone (SHSSB)	50 (35% of total in this Hospital)	92 (20%)	311,000	2.96
Stradreagh (WHSSB)	25 (39% of total in this Hospital)	39 (9%)	281,000	1.39
Other Hospitals	16	12 (3%)		
<b>Total*</b>	<b>145</b>	<b>453</b>	<b>1,685,000</b>	<b>2.67</b>

As the table shows, Muckamore Abbey Hospital has a higher proportion of long-stay patients than the other two hospitals. It is possible that these include people who originated from the other two boards although they are now deemed as falling within the EHSSB pool.

The higher proportion of short-stay admissions in Longstone and Stradreagh may result from 'respite admissions' which do not happen at Muckamore Abbey Hospital.

### Appendix 3: The numbers and prevalence rates for people in community settings with moderate to severe disabilities in each Board and Trust

(NB age is missing for certain cases hence the totals do not add to those presented in Table 14).

#### Southern Health and Social Services Board

Age Bands	Total Board			Armagh & Dungannon			Craigavon & Banbridge			Newry & Mourne		
	Total LD	Total Pop <sup>^</sup>	Ratio*	Total LD*	Total	Ratio	Total LD	Total Pop	Ratio	Total LD	Total Pop	Ratio
<b>0-4</b>	59	23,018	2.56	11	7,557	1.46	21	8,709	2.41	27	6,752	4.00
<b>5-9</b>	291	24,253	12.00	109	7,907	13.78	72	9,271	7.76	110	7,075	15.55
<b>10-14</b>	441	26,228	16.81	165	8,687	18.99	131	9,770	13.40	145	7,771	18.66
<b>15-19</b>	601	24,408	24.62	183	8,248	22.19	251	8,962	2.80	167	7,198	23.22
<b>20-24</b>	360	19,138	18.81	106	6,450	16.43	144	7,070	20.36	110	5,618	19.60
<b>25-29</b>	146	21,189	6.89	42	7,217	5.82	60	8,201	7.31	44	5,771	7.62
<b>30-44</b>	367	69,269	5.30	101	21,801	4.63	152	28,426	5.34	114	19,042	5.98
<b>45-59</b>	272	52,242	5.20	72	17,183	4.19	134	20,925	6.40	66	14,134	4.67
<b>60-64</b>	46	13,192	3.48	11	4,341	2.53	24	5,340	4.49	11	3,551	3.09
<b>65-74</b>	45	21,556	2.08	12	7,113	1.68	23	8,618	2.67	10	5,825	1.71
<b>75+</b>	12	16,626	0.72	7	5,494	1.27	-	6,771	-	5	4,361	1.14
<b>All ages</b>	<b>2640</b>	<b>311,119</b>	<b>8.49</b>	<b>819</b>	<b>101,998</b>	<b>8.03</b>	<b>1012</b>	<b>122,063</b>	<b>8.29</b>	<b>809</b>	<b>87,058</b>	<b>9.29</b>

## Western Health and Social Services Board

Age Bands	Total Board			Foyle			Sperrin Lakeland		
	Total LD	Total Pop^	Ratio*	Total LD	Total	Ratio	Total LD	Total Pop	Ratio
<b>0-4</b>	99	21,121	4.69	44	12,494	3.52	55	8,627	6.38
<b>5-9</b>	355	21,957	16.17	199	12,981	15.33	156	8,976	17.38
<b>10-14</b>	549	24,487	22.42	316	14,461	21.85	233	10,026	23.24
<b>15-19</b>	344	24,021	14.32	217	13,988	15.51	127	10,033	12.66
<b>20-24</b>	147	18,696	7.86	88	11,421	7.71	59	7,275	8.11
<b>25-29</b>	138	20,272	6.81	84	12,140	6.91	54	8,132	6.64
<b>30-44</b>	300	61,627	4.87	166	36,252	4.57	134	25,375	5.28
<b>45-59</b>	171	46,455	3.68	112	25,893	4.32	59	20,562	2.87
<b>60-64</b>	38	11,201	3.39	23	6,294	3.65	15	4,907	3.06
<b>65-74</b>	32	17,688	1.81	20	9,470	2.11	12	8,218	1.46
<b>75+</b>	10	13,691	0.73	5	6,645	0.75	5	7,046	0.71
<b>All ages</b>	<b>2,183</b>	<b>281,216</b>	<b>7.76</b>	<b>1274</b>	<b>162,039</b>	<b>7.86</b>	<b>909</b>	<b>119,177</b>	<b>7.62</b>

## Northern Health and Social Services Board

Age Bands	Total Board			Causeway			Homefirst		
	Total LD	Total Pop^	Ratio*	Total LD	Total	Ratio	Total LD	Total Pop	Ratio
<b>0-4</b>	70	28,971	2.41	24	6,814	3.52	46	22,157	2.07
<b>5-9</b>	575	30,390	1.89	131	6,746	19.43	444	23,644	18.78
<b>10-14</b>	914	33,887	26.97	265	8,907	29.77	649	24,980	25.98
<b>15-19</b>	831	32,292	25.73	185	8,656	21.38	646	23,636	27.33
<b>20-24</b>	425	27,352	15.53	100	7,246	13.81	325	20,016	16.24
<b>25-29</b>	143	29,948	4.77	29	7,335	3.95	114	22,613	5.04
<b>30-44</b>	407	99,579	4.08	96	24,805	3.87	311	74,774	4.15
<b>45-59</b>	247	78,919	3.13	61	20,492	2.97	186	58,427	3.18
<b>60-64</b>	54	20,425	2.65	15	5,663	2.65	39	14,762	2.64
<b>65-74</b>	44	31,647	1.39	12	7,553	1.58	32	24,094	1.32
<b>75+</b>	5	24,994	0.20	5	6,364	0.78	-	18,630	-
<b>All ages</b>	<b>3,715</b>	<b>442,899</b>	<b>8.38</b>	<b>923</b>	<b>115,076</b>	<b>8.02</b>	<b>2,792</b>	<b>327,823</b>	<b>8.51</b>

## Eastern Health and Social Services Board

Age Band	Total Board			Down Lisburn			North & West Belfast			South & East Belfast			Ulster Community & Hospital		
	Total LD	Total Pop^	Ratio*	Total LD	Total	Ratio	Total LD	Total	Ratio	Total LD	Total	Ratio	Total LD*	Total Pop	Ratio
<b>0-4</b>	136	41,623	3.27	31	12,232	2.53	8	9,392	0.86	59	11,089	5.32	38	8,910	4.26
<b>5-9</b>	500	46,052	10.86	186	13,600	13.67	77	10,915	7.05	156	12,085	12.91	81	9,452	8.57
<b>10-14</b>	1064	49,002	21.71	365	13,921	26.22	254	12,282	20.68	228	12,532	18.19	217	10,267	21.14
<b>15-19</b>	1402	49,396	28.38	384	13,241	29.00	404	12,127	33.31	318	13,929	22.84	296	10,099	29.31
<b>20-24</b>	884	44,748	19.76	260	10,398	25.02	266	8,799	30.23	175	17,232	10.15	183	8,319	22.00
<b>25-29</b>	260	43,919	5.92	62	11,029	5.62	61	8,282	7.37	66	15,439	4.27	71	9,169	7.74
<b>30-44</b>	704	146,245	4.81	192	39,679	4.83	214	28,720	7.45	160	44,642	3.58	138	33,204	4.16
<b>45-59</b>	485	114,192	4.25	116	30,084	3.85	145	21,452	6.76	118	32,286	3.65	106	30,370	3.49
<b>60-64</b>	80	29,360	2.72	24	7,334	3.27	23	6,386	3.60	22	8,679	2.53	11	6,961	1.58
<b>65-74</b>	84	51,906	1.62	19	11,726	1.62	26	11,663	2.23	21	16,762	1.25	18	11,755	1.53
<b>75+</b>	27	44,532	0.61	4	9,278	0.43	8	8,682	0.92	8	15,511	0.51	7	11,061	0.63
<b>All</b>	<b>5,626</b>	<b>665,969</b>	<b>8.45</b>	<b>1,643</b>	<b>172,522</b>	<b>9.53</b>	<b>1,486</b>	<b>143,534</b>	<b>10.35</b>	<b>1,331</b>	<b>200,346</b>	<b>6.64</b>	<b>1,166</b>	<b>149,567</b>	<b>7.80</b>

\* Estimates included to compensate for missing CHS data.

## Appendix 4: The numbers and prevalence rates for each Board and Trust including people with borderline and mild disabilities.

(NB age is missing for certain cases).

### Southern Health and Social Services Board

Age Bands	Total Board			Armagh & Dungannon			Craigavon & Banbridge			Newry & Mourne		
	Total LD	Total Pop <sup>^</sup>	Ratio	Total LD*	Total Pop	Ratio	Total LD	Total Pop	Ratio	Total LD	Total Pop	Ratio
0-4	64	23,018	2.78	13	7,557	1.72	23	8,709	2.64	28	6,752	4.14
5-9	412	24,253	16.99	168	7,907	21.25	106	9,271	11.43	138	7,075	19.50
10-14	640	26,228	24.40	240	8,687	27.62	220	9,770	22.51	180	7,771	23.16
15-19	818	24,408	33.51	255	8,248	30.02	366	8,962	40.83	197	7,198	27.36
20-24	417	19,138	21.79	126	6,450	19.53	170	7,070	24.04	121	5,618	21.53
25-29	147	21,189	6.93	42	7,217	5.82	61	8,201	7.43	44	5,771	7.62
30-44	367	69,269	5.30	101	21,801	4.63	152	28,426	5.34	114	19,042	5.98
45-59	272	52,242	5.21	72	17,183	4.19	134	20,925	6.40	66	14,134	4.66
60-64	46	13,192	3.49	11	4,341	2.53	24	5,340	4.49	11	3,551	3.09
65-74	45	21,556	2.09	12	7,113	1.68	23	8,618	2.66	10	5,825	1.71
75+	12	16,626	0.74	7	5,494	1.27	-	6,771	-	5	4,361	1.14
<b>All ages</b>	<b>3,240</b>	<b>311,119</b>	<b>10.41</b>	<b>1,047</b>	<b>101,998</b>	<b>10.26</b>	<b>1,279</b>	<b>122,063</b>	<b>10.47</b>	<b>914</b>	<b>87,058</b>	<b>10.49</b>

## Western Health and Social Services Board

Age Bands	Total Board			Foyle			Sperrin Lakeland		
	Total LD	Total Pop^	Ratio*	Total LD	Total	Ratio	Total LD	Total Pop	Ratio
<b>0-4</b>	99	21,121	4.68	44	12,494	3.52	55	8,627	6.37
<b>5-9</b>	355	21,957	16.16	199	12,981	15.33	156	8,976	17.37
<b>10-14</b>	549	24,487	22.42	316	14,461	21.85	233	10,026	23.23
<b>15-19</b>	344	24,021	14.32	217	13,988	15.51	127	10,033	12.65
<b>20-24</b>	147	18,696	7.86	88	11,421	7.70	59	7,275	8.10
<b>25-29</b>	138	20,272	6.80	84	12,140	6.91	54	8,132	6.64
<b>30-44</b>	300	61,627	4.86	166	36,252	4.57	134	25,375	5.28
<b>45-59</b>	171	46,455	3.68	112	25,893	4.32	59	20,562	2.86
<b>60-64</b>	38	11,201	3.39	23	6,294	3.65	15	4,907	3.05
<b>65-74</b>	32	17,688	1.80	20	9,470	2.11	12	8,218	1.46
<b>75+</b>	10	13,691	0.73	5	6,645	0.75	5	7,046	0.70
<b>All ages</b>	<b>2,183</b>	<b>281,216</b>	<b>7.76</b>	<b>1,274</b>	<b>162,039</b>	<b>7.86</b>	<b>909</b>	<b>119,177</b>	<b>7.62</b>

## Northern Health and Social Services Board

Age Bands	Total Board			Causeway			Homefirst		
	Total LD	Total Pop^	Ratio*	Total LD	Total	Ratio	Total LD	Total Pop	Ratio
<b>0-4</b>	82	28,971	2.83	25	6,814	3.67	57	22,157	2.57
<b>5-9</b>	729	30,390	24.30	175	6,746	25.90	554	23,644	23.43
<b>10-14</b>	1063	33,887	31.36	279	8,907	31.30	784	24,980	31.39
<b>15-19</b>	933	32,292	28.89	206	8,656	23.80	727	23,636	30.75
<b>20-24</b>	450	27,352	16.49	109	7,246	15.04	341	20,016	17.03
<b>25-29</b>	143	29,948	4.77	29	7,335	3.97	114	22,613	5.04
<b>30-44</b>	407	99,579	4.09	96	24,805	3.87	311	74,774	4.15
<b>45-59</b>	247	78,919	3.13	61	20,492	2.98	186	58,427	3.18
<b>60-64</b>	54	20,425	2.64	15	5,663	2.65	39	14,762	2.64
<b>65-74</b>	44	31,647	1.39	12	7,553	1.58	32	24,094	1.32
<b>75+</b>	5	24,994	0.20	5	6,364	0.79	-	18,630	-
<b>All ages</b>	<b>4157</b>	<b>442,899</b>	<b>9.38</b>	<b>1012</b>	<b>115,076</b>	<b>8.79</b>	<b>3,145</b>	<b>327,823</b>	<b>9.59</b>

## Eastern Health and Social Services Board

Age Band	Total Board			Down Lisburn			North & West Belfast			South & East Belfast			Ulster Community & Hospital		
	Total LD	Total Pop <sup>^</sup>	Ratio*	Total LD	Total	Ratio	Total LD	Total	Ratio	Total LD	Total	Ratio	Total LD*	Total Pop	Ratio
<b>0-4</b>	171	41,623	4.11	46	12,232	3.76	9	9,392	0.96	67	11,089	6.04	49	8,910	5.51
<b>5-9</b>	791	46,052	17.18	276	13,600	20.29	121	10,915	11.09	238	12,085	19.69	156	9,452	16.5
<b>10-14</b>	1,344	49,002	27.42	513	13,921	36.85	325	12,282	26.46	325	12,532	25.93	181	10,267	17.6
<b>15-19</b>	1,439	49,396	29.13	493	13,241	37.23	456	12,127	37.60	341	13,929	24.48	149	10,099	14.75
<b>20-24</b>	868	44,748	19.40	334	10,398	32.12	283	8,799	32.16	184	17,232	10.67	67	8,319	8.05
<b>25-29</b>	260	43,919	5.92	63	11,029	5.71	64	8,282	7.73	67	15,439	4.33	66	9,169	7.19
<b>30-44</b>	704	146,245	4.81	192	39,679	4.83	214	28,720	7.45	160	44,642	3.58	138	33,204	4.15
<b>45-59</b>	485	114,192	4.24	116	30,084	3.85	145	21,452	6.76	118	32,286	3.65	106	30,370	3.49
<b>60-64</b>	80	29,360	2.72	24	7,334	3.27	23	6,386	3.60	22	8,679	2.53	11	6,961	1.58
<b>65-74</b>	84	51,906	1.61	19	11,726	1.62	26	11,663	2.23	21	16,762	1.25	18	11,755	1.53
<b>75+</b>	27	44,532	0.60	4	9,278	0.43	8	8,682	0.92	8	15,511	0.51	7	11,061	0.63
<b>All ages</b>	<b>6,253</b>	<b>665,969</b>	<b>9.40</b>	<b>2,080</b>	<b>172,522</b>	<b>12.05</b>	<b>1,674</b>	<b>143,534</b>	<b>11.66</b>	<b>1,551</b>	<b>200,346</b>	<b>7.74</b>	<b>948</b>	<b>149,567</b>	<b>6.34</b>

\* Estimates included to compensate for missing CHS data.