

## 6.8 VULNERABLE ADULTS – LEARNING DISABILITIES

### 6.8 NEEDS OF SPECIFIC CLIENT GROUPS

#### INTRODUCTION

The framework for developing Learning Disabilities in Wales was laid out in the National Assembly's Advisory Group Report "Fulfilling the Promises". This report has been used in this section for the national picture of Learning Disabilities in Wales.

The formal definition of 'learning disabilities' or 'intellectual disabilities' includes the presence of:

- A significant intellectual impairment and
- Deficits in social functioning or adaptive behaviour (basic everyday skills)
- Which are present from childhood.

Services to people with learning disabilities therefore encompass both services to children and those to adults, with the need for a smooth transition as service users reach adulthood. *The needs of children with learning disabilities are included in the Children's section, para 6.4.1.*

'Significant impairment of intelligence' is usually defined as an intellectual quotient (IQ) score more than two standard deviations below the general population mean, in other words an IQ below 70 on a recognised IQ test. Deficits in social functioning or adaptive behaviour refer to how well people cope with both the natural and social demands of the environment.

#### DEMOGRAPHY<sup>1</sup>

"Most epidemiological studies of learning disability typically use IQ assessments to classify a person as having either a mild or severe learning disability, rather than using the combination of IQ and adaptive behaviour assessments recommended in current classification systems.

The birth prevalence of learning disabilities is difficult to estimate as it is not until later in life when IQ can be tested as a result of the characteristic delays in social functioning and adaptive skills becoming clear. Only a proportion of the conditions associated with even severe learning disabilities are identifiable at birth. Typically, the age-specific prevalence of severe learning disabilities grows through the pre-school and school years as children are identified. Estimates at the beginning of the 1990s suggested that there were about 5 people with **severe** learning disabilities per 1,000 total population aged 15-24 years. Allowing for mortality during childhood gave an estimated birth prevalence of at least 6 per 1,000.

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<sup>1</sup> Extract from Welsh Assembly Government (2001) : 'Fulfilling the Promises'

The major factor underlying upward pressure on the prevalence of learning disability is increased life expectancy. For example, one would have expected, on average, about 3.5-4.0 people per 1,000 aged 25-44 years, 2.0-2.5 per 1,000 aged 45-64 years and 1.0-1.5 per 1,000 aged over 65 years. The overall prevalence rate for people with severe learning disability was estimated at between 3 and 4 per 1,000 total population, probably in the region of 360-380 per 100,000. Applied to the population of Wales such a rate would have suggested that there were about 10,830 people with severe learning disabilities living in Wales.

Population screening studies of mild learning disability yielded much higher prevalence rates (about 25-30 people with mild learning disability per 1,000 total population) than studies using administrative populations (i.e., those known to agencies that provide specialist services to people with learning disabilities) (less than 10 per 1,000). The former figure is approximately what would be expected given a normal IQ distribution. Including a measure of adaptive behaviour would be likely to reduce such a rate considerably, in line with the lower administrative prevalence.

## POPULATION TRENDS

There are variations in local populations, as learning disabilities is not a single condition, but national trends are as follows:

Upward pressures on the **incidence** of learning disabilities include:

- increases in maternal age (associated with higher risk factors for some conditions associated with learning disability, such as Down's syndrome)
- improved survival of 'at risk' infants, such as low birthweight infants, due to improved health care
- increases in more recently significant pre-natal threats such as HIV infection and substance abuse
- an increase in the proportion of children growing up in poverty

Downward pressures on incidence of learning disabilities include:

- the impact of prenatal screening for Down's syndrome (estimated to reduce a 'natural rate' of 1.5 per 1,000 births to about 0.9-1.1 per 1,000)
- improved health care and support resulting in fewer 'at risk' infants developing learning disabilities.

The major factor underlying upward pressure on the **prevalence** of learning disabilities is their increasing life expectancy. Although some changes since then have reduced the occurrence of learning disabilities, increased life expectancy has outweighed downward trends. It is now thought that most adults with learning disabilities in developed nations who live past their third decade are likely to survive into old age and experience the normal ageing process. There are more adults with severe learning disabilities aged over 45 years than there are such children aged under 15 years."

## POPULATION IN CARDIFF

The number of people registered with Cardiff Council on the Learning Disability Register as of March 2003 are shown in the following table.

Place of residence	Aged under 16	Aged 16-64	Aged 65+	Total	2002 TOTAL
1. Community placements a. <b>own home</b>		301	47	<b>348</b>	360
1. Community placements b. <b>parents/family</b>	130	422	2	<b>554</b>	591
1. Community placements c. <b>foster home</b>	4	3	0	<b>7</b>	5
1. Community placements d. <b>lodgings/supported living</b>	0	21	2	<b>23</b>	22
1. Community placements subtotal (a-e)	134	747	51	<b>932</b>	
2. Health service accommodation (inc. hospitals/hostels etc.)	0	7	0	<b>7</b>	6
3. Local authority residential accommodation (staffed or unstaffed)	1	0	0	<b>1</b>	0
4. Private or voluntary residential accommodation (staffed or unstaffed)	1	44	14	<b>59</b>	69
5. Other accommodation	0	2	0	<b>2</b>	21
<b>TOTAL</b>	<b>136</b>	<b>800</b>	<b>65</b>	<b>1,001</b>	<b>1074</b>

Source: SSDA 900

Not every person with Learning Disabilities, or their parents/carers, would wish to be recorded on the Disability Register, so these figures underestimate the population. Current research by the Bro Morgannwg NHS Trust Special Projects Team suggests a total population within the county boundary of 1200 – 1400 people.

The caseload of adults (over 18 years) with learning disabilities by electoral division, is shown in the following table.

Electoral division	Total users at 31/7/2003	Rate per 1000 population 18-64
Adamsdown	30	5.1
Butetown	8	2.2
Caerau	52	8.3
Canton	60	7
Cathays	12	1
Criegiau	5	1.8
Cyncoed	24	3.8
Ely	53	5.7
Fairwater	29	3.5
Gabalfa	20	3.1

Grangetown	36	3.8
Heath	40	5.7
Lisvane	6	2.7
Llandaff	15	2.7
Llandaff North	26	5.4
Llanishen	28	3.1
Llanrumney	33	4.9
Pentwyn	35	3.1
Pentyrch	7	3
Penylan	27	3.2
Plasnewydd	33	2.5
Pontprennau/Old St. Mellons	16	2.9
Radyr & Morganstown	6	2
Rhiwbina	16	2.6
Riverside	33	3.7
Rumney	40	7.8
Splott	41	5.5
Trowbridge	34	3.3
Whitchurch	39	4.4
<b>Cardiff Total</b>	<b>804</b>	<b>3.9</b>
No fixed abode, etc.	2	
Living outside Cardiff area	39	
<b>Grand total</b>	<b>845</b>	

Source: Adult Services records

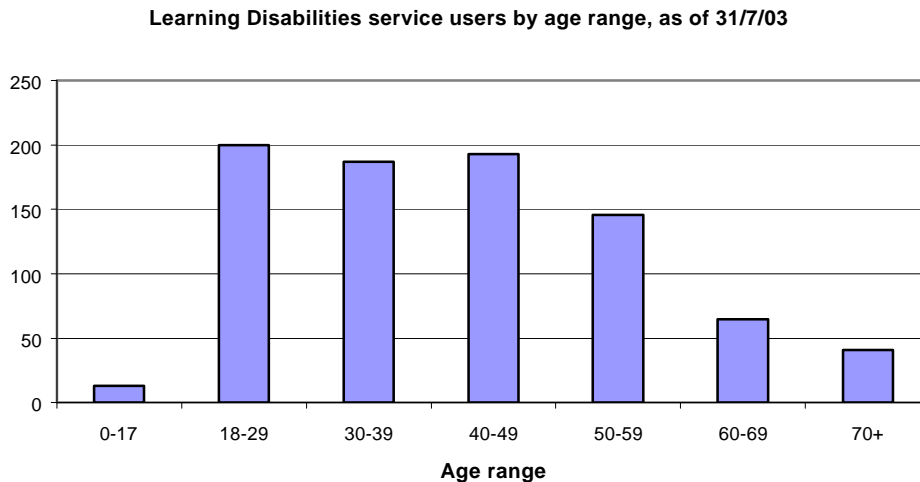
The geographical picture of service users is influenced by resettlement patterns following the closure of Ely Hospital, with higher than average caseloads found in Ely and Caerau. 39 people on the current caseloads have placements outside Cardiff boundaries, where there is no suitable service provision in Cardiff.

## Older People

In addition, there also appears to have been a 'bulge' in the UK childhood prevalence of learning disability for births between the mid-1950s and mid-1960s. There have been increases in the prevalence of people with severe learning disabilities between 1991 and 1998 in every 10-year age band between 35 years and 64 years of between 15 and 25 percent, together with a doubling of the prevalence of people aged between 65 and 74 years and the beginnings of a significant very old population. These estimates are consistent with the 22% reported increase in the number of people on local authority registers for people with learning disabilities in Wales between 1990 and 1999.

The comparison between 1990 and 1998 above shows that the higher mortality of people with severe learning disabilities reflected in declining age-specific rates as people age is reducing. Early mortality was greatest among people with multiple disabilities and, therefore, greater survival implies not only the emergence of a significant elderly population but also increased numbers of people with complex needs requiring support throughout adulthood.

A significant number of people with learning disabilities on the caseload of Learning Disabilities teams are now over 60:



*Source: Adult Services records*

### **Black and ethnic minorities**

Change in prevalence among non-white ethnic groups is likely to be greater than among white groups. The absolute numbers of people from ethnic minority populations with learning disabilities and the proportion of people with learning disabilities from ethnic minority populations are likely to increase throughout the adult age range as a result of the very young age structure of that population currently. Research has also found tentative evidence to suggest higher prevalence rates of learning disabilities amongst some minority ethnic groups, for example, South Asian groups. Higher prevalence rates in South Asian communities are most notable for children and young adults with severe learning disabilities.

Black and ethnic minorities represent 5% of the total service users with Learning Disabilities known to Cardiff Council.

### **NEEDS OF PEOPLE WITH LEARNING DISABILITIES<sup>2,3</sup>**

The identified needs of people with Learning Disabilities are as follows:-

- Accommodation - privacy, personal space and an appropriate level of personal security
- Personal support - in relation to basic activities of life such as eating, dressing and washing

<sup>2</sup> Department of Health (1992) : Social Care for adults with Learning Disabilities ( Mental Handicap).

<sup>3</sup> Foundation for People with Learning Disabilities (2001): 'To explore themes in the White Paper, Valuing People in Learning Disabilities, the fundamental facts'.

- Support with assisting the development of friendships and social relationships
- Teaching and supporting socially competent behaviour
- Opportunities for the development of personal and social skills and enhancing and maintaining competencies
- Everyday education, leisure and facilities in the community
- Developing occupational skills, finding employment and being supported in work
- Easy access to health care and other statutory services and entitlements
- counseling for the individual and their family/carers to make best use of available services
- Social work help and support to enable individuals and families to deal with emotional and practical stresses
- Appropriate services for the increasing number of older people with learning disabilities including those with additional psychiatric problems.
- Culturally appropriate services for people from black and ethnic minorities
- Freedom of choice, seeking control and involvement in decisions that affect their lives, NOT overprotection.
- Effective communication in a language (and format) accessible to the user, taking into account differing individual, cultural, and language needs.
- Full access to information about their rights, choices, support available, services, and benefits.

#### **6.6.7 PROVISION OF SERVICES AND IDENTIFIED GAPS – PEOPLE WITH LEARNING DISABILITIES**

To meet this diverse range of needs, both the Council and the Health Service are developing a co-ordinated approach, involving all relevant professionals, departments, agencies, providers to help plan and arrange a wider range of services for the future. Where appropriate services may be contracted from the voluntary and private sectors.

#### **Council Services**

Cardiff Council is currently in the process of drafting a Commissioning Strategy for people with Learning Disabilities. The strategy will be the main driver for the purchasing, provision and commissioning of social care for people with Learning Disabilities. It will be an active

and responsive process that will build where possible on the expressed wishes and preferences of individuals, recognising their strengths and aiming to meet their needs.

At present a range of services are offered to people with learning disabilities in Cardiff that are designed to help them achieve maximum independence and social inclusion within their communities. There are 845 adults with a learning disability currently known to Cardiff Adult Services (Table 1). Adult Service users within the Learning Disability specialism are fairly evenly divided between those living in supported or registered accommodation, and those living either alone or with their family.

Comprehensive assessment of the needs of the service user and carer, carried out by the multi disciplinary assessment teams, provides the basis for access to appropriate social care and health services.

**Table 1. Service users by Community Team (Adult Services)**

<b><i>Team</i></b>	<b>Number of service users</b>
Cardiff North East	205
Cardiff South East	187
Cardiff North West	221
Cardiff South West	232
<b>Total</b>	<b>845</b>

There are 2 multi disciplinary Community Teams (East and West) in 4 bases across Cardiff. The teams are comprised of social and health care staff, providing a comprehensive assessment service of community care and health care needs. The social care team members are in the main social workers, whilst health care staff comprise of specialist nurses and a range of health care professionals.

Community Care Assessments and reviews are carried out by Social workers and community nurses. The community teams are responsible for the assessment of carers needs, and this is taken into account when agreeing the community care plan. The development of the care plan is carried out in partnership with the service user, their carers and a range of professionals involved in their support.

The combined teams (East and West) have a staffing establishment of 58 health and local authority professional and administration staff. Supporting the community teams there are currently 7 staff in specialist posts covering supported accommodation, crisis intervention and commissioning.

### **Service provision**

Services to users are provided by a range of organisations within the statutory, voluntary and independent sector, and are designed to meet peoples assessed needs.

- Domiciliary care supports individuals within their family or own homes. Support is tailored to meet the identified needs, and aim to enable people to continue living

valued lives within their community. The procurement of domiciliary care accounts for over 50% of expenditure on learning disability services.

- Cardiff Council is developing a direct payments scheme to people with a learning disability.
- Day services within Cardiff are provided in a wide choice of venues, each aiming to meet specific areas of needs. Covering skills development, recreation and leisure, employment and training, day service providers can support people in larger day centres, in smaller community based resource centres or in community based work or activities. There are also strong links with adult education.
- Accommodation services are mainly community based and can be in residential homes or supported accommodation (where people have their own tenancy). In instances where people have nursing care needs accommodation may be situated in a specialist nursing home. In most instances, the levels of support are individually tailored to the persons assessed needs.

In addition to direct services, Cardiff, along with the Welsh Assembly Government and Voluntary Sector organisations, are committed to ensuring that there are strong independent advocacy and carer groups. 98% of the spending in Learning Disability services is directed to the purchasing and provision services groups. 2% is directed to the assessment and care management process<sup>4</sup>.

## **Current service gaps (Headline level only )**

### **Council Services**

- The introduction of the unified assessment will undoubtedly have a significant impact on the working practices of the care professionals (both health and social care). Skills in this new area will need to be developed.
- The ability to knit together health and social care issues seamlessly is a keystone in holistic care. The further strengthening of the integrated learning disability teams remains a priority.
- The production of a Commissioning Strategy that encompasses services to people with learning disabilities. Changes to the contracting process have already been instigated with the intention of enabling providers to work more flexibly.
- A transitions protocol has been agreed with children services and is ready for implementation. Multi agency teams for children with disabilities have yet to be established.

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<sup>4</sup> Cardiff Council (2002) : Social care Plan 2002 -2007

- The publication of the Protection of Vulnerable Adults Guidance has highlighted a need for assessments that consider risk, for services that can secure protection and safety for people in both planned and emergency services, and for implementation that is sensitive to the needs of the service user group.
- Whilst autism and learning disability are separate conditions, the learning disability community teams have a history of providing assessment and securing services for people with autism. It is hoped that local specialist services for support and accommodation can be developed and this will enhance our ability to meet the needs of people with autism appropriately.
- Access to appropriate respite services for people who live with families is an important service for service users and carers. Building on the existing quality of respite provision, greater capacity within respite services will enhance service users opportunities for independence and integration, whilst it will enable carers to continue supporting their relatives within their home.
- Improvements in health and social care have offered people with disabilities and longer and more active old age. This has created a need for more accommodation that can offer an appropriate level of support to people across the spectrum of need, including people who challenge services and people with complex health needs. To achieve this a range of accommodation models are required, including the continued development of the new Adult Placement service, as well as other supported accommodation and residential options.
- A small but significant group of people with learning disabilities may come into contact with the criminal justice system through offending behaviours. The development of specialist support and services for this client group will enable vulnerable people to be dealt with appropriately outside of the courts and prisons.
- Independent advocacy and support for self-advocacy is central to achieving service user involvement in the community care assessment, planning and review process. It is essential to find adequate and continuing independent funding for voluntary sector advocacy services that will maintain their quality and autonomy.
- Expand the Direct Payments Scheme for people with Learning Disabilities
- Develop the role of the Learning Disability Advisory Group

## Health Services

Bro Morgannwg Health Care Trust are Cardiff's partners in the provision of community services to people with a learning disability. Health staff provide specialist Nursing, Psychology, Occupational, Speech and Physiotherapy assessments. In addition to Community Care assessments, the Community Nurses are able to provide a specialist nursing interventions specific to learning disability health care needs.

Based within the Community Teams there are a range of specialist health care professionals who can advise and support families. Working in partnership with social care staff, the nurses and therapists provide a tertiary health care service. Where appropriate they can support service users into specialist or generic second level or primary health services. Close links to specialist psychiatric and psychology services are maintained through the health input into the multi disciplinary team approach.

The close partnership working within the community teams contributes to service assessment and delivery in the following ways:-

- It enables holistic assessment of vulnerable and disadvantaged people with specialist needs.
- It is a significant factor in creating joined up solutions to meeting service user needs.
- It is central to achieving the health care targets for people with learning disabilities and the Social Care Plan objectives of the Local Authority.

### **Welsh Centre for Learning Disabilities**

The Welsh Centre for Learning Disabilities is a multi-disciplinary academic section of the Department of Psychological Medicine at the University of Wales College of Medicine. First established in 1975, it brings together a range of expertise in clinical practice, research, teaching and service development associated with many aspects of the lives of people with learning disabilities.

The Centre seeks to promote the welfare of people with learning disabilities and their families. Its aims are to:

- Increase understanding of the social situation and well-being of people with learning disabilities and their families across the lifespan and the ways personal and environmental differences affect their experience and quality of life
- Increase understanding of how service supports can contribute to the social and personal well-being of people with learning disabilities and their families, and,
- Disseminate knowledge about effective service design and delivery in practice.

The three major activities undertaken in pursuit of the Centre's mission are Research , Teaching , Training and Service Development Consultancy . The Centre has a strong track record in undertaking policy-related research for the Department of Health and the National Assembly for Wales.

In February this year Jane Hutt announced that Professor David Felce the Director of the Centre would co-chair the Learning Disability Implementation Advisory Group set up to oversee the Welsh Assembly Government's response to 'Fulfilling the Promises'.

## **Bro Morgannwg Special Projects Team**

Bro Morgannwg NHS Trust has, with the assistance of the Welsh Assembly Government, has established a Special Projects Team to steer the development of its services for people with intellectual disabilities and challenging behaviour. The team has four major objectives :-

- To co-ordinate and further develop existing tertiary health services for people with intellectual disabilities and challenging behaviour
- To help set up a range of services for this new user group
- To ensure that all services supporting people who challenge have access to up-to-date, high quality training
- To conduct research that helps improve understanding of challenging behaviour

### **Current service gaps (Headline level only )**

#### **Health Services**

- Recent work on the implementation of Continuing Health Care criteria provides an opportunity for creating a greater clarity for the community teams when procuring appropriate services for individuals.
- As the new Local Health Boards develop into fully functioning bodies, their role will become central to the commissioning of effective services for people with Learning Disabilities. This will be based on evidence of need and a shared strategic intention within the health/social care partnership.

**The following service provision gaps have been identified by Bro Morgannwg NHS Trust, Special Projects Team for children and adults with intellectual disabilities and challenging behaviour :-**

- The system of 'Out of County Placements' to be reconsidered, with a view to bringing people back home to locally based quality services that are cost effective.
- To improve early identification and intervention for children and adults with intellectual disabilities and challenging behaviour
- Improve the skills of staff within educational and social care services to support challenging individuals
- Create more flexible health & social care housing models for this group

- Develop a range of forensic services for those in need
- Develop a range of services for children & adults with Autistic Spectrum Disorder
- Utilise the data from the mapping project in to identify additional gaps in service provision and construct a business plan to reduce dependency on out of area placements