

## **Chapter 6:**

# **The Physical Health of People with a Learning Disability.**

### **Overview**

An increasing number of people with a learning disability are living long and healthier lives. Greater numbers of children with complex health needs are now living into adulthood. The changing demography among the population of people with a learning disability is altering to reflect that of the general population with increasing life expectancy for greater numbers of people.

In order to maximise the benefits to people with a learning disability it is necessary that their right to equity of access to healthcare be recognised. Avoidable deteriorating physical health should not restrict the increasing opportunities for people with a learning disability. However research evidence in Northern Ireland and further afield shows that people with a learning disability have high levels of unmet health need and difficulties in accessing primary and secondary health services.

This chapter aims to provide an analysis of current research into the health of people with a learning disability in Northern Ireland and set it within in the wider context of research undertaken elsewhere within the United Kingdom and internationally.

It is structured in four main sections, namely:

**Section 1** defines physical health and equity of access to health care

**Section 2** considers the physical health status of people with a learning disability.

**Section 3** summarises the reported experience of people with a learning disability and their families

**Section 4** examines the factors in the wider environment that may impact on the use of health services by people with a learning disability.

## Section 1: Defining physical health

### A range of definitions and perspectives

Most people have their own definitions of health and what it means to be healthy. However a brief discussion with colleagues will often show that considerable differences exist among people about what it means to be healthy. Personal definitions of health are important to individuals and can vary widely, although they usually fall into one of two categories, those involving the presence of physical abilities and those that focus on the absence of illness. At a policy and service level the use of agreed definitions of health assists in providing some commonality and transparency about what is meant by the use of the term.

The mostly widely accepted and longstanding definition of health is that of the World Health Organisation which was incorporated within Investing for Health (DHSSPS, 2002). This emphasises that health is a broader concept than physical health which must also include mental and social well-being. It also highlights how health is about the presence of attributes and abilities (a positive concept) and that the absence of ill health does not of itself constitute the presence of health.

#### Box: The evolving definitions of health

*'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1946)*

*'the extent to which an individual or group is able to, on the one hand realise aspirations and satisfy needs; and on the other hand, to change and cope with the environment. Health is therefore seen as a resource for everyday life, not an object of living; it is a positive concept emphasizing social and personal resources, as well as physical capacities' (WHO, 1984 in Naidoo & Wills, 1994, p.21)*

*'a person's optimum state of health is equivalent to the set of conditions which fulfil or enable a person to fulfil his or her realistic chosen and biological potentials'.*  
(Seedhouse, 1986, p.61)

More recent attempts to define health have identified the functionality of health (Fleming, 1999) and built on the original WHO definition to include the importance of recognising that health influences the degree to which an individual can cope within and adapt to their environment and it may be limited by biological potentials and personal choice (Box). This is not to restrict the definition of health nor identify people who may be considered unhealthy, but rather to show how people with perhaps limited physical or mental abilities can still achieve a level of health within these apparent limitations.

This message is echoed by Fleming (1999) in stating that physical health status "is aggregated by factors such as genetic inheritance, the functioning of the major body systems, the physical fitness to perform those functions which are necessary for each individual and the presence or absence of physically disabling factors." He goes on to state that *"It should not be assumed that the presence of a disability necessarily lowers*

*the health status – individuals can still achieve optimum physical health status, for them, within the constraints of their disability” (p231).*

Building on the need to measure health functioning the WHO launched the International Classification of Functioning, Disability and Health (ICF) in 2001. This sought to move away from defining health on the basis of mortality rates and focus on how people live with their health conditions and how their situations can be improved to result in them leading more productive and fulfilling lives (WHO, 2001). In essence, it did not seek to define health but rather to provide an internationally agreed classification for measuring health.

The classification system is structured in two parts, firstly Functioning and Disability which includes the components of Body functions and Structures as well as Activities and Participation. The second part covers Contextual Factors and includes the components of environmental factors and personal factors.

Within each component health and health related domains have been identified together with relevant constructs that provide a framework for the assessment of an individual's health. It seeks to provide a classification system based on the 'components of health' rather than the consequences of disease. It is expected that this classification system will become integral to how functioning, health and disease are measured in the years to come and will supersede currently used definitions.

The message in the newer functional definitions and classifications is that all people should be considered to have the potential to achieve an optimum level of health for them and be involved in deciding what this involves. Therefore the presence of a learning disability should not result in a stereotype of the inevitability of poor physical health.

### **Factors that influence physical health**

The factors that may contribute to poorer health have been described as 'complex and inter related' (DHSSPS, 2002). The principal factors thought to impact on one's health can be grouped under the broad headings outlined in Table 1.

All of these factors potentially impact on the health of people with a learning disability as much as people without a learning disability. Indeed some may have more prominence in the lives of people with a learning disability when considering the growing evidence of harassment of and crimes against people with a learning disability within the UK that has included data collected in N Ireland (Mencap, 1997).

Similar to members of the general population, the limited opportunities available to some people with a learning disability to make informed decisions about their lifestyle due to restricted accessible information, poverty or other people making decisions about them may result in the development and maintenance of a lifestyle that does not provide good physical health (DHSSPS, 2002).

**Table 1: Broad areas that have been identified as having a potential impact on health (DHSSPS, 2002)**

- Disadvantage and social exclusion
  - Poverty
  - Unemployment
  - Low educational achievement
  - Poor social and community environment (including crime)
- Living conditions
- Working conditions
- The wider environment
- Individual's behaviour and way of life
  - Smoking
  - Drug misuse
  - Alcohol
  - Physical activity
  - Food and nutrition
  - Sexual health

Further to the factors listed in Table 1, many people with a learning disability will have additional difficulties that may arise from physical or sensory impairment, reduced communication abilities, particularly in relation to written materials.

For some people, the presence of a specific syndrome or related impairment that is associated with the origins of their learning disabilities may also increase their risk to physical ill health (co-morbidity), although actual physical ill health is not an inevitable outcome. For instance, examples include the increased risk of respiratory problems among people with Down syndrome, injuries that may arise if an individual with epilepsy has a seizure, or as a result of self injurious or other challenging behaviours (DoH, 1995).

The increased prevalence of mental health problems among people with a learning disability will also present additional difficulties for people in maintaining an optimum level of physical health (Emerson et al., 2001).

Neurological and musculo-skeletal abnormalities existing in the learning disability population also require effective management through adequate service provision to ensure that physical impairments are not compromising optimum physical health attainment.

### **Equity of Access to health care**

The values underpinning 'Investing for Health' (DHSSPS, 2002) are:

- Health is a fundamental human right
- Policies should actively pursue equality of opportunity and promote social inclusion
- Individuals and communities should be fully involved in decision making on matters relating to health

- All citizens should have equal rights to health, and fair / equitable access to health and health information according to their needs.

Central to the achievement of health is that right to equitable access to health and health information as noted above. An analysis of this concept defined equity of access to healthcare as the '*the moral right to have an equal opportunity, to enter and / or avail of a quality service, in order to meet a perceived health care need*' (Sowney & Barr, in press).

It recognised that the achievement of equity of access is dependent on the presence of antecedents including people with a learning disability having a desire to feel healthy, a perceived unmet health need, a previous knowledge of who can help, the ability to make comparisons or judge and a feeling of trust. It is argued that the presence of equitable of access to health care can be assessed by the degree to which people with a learning disability:

- Feel empowered by knowing that they have the right to avail themselves equally of the service
- Have opportunities to seek and gain access to a service within an equitable time frame
- Have confidence in the service provider
- Perceive a sense of fairness.

The above analysis demonstrates that is not enough for health services to exist, but that action needs to be taken to facilitate access to healthcare and that the services received must be at least of the quality provided to other citizens.

### **Physical health as a dynamic process**

In using the term health status Fleming (1999) seeks to show that an individual's health is not static, but rather it is a dynamic and changing process. All components of one's health can be influenced by a range of factors noted by Fleming such as genetic factors, physical fitness and physically disabling factors. Furthermore a number of broader influences which are often present in the lives of people with a learning disability such as disadvantage and social exclusion, poor living and working conditions, an individual's behaviour and way of life, together with other aspects in the wider environment can impact on one's health (DHSSPS, 2002).

Changes in the physical health status of people with a learning disability have become more evident in the past decade as increased research has been undertaken in this area. Broadly speaking the major causes of ill health among people with a learning disability are similar to that of the general population, in so far as coronary heart disease, stroke; cancer; sexual health; accidents, diabetes, thyroid problems, and respiratory problems are major causes of ill health (DoH, 1995; Horwitz et al., 2000). Turner and Moss (1996) also reported that people with a learning disability required attention to their health in respect of congenital heart problems, infections, visual and hearing impairments, skeletal problems, movement disorders and dental health.

However on further examination the research indicates that differences do exist in the physical health status of people with a learning disability in a number of areas. These relate primarily to a high level of unmet health need and some variation in the prevalence of conditions among the population of people with a learning disability.

## **Conclusions**

The main messages about health can be summarised as follows

- Health is more than the absence of ill health or disease.
- Many factors both biological and social impact on health.
- Health is a fundamental human right.
- People with a learning disability are not inevitably unhealthy and should be facilitated to achieve and maintain an optimum physical health status.
- Equity of access to health care for people with a learning disability will require action to facilitate the presence of the appropriate antecedents and ensure that the outcomes for them are of a comparable quality to those for other service users.
- Regular monitoring of a person's health status is important to maintain their optimum health.

## Section 2. The physical health status of people with a learning disability

Over the last ten years a number of research projects have been undertaken in Northern Ireland into the health of people with a learning disability. These involved health screening and assessment of the effectiveness of interventions to achieve health gain among people with a learning disability.

### Health screening for people with a learning disability

Services for people with a learning disability living within Northern Ireland were among some of the first in the United Kingdom to identify the scale of unmet health needs of people with a learning disability. The first project commenced in Down Lisburn Trust in 1992 (Meehan et al., 1995).

Two models for health screening of people with a learning disability have been undertaken within Northern Ireland. The initial approach was to set up specific health screening events for people with a learning disability within specialist services, such as day services. This approach used within Down Lisburn Trust involved community nurses - learning disabilities together with a general practitioner and at times a dentist undertaking a health check for people with a learning disability within specialist learning disability services. Between 1992 and 1999 health checks were completed for 398 adults and 164 children (Marshall et al., 2000).

The second approach used within Homefirst Trust and North & West Belfast Trust also involved collaborative working between community nurses – learning disabilities and general practitioners; however the health screening was completed within a local health centre (Leggett, 2001) or the person's local general practitioner surgery (McConkey et al., 2003). These projects both run over two years during which time health checks were completed with 61 and 122 people respectively.

Overall the data from these projects presents a picture of considerable unmet health needs among people with a learning disability. Results indicated that the majority of people with a learning disability had one or more previously undetected health needs identified. These ranged in severity from skin disorders, to endocrine disorders and abnormalities requiring further investigation and treatment (Table 2).

**Table 2: Overview of the findings of unmet health needs during health screening projects for people with a learning disability in Northern Ireland**

(Meehan et al., 1995; Barr et al., 1999; Leggett, 2001; Marshall et al., 2003; McConkey et al., 2003)

Areas of health screen	Examples of conditions detected
Blood pressure	Hypertension, hypotension
Weight	Obese, overweight, underweight
Oral Health	Poor oral hygiene, loose teeth, tooth decay, gum infection
Skin / Hair	Dry scalp, dandruff, varicose veins, eczema, psoriasis, acne
Urinalysis	Glucose, protein and blood present
Testicles	Undescended, swollen underdeveloped

<b>Breasts</b>	Inverted nipple, skin tags, breast lumps and male breast enlargement
<b>Feet</b>	Corns, verucca, fungal infection, damaged nails / nail beds, poor circulation
<b>Ears</b>	Excess ear wax, hearing difficulties
<b>Eyes</b>	Cataracts, reduced vision
<b>Blood tests</b>	Hypothyroidism, diabetes

Comparative analysis of the results from health screening for people with Down syndrome (n=76 people) and people with a learning disability who did not have Down syndrome (n=297) showed that people with Down syndrome were significantly more likely to have reduced vision and skin problems. However it also demonstrated that although a higher number of people with Down syndrome were overweight (60% compared to 52%) the difference was not statistically significant (Barr et al., 1999). In comparing the health status of adults and children with a learning disability Marshall et al., (2003) reported that many of the early indications of later health problems were present in younger children. These authors also identified that teenagers with a learning disability were significantly more likely to be obese than children with a learning disability who were under 12 years of age.

The findings of health screening among people with a learning disability within other parts of the United Kingdom and internationally reveals a consistent pattern of previously undetected health needs across a similar range of areas. As health screening has become more comprehensive further difficulties have also been reported in respect of health needs related to incontinence and gastrointestinal problems including gastro-oesophageal reflux and hiatus hernia (see Health Evidence Bulletins Wales – Learning Disabilities 2001)

The evidence from health screening research clearly shows a high level of unmet health need among people with a learning disability as well as establishing that among the population of people with a learning disability some groups of people may be at increased risk of particular health problems.

However there is also concern that people with a learning disability do not access the specialist screening services available to the wider community such as cervical screening, prostate cancer screening or mammography. Recently in England the National Screening Programme has made special efforts concerning cervical screening for women with a learning disability.

**Table 3: Overview of the findings of health screening projects within the other areas of the United Kingdom and internationally for people with a learning disability in Northern Ireland**

(Turner & Moss, 1996; Horwitz et al., 2000; Hunt et al., 2001; Cassidy et al., 2002; Hatton et al., 2003)

<b>Area of Health Screen</b>	<b>Examples of conditions detected</b>
<b>Optical / visual impairments</b>	(reduced vision, need for prescription glasses, cataracts, eye infections)
<b>Ear, Nose and Throat</b>	(hearing loss, ear wax)
<b>Dermatology</b>	(eczema, psoriasis, dry skin)

<b>Mobility problems</b>	(arthritis, obesity, foot problems)
<b>Dental health</b>	(problems with teeth, gums and mouth ulcers)
<b>Sexual health</b>	(menstrual problems, testicular and breast anomalies)
<b>Cardiovascular</b>	(obesity, hypertension)
<b>Endocrine</b>	(diabetes, thyroid problems)
<b>Gastrointestinal</b>	(pain & discomfort, reflux problems, peptic ulcers, constipation)
<b>Continence problems</b>	(reduced continence, urinary tract infections, pain & discomfort)

### **Prevalence rates of physical ill health compared to members of the general population**

It is clear that as the age of death of people with a learning disability increases the pattern of morbidity and mortality among this group of people is in many ways becoming similar to that of the general population. This is reflected in the reported increase in deaths arising from cardiovascular disease, stroke, and cancers while at the same time there has been a reduced in the number of deaths arising from infections (Hatton et al., 2003).

Much debate has taken place in respect of the incidence of ill health among people with a learning disability in comparison to that of the general population. Two main strategies have been used to answer this question; the first approach has involved the inclusion of control or comparison groups within research projects investigating the health of people with a learning disability. In the main these studies have tended to focus on hearing and visual impairments, conditions of the nervous system, skin disorders and obesity. These conditions are more 'visible' and data from observation and measurement can usually be collected to support the presence of these conditions without the need for most intrusive investigations that other conditions may need to confirm their presence.

In undertaking a review of comparative studies on the health problems of people with a learning disability Jansen et al. (2004) located eight studies that they considered robust and included control groups undertaken since 1995. The evidence from these studies does indicate that people with a learning disability have increased prevalence rates for epilepsy, diseases of the skin, sensory loss and increased risk of fractures.

A second approach for conditions that require more intrusive investigation or have a lower frequency has been the comparison the reported rates of particular conditions and illness among people with a learning disability with national prevalence rates for that condition. The most comprehensive review in this area has been undertaken in relation to cancer among people with a learning disability. The authors concluded that although the overall prevalence rates of cancer among people with a learning disability are similar to that of the general population there is evidence of an increased prevalence of particular types of cancer among people with a learning disability (Hogg et al, 2000). Cancers of the stomach and oesophagus, as well as testicular cancer have been reported at rates higher than those present in the general population.

Conversely people with a learning disability appear to have lower rates for lung, breast, urinary tract and prostate cancers (Duff et al., 2001; Patja et al., 2001; Cooke, 1997).

## **Oral Health**

Research in England and USA has suggested that the oral health status of people with a learning disability is worse than the general population with poorer oral hygiene, higher untreated diseases and more extractions (Nunn, 1987, Gordon et al, 1998). There is evidence too that people moving from institutional care into community settings have increased decay levels as their stay in the community increases despite equity of access and an initially lower prevalence of caries than in the general population (Tiller et al, 2001).

The primary reasons advanced for poorer oral health is a difficulty in accessing dental health services either because of the lack of suitable provision or the increased anxiety experienced by this client group to dental treatments (Kenny, 1999). Matthews et al (1993) reported low confidence among newly qualified dental graduates in treating patients with special needs.

A survey of over 70 general dental practitioners in Northern Ireland found that fewer than 10% of respondents had received any form of training to assist them in managing these patients (Barr et al, 2003).

Recent initiatives by the British Society for Disability and Oral care along with the Faculty of Dental Surgery of the Royal College of Surgeons are designed to provide improved clinical care pathways and local standards for oral healthcare. Community Dental Services are seen as having a particular function in meeting the particular needs of this client group (Hay, 2003).

A difficult issue at present is the requirement for general anaesthesia to be carried out only in Hospital. This has resulted in long-waiting lists for treatment. There is growing interest in the use of sedation techniques as an alternative (Hay, 2003).

Oral health promotion is also vital with this client group and carers in particular have a key role to play in this. The development of educational materials targeted at people with a learning disability is particularly necessary and the NHSSB have produced some excellent new resources.

## **Factors contributing to poorer health status**

The physical health status of people with a learning disability may be directly impacted upon by broad influences that can affect all members of the general population. The health of people with a learning disability is also impacted upon by specific risk factors that may arise due to the presence of a learning disability. Finally, the delay in detecting existing health needs and the limited effectiveness of response to these health needs will contribute to the poorer health status of people with a learning disability.

## **Social and environmental influences on health**

It is recognised that the health of any individual, including people with a learning disability will be impacted upon by a number of key factors, namely:

- Disadvantage and social exclusion
- Living conditions and economic wellbeing
- Working conditions

- The wider environment
- Individual's behaviour and way of life (DHSSPS, 2002)

The influence of several of these factors may be stronger in the lives of people with a learning disability, for instance, these may be a greater impact from disadvantage and social exclusion arising from higher rates of poverty, unemployment and low educational achievement (Band, 1998; Emerson et al., 2003). Limited opportunities for involvement in local community activities arising from a number of factors including lack of awareness of these opportunities, dependence on others for transport (often older carers) and the costs involved can result in people with a learning disability leading a more sedentary lifestyle.

Furthermore, poor nutrition and the long-term use of a large number of medications (polypharmacy) have been identified as particular risk factors among people with a learning disability (Beange, 2002).

The majority of people with a learning disability in Northern Ireland live in community settings with either parents, family members or in a range of residential facilities. The impact of living 'under supervision' may result in a dependency on others to identify health problems and to meet their health needs. Therefore the awareness and views of carers (family and professionals) will be an important influence in accessing healthcare. If carers do not have the knowledge and skills to recognise the indications of poor health, or assume that difficulties are related to the presence of learning disabilities and therefore not amenable to treatment health services may not be accessed. As a consequence people with a learning disability may find it more difficult to achieve the antecedents of having a desire to feel healthy, a perceived unmet health need, a previous knowledge of who can help, the ability to make comparisons or judge and a feeling of trust considered necessary for equity of access to health care.

### **Co morbidity: the presence of a learning disability as an additional risk factor**

It is not inevitable that people with a learning disability will develop ill health; however for some people with a learning disability the presence of particular syndromes or conditions associated with their learning disabilities may increase their likelihood of having physical health problems.

For instance, people with Down syndrome are recognised as having significantly more health difficulties in the areas of vision and hearing (Barr et al., 1999) and may also develop further difficulties related to cardiovascular problems, resistance to infections and their immune system (Stratford & Gunn, 1996). Many other syndromes present among people with a learning disability have associated health problems; this does not make the ill health inevitable, but highlights the need for regular monitoring and treatment (O'Brien et al., 2002; Lennox, 2002).

The presence of learning disabilities either as the result of a specific syndrome or of unknown origins is associated with increased prevalence of epilepsy, together with physical and sensory impairments (Jansen et al., 2004). The presence of these conditions may further increase the risk of sustaining physical injuries. This can directly impact on both the opportunities that people have for physical activity and the independence they develop. Furthermore increasing numbers of people with a learning disability, children, young adults and older people who require intensive nursing care and technological support arising from the presence of complex health needs have increased risks of infection and respiratory difficulties (Wake, 2003).

## **Delay in detecting and limited effectiveness of responses to existing health needs**

Research within Northern Ireland has reported a high degree of previously undetected health needs among people with a learning disability. These findings are consistent with those reported elsewhere within the United Kingdom and internationally (Horwitz et al., 2000; Hunt et al., 2001; Cassidy et al., 2002; Hatton et al., 2003).

The delay in identifying and responding to these unmet health needs increases the risk of future more serious health problems arising. For instance many of the unmet health needs are contributing factors to the presence in those who are obese of conditions, such as, hypertension, cardiovascular disease, stroke and diabetes. In addition the presence of pain, reduced mobility and the discomfort that may arise from untreated skin conditions may further reduce opportunities for inclusion in activities that promote health.

Finding unmet health needs among people with a learning disability over a number of years lends supports to a conclusion that either little has been done in the past to respond to the situation or that the action which has been taken has been ineffective. Marshall et al. (2003) highlighted the limitation of health screening in achieving health gain by demonstrating that in an attempt to follow up 122 people three months after being identified as overweight at health screening only 70 responded to questionnaires.

Furthermore, 29% of those people reported that no further action had been taken after the referral from the health screening service to parents and carers. For 35% of people a variety of actions including cutting down on food, taking exercise, eating more healthily and investigating for thyroid problems were reported, however only 2% were identified as actually achieving a weight loss. These results are in contrast to the weight loss achieved by 30% of people who completed a series of between 6-8 health promotion sessions.

A limitation of some of the health screening research in Northern Ireland is that although it reports the number of unmet needs identified and referrals made to other services, there is no clear indication of the action that these other services subsequently take and the outcomes achieved for the person with a learning disability (Meehan et al., 1995; Barr et al., 1999; McConkey et al., 2003). Therefore it is not possible to demonstrate how the identification of an unmet health need and the subsequent action resulted in health gain for many people with a learning disability, whilst the available evidence suggests that only limited health gains were achieved.

## **Barriers to accessing health services**

A number of factors have been identified as potential barriers for people with a learning disability having equity of access to health care services. These include factors listed below that may arise from the presence of learning disabilities, the previous experience of people with a learning disability, the abilities of professionals, the structure of services and negative attitudes towards people with a learning disability (Meehan et al, 1995; Baxter & Kerr, 2002).

- Fears of unknown places and investigations, leading to non co-operation
- Challenging behaviour, such as hyperactivity, shouting or self injurious behaviour
- Difficulties in meeting certain social expectations, such as waiting in queues, behaving appropriately in reception areas and interacting with health service staff

- Difficulties of professionals in assessing needs owing to insufficient training, equipment, or motivation, or problems owing to physical impairments of people being examined / treated
- Inability to communicate needs / symptoms, such as pain, discomfort, reduced physical or sensory ability
- Difficulty in reading and understanding published material or technical terms
- Lack of specialist health screening for people with a learning disability
- Failure of carers or people with a learning disability to recognise the need for health screening and reluctance to seek medical or nursing attention when required
- Assumptions that any changes in behaviour or health status are due to the presence of learning disabilities.

## Conclusions

In summary then,

- Research evidence from a number of studies undertaken in Northern Ireland demonstrates a wide range of unmet health needs among people with a learning disability
- Comparative research studies support the view that people with a learning disability have higher prevalence rates of health needs in relation to hearing, vision, conditions of the nervous system (e.g. epilepsy), skin disorders, obesity and some cancers (oesophageal, stomach and testicular).
- The physical health of people with a learning disability is impacted upon by the same broad factors that affect other members of the general population. In addition, people with a learning disability may encounter further challenges to their health arising from co- morbidity (due to the presence of learning disabilities), as well as the delay in identifying unmet health needs and the limited effectiveness of responses to these.
- Health screening of people with a learning disability can assist identify unmet physical health needs, but limited effectiveness in achieving physical health gain for people with a learning disability. To be effective specifically targeted actions, usually involving collaboration between primary care / acute general hospitals and specialist learning disability services need to be taken in order to facilitate people with a learning disability to achieve health gain.

## **Section 3: People with a learning disability and their families accessing mainstream health care**

People with a learning disability should have access to all mainstream health services provided to other members of the Northern Ireland population in the form of primary care services and acute hospital services. This section provides an overview of the reported experience of using primary care and acute general hospital services. In addition, some people with complex physical health needs may receive services from community and hospital based specialist learning disabilities services.

### **Primary Care**

#### **General Practitioner Services**

The majority of people with a learning disability live with parents, with other family members or a range of community based accommodation ranging from residential and nursing homes to independent and supported living. Therefore for the majority of people with a learning disability in Northern Ireland their general practitioners are the professionals responsible for providing general medical services to them. All people with a learning disability should be registered with a general practitioner and a dentist.

No studies have been undertaken in Northern Ireland which provide definite details of how many people with a learning disability are registered with a General Practitioner or Dentist, nor do any figures exist on the extent to which people with a learning disability use these mainstream services and other associated screening services such as cervical screening, visual screening, or hearing assessment (Band, 1998).

In a survey of 102 general practitioners and 35 practice nurses / nurse practitioners in the WHSSB area which asked people for their perceptions, 37% of general practitioners and 20% of nurses felt people with a learning disability used the practice as frequently as people who do not have learning disabilities, whilst 13% of general practitioners felt they used it more often. However the majority of nurses (63%) and 44% of general practitioners felt they used it less often (Finlay, 2002). Hatton et al. (2003) in an analysis of studies within the United Kingdom concluded that people with a learning disability visit their general practitioner as often as people who do not have learning disabilities; however they are less likely to receive regular health checks. It has also been reported that women with a learning disability are four times less likely to avail of cervical smear tests than other women in the general population and have a lower uptake of breast examinations.

#### **Identifying people with a learning disability in primary care**

Difficulties have also been reported in attempts to identify people with a learning disability on general practitioner registers for the purpose of health screening as no system exists for identifying people with a learning disability already on the practice register. In a survey within the WHSSB area 59% of general practitioners who were asked reported that they could not easily identify patients with a learning disability (Finlay, 2002). This can result in general practitioners identifying people they 'believed' to have learning disabilities with varying degrees of accuracy, at times causing annoyance and upset to those people identified as having a learning disability who did not have one (McConkey et al, 2003).

One approach to reduce these difficulties has been the collaborative working between primary care and specialist community nursing learning disability services. Through such collaboration it has been possible to refine and validate lists of people with a learning disability on practice registers, although this has not been without difficulties. In particular, issues relating to confidentiality and the sharing of information held by community nursing learning disability services.

These collaborative arrangements are presently in place as pilot projects within a few Trusts in Northern Ireland. Whilst in other Trusts further clarification is being sought about the sharing of information and the views of people with a learning disability. It is likely that some services will seek the permission of people with a learning disability prior to the sharing of information for the purpose of practice registers.

## **Acute General Hospital Services**

### **Contact with acute general hospitals services**

The current policy emphasis on inclusion and equity of access to health care including acute general hospitals is occurring at the same time the reducing capacity of specialist learning disability hospitals to provide complex health care for people with a learning disability who are acutely ill or injured (DHSS, 1995; NHSE, 1998). This means that people with a learning disability who develop physical health problems requiring hospital treatment will in the main receive this treatment within mainstream acute general hospitals. Due to the need for additional medical support, specialist dental services are no longer provided within learning disability hospitals and are provided within Day Procedures Units of several acute general hospitals in Northern Ireland.

However no studies have been completed that provide detailed information on either the extent of contact people with a learning disability have with acute general hospitals in Northern Ireland, or the quality of that experience. The first study in this area is nearing completion in the within the WHSSB area (Barr, 2004a). The project collected data from the parents and carers of 211 people who had contact with acute general hospitals in the WHSSB area between 2001-2003. It also held two focus groups with staff from within learning disability services and conducted a survey of 67 nurses within acute general hospitals. This project shows that between 2001-2003 a minimum of 211 people with a learning disability had contact with one of the three acute general hospitals in the WHSSB at least 525 times in total. Furthermore, over this time 106 people with a learning disability spent a total of at least 366 days in acute general hospitals. In addition to this, a large number of people attended hospitals for outpatient appointments several times over the previous two years.

### **The experience of contact with acute general hospitals**

A summary of some preliminary findings from this on going project (Barr, 2004a) are provided below:

- People with a learning disability have regular contact with acute general hospitals
- Limited use is made of opportunities for the use of pre appointment / pre admission assessments and advance planning.
- At times limited steps are taken to accommodate the individual abilities and needs of the person with a learning disability.
- People with a learning disability are often excluded from key discussions and decision about their care

- Further training is required by Hospital staff in relation to requirements for obtaining informed consent from people with a learning disability
- Nursing staff have limited knowledge and skills in relation to working with people with a learning disability.
- The majority of parents and carers perceived the need to remain in hospitals for the duration of contact in order to ensure the person with a learning disability received adequate care and supervision.
- Some people with a learning disability will require ongoing additional support when in an acute general hospital if treatment is to be completed successfully.
- More effective liaison arrangements between acute hospitals and learning disability services need to be put in place.
- There is a need for further training of nursing staff to work with people with a learning disability in acute hospital settings.

The above findings are similar to those as outlined below which have been reported by people with a learning disability, their parents and carers from elsewhere in Northern Ireland and the United Kingdom.

### **The views of people with a learning disability**

In 2002, a series of focus groups were held across Northern Ireland with people who have a learning disability which discussed a number of topics including health. The findings of this research reported that some people with a learning disability expressed fear due in part to uncertainty about what is happening and compounded by previous negative experiences during earlier contacts with acute general hospitals or health professionals (DHSSPS, 2002).

Several of these points have most recently been echoed within 'We have a dream' (DHSSPS, 2004) which emphasises the importance of health professionals communication; in the provision of information, listening to people with a learning disability and engaging directly with them rather than the parents / carer or professional who accompanies them.

Similar points have also been made by people with a learning disability who have participated in focus groups or individual interviews in England who have also reported a number of difficulties during their contact with acute hospitals. These have largely focused on being provided with limited information or explanations about what is going on and not feeling involved in the discussions and decisions that have taken place (Mental Health Foundation, 1996; Hart, 1999; Cumella & Martin, 2000). The confusion and fear that can arise from limited explanation and attempts to engage with people with a learning disability may result in difficulties in achieving informed consent and the required level of co-operation for the necessary investigations or treatment to be completed (Hart, 1999; Barr, 2004a).

### **Families and carers of people with a learning disability**

Most available research in relation to the use of acute general hospitals by people with a learning disability has been undertaken with family members of people with a learning disability who have had contact with acute general hospitals. The findings show that parents and carers highlight long waiting times often in inappropriate environments with limited information prior to and during contact with the hospital. They perceived poor quality of care in relation to hygiene, nutrition and maintaining the safety of the person

with a learning disability within an environment with limited opportunities for meaningful activities and in which the patient often becomes bored and restless. Furthermore limited forward notice of discharge, poor co-ordination of discharge and little or no support after discharge has been reported (Band, 1998; Fox & Wilson, 1999; Cumella & Martin, 2000; Whoriskey & Brown, 2002).

Parents have also reported the perceived need to stay in hospital during the period of contact. However little effort appears to be made to facilitate their stay in the hospital or make it comfortable, many parents have found the experience tiring and unpleasant (Fox & Wilson, 1999).

### **Specialist Learning Disabilities Services**

The reconfiguration of specialist hospital services as assessment and treatment facilities together with the emphasis on inclusion in mainstream services will further reduce their role in the provision of nursing and medical care for people with a learning disability who develop physical health problems. At present the care provided to people with physical health needs in specialist learning disability facilities focuses on providing treatment for existing conditions rather than investigation of illness or treatment for major injuries.

As with primary care, people with a learning disability living in community settings receive services from District Nursing services, which is co-ordinated through the general practitioner. District Nurses have a similar role with people with a learning disability as they do with other members of the general population. In addition, community nursing learning disability (CNLD) services in Northern Ireland also have some role in providing support to people with a learning disability in relation to their physical health. The role of the CNLD is as a secondary service to provide additional support when mainstream services need further assistance to work with people with a learning disability.

In a recent survey of CNLD's within Northern Ireland, the provision of support in relation to physical health care made up 33% of the CNLD caseload and was a frequent reason for referral to CNLD services (Barr, 2004b). The work undertaken by the CNLD includes health promotion activities, the administration and monitoring of on going treatments, as well as facilitating access to primary and secondary health care services, with less time spent on clinical procedures such as dressings or other medical prescribed treatments.

It is expected that as other community nursing services develop, such as community children's nursing and the altering role of the Health Visitor that this will result in change to the role and work of the CNLD. Their role will shift further from the provision of direct care to people with a learning disability that of health promotion / health facilitation and promoting equity of access to mainstream healthcare services.

### **Conclusions**

- Primary care and acute general hospital services have a key role to play in meeting the physical health needs of people with a learning disability.
- Difficulties exist at present in identifying the extent and nature of the use people with a learning disability make of primary care and acute hospital services.
- People with a learning disability, their families and nurses with services often report a difficult experience in using or providing service to people with a learning disability. The major difficulties relates to ineffective communication and limited confidence / knowledge / skills of the professional involved.
- The role of specialist learning disability services in providing investigation and complex treatment for the physical illness of people with leaning disabilities will reduce as specialist hospital reconfigure as assessment and treatment services.

## **Section 4: Factors impacting on the use of health services by people with a learning disability.**

A number of factors appear to impact on the access to and use of health services by people with a learning disability. These include factors relating to the policy guidance / service structures as well as the views and actions of professionals in services.

### **Wider plans for healthcare in Northern Ireland**

Despite the evidence that people with a learning disability have unmet health needs and at times higher prevalence rates for some physical health problems, there is limited attention to how these needs should be met within health policy documents at DHSSPS, HSSB and Trust level. Often the needs of people with a learning disability are included under the heading of 'vulnerable groups', together with a number of other groups. This approach fails to acknowledge the increased prevalence of some physical health problems and the particular support and facilitation people with a learning disability may have. It may also reinforce the stereotype of people with a learning disability as vulnerable and less able, which is not consistent with the emphasis on inclusion and supporting people to become empowered.

Another approach in wider plans for health care is to defer the work on the health needs of people with a learning disability through the inclusion of a 'comment' that further work needs to be done in relation to the needs of people with a learning disability, but no clear criteria set against which progress on this will be measured as has been undertaken other countries (Beange, Lennox and Parmenter 1999)

### **Limited Policy Guidance – who is responsible for services?**

In the absence of clear guidance, major variation exists across Northern Ireland ranging some innovative health orientated projects to inaction. Key to several of the health focused projects in primary care services that have occurred in recent years has been 'fortunate alliances' among people who have a particular interest in the health of people with a learning disability. It was this level of interest and insight that drove forward several projects rather than the requirement that action was taken; therefore in the absence of interest no action is taken.

Whilst limited research has been undertaken with Northern Ireland in relation to people with a learning disability receiving acute general hospitals services, similar confusion over responsibilities appears to be present. It is often the situation when people with a learning disability are in acute general hospitals there is an expectation by general nursing services that additional support will be provided by learning disabilities services (at their expense). No formal structures appear to exist within Northern Ireland for accessing the degree of support required and again major variations can occur across Northern Ireland. The absence of clear guidelines and stated statutory responsibilities makes it more difficult for people with a learning disability to be treated with equity in acute hospital services.

Furthermore the lack of clearly stated responsibilities and requirements also makes it difficult to obtain on going funding for projects aimed at promoting the physical health of people with a learning disability. As a consequence the innovative projects that have produced the research noted earlier on this report no longer exist, including Healthcheck 2000 (Down Lisburn Trust) and Challenge 2000 (North & West Belfast) and Footsteps to Health (Homefirst Trust).

Notwithstanding the fact that a review is presently underway and future policy will emerge from it, at present there is limited guidance on how health services should be delivered to people with a learning disability within Northern Ireland compared to other areas of the United Kingdom. Guidance in England, Scotland and Wales goes beyond broad statements of intent and identifies expected actions and responsibilities; it highlights the rights of people with a learning disability to access mainstream health services and the requirement for these services to take action.

This guidance also heightens the profile of the health needs of people with a learning disability within primary and acute care services as well as giving encouragement as to how this could be achieved (NHSE, 1998, 1999; DoH, 2003). The existing guidance was further strengthened by the requirements incorporated into the policy reviews which highlighted the right to health care, the need for registration with General Practitioners, health action plans and the development of health facilitation (SE, 1999; DoH, 2001). However within Northern Ireland no equivalent guidance exists and confusion remains about the main responsibilities of learning disabilities vis-à-vis mainstream health services to promote the physical health and meet the physical health needs of people with a learning disability.

### **Limited collaborative working between 'mainstream' and specialist services**

Despite an 'integrated' health and social care structure within Northern Ireland, specialist learning disability services and the nursing staff who work within them appear to have limited formal links with primary care services, and do not appear to be part of primary care networks (Barr, 2004b). Similar limited collaboration between primary care and specialist learning disability services has been reported in England (Thornton, 1999; Giraud-Saunders et al., 2003).

Nevertheless well-developed examples of joint working between primary care and learning disability services have been reported in Northern Ireland and elsewhere (Barr et al., 1999; Martin, 2003; McConkey et al., 2003). However these are the exception rather than the norm. Health facilitators within services in England have a specific role in working between learning disability and primary care services, in effect providing the co-ordinating link (DoH, 2001). At present there is no equivalent to health facilitators within Northern Ireland.

Whilst it is accepted by most general practitioners that they should meet the 'general medical needs' of people with a learning disability as part of their role, many do not believe they should be the ones providing on going health screening for people with a learning disability (Kerr et al., 1996; Bond et al., 1997, Stein, 2000). Consequently, general practitioners do not usually undertake the role of co-ordinating the health care for people with a learning disability, which many see as the role of the specialist learning disabilities services.

Evidence is available from within Northern Ireland and elsewhere in the United Kingdom to show that when primary care and specialist learning disabilities do work collaboratively, the health status of people with a learning disability can be improved (Jones & Kerr, 1997; Martin et al., 1997; Marshall et al, 2001; McConkey et al, 2003;). However as experience has shown any progress that has been made within Northern Ireland services in relation to health screening or health promotion has relied on 'project' or non recurrent funding, and gains made may be quickly lost now that these projects have ceased.

Equally, collaboration between acute general hospital services and learning disability services has resulted in the development of several acute liaison nurses within the England and Scotland, at present no similar posts exist with Northern Ireland. These projects have been evaluated very successfully and have taken considerable steps towards achieving equity of access to healthcare for people with a learning disability (further information available at [www.fons.org/networks/nlnldn/a2a](http://www.fons.org/networks/nlnldn/a2a)). In addition, acute liaison nurses have a role in providing training for staff as well as contributing to policy development, research and service development.

As the preceding examples show, to be effective collaborative working needs must go beyond providing information to primary care and acute general hospitals services about what needs to be done, it must include practical support, training and sharing of information.

### **No clear idea of scale**

Limited data exists about the frequency and reason for use of primary care services, nor does any clear data exist on the number of people with a learning disability availing themselves of screening services or making use of other clinics offered in primary care such as diabetes, asthma, or smoking cessation. In relation to acute general hospitals the only available data in Northern Ireland at present is contained in the draft report commissioned by the WHSSB (Barr, 2004a). Without more detailed information it is difficult to ensure that people with a learning disability have equity of access to services, or for planners to develop effective services to target people who may not be availing of existing services.

Within some Primary care services in Northern Ireland and England 'practice registers' of people with a learning disability are being developed. Such developments need the support of people with a learning disability and their families if these are to be effective. It is also important that clear guidelines exist in relation to the sharing of information between services and to provide people with the opportunity to opt in or out of such registers. Again collaborative working is required between learning disabilities and primary care / acute hospitals services in order to accurately identify people they believe to have a learning disability.

While a considerable body of research has been carried out within Northern Ireland it has been limited at times by being geographically localised studies, undertaken independent of each other, at times not building on the findings of previous work in Northern Ireland, and the interventions used may have been influenced by local service provision. These limitations make it difficult at times to directly compare the findings of the different studies with confidence, but do not detract from the convergence of findings which demonstrate the high level of unmet health needs and limited equity of access to health care among people with a learning disability in Northern Ireland, the UK and internationally.

In order to have a more complete picture of the health needs of people with a learning disability a co-ordinated approach needs to be taken to research across Northern Ireland, (perhaps with the use of pilot sites within an overall programme of research). This will provide a robust picture of the health status of people with a learning disability and the effectiveness of approaches to achieve health gain.

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## **Views of professionals in mainstream services**

### **Primary care**

The views of professionals in primary care towards people with a learning disability and skills in communication have been identified as factors influencing the service provided to people with a learning disability (Singh, 1997; Band, 1998). In a survey of general practitioners in the WHSSB area, Finlay (2002) reported that 48% of general practitioners and 49% of nurses did not feel they had adequate training to work with people with a learning disability, while 20% of general practitioners and 17% of nurses felt that had. The remaining 32% of general practitioners and nurses were uncertain about their degree of preparation. The reported limited preparation and uncertainty about how to work with people who have a learning disability is consistent with the findings reported elsewhere in the United Kingdom (Kerr et al., 1996; Bond et al., 1997; Stein, 2000; Gill et al., 2002).

It has also been reported that general practitioners have generally positive attitudes towards people with a learning disability and whilst accepting their responsibility to provide general medical services for people with a learning disability believe health screening should be provided within specialist services (Gill et al. 2002). In a survey of GPs within Down Lisburn Trust although the majority of general practitioners felt health screening would be helpful for people with a learning disability, three quarters of those responding felt these would be better provided within specialist services. However after dealing with referrals from a contact with a health screening service provided by Community Nursing Learning Disability services, general practitioners reported being more favourable to undertaking health screening (McConkey et al. 2002). This would support the importance of collaborative working between specialist and primary care services and demonstrates that such collaboration could lead to improve equity of access to health screening in primary care settings.

Most surveys have taken place with nurses and general practitioners with little information on the views of the wide range of other professionals. However research evidence also show that people with a learning disability often do not avail of other health services within community settings (dentist, optician, audiologist, speech and language therapist, dietician) (Band, 1998). Given the reported impact and views of general practitioners and nurses on the availability and access to services, further research is needed to establish the views of other professionals and the impact these have.

### **Acute hospitals services**

It is recognised that nurses within acute hospitals also report experiencing difficulties in working with people with a learning disability. Many report a limited degree of confidence and much uncertainty about what to do in working with people with a learning disability. This uncertainty in staff is also reflected in studies in Northern Ireland on the views of general nurses and other staff views towards caring for people with a learning disability in which they often reported limited knowledge, skills and experience in this area (Slevin & Sines, 1996; McConkey & Truesdale, 2000; Barr 2004a). Little research information exists in relation to the views of other professionals within acute general hospitals. However, one study undertaken in Northern Ireland which included 167 student therapists (mainly physiotherapists and occupational therapists) reported that therapists had significantly less confidence and felt more

unprepared to work with people with a learning disability than the nurses in the study (McConkey & Truesdale, 2000).

Using focus groups with staff from general hospitals in one area in England, Cumella and Martin (2000) identified four key areas of difficulty, namely poor information on admission, limited staff training in the needs of people with a learning disability, risk to other patients (actual or perceived) and difficulties in obtaining consent that at times made staff wary of undertaking interventions. Nursing staff in acute general hospitals highlight their lack of preparation to work with people with a learning disability during their pre and post qualification education. The nurses are clear that further education and opportunities to develop skills are required and emphasise the need for skills in communication, legal and ethical issues (particularly informed consent and restraint), working with families, working with people who present challenging behaviour and the resources available to support people with a learning disability (Band, 1998; Barr, 2004a).

### **Conclusions**

- Action to respond to the additional physical health needs of people with a learning disability is often not clearly stated in health policy documents.
- Lack of policy guidance and clear statements about the rights of people with a learning disability and service responsibilities exists in relation to the role of primary care and acute general hospitals services in responding to the health needs of people with a learning disability.
- Gains for people with a learning disability made in health screening and health promotion projects may be short term due to the lack of recurrent funding to support the continuation of such initiatives.
- Limited collaborative working arrangements exist on an on-going basis between primary care, acute hospitals and specialist learning disability services.
- There is need for investment in training and education of staffing mainstream health services to increase their capacity to work effectively with people with a learning disability
- A more co-ordinated programme of research on the physical health needs of people with a learning disability and their access to / use of health service would provide a robust platform from which further develop primary care, acute general hospital and specialist learning disability services.

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## Conclusion

This chapter has sought to provide an analysis of the research evidence in relation to the physical status of people with a learning disability and the responses of health services to this. It is clear that people with a learning disability continue to have a high level of unmet physical health need and that while some limited progress has been made yet more needs to be done. Experience elsewhere in the United Kingdom has shown that efforts to improve the physical health of people with a learning disability should now focus on:

- Addressing the issues associated with health for all, and responding directly to the inequalities and discrimination against people with a learning disability in relation to their equity of access to healthcare.
- Developing increased capacity within primary care and acute hospital services
- Actively involving people with a learning disability, their families and carers
- Reshaping the contribution of specialist learning disability services to support the achievement of equity of access to healthcare, whilst still having the capacity to respond to the needs of people who can not have their needs met within mainstream services at present (Giraud–Saunders et al., 2003).

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