

**Leicester City Primary Care Trust**  
**Directorate of Public Health and Health Improvement**  
**Health Care Needs Assessment: People with Learning Disabilities**

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**This needs assessment has used some overseas resources which use terminology which may not be used in the UK. Where possible this terminology has not been used in the main body of this report, but has been included when discussing the titles of resources used.**

## **Executive Summary**

This health needs assessment for people with learning disabilities is presented to the Leicester City Learning Disability Board. It looks at how services and support for people with learning disabilities may be improved. It should be viewed alongside the commissioning strategy and the Big Plan 2008-11; both of these have been influenced by consultation with service users and carers.

People with learning disabilities are amongst the most vulnerable members of society. They have a wide range of social and health care needs, and they may have co-existing conditions which contribute to need, such as physical or developmental disabilities, mental and physical ill-health and a range of behavioural problems.

Such needs often go unmet, with care increasingly taking place in the community and with family members often providing the majority of care. The physical and mental wellbeing of family members is therefore a crucial part of meeting the needs of those with learning disabilities. Yet, despite strategic changes earlier in the decade, in 2008, Michael reported there are still shortcomings in services for people with learning disabilities and that people with learning disabilities are not a priority.

The aetiology of learning disability can be subdivided into those conditions which arise at conceptions and those which arise during pregnancy, in labour and after a child's birth. They can be genetic, infective and environmental in origin. According to the Learning Disability Register held by the University of Leicester, there are approximately 1600 people with learning disabilities in Leicester. 60% are male, and 68% are from a White/White British ethnic background. The rate of Learning Disabilities on the Register in Leicester when compared to the General Practice population in Leicester is 4.62 per 1000, slightly higher than the 3.8 per 1000 nationally.

The risk of dying before the age of 50 has been shown to be 58 times greater than in the population generally. Life expectancy diminishes with severity of impairment. Predictors of early death include the inability to walk, cerebral palsy, incontinence and epilepsy. The leading cause of death in a study

based in London was respiratory disease. The prevalence of mental illness and behavioural disturbance is higher in all ages in all age groups of people with learning disabilities than in the general population.

Together these factors suggest that there is a need to address inequality in order to ensure that access to services is such that there is equity of outcome for people with learning disabilities.

## 1. Introduction

This needs assessment for people with learning disabilities is presented to the Leicester City Learning Disability Board, as a way of providing information for the need and demand for health care for people with learning disabilities. It aims to provide relevant information for the strategic planning and development of services for people with learning disabilities in Leicester. It is therefore aimed at commissioners of services as a way of influencing service provision.

It is important from the outset to state that people with learning disabilities are individuals, and that they should be respected as citizens and supported to make individual choices. They should not experience abuse, discrimination, harassment or exclusion from the community.

The health care needs assessment will focus on the health of children, adults and older adults with learning disabilities. It will review the current evidence about the health needs of people with learning disabilities; it will provide intelligence which will enable commissioners to identify where services meet needs and where there are gaps. It will make recommendations to meet the gaps and inequities in service provision.

The demographics of the population with learning disabilities are changing. The number of people with learning disabilities in the United Kingdom increased by 53% in the period between 1960 and 1995, an average increase of 1.2% per year<sup>1</sup>. This increase is thought to be because of the improving socio-economic conditions coupled with advances in health care. In addition a study has projected a further increase of 11% for the period 1998-2008<sup>2</sup>. This was based upon evidence that more people with learning disabilities will survive into older age. However, this needs assessment shows that there is an underrepresentation of older people with learning disabilities in Leicester compared with the population of the city in general.

One example of the complexity of the issue of learning disability is in the

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<sup>1</sup> McGrother, C. et al, 2001 Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire

<sup>2</sup> McGrother, C. et al, 2001 Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire

prevalence of Down's syndrome. For, whilst screening for Down's syndrome during pregnancy has been accompanied by an increase in terminations of pregnancy where Down's syndrome has been shown to be present, the birth prevalence for Down's syndrome is increasing. This is thought to be mainly because of increased survival at birth in particular of those children with Down's syndrome who have congenital heart disease<sup>3</sup>.

There are other examples of why the health care of all people with learning disabilities is a complex problem for the delivery of health and social care. For instance there is a general increased life expectancy of people with learning disabilities and an increase in the number of people with the most severe disabilities.

People with learning disabilities are amongst the most vulnerable members of society. They have a wide range of social and health care needs, and they may have coexisting conditions which contribute to need, such as physical or developmental disabilities, mental and physical ill-health and a range of behavioural problems. It is often the presence of these conditions that defines need for services. Such people also have needs which occur as a result of social exclusion, such as poverty, unemployment and lack of adequate accommodation. Children with mild learning disabilities may need specialist support in mainstream education. Adults may need the same support and access to benefits as others who are in socially excluded groups. Others with higher levels of disability may have a lifelong need of care.

Such care increasingly takes place in the community, with family members often providing the majority of care. Thus service planning and commissioning must include the needs of carers. This is particularly important given that people with learning difficulties are increasingly reliant on carers who are ageing themselves.

Many individuals with learning disabilities will predominantly need social care services, although, health services play a significant role to ensure that all needs are met. Disability may lead to the need for additional and/or specialist support/benefits and services. However, it is important that generic services should always be accessible to people with learning disabilities. Thus service

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<sup>3</sup> NHS Scotland, 2004 People with Learning disabilities in Scotland. TSO, Edinburgh

planning should be based on a partnership between health, social care, housing, education, carers and service users.

People with learning disabilities generally have higher levels of health need than the population as a whole; these needs often go unmet<sup>4</sup>. The pattern of types of health need experienced by people with learning disabilities differ from the general population as do the main causes of death.

The validity of this evidence has been recognised by policy makers, and a number of reports and strategic initiatives, for instance the *Michael's Report*, have been commissioned and acknowledged. However, in spite of this recognition there is a perception that poor access to treatment persists. Indeed during a debate at Westminster on 14 July 2010, MPs were told that nearly half of all doctors and a third of nurses admit that people with a learning disability receive a poorer standard of healthcare than the rest of the population.

Leading the debate was Tom Clarke MP, who presented evidence of a "damning indictment of what many people with learning disabilities experience in the NHS". The care services minister Paul Burstow said that the debate highlighted the importance of annual health checks for people with a learning disability. During the debate it was suggested that only just over one in five people with a learning disability received an annual health check.

Mencap is one of a number of third sector organisations advocating for people with learning disabilities. As a response to the evidence of iniquity in the provision of healthcare to people with learning disabilities, Mencap has developed a campaign called *Getting it Right*. This campaign suggests at the outset that people with a learning disability are not getting equal access to healthcare. A plethora of factors may contribute to this, such as poor communication, assumptions about quality of life and a lack of understanding of learning disabilities amongst healthcare professionals. The ultimate result is that patients with a learning disability are getting poorer standards of care, and are even dying.

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<sup>4</sup> NHS Scotland, 2004 People with Learning disabilities in Scotland. TSO, Edinburgh

To address such faults Mencap believes that:

- healthcare professionals need support, encouragement and guidance to make reasonable adjustments for patients with a learning disability
- members of the public should be given the tools to persuade health professionals and healthcare authorities to make adjustments and treat people with a learning disability equally

Mencap has worked with healthcare professionals and Royal Colleges to develop the *Getting It Right Charter*.<sup>5</sup> The charter spells out the nine key activities that all healthcare professionals should make to ensure that there is equal access to health. These are:

- Make sure that hospital passports are available and used
- Make sure that all health care staff understand and apply the principles of mental capacity laws
- Appoint a learning disability liaison nurse in hospital(s)
- Make sure every person with a learning disability can have an annual health check
- Provide ongoing learning disability awareness training for all staff
- Listen to, respect and involve families and carers
- Provide practical support and information to families and carers
- Provide information that is accessible to people with a learning disability
- Display the *Getting It Right* principles for everyone to see

Mencap also describe incidents in which people with learning disabilities have suffered from inequality in care. The following are extreme examples, which resulted in the death of the person, but they warrant consideration as evidence of what can result when the care of people with learning disabilities is inadequate:

Emma died on 25 July 2004. She had been diagnosed with cancer and her mother was told she had a 50% chance of survival with active treatment. However, doctors decided that Emma would not cooperate with treatment

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<sup>5</sup> Mencap 2010 Getting It Right Charter at [www.mencap.org.uk/case.asp?id=14966](http://www.mencap.org.uk/case.asp?id=14966)

because of her learning disability. She was not treated and died aged 26.

Tom died on 25 May 2004. His parents had repeatedly told social care and health professionals that the change in his behaviour was because he was in pain. However, no assessment of his physical health needs was made until it was too late to save him. Tom died of oesophagitis and aspiration pneumonia aged 20.

## 2. Policy Context

The policy direction for meeting the health care needs of people with learning disabilities has been underpinned by a commitment to social justice and inclusion. There has been a focus on increasing community based care and ensuring that there are no variations in the outcomes of care.

In 2001, a national strategy for learning disabilities, *Valuing People*<sup>6</sup>, was published by the Department of Health, offering guidance on the organisation and development of services. It emphasised four key principles for the future delivery of health care for people with learning disabilities, these were; **rights, independence, choice and inclusion**. Despite the development of this strategy, there is a significant amount of service development required to ensure that people with learning disabilities have access to high quality comprehensive health and social care.

The policy initiatives suggest a *modus operandi* to address the disadvantages to meet the typically additional and complex needs of this population and the fact that people with learning disabilities are provided with fewer opportunities. *Valuing People* accepted that there are some key outstanding issues which need to be considered, such as poorly co-ordinated services, insufficient support for carers, substantial unmet health care needs, little choice, limited opportunities or lack control over their own lives experienced by people with learning disabilities.

Despite the strategic changes earlier in the decade, in 2008, Michael reported there were still shortcomings in services for people with learning disabilities and that people with learning disabilities are not a priority. One of the recommendations to the *Michael's Report (Healthcare for all)*<sup>7</sup> was that the Department of Health should amend the *Core Standards for Better Health*, to include the need for reasonable adjustments to the delivery of services for people with learning disabilities. The report also emphasised that Primary

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<sup>6</sup> DH, 2001, Valuing People, [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4009153](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009153)

<sup>7</sup> DH, 2008 Michaels Report: Healthcare for all [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_106126.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf)

Care Trusts (PCTs) should commission direct enhanced services to provide regular health checks and to improve data, communication and integration, in a bid to reduce the risk of premature avoidable death for people with learning disabilities.

Clearly, with the abolition of PCTs, and a move towards Practice Based Commissioning is it necessary to ensure that the new commissioners are cognisant of the high levels of unmet need and receive less effective treatment experienced by people with learning disabilities. In addition, new commissioning bodies should also be aware that and that there is the Disability Discrimination Act and the Mental Capacity Act set out a clear legal framework for the delivery of equal treatment<sup>8</sup>.

Additional good practice outlined in the policy context suggests that there are requirements for service commissioners to identify and assess the needs of those people with learning disabilities, in for example the Joint Strategic Needs Assessment. This assessment of needs should drive the development of services and should be done in consultation with patients, carers and the public.

In Leicester there is a Learning Disability Partnership Board governing NHS Leicester City's (NHSLC) services through the Leicester City Health Action Planning Subgroup led by the Leicestershire Partnership NHS Trust. The local action plan 2005/08 included increasing awareness on learning disability issues, involving patients, carers and clinicians in the training, planning and development of services, reducing barriers to access and improving quality of mainstream services. The Learning Disability Partnership Board is aligned to the One Leicester vision of partnership for Leicester. This aims to transform the economic, social and environmental well being of the city over the next 25 years.

The Big Plan 2008-11 which was based on consultation with people with learning disabilities and their carers, set out the vision for the future development and improvement of services for adults with learning disabilities in Leicester. It focused upon other important policy initiatives, such as personalisation, employment, housing and support.

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<sup>8</sup> ibid

Locally there is also a Leicestershire Learning Disability Register, which is a joint initiative between the University of Leicester and the local health care trusts. It was established in 1987, in response to carer and client demands for better coordination and continuity of care. The Register facilitates the planning, evaluation and monitoring of services for people with learning disabilities by generating evidence-based public health intelligence<sup>9</sup>. Each registered person is visited every 5 to 7 years, and information is collected through interview.

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<sup>9</sup> Reyes-Beaman, S., 2008 Learning Disabilities in Leicester (unpublished essay).

### 3. Definitions

It is important to look at definitions of learning disabilities, not because of allocation of resources or to judge, but to underpin the classification of conditions. The term learning disability usually refers to a group of individuals with a history of developmental delay; a delay in, or failure to acquire a level of adaptive behaviour and/or social functioning expected for their age; and in whom there is evidence of significant intellectual impairment.

Systems which are used to classify people with learning disabilities generally combine a measure of intellectual functioning, such as intelligence quotient (IQ) with measures of behavioural functioning. The main classification systems are:

- **ICD-10:**

F7: Mental Retardation. This is a bi-axial classification based on IQ and impairment of behaviour<sup>10</sup>.

**Table 1: ICD-10 codes and IQ scores**

Code	IQ score
F70 Mild	50-69
F71 Moderate	35-49
F72 Severe	20-34
F73 Profound	<20

Although classification is based on the IQ test result, clinical judgement is also taken into account.

F84: Pervasive Developmental Disorders. There are a number of sub-categories to this section, including autism spectrum disorders.

- **DSM-IV<sup>11</sup>:**

This adopts a multi-axial approach focusing on intellectual functioning which is below average (IQ of 70 or less), concurrent deficits in adaptive functioning,

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<sup>10</sup> ICD-10 codes at [www.who.int/classifications/icd/en/](http://www.who.int/classifications/icd/en/)

<sup>11</sup> DSM-IV at [www.psychiatryonline.com/resourceTOC.aspx?resourceID=10](http://www.psychiatryonline.com/resourceTOC.aspx?resourceID=10)

and onset before age 18. Sub-classification is based on severity.

- **American Association on Mental Retardation Manual of Definitions<sup>12</sup>:**

This is based on three criteria:

- 1) Below average intelligence
- 2) Deficits in adaptive behaviour (such as communication and self care)
- 3) There should be evidence of 1 and 2 in the developmental period.

There are additional factors in this classification, based on the intensity and provision of support.

In England and Wales the Mental Health Act 1983 included the terms 'mental disorder', which includes arrested or incomplete development of the mind. It also included 'mental impairment' and 'severe mental impairment'. These are specific legal terms and are not synonymous with mental illness, learning disabilities or intellectual impairment.

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<sup>12</sup> **American Association on Mental Retardation Manual of Definitions**  
[www.aamr.org/content\\_100.cfm?navID=21](http://www.aamr.org/content_100.cfm?navID=21)

#### 4. Evidence

An objective of this needs assessment is to determine, from available evidence, the numbers of people with learning disabilities in Leicester, the interventions which are likely to produce the best outcomes for them and the gaps which exist in terms of current service delivery.

The needs assessment draws on the Health Needs Assessment Report: People with Learning disabilities in Scotland<sup>13</sup>; the Nottingham City Joint Strategic Needs Assessment (April 2009)<sup>14</sup> and Learning Disabilities<sup>15</sup> (Rees et al) from Health Care Needs Assessments Volumes 1 and 2. These assessments are complemented by local information from the Learning Disabilities Register held by the University of Leicester.

The incidence and prevalence data, the evidence for the effectiveness of different treatments have been considered against the categories of strength of evidence based on Shekelle et al<sup>16</sup> (1999), which are shown in Table 2.

**Table 2: Classification Schemes for evidence and recommendations**

Categories of evidence	
Ia	Evidence from meta-analysis of randomised controlled trials.
Ib	Evidence from at least one randomised controlled trial.
IIa	Evidence from at least one controlled study without randomisation.
IIb	Evidence from at least one other type of quasi-experimental study.
III	Evidence from non-experimental descriptive studies, such as comparative studies, correlation studies and case control studies.
IV	Evidence from expert committees' reports or opinions and/or clinical experience of respected authorities

<sup>13</sup> NHS Health Scotland 2004 People with learning disabilities in Scotland. TSO, Edinburgh

<sup>14</sup> [www.nomadplus.org.uk/.../JSNA%20UPDATE%20April%2009\\_Introduction.pdf](http://www.nomadplus.org.uk/.../JSNA%20UPDATE%20April%2009_Introduction.pdf)

<sup>15</sup> Rees S, et al Learning Disabilities in Health Care Needs Assessment Volumes 1 and 2 First Series Second Edition. Radcliffe, Oxford.

<sup>16</sup> Shekelle, P. 1999 Developing Guidelines in BMJ 27/2/99 318:593-6.

## 5. Aetiology

The aetiology of intellectual impairment can be subdivided into those conditions which arise at conceptions and those which arise during pregnancy, in labour and after a child's birth. No aetiological cause is found in about 30% of cases of mild or severe learning disabilities. These factors are listed in Table 3, and focus upon genetic, infective and environmental causes.

**Table 3: Aetiological factors which cause learning disabilities<sup>17</sup>**

Aetiological factor	Timing of injury/exposure			
	Antenatal		Perinatal	Postnatal
Genetic	Chromosome aberrations	Secondary neurological damage		
	Trisomies:	Disorders of: Protein metabolism e.g. phenylketonuria Lipid metabolism e.g. Tay-Sachs Carbohydrate metabolism		
	21 Downs Syndrome 18 Edwards Syndrome			
	13 Patou syndrome			
Sex linked: E.g. fragile X syndrome				
Infective	Rubella, with more severe damage the earlier in pregnancy		Herpes Simplex	Meningitis
	HIV			Encephalitis
	Toxoplasma			Encephalopathy e.g. measles
	Cytomegalovirus			Whooping Cough - secondary to brain injury
Environmental	Nutritional deficiencies e.g. iodine		Birth injury	Trauma: Accidents and non-accidental injury resulting in head injury
	Rhesus incompatibility			Lead
	Drugs/alcohol		Trauma Hypoxia	Nutrition
	Irradiation		Hypoglycaemia	

<sup>17</sup> Rees, S. et al 2004. Learning disabilities in Health Care Needs Assessment. Ratcliffe, Oxford.

## **5.1 Genetic Factors**

Internationally, iodine deficiency is the commonest cause of severe learning disabilities. In the U.K. the commonest causes are related to genetic factors. Non-inherited Down's syndrome causes about 30% of cases at birth. The second most common known causes are X-linked disorders, most commonly fragile X syndrome. Other single gene disorders, of which more than 200 have been identified, account for 12% of cases. Known genetic disorders cause only 5-10% of cases of mild learning disabilities, although more are being identified.

## **5.2 Non-genetic factors**

25% of severe learning difficulties which result from non-genetic causes are related to infection, non-accidental injury and accidents. A further 10% are caused by obstetric complications and injuries at birth. This may account for observed associations between learning disabilities and factors such as epilepsy and cerebral palsy. Infective causes are uncommon and the outcome is variable. For example, rubella in early pregnancy can severely affect the development of children who survive, with infection later in the pregnancy tending to have a less severe effect. Antenatal HIV infection may cause delay in cognitive development and toxoplasma and cytomegalovirus can also have an impact. Dietary folate deficiency is associated with an increased risk of neural-tube defects.

## 6. Incidence and Prevalence

### 6.1 Measuring incidence and prevalence

There are a number of factors which hamper the calculation of prevalence and incidence of learning disabilities. The fact that the underlying causes of learning disabilities can be genetic, infection and environmental implies that there is a broad spectrum of disorders covered by the single generic term. In addition, the meaning of those terms which are related to learning disabilities have been changed over time.

A study in Scotland called *The Same as You?*<sup>18</sup>, estimated that about 20 in every 1000 people have a mild to moderate learning disability and that 3-4 people in every 100 have severe or profound disabilities. In a critical review of recent studies Roeleveld et al<sup>19</sup> found that the prevalence of learning disabilities varied from 2 to 85 per 1000 population. The review found an average of 3.8 per 1000 for severe learning disabilities and 34 per 1000 for mild learning disabilities.

More males are born with learning disabilities than females<sup>20</sup>; this is because some causes of learning disabilities which are genetically determined are specifically related to males. The gender ratio of people with learning disabilities is about 60% male and 40% female<sup>21</sup>. These proportions change with age, as females are more likely to live longer.

With regard to the medical conditions, there are a number which particularly pertain to people with learning disabilities. The frequency of most common medical conditions, for example, is similar between those with learning disabilities and the population generally. However there is an increased frequency of thyroid disorders, non-ischaemic heart disease and sensory impairment<sup>22 23</sup>. People with learning disabilities have lower levels of arthritis

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<sup>18</sup> Scottish Executive, 2000 *The Same as You? A review of Services for People with Learning Disabilities*. TSO, Edinburgh (IV)

<sup>19</sup> Roeleveld, L. et al 1997 The prevalence of mental retardation: A critical review of recent literature. *Developmental Medicine & Child neurology* **41**, pp 233-9 (III)

<sup>20</sup> Fryars, T 1997. Impairment, disability and handicap: Categories and classification. In *Seminars in the Psychiatry of Learning Disabilities* (ed O. Russell), Gaskell, London (IIb).

<sup>21</sup> NHS Scotland 2004. *People with Learning disabilities in Scotland*. TSO, Edinburgh (IV).

<sup>22</sup> Kapell, D., et al, 1998 Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation* 1998: **36(4): pp 269-**

and back pain, when compared with the general population<sup>24</sup>. People with learning disability have fewer natural teeth (on average less than 20 including teeth which have been capped or filled) than the general population. However, although they have high levels of poor oral hygiene this is no worse than the general population<sup>25</sup>.

People with learning disabilities are less likely to smoke than the general adult population. Smoking habits have changed so much in the last decade, in general. The Welsh Health Survey 1995 suggested that fewer people with learning disability were recorded as being smokers or ex-smokers, compared with the general adult population of Wales. The current smoking prevalence in the general population of Leicester is approximately 21% and evidence suggests that the prevalence of smoking for people with learning disabilities is lower still. Anecdotal evidence suggests that those with learning disabilities who do smoke are more likely to have a certain degree of independence and may have been initiated into smoking by others.

Life expectancy is a key measure of Public Health, and can be used to determine the health of a population. The life expectancy of the population of people with learning disabilities is increasing, but it remains lower than that of the general population<sup>26</sup>. At the end of the 1920s the average life expectancy for a child with Down's syndrome was 9 years<sup>27</sup>, and for people with learning disabilities in general in the 1930s the average life expectancy was 15 years for males and 22 years for females<sup>28</sup>. Today life expectancy for people with learning disabilities is much longer, although they still have an increased risk of early mortality.

The risk of dying before the age of 50 has been shown to be 58 times greater than in the population generally. Life expectancy diminishes with severity of impairment. For example, those with a mild impairment may differ little from

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### **79 (IIa).**

<sup>23</sup> Beange, H. et al, 1995. Medical disorders of adults with mental retardation: a population study. *American Journal on Mental Retardation* 1995; **99(6): pp 595-604 (IIa)**.

<sup>24</sup> Welsh Office. 1996. Welsh Health Survey 1995. London. HMSO (IV),

<sup>25</sup> Royal College of Surgeons, Oral Health Care Guidelines for people with a learning disability (IV).

<sup>26</sup> McGuigan, S.M. et al. 1995. Age-specific standardised mortality rates in people with Learning Disability. *Journal of Intellectual Disability Research*; **39** pp 527-31 (IIa).

<sup>27</sup> Penrose, L. 1949. The incidence of mongolism in the general population. *Journal of Mental Science* **9** p 10 (Ia).

<sup>28</sup> Puri, B.K. et al 1995. Mortality in a hospitalised mentally handicapped population: A 10-year survey. *Journal of Intellectual Disability Research* **39** pp 442-6 (Ia).

the general population. Other evidence suggests that up to the age of 35 years mortality rates people with Down's syndrome are similar to those with learning disabilities in general. However, after the age of 35 mortality rates for people with Down's syndrome doubles every 6.4 years compared with 9.6 years in people with learning disabilities linked with other causes<sup>29</sup>. According to *People with Learning Disabilities in Scotland*<sup>30</sup> life expectancy is shortest for people with learning disabilities who are the least able.

Predictors of early death include the inability to walk, cerebral palsy, incontinence and epilepsy. The leading cause of death in a study based in London was respiratory disease (52% of cases compared with 15% in the general population). There may be issues relating to sub-optimal treatment as well as poor diagnosis. Other evidence points to those with learning difficulties and hearing impairment, reduced mobility, tube feeding and male gender as having higher rates of mortality than the general population.

Thus, respiratory disease, often as a result of aspiration of food, posture and feeding problems, is one leading cause of death among people with learning disabilities. In addition, there are high rates of cardiovascular disease, although this contrasts with the general population as the main cause is congenital, rather than ischaemic, heart disease.

This reduced life expectancy shows that people with learning difficulties are disadvantaged in comparison to the general population. Where there are services available people with learning disabilities benefit less from them. Therefore there is a need to address this inequality.

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<sup>29</sup> Strauss, D. & Eyman, R. 1996. Mortality of people with mental retardation in California with and without Down syndrome, 1986-91. *American Journal on Mental Retardation* **100** pp 643-53 (1a).

<sup>30</sup> NHS Scotland 2004. *People with Learning disabilities in Scotland*. TSO, Edinburgh (IV)

**Table 4: Studies of the prevalence of people with Learning Disabilities<sup>31</sup> (for individual sources see endnotes)**

Year	Age Group	Geographical Area	Study population with learning disabilities	Study Type	Prevalence per 1000				
					Mild	Moderate	Severe	Profound	Total
1997 <sup>i</sup>	Lifespan	Worldwide	N/A	Critical review	34	3.8			37.8
1998 <sup>ii</sup>	median age 10.8 years	Norway	185	Population based of 1980-85 birth cohort	3.5	1.5	0.4	0.8	6.2
1999	Unspecified	France	1,150	Retrospective survey of 1976-85 birth cohort	N/A	3.5 combined			N/A
2001 <sup>iii</sup>	Lifespan	USA	945,091	Non-institutionalised population cross-sectional survey 1994-5	N/A	N/A	N/A	N/A	7.8
2002 <sup>iv</sup>	20 yrs and over	Leicestershire	105	Population based cross-sectional administrative prevalence in 1991	N/A	N/A	N/A	N/A	3.58
2002 <sup>v</sup>	14-20 yrs	Ontario	225	Population based screening study in 1994	3.54	3.64 combined			7.18
2003 <sup>vi</sup>	11.5 yrs	Northern Finland	105	Population based 1985-86 birth cohort	7.49	1.71	0.75	1.28	11.23
2003 <sup>vii</sup>	Children	Western Australia	3,426	Population based 1983-92 birth cohort	10.6		1.4		12 +/- 2.3 per 1000 unspecified

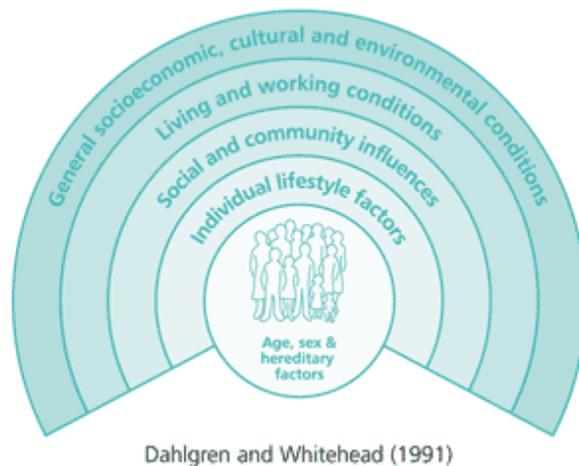
One of the most important issues to consider for the health and wellbeing of people with learning disabilities is the link between risks factors for poor health outcomes and socio-economic factors. Poor physical and mental health is both a contributor to and a consequence of wider health inequality<sup>32</sup>. Health, individual resilience to illness and social exclusion are influenced by and interact with a range of factors. The *Independent Inquiry into Health Inequalities report*<sup>33</sup> adopted a socio-economic model of health in line with the weight of scientific evidence. This model is shown in Figure 1, below.

<sup>31</sup> NHS Scotland 2004. People with Learning disabilities in Scotland. TSO, Edinburgh (IV)

<sup>32</sup> DH, 2009, *Hew Horizons*, London HMSO (III)

<sup>33</sup> Acheson, D., et al, 1998, *Report of the Independent Inquiry into inequalities in health*, London, HMSO (Ib)

**Figure 1: Socio-economic model of influences on health**



The model shows the main determinants of health which have a cumulative effect on health and wellbeing. At the centre are factors which cannot be altered, such as gender and genetic factors. These clearly have an impact on those people with learning disabilities, and will have a concomitant impact on the other factors which influence health.

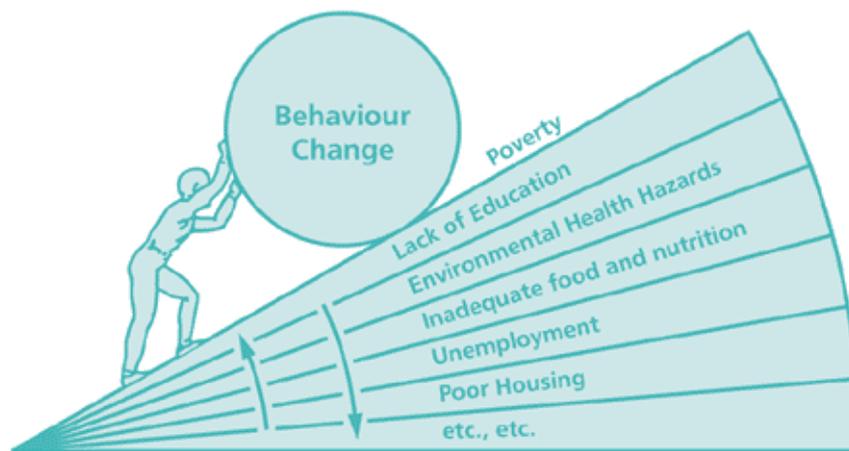
Surrounding the centre are factors which can be modified, but would also need to be given consideration for people with learning disabilities. The first layer represents personal behaviour and individual lifestyle, which comprises factors that have the potential to promote or damage health, such as smoking and physical activity. The second layer is made up of social and community factors, in effect the impact of social interaction on sustaining health and the adverse effect of isolation. Layer three includes living and working conditions and the outer layer represents economic, cultural and environmental conditions prevalent in society as a whole.

Many of these influences on health are underpinned by a social gradient, with conditions conducive to health becoming less favourable with declining social status. People from the more deprived quintiles have a greater exposure to health hazards and risk factors, resulting in health inequalities. The *Annual Report of the Director of Public Health for Leicestershire 2001*<sup>34</sup> used the diagram below to show how promoting healthy lifestyles for people in disadvantaged circumstances is unlikely to be effective without appropriate

<sup>34</sup> LHA, 2001, Annual Report of the Director of Public Health for Leicestershire 2001, Leicester, LHA (III)

support and structural changes. Again this is likely to have a significant impact on people with learning disabilities. Marmot et al<sup>35</sup> suggested that the impact of this social gradient is such that better a social and economic position results in better health. One explanation for this is that relative deprivation may provoke negative emotional and cognitive responses to inequity<sup>36</sup>.

**Figure 2: Barriers to behaviour change based on socio-economic model (LHA, 2001)**



Measures of deprivation and disadvantage, such as unemployment, overcrowding, few educational qualifications and those who are lone parents with dependent children have been shown to have a detrimental impact on health<sup>37</sup>. Relative deprivation is also associated with increased risk of mental illness<sup>38</sup> with those in lower income groups having higher rates of mental illness, decreased rates of trust and social capital<sup>39</sup>. In turn mental illness further exacerbates inequality as it increases poorer economic, health and social outcomes<sup>40</sup>. On measures of deprivation Leicester has a rate which is higher than the national average<sup>41</sup>.

<sup>35</sup> Marmot, M. et al 2010, Fair society, healthy lives. Strategic review of health inequalities in England post 2010 (III) [www.ucl.ac.uk/gheg/marmotreview](http://www.ucl.ac.uk/gheg/marmotreview)

<sup>36</sup> Marmot, M and Wilkinson, R., 2006 Social Determinants of Health 2<sup>nd</sup> Ed Oxford, OUP (III)

<sup>37</sup> Barry, M. and Friedli, L., 2008 The influence of social, demographic and physical factors on positive mental health in children, adults and older people: State of science review. Foresight SR-B3 v1 Stage. Foresight, Mental Capital and Wellbeing: Meeting the challenge of the 21<sup>st</sup> century. Government Office for Science, London (III)

<sup>38</sup> Melzer, D. et al, 2004 Social Inequalities and the distribution of common mental illness. Maudsley Monographs, Hove, Psychology Press (IIb)

<sup>39</sup> Wilkinson, R. and Pickett, K., 2007 The problems of relative deprivation: why some societies do better than others. Social Science and Medicine 65(9) pp 1965-78 (III)

<sup>40</sup> WHO, 2005 Mental Health Declaration for Europe. Facing the challenges. Building Solutions. [www.euro.who.int/document/mnh/edoc.pdf](http://www.euro.who.int/document/mnh/edoc.pdf) .

<sup>41</sup> SCMC, 2003 The economic and social costs of mental illness

One tool which could be used by commissioners to address such inequalities is to develop and implement a health gain schedule. This would represent a clear undertaking by providers of health care to deliver the health services to the level and standard detailed by service commissioners. It would also enable the commissioners to secure quality health services for people with learning disabilities, which are responsive to need, deliver equitable outcomes and which deliver ongoing improvements in the health and well-being of the population.

## 6.2 People on learning disability register in Leicester

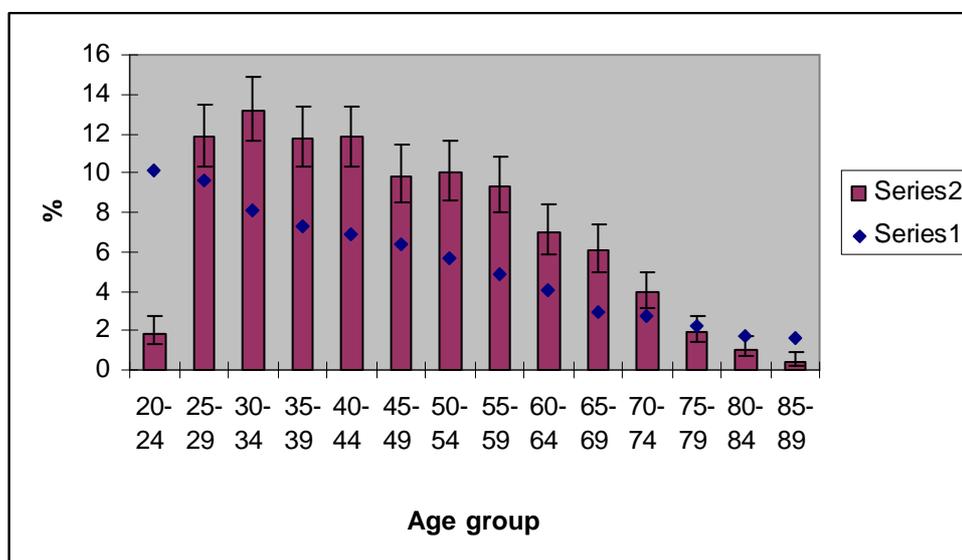
The Register of people with learning disabilities in Leicester is a valuable source of information, and is possibly the best source of local data. Stakeholders are currently looking for ways of collecting valid general practice level data, which could further improve the accuracy of the data currently held. In April 2010 there were 1611 people on the register. The rate of people on the LD register, against the population of 347,774 registered with the General Practices in Leicester, is 4.62 per 1000. This figure is slightly higher than the 3.8 per 1000 in the review quoted in section 5.1.

**Table 5: People on the Learning Disability Register in Leicester by age group (Source: University of Leicester)**

Age group	Freq	%	95% CI	
			Lower	Upper
20-24	30	1.86	1.3	2.7
25-29	190	11.81	10.3	13.5
30-34	211	13.12	11.6	14.9
35-39	189	11.75	10.3	13.4
40-44	190	11.81	10.3	13.4
45-49	158	9.82	8.5	11.4
50-54	161	10.01	8.6	11.6
55-59	150	9.3	8	10.8
60-64	113	7.02	5.9	8.4
65-69	98	6.09	5	7.4
70-74	63	3.91	3.1	5
75-79	31	1.92	1.4	2.7
80-84	17	1.05	0.7	1.7
85-89	7	0.43	0.2	0.9
Total	1608	100		

Table 5 shows 1608 of these people according to age group. When compared with the proportion of the registered General Practice population of 347,774, it shows that there are significantly higher proportions of people on the LD register aged between 30 and 69 and significantly lower proportions of people aged over 75 years (Figure 3).

**Figure 3: People on the Learning Disability Register in Leicester by age group compared with General Practice population of Leicester (Source: University of Leicester)**



(Legend: Series 1: General Practice population; Series 2: LD register)

Section 5.1 also suggested that the national proportion of males and females with learning disabilities is approximately 60:40. This is also the case with those people recorded on the LD register in Leicester. The 672 female cases amount to 41.7% (95% CI; 39.3, 44.1) of the 1611, and the 939 males comprise 58.3% (95% CI; 55.9, 60.7). The ethnicity of the people who are on the LD register is discussed in more detail below.

With regard to residential area, the parameters recorded for the purposes of the LD register are either city east or city west. This is shown in Table 6, which indicates that people with learning disabilities are equally spread over both the eastern and western ward areas of Leicester.

**Table 6: People on the Learning Disability Register in Leicester by sex, ethnic background and residence (Source: University of Leicester)**

	Freq	%	Lower	Upper
<b>Sex</b>				
Female	672	41.7	39.3	44.1
Male	939	58.3	55.9	60.7
Total	1611	100.0		
<b>Ethnicity</b>				
Asian	414	25.7	23.6	27.9
Black	42	2.6	1.9	3.5
Mixed	17	1.1	0.7	1.7
Not known	106	6.6	5.5	7.9
Other	9	0.6	0.3	1.1
White	1023	63.5	61.1	65.8
Total	1611	100.0		
<b>Residential area</b>				
City East	795	49.3	46.9	51.8
City West	816	50.7	48.2	53.1
Total	1611	100.0		

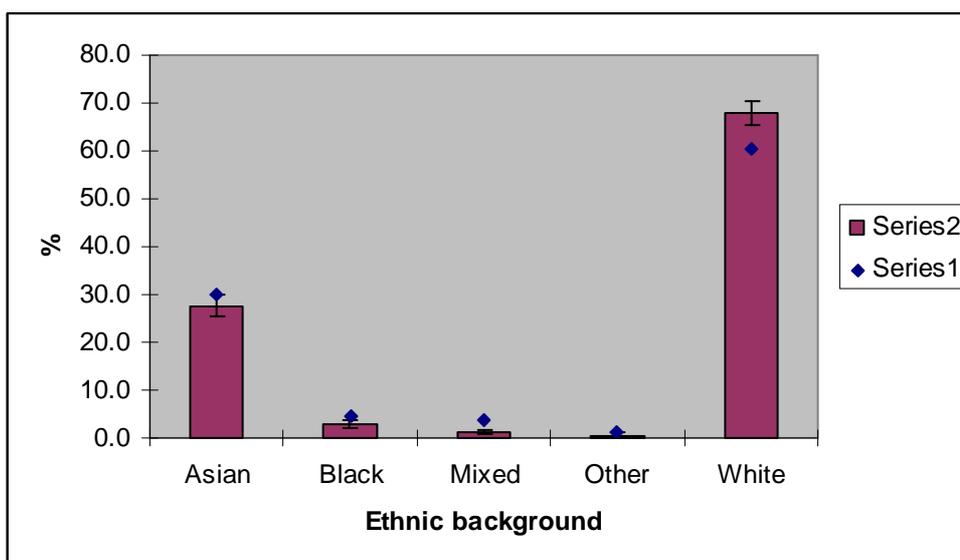
Table 7, below, shows the proportions of the ethnic backgrounds of those people on the LD register without the 106 people whose ethnic background is not recorded. This data is compared with the latest available ethnicity data for Leicester. It is important to note that this data is for people aged over 16 years, so it is not exactly comparable to the register which starts from age 20 years.

The data suggests that 68% of people on the LD register are from a White/White British ethnic background. This is an over representation when compared with the General Practice population of Leicester who are aged over 16 years, which is estimated as 60.4%. Given that studies have indicated that the prevalence of learning disabilities among people from Asian/Asian British ethnic backgrounds is higher than the population generally, the proportion of people on the register from an Asian/Asian British ethnic background appears to be lower than expected at 27.5% compared with the Leicester Practice Population of 29.9%.

**Table 7: People on the Learning Disability Register in Leicester by ethnic background (Source: University of Leicester)**

	Freq	%	Lower	Upper	Leicester >16yrs
<b>Ethnicity</b>					
Asian	414	27.5	25.3	29.8	29.9
Black	42	2.8	2.1	3.8	4.7
Mixed	17	1.1	0.7	1.8	3.6
Other	9	0.6	0.3	1.1	1.4
White	1023	68.0	65.6	70.3	60.4
Total	1505	100.0			100.0

**Figure 4: People on the Learning Disability Register in Leicester by ethnic background compared with GP population of Leicester (Source: University of Leicester)**



(Legend: Series 1: General Practice Population; Series 2: LD register)

### **Key Messages from LD register:**

- **The rate of Learning Disabilities on the Register in Leicester when compared to the General Practice population in Leicester is 4.62 per 1000, slightly higher than the 3.8 per 1000 nationally.**
- **Significantly higher proportions of people on the LD register are aged between 30 and 69 and significantly lower proportions of people aged over 75 years.**
- **The ratio between males and females with Learning Disabilities is approximately 60:40.**
- **There is an over representation of people when compared with the population of Leicester, aged over 16 years, which was estimated as 60.4%.**
- **Given that studies have indicated that the prevalence of learning disabilities among people from Asian ethnic background is higher than the population generally, the proportion of people on the register from an Asian/Asian British ethnic background appears to be lower than expected at 27.5% compared with the Leicester General Practice Population of 29.9%.**

### **6.3 Physical impairment**

Long term cohort studies have shown that there is an effect of social class on cognitive development. In addition, the incidence of specific conditions, such as cerebral palsy, is also associated with socio-economic deprivation. One possible explanation for such trends is poor nutrition and low uptake of screening in the antenatal period among people in lower socio-economic groups. There is some evidence to suggest that there is an increased prevalence of learning disabilities in the Asian/Asian British Asian population<sup>42</sup>.

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<sup>42</sup> Emerson, E. et al. 1997. Is there an increased prevalence of severe learning disability amongst British Asians? *Ethnic Health* 1997 2(4) pp 317-21 (11b).

## 6.4 Syndromes

The term trisomy is used to describe the presence of three chromosomes, rather than the usual pair of chromosomes. For example, if a baby is born with three number 21 chromosomes, rather than the usual pair, the baby would be said to have trisomy 21. Trisomy 21 is also known as Down's syndrome. Other examples of trisomy include trisomy 18 and trisomy 13. Again, trisomy 18 or trisomy 13 means there are three copies of the number 18 chromosome (or of the number 13 chromosome) present in each cell of the body, rather than the usual pair.

### 6.4.1 Down's syndrome

The frequency of Down's syndrome is associated with maternal age. When the maternal age is 20 the risk is 0.5 per 1000 births; this rises to 10 per 1000 when the maternal age is 40 and 150 per 1000 at age 50<sup>43</sup>. Despite routine antenatal screening for Down's syndrome in the UK, the birth prevalence is rising; in 1996 the observed birth prevalence was 0.91 per 1000 births, this rose to 1.04 per 1000 in 1998<sup>44</sup>. The majority of people with Down's syndrome have an IQ of between 35 and 55, although 10% have an IQ of less than 20.

People with Down's syndrome have a higher incidence of physical health problems than the population in general. For example; 30-45% have congenital heart disease; 6% have gastro-intestinal problems; 1% develop childhood leukaemia; 70% have hearing problems; 50% have sight problems; there is a higher rate of periodontal disease; there is evidence of higher rates of early onset dementia<sup>45</sup>. There is evidence of early mortality for people with Down's syndrome, who are aged over 35 years, in comparison with other groups with intellectual impairment. Approximately 50% of those with Down's syndrome live until 60 years of age.

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<sup>43</sup> Nicholson, A. et al 1992. Prediction of the number of Down's syndrome Infants to be born in England and Wales up to the year 2000 and their likely survival rates. *J Intellect Disabil Res* 1992; 36 pp 505-17 (Ib).

<sup>44</sup> Huang, T. et al 1998. Birth prevalence of Down's syndrome in England and Wales 1990 to 1997. *J Med Screen* 1998; 5 pp 213-4. (Ia)

<sup>45</sup> Turner, S and Moss, C. 1996. The health needs of adults with learning disabilities and the Health of the Nation Strategy. *J Intellect Disabil Res* 1996; 40 pp 438-50 (Ib).

Compared with people with learning disabilities, those with Down's syndrome have a significantly higher rate of hypothyroidism<sup>46</sup>. This is a condition in which a person does not produce enough thyroid hormone. The condition may be present at birth or it may be acquired.

The symptoms of low thyroid hormone are difficult to distinguish, especially in infants. They include decreased growth, decreased development, an enlarged tongue, decreased muscle tone, dry skin and constipation. They are difficult to differentiate because such symptoms may be expected to be found in an infant with Down's syndrome. In adults the symptoms could be dry skin, poor memory, slow thinking, muscle weakness, fatigue, muscle cramps, cold intolerance, puffy eyes, constipation and hoarseness.<sup>47</sup> Some studies have showed a correlation between hypothyroidism and neurobehavioural and neuromuscular differences, increased cardiovascular problems because of raised lipid levels and impairment of myocardial function. The presence of anti-thyroid antibody is higher amongst people with Down's syndrome. Anti-thyroid antibodies are rare in children under 8 years of age, but titres increase with age<sup>48</sup>.

Thus regular screening of the thyroid function is recommended for children with Down's syndrome at birth, 6 months of age, 1 year of age, and once a year thereafter, regardless of their growth.

With regard to the number of people with Down's syndrome in Leicester, Table 8, shows that the NCHOD data suggests that in 2009 there were 121 people aged between 18 and 64 in the city. In the next 5 years this is projected to rise to 126 people. By the year 2030 it is estimated that there will be 136 people aged between 18 and 64 with Down's syndrome in Leicester.

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<sup>46</sup> Kapell, D., et al, 1998 Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation* 1998: **36(4): pp 269-79 (III)**.

<sup>47</sup> Toscano, E., et al 2003. Subclinical hypothyroidism and Down's syndrome; studies on myocardial structure and function (IIa)

<sup>48</sup> Rubello, D. et al. 1996. Natural course of subclinical hypothyroidism in Down's syndrome: prospective study of results and therapeutic considerations. *J Clin Gastro* 1996: 23(3) pp 181-4 (Ia).

**Table 8: Number of people age 18 to 64 with Down's syndrome in Leicester (Source NCHOD) 2009 with 5 year and 20 prediction.**

Age group	Year				
	2009	2010	2011	2012	2013
18 to 24	27	27	27	26	26
25 to 34	30	31	32	33	34
35 to 44	26	26	25	25	25
45 to 54	22	22	23	23	23
55 to 64	17	17	18	18	18
Total aged 18 to 64	121	123	124	125	126
	2009	2015	2020	2025	2030
18 to 24	27	25	24	25	28
25 to 34	30	35	36	34	33
35 to 44	26	25	27	30	30
45 to 54	22	24	24	23	24
55 to 64	17	18	20	21	21
Total aged 18 to 64	121	127	129	132	136

#### 6.4.2 Other Trisomies

Trisomy 18 (Edwards syndrome) and trisomy 13 (Patau syndrome) are genetic disorders that present a combination of birth defects including severe mental retardation, as well as health problems involving nearly every organ system in the body. 90% of babies born with trisomy 18 or 13 die before their first birthday, although between 5 and 10% survive the first year of life. Rare cases of trisomy 18 or 13 have survived until their teens. The fact that a significant proportion of infants succumb within the first 24 hours is a major contributing factor to the short median survival time.

As life expectancy is short, one of the reasons why it is important to consider such conditions is that parents will require counselling following pre or postnatal diagnosis. Brewer et al<sup>49</sup> found that there have been six population surveys of survival in trisomy 18, comprising 430 unselected cases and two such studies of trisomy 13 involving 35 cases. Using information available on infants with trisomy 13 or 18 born in Scotland from 1974 to 1997, this study included a calculation of median survival times in this population and prepared

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49 Brewer, C. et al 2002 Survival in trisomy 13 and trisomy 18 cases ascertained from population based registers Journal of Medical Genetics 2002;39:54(la)

revised figures which take into account continued survival.

They reviewed 32 cases of trisomy 13 from Scottish Trisomy Register and the Glasgow Register of Congenital Anomalies. The median survival time was 8.5 days (range 1-412 days). For infants with trisomy 18, data were complete in 59 out of 63 cases recorded in the Scottish Trisomy Register and in all 25 cases recorded in the Glasgow Register of Congenital Anomalies giving a total of 84 cases for analysis. The median survival was 6 days (range 1-975 days).

Babies with trisomy 18 appear thin and frail. They fail to thrive and have problems feeding. Trisomy 18 causes a small head size, with the back of the head prominent. Ears are usually low set on the head. The mouth and jaw are unusually small and such children usually have a shortened sternum. At birth, these babies are small for their age, even when delivered full-term, and have a weak cry. Their response to sound is decreased and there is often a history of infrequent foetal activity during the pregnancy. About 90 percent of babies with trisomy 18 have heart defects. They clench their fists because extending the fingers fully is difficult. Such children have joint contractures, with limbs in a bent position. Babies with trisomy 18 may also have spina bifida, eye problems, cleft lip and palate, and hearing loss. It is also common to see feeding problems, slow growth, seizures, high blood pressure, kidney problems and scoliosis (curvature of the spine). In males, the testes sometimes fail to descend into the scrotum.

Babies with trisomy 13 often have low birth weight, even when born full-term. They have a small head, with a sloping forehead. Usually, there are major structural problems with the brain which are diagnosed shortly after birth. Often, the front of the brain does not divide properly, resulting in a condition called holoprosencephaly. This can cause changes in the development of the baby's face, where the eyes are close set, or the nose or nostrils are underdeveloped. Cleft lip and cleft palate are present in 60 to 80 percent of babies with trisomy 13. Eye problems are common and the ears are low-set and unusual in shape. Sometimes, babies with trisomy 13 can have scalp abnormalities (cutis aplasia) which resemble ulcers. They can also have birthmarks which are purplish-red in colour; the colour is due to tiny blood vessels close to the skin (haemangioma).

The frequency of Patau syndrome and Edward's syndrome also increase with

older maternal age. These syndromes are linked to Trisomies 13 and 18. The frequency of these syndromes is about 0.25 to 0.3 per 1000 population. In Leicester there are about 5000 births per year, so extrapolating this rate would result in 1 to 2 cases per year locally.

### **6.4.3 X-linked disorders**

Fragile X syndrome is the most common X-linked disorder. It occurs when the causative gene, Fragile X Mental Retardation 1 (FMR1), fails to make a protein required for the development of the brain. People with only a small change in the gene might not show any signs of Fragile X. People with bigger changes can have severe symptoms. These might include; intelligence problems, ranging from learning disabilities to severe mental retardation; social and emotional problems, such as aggression in boys or shyness in girls; speech and language problems, especially in boys. The most noticeable and consistent effect of Fragile X is on intelligence. More than 80% of males with Fragile X have an IQ of 75 or less. The effect of Fragile X is more variable in females. Some females have mental impairment, learning difficulties, whilst some have a normal IQ.

Physical problems which manifest themselves in adolescents and adults with Fragile X are long ears, faces, and jaws. Many people with Fragile X may also have loose, flexible joints. They may have flat feet and be able to extend joints like the thumb, knee, and elbow further than normal. Many children with Fragile X are bothered by certain sensations, such as bright light, loud noises, or the way something feels. Some do not like to be touched, or have trouble making eye contact with other people.

The symptoms of Fragile X are usually treated with educational, behavioural or physical therapy, and with medicines. Getting treatment early for Fragile X can help. The frequency most often quoted of this disorder is 0.8 per 1000. This would equate to 4 people born with Fragile X in Leicester every year, based on 5000 births per annum. The frequency is also associated with maternal age.

Other X-linked disorders, such as triple X and XXY (Klinefelter syndrome) occur in about 1 per 1000 population of live births (approximately 5 births per year in Leicester). The latter describes a condition in males who have an extra X chromosome in most of their cells. Instead of having the usual XY

chromosome pattern that most males have, these men have an XXY pattern. As not every male with an XXY pattern has all the symptoms of Klinefelter syndrome, it is common to use the term XXY male to describe these men, or XXY condition to describe the symptoms. Scientists believe the XXY condition is one of the most common chromosome abnormalities in humans.

Triple X syndrome is also called trisomy X or 47, XXX. It is characterized by the presence of an additional X chromosome in each of a female's cells. Triple X syndrome results from an extra copy of the X chromosome in each of a female's cells. As a result of the extra X chromosome, each cell has a total of 47 chromosomes (47, XXX) instead of the usual 46. Some females with triple X syndrome have an extra X chromosome in only some of their cells. This phenomenon is called 46, XX/47, XXX mosaicism. Most cases of triple X syndrome are not inherited. The chromosomal change usually occurs as a random event during the formation of reproductive cells.

Although females with this condition may be taller than average, this chromosomal change typically causes no unusual physical features. Most females with triple X syndrome have normal sexual development and are able to conceive children.

Triple X syndrome is associated with an increased risk of learning disabilities and delayed development of speech and language skills. Delayed development of motor skills (such as sitting and walking), weak muscle tone (hypotonic), and behavioural and emotional difficulties are also possible, but these characteristics vary widely among affected girls and women. Seizures or kidney abnormalities occur in about 10 percent of affected females. It is unclear why an extra copy of the X chromosome is associated with tall stature, learning problems, and other features in some girls and women.

Individuals with X-linked disorders have a range of IQs, usually low normal or mildly impaired, and many will have learning difficulties<sup>50</sup>.

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<sup>50</sup> Plomin, R. et al 1997. Cognitive disabilities. In Behavioural Genetics (3<sup>rd</sup> Ed) Basingstoke, Freeman and Co (Iib).

**Key Messages:**

- **People with Down's syndrome have a higher incidence of physical health problems and early death than the population in general.**
- **Counselling is required for parents of children with Trisomies and other disorders.**
- **NCHOD data suggests that in 2009 there were 121 people aged between 18 and 64 in the city. In the next 5 years this is projected to rise to 126 people.**
- **By the year 2030 it is estimated that there will be 136 people with Down's syndrome in Leicester.**
- **The frequency of syndromes linked to Trisomies 13 and 18 is about 0.25 to 0.3 per 1000 population, which would result in 1 to 2 cases per year locally.**
- **The frequency most often quoted for Fragile X is 0.8 per 1000, which would equate to 4 people born with Fragile X in Leicester every year, based on 5000 births per annum.**

**6.4.4 Metabolic disorders: Phenylketonuria**

The term metabolic disorders can be applied to disorders of protein, lipid, carbohydrate or mucopolysaccharide production which can occur. These disorders are rare. Phenylketonuria (PKU) is the most common, with a birth frequency of 0.05-0.07 per 1000 live births. For Leicester this would mean 1 case every 4 to 5 years.

Those with PKU have an excess amount of phenylalanine in their body. Phenylalanine is a naturally occurring substance found in most foods containing protein. In PKU there is a defect in the enzyme phenylalanine hydroxylase, which results in the body being unable to break down phenylalanine. This enzyme is responsible for converting phenylalanine into the essential amino acid, tyrosine. If left untreated the result is a build up of phenylalanine in the body's tissues which can adversely affect brain development and cause learning difficulties.

If it is diagnosed soon after birth PKU can be successfully treated. In the UK, PKU is one of the metabolic conditions which can be identified by the heel prick, Guthrie screening test. This is carried out on all newborn babies by either midwives or health visitors shortly after birth. The amount of phenylalanine in the blood is measured. If abnormally high levels of phenylalanine are detected and PKU is diagnosed, treatment can be started at an early age.

Treatment for PKU involves eating a controlled diet that is low in protein. Therefore, someone with PKU must avoid eating foods that are high in protein, such as meat, poultry and dairy products. Instead, a diet containing an artificial protein that does not contain phenylalanine is recommended in order to lower the amount of phenylalanine that accumulates in the child's body. This treatment usually allows the child to grow and develop normally.

However, even with early institution of dietary therapy people with PKU have a mean IQ which is slightly lower than population matched unaffected individuals. Behavioural and psychological problems remain in some children and adults<sup>51 52</sup>. Many treated individuals with PKU have significant learning disabilities, especially in mathematics, language, visual perception, visual motor skills, abstract thinking and problem solving.

The dietary control of PKU requires the use of special dietary products. A lot of time and effort is attached to achieving this control and consequent acceptable levels of phenylalanine. As with other chronic illnesses decrease compliance and poor dietary control may increase with age. Older people who have discontinued therapy are at risk of suffering loss of intelligence. Some of changes can be seen in magnetic resonance imaging of the brain<sup>53 54</sup>. There is also some evidence of psychiatric disorder in people with PKU. Pietz et al<sup>55</sup> found that the main disorders were those in the depression category of ICD-10., they were more frequent in females.

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<sup>51</sup> Waisbren, S., et al Review of neuropsychological functioning in treated Phenylketonuria: an information processing approach. *Acta Paediatr.* 1994;407 pp 98-103 (III).

<sup>52</sup> Ris, M. et al., Adult psycho-social outcome in early-treated Phenylketonuria. *J Inherit Mental Dis* 1997;20 pp 499-508 (III).

<sup>53</sup> Cleary, M. et al Magnetic resonance imaging in Phenylketonuria: reversal of cerebral white matter change. *J Paediatr* 1995;127 pp 251-5 (IIa).

<sup>54</sup> McCombe, P. et al Spasticity and white matter abnormalities in adult Phenylketonuria *J Neurol Neurosurg Psychiatry* 1992;55 pp 359-61 (III).

<sup>55</sup> Pietz, J. et al Psychiatric Disorders in Adult Patients With Early-treated Phenylketonuria, *Pediatrics* Vol. 99 No. 3 March 1997, pp. 345-350 (III).

### **Key Messages:**

- **The prevalence of PKU 0.05 to 0.07 per 1000 live births, which would equate to approximately 1 case in Leicester every 4 to 5 years.**
- **Screening for PKU is carried out on newborn babies at age between 5 and 8 days.**
- **If high levels of phenylalanine are found then a low protein diet is followed.**
- **People with PKU are also at risk of suffering with mental health problems such as depression.**

### **6.4.5 Epilepsy**

People with learning disabilities have a higher risk of having epilepsy than the general population. This risk increases with the severity of the impairment. The risk of epilepsy in the general population is 0.5%. For those with a mild intellectual impairment, an IQ of between 50 and 70, the risk is approximately 4%. For those with moderate to severe impairment, an IQ range of 20 to 50, the risk is 30%. 50% of those with an IQ of less than 20 have had at least 1 epileptic seizure<sup>56</sup>. Epilepsy is more common in those who have suffered brain injury in the perinatal or post-natal period. Seizures are a cause of excess mortality in people with learning disabilities and there is evidence that they may be linked with mental ill health problems too. However, false positive and false negative diagnoses of epilepsy in people with learning disabilities are possible.

14-24% of people with learning disabilities are affected by epilepsy. If these figures are applied to the 1608 on the LD register, then between 226 and 386 people with a learning disability in Leicester could have epilepsy.

The frequency of life-time history of epilepsy in people with learning disabilities ranges from 7-15% of people with mild to moderate intellectual disability, 45-67% of people with intellectual disability and 50-82% of people with profound disability. The cumulative prevalence of epilepsy at 22 years of age is much higher among those people with learning disabilities and cerebral

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<sup>56</sup> Bird, J. 1993. Epilepsy and Learning Disabilities. In Seminars in the Psychiatry of Learning Disabilities (ed O. Russell), Gaskell, London (IV).

palsy (38%) compared with those who do not (15%).

For people with learning disabilities multiple seizures are common and up to 75% of patients remain refractory to treatment. People with learning disabilities suffer with a range of seizures in comparison to the general population. For example, typical and atypical absences, myoclonus seizures, tonic and atonic seizures are all common amongst people with learning disability, although tonic-clonic and complex partial seizures are the most frequently observed.

There have been recent developments in the management of epilepsy for people with Learning Disabilities. For instance Kerr et al<sup>57</sup> looked to establish an evidence-based guidance for key issues in the management of epilepsy in people with intellectual disabilities. Two recent reviews have also looked at the issue of Learning Disabilities and epilepsy. Fitzgerald et al (2009)<sup>58</sup> looked at the experience of epilepsy, learning disability and mental health problems when occurring in the same individual, suggesting there is a limited evidence-based guiding management strategy, although the most popular anti-epileptic drugs prescribed were found to stabilise a person's mood as well as having an anti-epileptic effect.

Chapman et al 2009<sup>59</sup> looked at difficulties in diagnosing epilepsy in people with learning disabilities, suggesting it may be misdiagnosed in around 25% of cases. The review found eight studies from 105 which met the inclusion criteria, six cohort studies and two case studies. They identified four broad themes from the studies:

- Methods of diagnosis
- Level of misdiagnosis
- Impact of misdiagnosis
- Potential reasons for misdiagnosis

They concluded that that training and awareness-raising for health

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<sup>57</sup> Kerr M, et al. 2009 Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *Journal of Intellectual Disability Research*, 2009, 53, (8):687-694. (IV)

<sup>58</sup> Fitzgerald, B. and , R.H. 2009 Epilepsy, mental health, adults with learning disability – reviewing the evidence. *Psychiatry* 2009; 8 (11):422-424 (Ia) .

<sup>59</sup> Chapman et al 2009 at <http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=345372> last accessed 30<sup>th</sup> November 2010 (Ia)

professionals and family members about misdiagnosis is important, and that future research could gather information about levels of misdiagnosis of epilepsy amongst people with learning disabilities, the impact of reviewing diagnoses, staff and family knowledge, ways of improving diagnosis and knowledge, and the attitudes and experiences of people with learning disabilities and their families.

Many other recent studies have looked at the problem of epilepsy when linked to Learning Disabilities. Bajaj et al (2009)<sup>60</sup> audited practice against NICE guidelines for epilepsy (2004) which included special considerations for people with learning disabilities. After raising awareness about the guidelines, structured yearly reviews were completed in 100% of cases and risk assessment in 75%.

Recent evidence from a study of the rates of seizures in people with Down's syndrome found epileptic seizures present in 6% of 252 children and adolescents participants. Electroencephalography was found to be abnormal in people with Down's syndrome with epilepsy in 100%. 40% of patients with Down's syndrome and epilepsy were found to be seizure-free.

Epilepsy also has an effect on the quality of life for individuals with Learning Disabilities. Kerr et al (2009)<sup>61</sup> suggest that social and economic well-being appears to be affected by an increase in restrictions on activities associated with epilepsy in people with Learning Disabilities. Furthermore, although there is limited knowledge of the long term impact of epilepsy on quality of life, mental health and wellbeing and cognition, there is evidence of a high rate of challenging behaviour and mental illness in this population.

The treatment of people with Learning Disabilities and epilepsy has also been considered in recent studies. Ring et al (2009)<sup>62</sup> reported that for 183 individuals with epilepsy and learning disabilities known to community health services in one geographic area 12% recorded more than 20 seizures per month. In relation to the pharmaceutical therapy which they were receiving, 73 were receiving mono-therapy, (one type of anti-epileptic drug), 66 were

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<sup>60</sup> Bajaj, N. et al. NICE guidelines for epilepsy in learning disabilities service. *Psychiatric Bulletin*. 33(2):0955-6036 (IV).

<sup>61</sup> Kerr M, et al. 2009 Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *Journal of Intellectual Disability Research*, 2009, 53, (8):687-694. (IV)

<sup>62</sup> Ring H, et al. How is epilepsy treated in people with a learning disability? A retrospective observational study of 183 individuals. *Seizure* 2009; 18(4):264-268 (IIb).

treated with two anti-epileptic drugs and 42 were prescribed three or more anti-epileptic drugs. The authors concluded that the optimal treatment for patients in this category was not yet known, because there was no evidence to indicate whether any kind of combination of drugs was associated with significantly lower seizure frequency.

With regard to specific treatments of epilepsy, Carmeli et al (2009)<sup>63</sup> looked at the role of nitric oxide (NO) and interleukin-6 (IL-6) in seizures, suggesting a consideration of chemical inhibitors might be helpful against the function of NO and IL-6. Carpay et al (2009)<sup>64</sup> looked at the long-term usefulness of 'new anti-epileptic drugs (AEDs)' (lamotrigine, Topiramate, Levetiracetam, Gabapentin and Pregabalin) in institutionalised patients with Learning Disabilities. They found that that these medications were tried after a substantial number of other regimens had failed, with the most frequently used being lamotrigine (68%) and Levetiracetam (58%). They conclude that the new anti-epileptic drugs were quite often successful in this very therapy-resistant population.

Martin et al (2009 a)<sup>65</sup> looked at anticonvulsive therapies. Stiripentol (STP) is a new antiepileptic drug, which has been shown to be effective in the treatment of severe myoclonic epilepsy in infancy (Dravet syndrome). STP has strong pharmacological interactions with other drugs and relatively high incidence of adverse events. The study concluded that it might be considered as a possible treatment option for adult patients with pharmaco-resistant epilepsies and severe intellectual disabilities. Martin et al (2009 b)<sup>66</sup> also looked at treatment with Topiramate in a non-interventional single-arm study and found 52% of the 21 patients evaluated experienced at least 50% seizure reduction during the 24-week treatment period. There were two unexpected deaths attributed to sudden unexpected death in epilepsy.

Finally, Huber et al (2009) looked at the impact of tapering barbiturate use in

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<sup>63</sup> Carmeli Eli, et al. Nitric oxide and interleukin-6 levels in intellectual disability adults with epilepsy. *Research in Developmental Disabilities*. 2009; 30(3):567-571. (1a)

<sup>64</sup> Carpay J et al. Retention of new AEDs in institutionalized intellectually disabled patients with epilepsy. *Seizure* 2009; 18(2):119-1311 (1a).

<sup>65</sup> Martin P, et al. Anticonvulsive treatment of adult, learning disabled epilepsy patients. Adjunctive treatment with stiripentol. *Zeitschrift fur Epileptologie* 2009; 22(3):170-174 (1a).

<sup>66</sup> Martin P, et al. Topiramate in patients with epilepsy and intellectual disability. *Epilepsy and Behavior* 2009; 14(3):496-502 (1a).

85 patients with epilepsy and intellectual disability. Despite considerably reducing the number of barbiturate medications, removal of barbiturate side effects was achieved in only one out of four patients.

In 2004 the National Institute for Clinical Excellence (NICE)<sup>67</sup> and the National Collaborating Centre for Primary Care (NCC PC) issued a clinical practice guideline on the diagnosis and management of epilepsy in children and adults. The guideline aimed to ensure that people with epilepsy have access to treatments and interventions that are based on the best available evidence. The priorities highlighted in the guideline included:

- All individuals with a recent onset suspected seizure should be seen urgently by a specialist to ensure precise and early diagnosis and initiation of therapy.
- Drug therapy should be tailored to seizure type, epilepsy syndrome, co-medication, co-morbidity and individual lifestyle factors and preferences.
- All individuals with epilepsy should have an agreed comprehensive care plan which is based on collaboration between the individuals, their family and/or carers and primary and secondary care providers.
- All individuals with epilepsy should have a regular structured review at least annually.
- Individuals with epilepsy should be referred to a tertiary service as soon as possible if their seizures are not controlled and/or there is uncertainty about their diagnosis or treatment failure.
- Individuals with epilepsy and their carers should participate as partners in all decisions about their healthcare.
- Women of childbearing potential should be fully informed about treatment choices and their options during pregnancy and the postnatal period to minimise risk to the child and mother.

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<sup>67</sup> NICE, 2004 The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. Clinical Guideline 20 at <http://www.nice.org.uk/nicemedia/live/10954/29533/29533.pdf>

### **Key Messages:**

- **People with learning disabilities have a higher risk of having epilepsy than the general population.**
- **Estimates suggest that between 14-24% of people with learning disabilities are affected by epilepsy. If these figures are applied to the 1608 on the LD register, then between 226 and 386 people with a learning disability in Leicester could have epilepsy.**
- **Epilepsy may be misdiagnosed in around 25% of cases.**
- **Training and awareness-raising for health professionals and family members about misdiagnosis is important.**
- **NICE Clinical Guidance 20 offers evidence and recommendations for the diagnosis and management of the epilepsies in children and adults in primary and secondary care.**

#### **6.4.6 Cerebral palsy**

Cerebral palsy develops in approximately 2-3 births in every 1000<sup>68</sup>, which would equate to 10 to 15 new cases in Leicester given that the annual number of births is about 5000<sup>69</sup>. It is a general term which refers to a set of neurological conditions that affect a child's movement and coordination. These conditions are caused by damage to the brain, which normally occurs before, during, or soon after birth. The symptoms of cerebral palsy vary from child to child. Some children will have problems walking, while others will be profoundly disabled and require life-long care. Cerebral palsy is not a progressive condition, but it is a condition which can cause problems in later life. Survival with cerebral palsy is significantly poorer in those with severe disability. Severe cognitive, motor (manual and ambulatory), and visual disabilities have independent effects on the probability of survival.

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<sup>68</sup> Bakketeig, L. 1999. Only a minor part of cerebral palsy cases begin in labour (editorial). *BMJ* 1999; **319 p 1017 (IV)**.

<sup>69</sup> NHS Leicester City 2008. Annual Report of the Director of Public Health 2008-09. Leicester. NHSLC (IV).

Evidence suggests that up to half of those people with cerebral palsy will have some difficulty with intellectual functioning and that as much as a third of people with cerebral palsy will have an IQ of less than 50<sup>70</sup>. In the UK approximately 92-136 people per 100,000 have severe learning disabilities and cerebral palsy. The risk of cerebral palsy increases with premature birth and low birth weight. The numbers of people who have cerebral palsy are likely to increase with advances in neonatal care.

According to Hutton and Hemming and the UK Cerebral Palsy collaboration<sup>71</sup> there are a number of characteristics of cerebral palsy:

About three in ten children with cerebral palsy have severe learning difficulties and about one in four children with cerebral palsy are reported to have epileptic seizures. There are more boys born with cerebral palsy than girls: For every 100 girls with cerebral palsy, there are 135 boys. Just under a half of children with cerebral palsy were born prematurely, that is they were born before 37 weeks gestation.

Just over a half of children with cerebral palsy are affected by bilateral spastic cerebral palsy; a third of children with cerebral palsy are affected by hemiplegic spastic cerebral palsy; about one in twenty children with cerebral palsy have dyskinetic and ataxic cerebral palsy. The motor problems which affect those with cerebral palsy mean that one in three children with cerebral palsy are unable to walk; about one in four cannot feed or dress themselves; one in five children cannot walk and cannot use their hands.

People with cerebral palsy have sensory problems. For example, about one in fifty children with cerebral palsy are deaf, they have bilateral severe hearing loss; about one in eleven children with cerebral palsy are blind.

With regard to life expectancy, the longer people with cerebral palsy live the longer they are likely to live. Once a child with cerebral palsy has lived to age ten years he or she has a better chance of living a long life. If a person with cerebral palsy lives to age 18, they are more than likely to live beyond age 40.

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<sup>70</sup> Pharoah, P., et al 1998. Epidemiology of cerebral palsy in England and Scotland, 1984-9. *Arch Dis Child Fetal Neonatal* 1998; **78**; pp 21-5 (1a).

<sup>71</sup> [www2.warwick.ac.uk/fac/sci/statistics/staff/academic/.../scope4.pdf](http://www2.warwick.ac.uk/fac/sci/statistics/staff/academic/.../scope4.pdf) Accessed 23/11/2009.

However, the more severe impairments which a child has the less likely it is that he or she will live to be an adult. Children who are mildly affected by CP can expect to have much the same length of life as a child without CP. A child aged 2, with cerebral palsy, who cannot walk has three chances in four to live to adulthood. Of a hundred children aged five who cannot walk, and cannot feed or dress themselves, 63 will live to the age of 20, and 50 will live to age 30. A child aged 2, with cerebral palsy who cannot walk, and cannot feed or dress him or herself, who also has severe learning difficulties is as likely as not to live to age 25.

There are other factors involved in life expectancy which include sensory loss and activities of living. Half of five year old children who cannot walk, and cannot feed or dress, have severe learning difficulties and are blind will live to be adults. A quarter of two year old children who cannot walk, and cannot feed or dress, have severe learning difficulties and are blind will live into their thirties. A child of two who cannot walk, but is not otherwise severely affected, is very likely (95%) to live to 20 years.

A child of two who cannot walk, or feed and dress but who can see, and does not have severe learning difficulties has a four in five chance of reaching age 20 years. A child of two who cannot walk, or feed and dress and has severe learning difficulties, but who can see, has a three in five chance of reaching age 20 years. A child of two who cannot walk, or feed and dress and has severe learning difficulties, and is blind has a two in five chance of reaching age 20 years. Children who were born preterm have a slightly better outlook than a child with the same impairments who was born at term.

A third of those children with cerebral palsy who die young have cerebral palsy as their underlying cause of death. One in five of those children with cerebral palsy who die young have respiratory disease. Only one in 25 of those children with cerebral palsy who die young have epilepsy as their underlying cause of death. Adults with cerebral palsy die from the same diseases as other people. Heart attacks and strokes are common, as are cancers.

### **Key Messages:**

- **Cerebral palsy develops in approximately 2-3 births in every 1000<sup>72</sup>, which would equate to 10 to 15 new cases in Leicester given that the annual number of births is about 5000**
- **Evidence suggests that up to half of those people with cerebral palsy will have some difficulty with intellectual functioning and that as much as a third of people with cerebral palsy will have an IQ of less than 50**
- **With regard to life expectancy, the longer people with cerebral palsy live the longer they are likely to live. Sensory loss and ability to perform activities of living have an impact on the life expectancy of people with cerebral palsy.**
- **A third of those children with cerebral palsy who die young have cerebral palsy as their underlying cause. One in five of those children with cerebral palsy who die young have respiratory disease and one in 25 have epilepsy.**
- **Adults with cerebral palsy die from the same diseases as other people. Heart attacks, strokes and cancers are common.**

#### **6.4.7 Neural-tube defects**

In the mid-1990s the incidence of anencephaly was estimated to be 0.3 per 1000 births. In this case births included live, still births and pregnancy terminations for neural-tube defects. For spina bifida the rate was 0.38 per 1000. Intellectual impairment is associated with neural-tube defects. When this figure is extrapolated for Leicester, it equates to about one person born per year with neural-tube defects.

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<sup>72</sup> Bakketeig, L. 1999. Only a minor part of cerebral palsy cases begin in labour (editorial). *BMJ* 1999; **319** p 1017 (IV).

## 6.5 Mental disorders

The prevalence of mental illness and behavioural disturbance is higher in all ages in all age groups of people with learning disabilities than in the general population. There is evidence that the exact figures for this prevalence may be difficult to determine because of poor detection, misdiagnosis and the effects and side effects of medication<sup>73</sup>.

The aetiology of mental ill health for people with learning disabilities is the same as in the general population. Social, environmental and biological factors are all involved. Psychiatric disorders are more prevalent in adults with learning disabilities than in the general population<sup>74</sup>. Between 30% and 50% of people with learning disabilities may show a variety of behaviours which are precipitated by problems with communication and physical and mental illness. Rates of schizophrenia are three times higher than in the general population<sup>75</sup>.

There is evidence for a subgroup of patients with mental illness and borderline intellectual functioning who are difficult to treat in mental health services. Many disorders generally go undetected and therefore untreated. Appropriate services are often unavailable or inaccessible<sup>76</sup>. In 2006 Hassiotis et al suggested that there is generally poor provision for children and the elderly who have dual diagnosis of learning disabilities and mental illness<sup>77</sup>.

## 6.6 Challenging behaviours

Challenging behaviours which are accompanied with learning disabilities have a large impact on both those with learning disability and their families. Totsika et al<sup>78</sup> found levels of challenging behaviour to be high in adults with learning

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<sup>73</sup> Tonge B and Einfeld S. 2000 The trajectory of psychiatric disorders in young people with intellectual disabilities, *Australian and New Zealand Journal of Psychiatry*, 34, 80-84.

<sup>74</sup> Deb, S., et al Mental disorder in adults with intellectual disability: prevalence of functional psychiatric illness among a community based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*. 45 pp 495-505 (IIa).

<sup>75</sup> Reid, A., Psychiatry and learning disability. *Br J Psychiatry* 1994; 164 pp 613-8 (III)

<sup>76</sup> Hassiotis, A., et al Mental Health Services for people with learning disabilities *BMJ* 2006 321 pp 583-4 (IV)

<sup>77</sup> *ibid*

<sup>78</sup> Totsika V, et al. Persistent challenging behaviour in people with an intellectual disability. *Current*

disabilities. The levels of challenging behaviour were also found to be stable over time, especially in individuals with autism. Evidence about the factors driving high levels of persistent challenging behaviour is limited.

With regard to specific treatments and therapies, Oliver-Africano et al<sup>79</sup> explored the role of drug treatments, such as antipsychotics, mood stabilisers and antidepressants for people with challenging behaviour. They suggest that the use of drug treatment should be sparing and reserved for patients putting themselves and others at particular risk as a consequence of their behaviour. These conclusions are echoed by Matson and Neal<sup>80</sup> who suggest in their review that the effectiveness of psychotropic medications in managing challenging behaviour is at best minimal, and that controlled studies of higher scientific quality are required. They urge that alternative psychologically based interventions should be considered.

Tyrer et al<sup>81</sup> looked at the effects and cost-effectiveness of Haloperidol, Risperidone and placebo on aggressive challenging behaviour in adults with intellectual disability. The trial found that aggression declined dramatically with all three treatments by 4 weeks, with placebo showing the greatest reduction. Placebo-treated patients showed no evidence of inferior response in comparison to patients receiving neuroleptic drugs. The authors concluded that there were no significant important benefits conferred by treatment with Risperidone or Haloperidol, and treatment with these drugs was not cost-effective. They recommended that prescription of low doses of neuroleptic drugs in intellectual disability on the grounds of greater responsiveness and greater liability to adverse effects also needs to be re-examined.

Hassiotis et al<sup>82</sup> looked at the effectiveness and costs associated with treatment by a specialist behaviour therapy team. They found significant differences in transformed total scores on the Aberrant Behaviour Checklist and transformed lethargy and hyperactivity subscale scores. They concluded that use of a specialist behaviour therapy team in addition to standard

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Opinion in Psychiatry 2009; 22(5):437-441 (IV)

<sup>79</sup> Oliver-Africano P, et al. Aggressive behaviour in adults with intellectual disability: Defining the role of drug treatment. *CNS Drugs* 2009; 23(11): 903-913 (Ib).

<sup>80</sup> Matson J.L, et al. Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. *Research in Developmental Disabilities* 2009; 30(3):572-586 (IV).

<sup>81</sup> Tyrer P. Neuroleptics in the treatment of aggressive challenging behaviour for people with intellectual disabilities: a randomised controlled trial NACHBID. *Health Technology Assessment* 2009;13(21): 1-76.

<sup>82</sup> Hassiotis A, et al. Randomized, single - blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities. *American Journal of Psychiatry* 2009; 166(11):1278-1285

treatment appeared to be more effective in improving challenging behaviour and may have financial advantages over standard treatment. Raghavan et al<sup>83</sup> evaluated the effectiveness of a specialist liaison service in increasing access to and uptake of services for young people with intellectual disabilities and mental health needs from the Pakistani and Bangladeshi communities. They found that participants in the treatment group had statistically significantly more frequent contact with more services and with more outcomes from such contacts than did controls.

They concluded that the liaison worker model was found useful by families, and that this perception was borne out by the results of the study. Results from focus groups showed the treatment group felt better equipped than the control group in seeking contact with appropriate services, and also better equipped to help their son or daughter.

Felce et al<sup>84</sup> collected data on age, gender, adaptive and challenging behaviour, social impairment and psychiatric status of 312 adults with learning disabilities and found that challenging behaviour was higher among participants meeting threshold levels on psychiatric screen. They suggest their findings reinforce previous studies suggesting psychiatric morbidity among people with learning disabilities is associated with higher levels of challenging behaviour.

Two studies looked at family carers, Hatton et al<sup>85</sup> carried out semi-structured interviews with seven majority ethnic family members to explore perceptions of challenging behaviour, support and impact of the person on the family. A number of themes emerged, including the varied relationships with local communities in acceptance and support and the largely negative relationships with services. Families from minority ethnic communities were more likely to report negative experiences. Woodhouse and McGill<sup>86</sup> looked at parental

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<sup>83</sup> Raghavan R, et al. Randomised controlled trial of a specialist liaison worker model for young people with intellectual disabilities with challenging behaviour and mental health needs. *Journal of Applied Research in Intellectual Disabilities* 2009; 22(3):256-263.

<sup>84</sup> Felce D, et al. A general practice-based study of the relationship between indicators of mental illness and challenging behaviour among adults with intellectual disabilities. *Journal of Intellectual Disability* 2009; 53(3): 243-254.

<sup>85</sup> Hatton C, et al. Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact. *Journal of Applied Research in Intellectual Disabilities* 2009; 23(1):63-74.

<sup>86</sup> Wodehouse G, et al. Support for family carers of children and young people with developmental disabilities and challenging behaviour: what stops it being helpful? *Journal of Intellectual Disability Research* 2009; 53(7): 644-653

perceptions and concerns of 13 mothers caring for a child with learning disabilities and challenging behaviour. They found problems reported with generic disability services including accessing good services, obtaining relevant information, working relationships with professionals and issues with respite provision, in addition to concerns about challenging behaviour-specific provision including workers suggesting ineffective strategies, lack of expertise, insufficient input and exclusion from services. The authors conclude that there is a need for more preventative approaches, widespread adoption of effective behaviour management and improved partnership between professionals and families.

Bhaumik et al<sup>87</sup> reviewed 51 people leaving long stay hospital with a view to assessing changes in aggressive challenging behaviour and psychotropic drug use following resettlement. A person-centred approach was used. They found statistically significant reductions in scores on the Modified Overt Aggression Scale at the 6-month post-resettlement for people moving to supported living, residential homes, nursing homes and group as a whole with reductions seen in all four types of aggressive behaviour. The conclusion of the study was that strong and consistent reductions in observed aggressive challenging behaviour were found and that factors associated with relocation, (improved quality of life, greater community participation and increased contact with friends and family) may have played a role in reducing anger and frustration leading to an observed decrease in aggressive behaviour.

A number of studies focused on self inflicted injury. Cooper et al<sup>88</sup> carried out a prospective cohort study in a general community setting and found point prevalence of self injurious behaviour of 4.9%. The two-year incidence was 0.6% and two-year remission rate was 38.2%. They found lower ability levels, not living with family carers, having attention deficit hyperactivity disorder, visual impairment, and not having Down syndrome were independently related to self harm. As a result they state that their findings suggest that self injurious behaviour was not found to be as enduring and persistent as previously thought.

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<sup>87</sup> Bhaumik S, et al. Aggressive challenging behaviour in adults with intellectual disability following community resettlement. *Journal of Intellectual Disability Research* 2009; 53(3):298-302

<sup>88</sup> Cooper S.A, et al. Adults with intellectual disabilities: prevalence, incidence and remission of self-injurious behaviour, and related factors. *Journal of Intellectual Disability Research* 2009; 53(3):200-216.

Danquah et al<sup>89</sup> also identified a number of factors predictive of ongoing self harm; they found that two factors, self-biting and verbal ability independently predicted continued self harm. They suggested that biochemical mechanisms may also be a factor in chronic self harm behaviour.

## **6.7 Autistic spectrum**

The term autistic spectrum refers to developmental disability that affects social and communication skills.

### **6.7.1 Definition and prevalence of autism**

Autism is a lifelong developmental disability, which is often referred to as part of the autism spectrum or an autism spectrum disorder (ASD). The word 'spectrum' is a way of describing the fact that while everyone who has autism will share three main areas of difficulty, individual conditions will vary. For instance, whilst some people with an ASD will be able to perform a range of activities of daily living whilst others will require specialist support to perform them. The three main areas of difficulty which all people with an ASD share are difficulties in:

- social communication
- social interaction
- social imagination

### **6.7.2 Diagnostic criteria**

Kanner<sup>90</sup> suggested that there were 5 features which should be considered as diagnostic of childhood autism. These were: a profound lack of affective contact with other people; an anxiously obsessive desire for the preservation of sameness in a child's routines and environment; a fascination for objects, which are handled with skill in fine motor movements; mutism or a kind of language that does not seem intended for inter-personal communication; good cognitive potential shown in feats of memory or skills on performance tests. Kanner also emphasised that these features would be evident before a child

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<sup>89</sup> Danquah A, et al. An investigation of factors predictive of continued self-injurious behaviour in an intellectual disability service. *Journal of applied Research in Intellectual Disabilities* 2009; 22(4): 395-399

<sup>90</sup> Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-250.

was 30 months old. Kanner and Eisenberg<sup>91</sup> added to Kanner's earlier work by modifying the diagnostic criteria, suggesting that two factors are essential;

- a profound lack of affective contact
- elaborate repetitive, ritualistic behaviour

They considered that, if these two features were present, the rest of the typical clinical picture would also be found.

Rutter<sup>92</sup> suggested four criteria for defining childhood autism. These were:

- impaired social development which has a number of special characteristics out of keeping with the child's intellectual level
- delayed language development that also has certain defined features and is out of keeping with the child's intellectual level
- insistence on sameness as shown by stereo-typed play patterns, abnormal preoccupations or resistance to change
- that these patterns of behaviour are present before 30 months.

Other attempts to come to a definition of childhood autism include the DSM-IV criteria and the ICD-10 criteria, both of which highlight the issues which have been already raised. For a diagnosis of autism under the criteria laid out by DSM-IV, an autism screening tool must show that a child has all three primary areas:

- **qualitative impairment in social interaction, as manifested by at least two of the following:**

(a) A marked impairment in the use of multiple nonverbal behaviours, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) The failure to develop peer relationships appropriate to developmental level

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<sup>91</sup> Kanner, L. & Eisenberg, L. (1956). Early infantile autism 1943-1955. *American Journal of Orthopsychiatry*, 26, 55-65.

<sup>92</sup> Rutter, M. (1978) Diagnosis and definition. In M. Rutter & E. Schopler (Eds.), *Autism: A Reappraisal of Concepts and Treatment* (pp.1-25). New York: Plenum Press.

(c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) A lack of social or emotional reciprocity

- **qualitative impairments in communication, as manifested by at least one of the following:**

(a) A delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) In those individuals who have adequate speech there is a marked impairment in the ability to initiate or sustain a conversation with others

(c) A stereotyped and repetitive use of language or idiosyncratic language

(d) A lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

- **restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities as manifested by at least one of the following:**

(a) An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) An apparent inflexible adherence to specific, non-functional routines or rituals

(c) A stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)

(d) A persistent preoccupation with parts of objects

DSM-IV also looks at 2 other criteria:

- Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

- The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder

The ICD-10 criteria also considers that childhood autism is a pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and consists of the 3 characteristic types in the areas of social interaction, communication, and restricted, repetitive behaviour.

In autism there are always qualitative impairments in reciprocal social interaction, which take the form of an inadequate appreciation of socio-emotional cues, these may include poor use of social signals and a weak integration of social, emotional, and communicative behaviours; and, especially, a lack of socio-emotional reciprocity.

Qualitative impairments in communications are universal. These take the form of a lack of social usage of whatever language skills are present; impairment in make-believe and social imitative play; poor synchrony and lack of reciprocity in conversational interchange; poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes; lack of emotional response to other people's verbal and nonverbal overtures; impaired use of variations in cadence or emphasis to reflect communicative modulation; and a similar lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

The condition is also characterized by restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. These take the form of a tendency to impose rigidity and routine on a wide range of aspects of day-to-day functioning; this usually applies to novel activities as well as to familiar habits and play patterns. In early childhood particularly, there may be specific attachment to unusual, typically non-soft objects.

The specific manifestation of deficits characteristic of autism change as the children grow older, but the deficits continue into and through adult life with a broadly similar pattern of problems in socialization, communication, and interest patterns. For a diagnosis of autism to be made these developments must have been present in the first 3 years, although the syndrome can be diagnosed in all age groups.

### 6.7.3 Prevalence

There are over half a million people in the UK with an autism spectrum disorder, or approximately 1%. In a city, such as Leicester with a population of about 300,000 people, that would equate to about 3000 people with an ASD. 80% of individuals with ASD have significant intellectual disability. Conversely, autistic 'traits' are very common amongst people with intellectual disability: the full syndrome occurs in 17% overall and 27% of those with an IQ < 50.

### 6.7.4 Male: Female Ratios

The information supplied by ICD-10 suggests that the disorder occurs in boys three to four times more often than in girls. This is generally the pattern in most studies and the excess of boys noted in Kanner's<sup>93</sup> original paper. Some studies suggest that when autism is observed in females it is less severe than in males (Lotter<sup>94</sup>; Brask<sup>95</sup>; Wing<sup>96</sup>; Ritvo et al.<sup>97</sup>; Gillberg et al.<sup>98</sup>).

With regard to functionality, along the spectrum of the disorder, somewhere between one and two thirds of the population are severely or profoundly affected. Gillberg<sup>99</sup> and Gillberg et al.<sup>100</sup> observed that children diagnosed as autistic who were either severely affected or had normal or near normal intelligence.

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<sup>93</sup> Kanner, L. 1943 Ibid

<sup>94</sup> Lotter, V. (1967b). *The prevalence of the autistic syndromes in children*. Unpublished PhD thesis, University of London. (III)

<sup>95</sup> Brask, B. H. (1972). A prevalence investigation of childhood psychoses. In *Nordic Symposium on the Comprehensive Care of the Psychotic Children* (pp. 145-153). Oslo: Barnepsykiatrist Forening (III).

<sup>96</sup> Wing, L. (1981b). Sex ratios in early childhood autism and related conditions. *Psychiatry Research*, 5, 129-137(III).

<sup>97</sup> Ritvo, E.R., Freeman, B.J., Pingree, C., Mason-Brothers, A., Jorde, L., Jenson, W. R., McMahon, W.M., Peterson, P. B., Mo, A. & Ritvo, A. (1989). The UCLA-University of Utah epidemiological study of autism: Prevalence. *American Journal of Psychiatry*, 146, 194-245. (IIa)

<sup>98</sup> Gillberg, C., Steffenburg, S. & Schaumann, H. (1991). Is autism more common now than ten years ago? *British Journal of Psychiatry*, 158, 403-09 (III).

<sup>99</sup> Gillberg, C. (1992). The Emmanuel Miller Memorial Lecture 1991. Autism and autistic-like conditions: Subclasses among disorders of empathy. *Journal of Child Psychology and Psychiatry*, 33, 813-842

<sup>100</sup> Gillberg, C., et al 1991 ibid

## **6.8 Asperger Syndrome**

### **6.8.1 Definition**

Asperger Syndrome (AS) is a neuro-biological disorder generally considered as belonging to the spectrum of autism. Patients with AS have intellectual capacity within the normal range with however a distinct profile of abilities apparent since early childhood. They can exhibit behaviour and marked deficiencies in social and communication skills. People with AS have difficulties in the same three areas highlighted above for ASD:

- social communication
- social interaction
- social imagination.

But whilst there are similarities with autism, people with AS have fewer problems with speaking and are often of average, or above average, intelligence. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. These may include dyslexia and dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD) and epilepsy. People with AS sometimes find it difficult to express themselves emotionally and socially. For example, they may:

- have difficulty understanding gestures, facial expressions or tone of voice
- have difficulty knowing when to start or end a conversation and choosing topics to talk about
- use complex words and phrases but may not fully understand what they mean
- be very literal in what they say

People with AS can be imaginative in the conventional use of the word. For example, many are accomplished writers, artists and musicians. However, they may have difficulty with social imagination, including

- imagining alternative outcomes to situations and finding it hard to predict what will happen next

- Understanding or interpreting other people's thoughts, feelings or actions. The subtle messages that are put across by facial expression and body language are often missed
- Having a limited range of imaginative activities, which can be pursued rigidly and repetitively.

People with AS may have difficulties with one or more of the senses (sight, sound, smell, touch, or taste). The degree of difficulty varies from one individual to another. Most commonly, an individual's senses are either intensified (over-sensitive) or underdeveloped (under-sensitive). For example, bright lights, loud noises, overpowering smells, particular food textures and the feeling of certain materials can be a cause of anxiety and pain for people with AS. People with sensory sensitivity may also find it harder to use their body awareness system. This system tells us where our bodies are, so for those with reduced body awareness, it can be harder to navigate rooms avoiding obstructions, stand at an appropriate distance from other people and carry out 'fine motor' tasks such as tying shoelaces. Some people with AS may rock or spin to help with balance and posture or to help them deal with stress.

### **6.8.2 Prevalence**

AS is an uncommon disorder and information on prevalence is limited but it appears to be more common in males. This population in Leicester would be a proportion of the population of people with an ASD.

## 7. Physical and sensory health problems

People with learning disabilities are a heterogeneous group. They are at risk of poor physical health. Their disability, the risk of poor physical and mental health, means that they are risk of dying early. This section is a brief discussion of some of the physical and sensory health problems which may have an impact on people with learning disabilities.

### 7.1 Cancer

Malinge et al<sup>101</sup> summarises the clinical manifestations and characteristics of leukaemia in Down syndrome reporting on current knowledge of the way in which trisomy 21 affects haematopoiesis and the specific genetic mutations found in leukaemia associated with Down syndrome. This needs assessment has shown that people with Down syndrome show a spectrum of clinical abnormalities, including cognitive impairment, cardiac malformations and craniofacial dysmorphism.

In addition to these illnesses, haematologists have noted that people with Down Syndrome can also show macrocytosis, abnormal platelet counts and may also have an increased incidence of transient myeloproliferative disease, acute megakaryocytic leukemia, and acute lymphoid leukemia. The review summarises the clinical manifestations and characteristics of these types of leukaemia, and provides an update on therapeutic strategies. It discusses recent advances in Down syndrome leukaemia research, and highlights the improved strategies for treating both myeloid and lymphoid malignancies in this population.

Tuffrey-Wijne et al.<sup>102</sup> looked at the needs and experiences of people with learning disabilities and who have cancer from their own perspective. The study utilised participant observation as the main data collection method. They found that previous experience of life (deprivation, loneliness, lack of autonomy and power) shaped participants' experiences of cancer. People with learning disabilities depend on others to negotiate contact with the healthcare system and this could lead to delayed diagnosis and a lack of treatment

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<sup>101</sup> Malinge S, et al. Insights into the manifestations, outcomes, and mechanisms of leukemogenesis in Down syndrome. *Blood* 2009; 113 (12):2619-28.

<sup>102</sup> Tuffrey-Wijne I, et al. People with learning disabilities who have cancer: an ethnographic study. *British Journal of General Practice* 2009; 59(564):503-9.

options. The conclusion of the study suggests that there are significant gaps in knowledge and training among health professionals, leading to disengaged services unaware of the physical, emotional, and practical needs of people with learning disabilities, and their carers.

## **7.2 Coronary Heart Disease**

Coronary heart disease is the second most common cause of death amongst people with learning disabilities, with rates increasing amongst people with learning disabilities as a result of increasing life expectancy and an increase in exposure to risk factors as a result of lifestyle changes associated with living in community settings.

A review conducted by Vis et al<sup>103</sup> focused on the heart and vascular system in patients with Down syndrome. This found an overrepresentation of septal defects and underrepresentation of defects like transposition of the great vessels or aortic co-arctation; that atrioventricular septal defect symptoms usually occur in infancy, with people with Down syndrome at higher risk for pulmonary arterial hypertension. The authors recommended routine screening on thyroid dysfunction to reduce cardiac impairment.

## **7.3 Dental health**

While the epidemiology of dental disease in people with an intellectual disability has not been extensively studied, several studies have indicated high rates of dental disease in this population. Scott et al 1998<sup>104</sup> noted that various types of dental disease, particularly periodontal disease, oral mucosal pathology, and moderate to severe malocclusion, were up to seven times as frequent compared to the general population. In a population study of adults with an intellectual disability, Beange et al<sup>105</sup> found that dental disease was the most frequent health problem, occurring in 86% of subjects.

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<sup>103</sup> Vis J.C, et al. Down syndrome: a cardiovascular perspective. [Review]. *Journal of Intellectual Disability Research*; 2009; 53(5):419-25 (IV).

<sup>104</sup> Scott A, March L & Stokes ML. 1998 A survey of oral health in a population of adults with developmental disabilities: Comparison with a national oral health survey of the general population. *Australian Dental Journal*, 43, 4, 257-61 (III).

<sup>105</sup> Beange H, McElduff A & Baker W. 1995 Medical disorders of adults with mental retardation: a population study. *American Journal on Mental Retardation*, 99, 6, 595-604 (IIa).

## 7.4 Sensory impairments

Sensory impairments amongst people with an intellectual disability have health, educational and environmental implications. Individuals with such impairments require more input to attain equal outcomes.

High frequencies of disorders related to visual impairment have been found in several surveys. Warburg<sup>106</sup> found that non-correctable visual impairment was present in 10% of adults, a rate which is at least 7 times higher than in the general population. Adults with Down syndrome aged 30 years and over are at risk for premature age-related cataract<sup>107</sup>, increasing refractive errors, and degenerative changes to the cornea<sup>108</sup>.

Deafness is common in this population, often unrecognised, and if recognised then often the treatment is sub-optimal<sup>109</sup>. Hearing loss as a result of impacted earwax is a frequent problem in adults with learning disabilities<sup>110</sup>. Those people with learning disabilities who are aged 30 years and over, especially those with Down syndrome, are at risk for early age-related hearing loss<sup>111</sup>.

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<sup>106</sup> Warburg M. 1994 Visual impairment among people with developmental delay. *Journal of Intellectual Disability Research*, 38, 423-432.

<sup>107</sup> Eissler R & Longnecker LP. 1962 The common eye findings in mongolism. *American Journal of Ophthalmology*, 54, 398-406.

<sup>108</sup> Volker-Dieben HMJ, Odenthal MTP, d'Amaro J & Kruit J. 1993 Surgical treatment of corneal pathology in patients with Down Syndrome. *Journal of Intellectual Disability Research*, 37, 169-75.

<sup>109</sup> Wilson D & Haire A. 1992 Health care screening for people with mental handicap in the United Kingdom. In (Ed) Roosendaal J. *Mental Retardation and Medical Care*. Uitgeverij Kerckebosch, Zeist, 58-67.

<sup>110</sup> Crandell CC & Roeser RJ. 1993 Incidence of excessive /impacted cerumen in individuals with mental retardation: a longitudinal investigation. *American Journal on Mental Retardation*, 97, 568-574.

<sup>111</sup> Evenhuis HM, Van Zanten JA, Brocaar MP & Roerdinkholder WHM. 1992 Hearing loss in middle aged persons with Down syndrome. *American Journal on Mental Retardation*, 97, 47-56.

## **8. Treatments and services**

Currently there are a range of service providers for people with learning disabilities. Health care is provided by universal services in primary care. There is a need for all General Practice clusters to know who has a learning disability and how many people with a learning disability there are on the caseload. As there are risks to physical and mental health associated with learning disabilities it is important that those people with learning disabilities have adequate access to services and the health and wellbeing of their carers. There is a need therefore to ensure that primary care offer NICE compliant services for health issues such as cancer, epilepsy, heart disease and dementia, in such a way that is accessible to people with learning disabilities.

Specialist health care for people with learning disabilities is provided by Leicestershire Partnership NHS Trust. Other services involved in the treatment of people with learning disabilities are the community dental services, physiotherapy and occupational therapy. The commissioning organisation for health care currently is NHS Leicester City. Social services are commissioned by the local authority.

With respect to the mental health and wellbeing of people with learning disabilities commissioners need to ensure that services implement strategies to maximise the quality of identification and management of mental disorders for those people with the dual diagnosis of learning disabilities and mental illness.

Specialist commissioning from the Strategic Health Authority underpins dental treatment for people with learning disabilities. Currently the service is provided by Leicestershire County and Rutland PCT. Dental provision is one element of a general service which was provided for patient groups who have difficulties gaining access to General Dental Service or Personal Dental Service providers. The service in Leicester is based at Prince Philip House. The skill mix consists of dentists, dental therapists, dental hygienists, dental nurses and oral health promotion teams. The service sees a full range of patients, a proportion of which are people with learning disabilities. The total number of people referred to the service is about 2500 per year.

The service aims to ensure that education and behavioural interventions, which ensure that appropriate dietary habits are established and oral hygiene practices are made a part of the daily life of persons with learning disabilities and their carers. The service also schedules dental appointments for oral examinations and prophylaxis at regular intervals for those with active disease and those at high risk for oral disease.

## **9. Recommendations**

### **Commissioners should ensure that**

- A learning disabilities commissioning (well-being and illness) strategy based on assessed need and targeted appropriately, which includes an emphasis on how services to support the physical health and well-being of people with learning disabilities.
- There is a register of all people with learning difficulties who are registered with General Practices in Leicester.
- People with learning disabilities have access to a health checks programme aimed at helping to prevent heart disease, stroke, and diabetes and kidney disease.
- The effects and side effects of medication discussed with people with learning disabilities and their families/carers.
- Treatment is available which may alleviate the physical needs of people with learning disabilities such as exercise prescriptions, weight management, smoking cessation, alcohol harm reduction.
- There are physical health interventions for people with learning disabilities in secondary care settings which take into account the impact of acute illnesses, such as infection and dehydration on people with learning disabilities.
- NICE compliant treatment is offered to meet the physical health needs of people with learning disabilities; such as CG 66 Diabetes, CG 18 hypertension, CG 107 COPD, CG 43 Obesity, CG 108 Heart Failure, CG 68 Stroke, CG 20 Epilepsy.

- Services implement strategies to maximise the quality of identification and management of disorders for those people with the dual diagnosis of learning disabilities and mental illness.
- Dental services for people with learning disabilities are able to schedule dental appointments for oral examinations and prophylaxis at regular intervals for those with active disease and those at high risk for oral disease; offer preventive therapies such as fluoride or anti-microbial agents where indicated; adopts a multidisciplinary team approach which includes input from medical professionals and mental health providers, as well as dentists and other dental professionals.
- There is access to screening for age-related visual loss at 45 years and every 5 years thereafter for people with learning disabilities and that there is a vision check at age 30 years for adults with Down syndrome.
- There are equality impact assessments for services which take into account the health and wellbeing of people with learning disabilities; and that these assessments are cross referenced with other equality issues (e.g. race, sexual orientation, physical disability, gender, religion/fait, human rights) in relation to all policies and services.
- The contracts with all service providers of services for people with learning disabilities should include a health gain schedule.

Mark Wheatley

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Sources for Table 4

- <sup>i</sup> Roeleveld, L. et al 1997 The prevalence of mental retardation: A critical review of recent literature. *Developmental Medicine & Child neurology* **41**, pp 233-9
- <sup>ii</sup> Stromme, P. and Valvatne, K., 1998. Mental Retardation in Norway: prevalence and sub-classification in a cohort of 30037 children born between 1980 and 1985. *Acta Paediatrica* **87** pp **291-6**
- <sup>iii</sup> Cans, C. et al 1999. Aetiological findings and associated factors in children with severe mental retardation. *Developmental Medicine and Child Neurology* **41** pp 233-9
- <sup>iv</sup> Larson, S.A., et al 2001. Prevalence of mental retardation and developmental disabilities; estimates from the 1994/5 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation* **106** pp 231-52
- <sup>v</sup> McGrother, C. et al Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire
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- <sup>vii</sup> Leonard H. et al., 2003 Prevalence of intellectual disability in Western Australia. *Paediatric and Perinatal Epidemiology* **17**, 58-67.