Health Needs Assessment for People with Learning Disability in Greater Glasgow and Clyde
Acknowledgements

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# Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
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<tr>
<td>AHP</td>
<td>Allied Health Professional</td>
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<tr>
<td>ALDT</td>
<td>Area Learning Disability Team</td>
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<td>APPG</td>
<td>All-Party Parliamentary Group on Epilepsy</td>
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<td>ASD</td>
<td>Autism Spectrum Disorders</td>
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<tr>
<td>CHD</td>
<td>Coronary Heart Disease</td>
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<tr>
<td>CHP/CHCP</td>
<td>Community Health Partnership/Community Health Care Partnership</td>
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<tr>
<td>CLDN</td>
<td>Community Learning Disabilities Nurse</td>
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<tr>
<td>CLDT</td>
<td>Community Learning Disabilities Team (at Inverclyde)</td>
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<tr>
<td>CNST</td>
<td>Complex Needs Support Team</td>
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<tr>
<td>CYPWLD</td>
<td>Children and Young People with Learning Disabilities</td>
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<td>DS</td>
<td>Down Syndrome</td>
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<td>GG</td>
<td>Greater Glasgow</td>
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<td>GG&amp;C</td>
<td>Greater Glasgow and Clyde</td>
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<tr>
<td>GI</td>
<td>Gastro-intestinal</td>
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<tr>
<td>GORD</td>
<td>Gastro-oesophageal Reflux Disease</td>
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<td>ILDT</td>
<td>Integrated Learning Disabilities Team (at East Renfrewshire)</td>
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<td>IQ</td>
<td>Intelligence Quotient</td>
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<td>JLDT</td>
<td>Joint Learning Disabilities Team (at East Dunbartonshire)</td>
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<td>LD</td>
<td>Learning Disabilities</td>
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<tr>
<td>LDS</td>
<td>Learning Disabilities Service (at West Dunbartonshire)</td>
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<td>LNA</td>
<td>Local Needs Assessment</td>
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<td>NDSCA</td>
<td>National Down Syndrome Cytogenetic Register</td>
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<td>NHS GG&amp;C</td>
<td>NHS Greater Glasgow and Clyde</td>
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<td>NNA</td>
<td>National Needs Assessment</td>
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<tr>
<td>OT</td>
<td>Occupational therapist</td>
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<tr>
<td>PAMIS</td>
<td>Profound and Multiple Impairment Service</td>
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<tr>
<td>PEG</td>
<td>Percutaneous Endoscopic Gastrostomy</td>
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<tr>
<td>PWLD</td>
<td>People/person with Learning Disabilities</td>
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<tr>
<td>PWDS</td>
<td>People with Down Syndrome</td>
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<tr>
<td>QOF</td>
<td>Quality and Outcomes Framework</td>
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<tr>
<td>SIR</td>
<td>Standardized Incidence ratio</td>
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<td>SMR</td>
<td>Standardized Mortality ratio</td>
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<tr>
<td>RCSLT</td>
<td>Royal College of Speech and Language Therapists</td>
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<td>RLDS</td>
<td>Renfrewshire Learning Disabilities Service</td>
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<tr>
<td>SCLD</td>
<td>Scottish Consortium for Learning Disabilities</td>
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<tr>
<td>SLT</td>
<td>Speech and Language Therapist</td>
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<td>SUDEP</td>
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1. The big picture

“People with learning disabilities are individuals. They should be valued for their differences, respected as citizens, supported to speak for themselves and make their own choices. They should not experience discrimination, abuse, harassment or exclusion from the community, of which they are a full part.” – Health Needs Assessment Report. People with Learning Disabilities in Scotland (2004).

“Disabled people, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.” - United Nations (1975) The Declaration on the Rights of Disabled Persons.

“People with learning disabilities and their families are entitled to as full a life as possible. They are entitled to feel valued and to be included in society. They and their carers generally know best what support they need and they should be at the heart of decisions that affect their lives. Barriers that prevent people getting the right help quickly need to be removed and support services should be improved. We all need a better understanding of people with learning disabilities if they and their carers are to get better services and opportunities.” The Same As You? A Review of Services for People with Learning Disabilities (2000).
2. Executive summary

2.1 Epidemiology

1. In Greater Glasgow and Clyde (GG&C), the prevalence of moderate to profound learning disabilities (LD) may be in the range of 3.2-3.8 per 1,000. At present, the primary care local enhanced service LD register (LES LD register) does not record ability level, and so exact prevalence of specifically moderate to profound LD cannot be reported. However, everyone on the register has been verified to have LD. Estimates of mild LD vary, depending on the data source. The ascertained prevalence of LD according to the LES LD register is 5.3 per 1,000. This is the group of people who do, or may in future, call upon the LD services.

2. There are many more people with mild learning impairments than with moderate to severe learning impairments, but the proportion with mild learning impairments who have mild LD can vary considerably over time and with geography, as there are numerous factors that impact on it. Moderate to profound learning impairments are synonymous with moderate to profound LD, and vary to a much lesser extent over time and with geography.

3. From an epidemiological perspective, there is an attraction in considering the population with moderate to profound LD separately from the population with mild LD, as invariably everyone with moderate to profound LD can be ascertained. Conversely, ascertainment of the population with mild learning impairments is variable, dependent upon local social attitudes, local service protocols, and local historical factors influencing service delivery and organisation.

4. In GG&C, specialist LD services provide for persons with mild to profound LD; this is not uniform throughout the UK. From a service perspective, the relevant population for service planning is that who are calling upon, or may call upon services i.e. the people identified to have LD by their primary health care team, their family, their carers, and by themselves. “True” prevalence is of no practical importance unless something happens in society to make the undeclared portion of the population start to demand services unexpectedly. Services do not really need to know this: they need to know how many people in their area are identified/identify themselves as having LD and are likely to call upon the service, and the needs they are likely to present.

5. To follow trends in prevalence of LD over time, it is helpful to focus on the group with moderate to profound LD (although greatest variation will be in the group with mild LD). For GG&C, this can be derived from other work. Options include scaling up findings from a circumscribed proportion of the Greater Glasgow (GG) population who had health checks in 2002-4 (n=1,023), or applying rates from other areas such as Leicestershire age specific prevalence rates to the equivalent age groups in GG&C aged 20 years and older. Both approaches are reported. It is difficult to extrapolate expected rates from published estimates, as these vary, with recent studies of adults reporting rates from 2.19-4.14 per 1,000; a lifespan study reporting 1.3 per 1,000; and studies in childhood reporting rates from 1.4-11 per 1,000. Differences are due to different definitions of LD, age groups, and
methodology, and probably also genuine geographical differences. Extrapolation from older studies may not be valid in view of changes in definition, cohort effects and the Flynn effect (a substantial increase in average IQ scores on intelligence tests which may be about three IQ points per decade, although stagnation has been identified in Scandinavian countries after 1990’s).

6. Summary estimates of moderate to profound LD using the health check information from 2002-4 (61.1% of whom had moderate to profound LD) and LES LD register as of December 2008 are 3.2 per 1,000; rates for Leicestershire are 3.7 per 1,000.

7. Ideally, GG&C would benefit from having a complete, accurate and regularly updated ‘ascertained prevalence LD register’ that records information about the level of ability for all registrants, based on measures of adaptive behaviour. In GG&C, there is no LD observatory commissioned to provide a public health function. The information that exists at present must therefore be interpreted within context, and the purpose for which it was derived. The LES LD register was not designed to provide data on historical trends, and so local data is not available.

8. There is no accurate way of measuring the trend over time in prevalence of moderate to profound LD in GG&C, or elsewhere in the UK. The most reliable trend estimates available are probably those provided by the Leicestershire LD register for moderate to profound LD, but these are difficult to interpret because of limited published data, recent changes in definition of LD made by the register, and the number of people on the register for whom their ability level is not known.

9. Research from Leicestershire suggests prevalence will rise at 1.28% per annum between 2003 and 2013. This forecast suggests that GG&C will accumulate another 34 people with LD (PWLD) with moderate to profound impairment every year (ranging from 2 for East Renfrewshire CHCP to 5 for SW Glasgow CHCP) assuming the percentage of 61.1% reported in the health check information. The equivalent figures assuming the Leicestershire baseline prevalence would be 41 new cases per annum (ranging from 3 for East Renfrewshire CHCP and 4 for SW Glasgow CHCP). These assumptions should however, be treated with caution, as they are based on limited information.

10. Estimates of predicted rises in numbers of people with LD (PWLD) on administrative registers of 1.1% and 0.7% per annum (between 2001 and 2011 and between 2001 and 2021, respectively) have been provided by Emerson and Hatton (2004) for England[1]. If these are applied to GG&C, this would suggest 51 additional cases per annum being added to the LES LD register for the entire Board area, (ranging from 3 for East Renfrewshire CHCP and 7 for SW Glasgow CCHP). However, such predictions should be treated with caution in view of the assumptions involved.

11. These modest predicted increases from Emerson and Hatton conceal the marked increases expected in persons within the 50 years and above age group (2.8% and 2.4% per annum between 2001 and 2011 and between 2001 and 2021, respectively), who are significantly more likely than younger adults to rely on public funding for supported accommodation.

12. Other predictions[2] suggest that currently in GG&C there are between 3,410 and 3,502 people using adult social services for critical, substantial or moderate need (excluding the more variable numbers of people with mild LD) and that in 5 years this will have risen to a range of 4,338 to 4,856, the range depending on the percentage of children with special educational needs and LD who will be
eligible for adult LD social services. By 2026, this is expected to have risen to a range of 6,288 to 7,776.

13. The estimated number of new entrants to adult social care services with multiple and profound LD predicted for GG&C based on these projections by Emerson and Hatton ranges from the current high of 18 per annum to the lowest annual entry of 13 predicted for 2020, with an average of 15. The decline expected over the next 10 years is due to the falling birth rates that existed until 2001.

14. The rate of rise in prevalent numbers of people with moderate to profound LD over the past 30 years is not as steep as many LD services staff suspect on the basis of perceived workloads. Other factors may have come into play in recent years, in addition to the ageing of the population with LD, to create a perceived impact of much greater demand on LD health and social services.

15. Life expectancy is the ideal measure of public health standards in any population, including that of PWLD. Unfortunately, this is very difficult to measure accurately in GG&C because of the small population size. The considerable efforts involved with maintaining high quality datasets required to measure life expectancy (complete identification and recording of the details of each death in all PWLD in GG&C) may not be warranted by the quality of the information gained unless ascertainment registers such as the LES LD register achieves a high sensitivity and specificity and is linked to the General Register Office for Scotland register of deaths.

16. In 2007, there were 7 babies born live with Down Syndrome (DS) in GG according to the EUROCAR dataset and they were all born to women aged 35 years and older. Extrapolation suggests that there might be 10 born in GG&C in that same year. This is less than the 15 predicted by the England and Wales rates obtained from the National DS Cytogenetic Register, but rates fluctuate due to low numbers.

17. The role of social deprivation and high rates of alcohol consumption in parts of GG&C in the aetiology and presentation of LD require further exploration. Foetal alcohol syndrome remains an under-researched area and the demography of GG&C and its alcohol consumption patterns may make it particularly vulnerable to this cause of mild LD.

2.2 Health needs

1. PWLD are a heterogeneous group, and their additional health needs vary, and can be due to the specific cause of their LD. Within the context of the person’s communication needs, the health and social needs of people with mild LD differ from people with moderate to profound LD. Both groups can be vulnerable but in different ways and the characteristics and prevalence of various conditions experienced by these two groups need to be measured and provided for in appropriate ways. With some exceptions, people with mild LD are more likely to be able to use mainstream health services and be subject to population-wide public health approaches while people with moderate to profound LD are more likely to require a combination of specialist LD and mainstream services and may not benefit from the same public health initiatives, which are not aimed at the needs most relevant to them. However, as people with mild LD are far more numerous and their needs less immediately
obvious, there is a greater risk of inadequate or no support being offered. They sometimes access health care without support, and this may contribute to health needs being unmet.

2. Inadequate provision of services for children and young people with LD and mental illness was demonstrated in the UK (Mental Health Foundation), and referred to in the national needs assessment (NNA). In parts of GG&C this appears to also be an issue.

3. Assessment and planning for transition in the acute sector is unsatisfactory and young adults with severe/profound LD and complex needs as old as 30 years of age are still being admitted to the respiratory, orthopaedic, neurology and rehabilitation wards at Yorkhill hospital they used as children.

4. The NNA highlighted the potential for considerable pressures on both family and paid carers of PWLD, the considerable expectations in terms of meeting complex health needs, and the wide range of training, some of it quite sophisticated, that they should have to fulfil these expectations. The high staff turnover that sometimes occurs in independent provider organisations means that training may need to be offered on a continual basis.

5. Tier 3 community LD staff have a role in working with care providers responsible for supporting independent living and day opportunities. The monitoring and reporting role of community LD staff could be strengthened to improve the overall standard and consistency of health care supported in social care settings.

6. Family carers, based on existing evidence provided in the NNA, will need support to help them absorb a 24/7 responsibility including by ensuring that NHS services across the Board respond appropriately when required.

7. The NNA devoted considerable attention to the fact that PWLD experience barriers to their health needs being met by services, including the NHS, attributing these to a combination of factors affecting access. Additionally, some structural and management features of the way health and social services are organised may impede the effective and efficient access and delivery of health and social services to PWLD.

8. Many PWLD have communication impairments or complex communication needs affecting their ability to understand and relay information. Sensory impairments, particularly hearing impairments, also impact on effective understanding and communication. A person to person approach to communication support is needed, including: assessing communication needs; adapting interactions and the environment to best meet needs; providing accessible written information; providing training in communication in collaboration with carers; and providing specialist support for e.g. engaging in decision-making, consent to interventions, and adult support and protection. Speech and language therapists can advise and train health staff where required.

9. With the exception of people with DS (PWDS) who appear to be protected from the development of solid tumours, PWLD appear to be at greater risk of gastro-intestinal cancer than the general population. They also have a higher prevalence of gastro-oesophageal reflux disorder (GORD), which is a risk factor for oesophageal cancer and causes strictures; *Helicobacter pylori*, which is a
risk factor for ulceration; and chronic constipation. The high prevalence of chronic constipation, physical inactivity and consumption of an energy rich diet are risk factors for colonic and rectal cancer.

10. Dementia is about 4 times more common in PWLD than in the general population. There is a 50% lifetime risk of a PWDS developing dementia. A review of the literature does not support proactive screening. Guidelines issued jointly by the British Psychological Society and Royal College of Psychiatrists recommends consideration given to baseline assessments at age 30 in PWDS, depending on local priorities. In GG&C routine assessment of skills/functional level of all persons referred to the LD service as part of the initial assessment process (using a tool such as the Vineland scale), would address several purposes.

11. PWLD experience very high rates of mental ill health and/or problem behaviour. Together these two groups of conditions pose the greatest challenges and workloads to LD services. The provision of acute assessment beds (numbers per capita) meets national guidance, but delayed discharges mean that accessibility is limited. Some Community LD Nurses (CLDN) based in LD teams express a desire for more training or experience to effectively contribute to the stepped model of care desired by the LD clinical psychologists and psychiatrists.

12. Epilepsy in PWLD is very common, often refractory to treatment and linked to sudden death. There is a historical legacy of suboptimal epilepsy services generally in the UK that is particularly undesirable in relation to PWLD who need the support from, and additional time with, high quality specialist healthcare staff who are experienced in both LD and epilepsy. The prevalence of epilepsy is higher in areas of greater deprivation, which is therefore also relevant in parts of GG&C. There is evidence to suggest that the current configuration of medical and nursing services for people with LD and epilepsy in GG&C is sub-optimal, and could be better joined-up.

13. LD clinical prescribing issues are of critical importance in mental health, problem behaviour, epilepsy and a range of other clinical conditions affecting PWLD. These issues are complicated by a range of underlying factors, such as dysphagia and reliance on PEG feeding, and also because of complex drug reactions and interactions. Healthcare staff in LD teams, tier 4 LD specialist services and mainstream services should ideally be able to access LD clinical pharmacists for specialist advice. At the moment, this service is only available to staff working in tier 4 services in GG.

14. The ability to offer effective treatment for mental ill-health and problem behaviours in PWLD should be health priorities for GG&C LD services based on the epidemiological evidence of need and the evidence of current expenditure on costly packages of care needed by these clients.

15. The prevalence of sensory impairments in PWLD is high. Many PWLD will require access to specialist equipment and the additional skills of specialist staff. Fixed term funding from the Scottish government in the RNIB Project Assessment Worker model has had significant success in supporting persons to access mainstream optometry services, and to implement the necessary environmental adaptations to improve quality of life.

16. Respiratory causes are still the commonest cause of death in PWLD. Aspiration causing asphyxia and aspiration pneumonia are more commonly implicated as causes of death in younger PWLD
because of a range of factors that are common in PWLD. Preventing aspiration in PWLD and dysphagia, GORD and SUDEP are important challenges in protecting the airway that carers are expected to rise to. This highlights the need for carers to fully understand the complexities of the condition their client/relative is living with and the need for training in sufficient quality and quantity.

17. In the general population, the prevalence of coronary heart disease (CHD) in GG&C for both genders combined according to the Quality and Outcomes Framework register in 2007/8 was 4.46%. The prevalence of CHD in PWLD in GG for both genders during 2002-4 was only 1.8%, suggesting that PWLD in GG&C are not yet subject to the high rates of this disease, although the population with LD is younger than the general population accounting in part for this finding, together with the lower rates of smoking. PWLD have been benefiting from increasing life expectancy for about 30 years and although one would expect them to increasingly suffer from the degenerative diseases associated with aging, including CHD, this had not yet materialised. This suggests that PWLD are not subject, to the same extent, to the priority causes of morbidity and mortality targeted by key government health improvement programmes such as Keep Well.

18. Cancers profiles differ in PWLD compared with the general population, partly because they do not tend to smoke or use alcohol. However, they are at higher risk from gastrointestinal cancer and some genetic causes of LD are linked to a higher risk of specific tumour types. PWDS appear to be relatively protected from solid tumours (including breast cancer) but have a higher rate of leukaemia. As PWLD continue to enjoy greater longevity cancer rates are expected to rise and cancer services will need to adjust to deliver a user-friendly service to PWLD.

19. The prevalence of diagnosed diabetes in PWLD in GG&C is slightly higher than for the general population, and the high prevalence of obesity and psychotropic drug prescription may contribute. It is difficult to predict the impact of rising obesity prevalence on the prevalence of diabetes in PWLD.

20. PWLD are referred to the Glasgow Dental Hospital for secondary and tertiary dental and oral surgical care on the same basis as the general population. A community-based Special Needs Dental Service that is sited in 9 settings is able to offer a user friendly and expert service to PWLD, including people with dental phobias.

21. The prevalence of obesity and morbid obesity is higher in PWLD, particularly in women and PWDS. This increase is for people with mild to severe LD. Sedentary lifestyles and poor diet contribute to this. For PWDS, there is lack of evidence that this higher prevalence impacts on life expectancy, as PWDS are resistant to cardiovascular disease, but it conceivably may contribute to their high rate of respiratory disease, arthritis and impaired mobility. Obesity in PWLD, including PWDS, should be addressed using appropriate multi-component interventions, which need to be developed. Carers have an important role to play.

22. Underweight and malnutrition may be a threat to health of PWLD and the service needs to be able to address it. Osteoporosis is common in PWLD and has multifactorial causes e.g. sedentary in-door life style, under-nutrition, antiepileptic and antipsychotic drug use. Under-nutrition related to severe dysphagia can be improved with postural management, requiring a multi-disciplinary team approach.
23. Dysphagia is a serious problem for some PWLD and in some instances has led to death. Improving the safety of individuals with dysphagia is essential and providing individual management guidelines can reduce the risks.

24. Despite the endorsement of the NNA for Postural Management, Postural Management Clinics or full postural management programmes for PWLD are not always available in some parts of GG&C.

25. PWLD have a higher incidence of foot and toenail problems than the general population; if not addressed these can impair mobility.

26. The NNA highlighted the high susceptibility of many PWLD to infections by virtue of their constitution (predisposition to GORD), swallowing problems leading to aspiration pneumonia, prior history of exposure to infection in institutional settings, and use of congregate settings such as day centres. In some circumstances, advice from the Public Health Protection Unit at NHS GG&C may be helpful.

27. Sexual and relationship education for PWLD requires expertise, patience, and specialised equipment. The Feeling Good Clinics at the Sandyford in Glasgow provide fast-tracked and extended appointments for sexual health services for PWLD. Sexual health service referral rates at the Sandyford by PWLD suggest modest uptake rates thus far, but data capture has been sporadic and plans are underway to improve routine data collection aimed at informing future service planning.

28. The NNA suggests that PWLD are highly susceptible to accidents. During this local needs assessment (LNA), interviews with staff revealed examples of accidents and unintentional injuries in PWLD. The current collection of health information, including that on accidents in PWLD, is not sufficiently robust to inform any new policies.

29. The NNA provides a section on the abuse of PWLD, including references that focus on the potential for abuse within support services. The Adult Support and Protection Scotland (2007) Act was passed to protect adults from harm; and includes the requirement to establish committees with functions relating to the safeguarding of adults who are at risk of harm. The NHS board is required to delegate specific responsibilities under the act.

30. The types of health needs PWLD most commonly experience differ from those most commonly experienced by the rest of the population, and some types of health needs are specific to PWLD. The leading causes of death for people with LD differ from the leading causes of death for the rest of the population. The 2004 NNA states that ‘the most effective public health initiatives for PWLD would be those that target their leading causes of ill-health and death; however, such initiatives do not currently exist – as they are not of particular relevance to the rest of the population’. Hence, given limited resources (human and financial), they should be focussed on developing and promoting the uptake of evidence-based, cost-effective public health initiatives that do target the leading causes of ill-health and death in PWLD, based on a needs assessment.

31. In GG in 2002-4, only 45% of women prescribed oral contraception (some of whom also smoke) had had cervical screening; a lower rate than for the general population. Women with mild LD are more at risk of cervical cancer than women with severe or profound LD and more likely to be offered
screening. All women with LD should be routinely invited for cervical screening as per national guidelines so that they and their carers have an opportunity to make the decision as to whether to take up this preventive measure. Women with LD who are suspected to be at risk from cervical cancer based on the presence of known risk factors should be encouraged to undergo cervical screening; this may require preparatory work in advance. Heavily promoting cervical screening to all women with LD is probably not justified. Conversely, the preventative measure of immunisation against human papilloma virus is justified for girls with LD.

32. Breast cancer rates in women with LD are similar to those in the general female population, and breast cancer is the commonest malignancy in women. Women with LD should be offered breast screening as for other women, and they, and their carers, may require preparatory work in advance. It is important that carers are provided with information on breast awareness. There may be an unfavourable benefit : risk ratio for women with DS. Decisions should be made on an individual basis, taking account of the person’s individual risk profile e.g. family history.

33. A recent review of health checks for people with LD by staff at Lancaster University identifies some gaps in the existing literature, but finds the evidence supports proactive health checks. The optimum period of time to repeat the health checks is not known, but as health status is not static, regular repeated health checks may be justified.

2.3 Recommendations

There are several recommendations to improve services for PWLD in GG&C. These include recommendations in the areas of information and planning; protocols and care pathways; professional roles, service organisation, and operational management; strategy and planning; and health promotion, screening and health improvement.
3. Introduction

This local health and social needs assessment (LNA) of people with learning disabilities (PWLD) in Greater Glasgow and Clyde (GG&C) was commissioned by the Director of the Mental Health Partnership of NHS GG&C. A strategic overview of the LNA was provided by the Way Forward Planning Group, throughout its development. The LNA presents an epidemiological analysis of the current and future predictions of the numbers of PWLD in the NHS GG&C board area, provides an overview of the health and social needs of PWLD, describes the local services for PWLD, and integrates this information to make recommendations for the future provision for PWLD. The LNA is focused on adults with learning disabilities (LD), but does deviate from this remit in places to briefly consider children and young people with LD (CYPLD).

The LNA was prepared in 2008-2010. Information was drawn from a number of sources. The LNA adapted the national “Health Needs Assessment Report. People with Learning Disabilities in Scotland”, which was published by NHS Health Scotland in 2004. This national health and social needs assessment (NNA) was adapted to be more relevant to the population in GG&C. Additionally, a series of literature reviews were undertaken, to update the knowledge presented, based on literature reported since publication of the NNA, and more recent policy documents and legislation was also reviewed. Reports to inform the LNA were prepared using locally collected information, to give actual measurements on the numbers of PWLD in GG&C and their health status. Comparative data on the number of PWLD was obtained from the Leicestershire LD register. Information was sought from numerous academic experts and experienced practitioners across the UK, and from third sector organisations. Many of the staff (162) who work in the local service contributed their perceptions, including staff working in the LD teams (12 in Inverclyde, 13 in West Dunbartonshire, 7 in East Renfrewshire, 12 in Renfrewshire, 5 in North Glasgow, 18 in East Glasgow, 24 in South West Glasgow, 8 in South East Glasgow, 3 in West Glasgow). Sixteen members of support provider organisations also contributed, as did the Director of the Scottish Consortium for LD. An iterative process was used whereby initial drafts of the LNA were discussed at the Way Forward group, and a stakeholder group appointed by the Way Forward group provided reviews and comments, from which the LNA was refined.

The recommendations in the LNA are derived from an integration of these findings, and are directed to the Way Forward Planning Group who are responsible for considering them, and taking them forward as considered appropriate by that group.
4. Epidemiological analysis of current and future numbers of PWLD in NHS GG&C

4.1 Introduction

The ‘true prevalence of intellectual impairment’ depends on the prevalence of intellectual impairment at birth and that developing thereafter but before adulthood, and subsequent mortality rate. It is the actual numbers of people in a population, regardless of whether or not they are in contact with services, who have a quantifiable intellectual impairment from childhood as measured by objective means (an intelligence quotient (IQ) of 70 points or less). Amongst the adult population, it will never be known with absolute accuracy as it would require psychometric assessment of the whole general population in a defined area. The true prevalence of moderate/severe/profound intellectual impairment can be known with greater accuracy, partly because it is difficult to conceal, and partly because changes in social and societal factors have minimum impact on it, and causes are similar in western countries.

The ‘true prevalence of learning disability (LD)’ relates to the total number of people with an intellectual impairment in a population who are disabled by that impairment, either because of its severity or by virtue of it combining with other factors either in the person or their environment. It will include all people with a moderate to profound intellectual impairment and all people with a mild impairment for whom other factors combine with their intellectual impairment to result in LD, regardless of whether or not they are in contact with services. It also will never be fully known as it would require a door-to-door census type survey involving comprehensive testing of IQ, social functioning, and support needs. Published estimates of true prevalence of LD vary substantially, and are influenced by geography. Additionally, “true prevalence” is variable with time in view of the Flynn effect (a substantial increase in average IQ scores on intelligence tests which may be about three IQ points per decade, although stagnation has been identified in Scandinavian countries after 1990’s), and as social attitudes to disabilities vary, as the ICD-10 and DSM-IV-TR definitions of LD are social constructs, not merely a statistical construct.

The ‘ascertained prevalence rate of LD’ relates to the number of people with LD officially recorded. These rates would be higher than ‘true prevalence of intellectual impairment’ and higher than ‘true prevalence of LD’ if they include people who do not have intellectual impairment but are disabled by other factors or people who have been mislabelled as having an intellectual impairment who have a range of other types of health and social service needs. The ascertained prevalence rate of LD might be lower than the true prevalence rate if not all persons with LD are identified. This will depend upon the local services, how accessible they are, and the extent to which services are provided via a specialist LD model or mainstream model, and detection rates in primary care. These rates are useful in health service
planning as they are immediately available and they give an indication of the demand for health and social services.

Very often, ascertained prevalence rates are mistaken for true prevalence rates. Estimates of both types of prevalence rates are influenced by the design of the study to determine them, the assessment criteria used, and the method applied for the identification of cases, amongst other factors. Prevalence rates for all ability levels of LD combined vary from 2 to 85 per thousand throughout the world, and this variation includes genuine differences in prevalence as well as differences in the methodology and interpretation of studies.

This section of the LNA attempts to estimate the current and future numbers of, and characterise where possible, PWLD in Greater Glasgow and Clyde (GG&C).

4.2 Moderate to profound intellectual impairment and LD

4.2.1 Literature review

There is an attraction in considering the population with moderate to profound LD separately from the population with mild LD, as invariably the entire population can be ascertained[^3], with exceptions being very rare. Conversely, ascertainment of the population with mild LD is variable, dependent upon local social attitudes, local service protocols, and local historical factors influencing service delivery and organisation. Hence, to follow trends in prevalence of LD over time, it is helpful to focus on the group with moderate to profound LD. Therefore this section will consider first the literature on the prevalence of LD, and then compare information from GG&C with that from the Leicestershire LD register, the Brent LD register, and pooled data from 24 English Authorities, to consider the prevalence of moderate to profound LD in GG&C.

Measuring the prevalence of LD is a challenging task, and there are limitations to work that has attempted to do this. The country of study, sample population, age range, definition of LD used, and the method of ascertainment can all have a significant impact on the identified rate. Even the most recent studies have a wide variation in reported rate. Most studies have been conducted with children, and few with adults. Studies between 1960-1987 were reviewed by Roelveld et al[^4]. More recent studies are summarised in appendices 1-3[^5]-[^27]. The NNA reviewed studies as of 2003, and found that although there is large variation in prevalence for mild LD, the range for moderate to profound LD was tighter, varying from 2.7 to 3.8 per 1,000[^4][^19][^21][^23][^28]. However, all but one of these studies are of children or are lifespan rather than adult studies. The recent studies summarised in appendices 1-3 are separated into studies on adults, then lifespan studies, then on children, given that age range affects prevalence. The tables are excerpts from Elita Smiley’s MD thesis, 2010, University of Glasgow. As seen in the tables in appendices 1-3, the more recent adult studies found prevalence rates of 2.19, 2.3, <3.6, 4.14 and <4.3 per 1,000.

The older studies published between 1960-1987 are probably of lesser relevance to today’s population. They found wide variation in reported rates (2-85 per 1,000)[^4]. Almost all were studies of children or lifespan studies. There was some consistency in demonstrating that prevalence rises in childhood, peaking at about 10-15 years[^4][^29]. This is due to the delay in confirming LD for some children. No
conclusions regarding age-specific rates in adulthood can be drawn as only three adult populations were included, with very limited information on them. The most recent of the adult studies was published in 1973, and given cohort effects, with prevalence varying with time, they may not provide findings relevant today for this reason as well. Additionally, the accepted definition of learning disabilities changed in 1973, which significantly affects the ascertained rates.

Given the variation between studies for mild LD, it is difficult to generalise the findings regarding prevalence rates to the population in GG&C. Therefore more detailed information is presented to draw comparisons between LD registers, to consider the likely local prevalence of LD, and limitations to our existing information.

4.2.2 Data within GG&C

There are two sources of information from GG&C which are presented in this LNA. The first is the primary care database of adults with LD (the LES LD register), which is used to deliver the service and administer payments to GPs for participating in the enhanced service. This was derived by bringing together information from the specialist LD health service, social work services, day services, the financial system paying for services for people with LD and the health board, to establish a database of PWLD. This was subsequently updated via primary health care in 2002. In 2006, further work with primary health care built on this, and the LES LD register was formed to administer the LES LD. Further work on the database extended it to cover Clyde when the services merged, and the updates via primary care are regularly repeated, most recently in 2009. Everyone on the LES LD has been verified to have an LD. Deaths are notified to the register on a continual basis. Caldicott guardian approval was granted for the register, and this was most recently renewed in 2009.

The second source of local information, reported chiefly in the chapter on health and social needs, comes from a proportion of the health checks conducted in 2002-2004. This comprises complete geographical boundaries based on the former LHCC primary care organisation within GG, and relates to information on 1,023 persons. In 2002-4, a research assistant was employed to access the routine data held in the health check records. Special reports on the health check information were prepared for this LNA in 2008 and in 2009, to characterise the local LD population.

Social services datasets held in Greater Glasgow (Carefirst) and Clyde (Swift) CH(C)Ps do not routinely record ability level of LD clients in contact with services, and neither does the health dataset collected in Clyde (TOREX). The LES LD register does not routinely record the ability level of the persons with LD. Ability level is recorded for persons who had a health check. Ability is being measured using the Vineland scale.

4.2.3 Age specific estimate for summary prevalence of moderate to profound LD in GG&C

There are just 81 children and young people aged 16-19 on the LES LD register. This is because the LES LD only covers ages 18 and over, so none was identified via primary health care in the 16-17 year age bracket. Conversely, the LD service is responsible for PWLD when they transition from children’s services from age 16 upwards, so there are some aged 16 and 17 on the register, but they are an undercount of the population at those ages. Historically, transition from education to adult day services
was at age 19, however with the introduction of the adult support for learning act this is now 18. The report on the health check information suggests 61.1% of the 1,023 GG residents with LD who had a health check during 2002-4 had moderate to profound LD. If this same percentage for PWLD in GG during the 2002-4 period is applied to the number of adults on the GG&C LES LD register to predict how many adults have moderate to profound LD (n=3,177), an estimated per capita prevalence is 3.2 per 1,000 adults. This compares to an estimated prevalence of moderate to profound LD based on the Leicester LD register\(^{i}\) of 3.7 per 1,000 adults (at age 20 years and over), or 3.9 per 1,000 based on the Brent LD register\(^{ii}\) (at age 16 years and over). Seventy-six percent of persons on the Leicestershire register are thought to have moderate to profound LD, compared with 54.3% on the Brent register (as assessed by a clinical psychologist), 69.3% on the Irish national LD register, and 61.1% of the GG health check cohort. These variations in the number with mild LD are likely to relate to local factors about how service delivery and organisation has evolved for persons with mild LD, although there may also be genuine differences in prevalence. If the rates found in Leicestershire (76%) are similar to those in the wider GG&C area, rather than the 61.1% in the GG health check group, then applying this figure to the GG&C LES LD register, then the predicted per capita prevalence rises to 3.8 per 1,000.

Age-specific prevalence rates for people aged 20 years and older from the Leicester LD register\(^{iii}\) are shown in more detail in table 1. Prevalence of mild or borderline LD is higher in the younger adult age groups in this particular dataset than in the older groups, demonstrating how disproportionate numbers of people with mild LD can distort statistics obtained from different LD registers if the cognitive function or adaptive behaviour of the entire register is not known. The corollary of this is that the proportion with moderate to severe LD is highest for the older age groups.

There is a decline in both ascertained prevalence (green shading) and prevalence of moderate to profound LD (pink shading) with increasing age group which reflects the fact that the numerator is shrinking in each successively more elderly age group. So in Leicestershire, most people with an LD are identified by age 20 and then start to leave the register presumably through higher death rates with aging. Of those who have had their ability assessed, the number with moderate to profound LD is similar across the age groups 20-29 years, 30-39 years, and 40-49 years (blue shading). The largest proportion of persons who had not been assessed were in the 20-29 year group, then the 30-39 year group, hence these figures may be less reliable at those age ranges. For the 20-29 year group, 507 had been assessed to have adaptive behaviour in this range, and 310 had not been assessed, of whom 228 were added to the moderate to profound group.

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\(^{i}\) Data supplied by Freya Tyrer and Cath McGrother, Leicestershire LD register

\(^{ii}\) Data supplied by Mark Tilley, Brent LD Partnership.

\(^{iii}\) Ability level on the Leicester LD register is assessed using the Leicestershire LD tool (a brief 7 item questionnaire shown to have 95% sensitivity and 65% specificity to detect moderate to profound LD according to determined developmental level as assessed by the Vineland scale with the 322 persons on the register for whom Vineland Scale scores are available). Not everyone has been assessed with the LD tool, particularly at younger age groups. Of the 3,582 people on the Leicester LD register as of March 2008, 2,284 (or 63.8%) were identified as having moderate to profound LD, 730 (20.4%) had mild or borderline ID and 568 (15.9%) had an ‘unknown level of ID’.
Table 1: Leicestershire LD Register\textsuperscript{iv} figures\textsuperscript{v} providing estimates of intellectual disability (ID) by age group and by ability for people aged 20 years and above, as of 4 March 2008. The Register covers the City Leicestershire, Rutland and Leicestershire with a total population of over 700,000. The data was kindly provided by Freya Tyrer of the Leicestershire LD Register.

<table>
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<tr>
<th>Age</th>
<th>Pop'n</th>
<th>Mod to Prof</th>
<th>Mild/Borderline</th>
<th>% Mod-Prof</th>
<th>Un-known b/c no Health Check</th>
<th>Est add. nos mild/ borderline</th>
<th>True mild/borderline</th>
<th>Est add. nos of mod-prof</th>
<th>&quot;True&quot; Mod-Prof</th>
<th>Prev rate based on interview per 1,000</th>
<th>Prev Mild-Borderline per 1,000</th>
<th>Prev Mod-Prof (Est)</th>
<th>Total on register</th>
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<td>2284</td>
<td>730</td>
<td>568</td>
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<td>877</td>
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<td>2705</td>
<td>3.16</td>
<td>1.21</td>
<td>3.74\textsuperscript{xii}</td>
<td>3582</td>
<td>4.95</td>
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</table>

\textsuperscript{iv} The website of the Leicestershire LD Register is \url{http://www2.le.ac.uk/departments/health-sciences/extranet/EEC/health-and-disability/projects/LDR}

\textsuperscript{v} The figure of 3.7 per thousand is arrived at by interviewing clients who are registered with the Leicestershire LD register using the 7 item Leicestershire LD tool derived from the Vineland Scale, Tyrer et al 2007\textsuperscript{30} to which a cut off point is applied to achieve 95% sensitivity and 65% specificity, to predict developmental age. At the time of this query, 3.2 per 1,000 of the Leicestershire LD registered population were identified as experiencing a moderate, severe or profound LD but as the uptake of the assessment was incomplete the estimate of 3.2 was rounded up to 3.7, based on the assumption that the distribution in the non-assessed clients (‘unknown’) resembled that of clients who had undergone assessment (email communication from F Tyrer, 4 March 2008). This compares to the 3.6 per 1000 with all levels of ability (mild to profound LD) that was reported by the Leicestershire researchers in 2002\textsuperscript{6}.
4.2.4 Predicted range of crude prevalence rates of moderate to profound LD by CH(C)P area

From the information considered, we cannot state the definitive prevalence of moderate to profound LD in GG&C, because information is only readily available for 1,023 persons. It is possible for some areas to have higher prevalence depending on geographic clustering factors, including the group provision of some accommodation/support for persons with particular types of need such as problem behaviours, which are more common at lower ability levels. Therefore, it may be useful for CHCPs/CHPs to be aware of their minimum and maximum likely numbers of adults with moderate to profound LD.

The overall prevalence of moderate to profound LD, for all ages and both genders, has usually been estimated by the published literature to be around 3–4/1000 population, although this is an average across different studies based on varying methodologies and using diverse definitions of LD\(^{32}\). This would amount to between 2,750 and 3,667 adults aged 20 years and older in the GG&C based on the mid-year population estimate for 2006 of 1,191,584. Figure 1, based on this general range of rates, gives the upper and lower estimates for the nine main CHCPs in NHS GG&C (excluding North and South Lanarkshire CHPs which are to be covered by NHS Lanarkshire).

**Figure 1: Predicted number of adults aged 20 years and older with moderate to profound LD by CHCP/CHP in NHS GG&C assuming range of prevalence at 3-4 per 1,000 population.**

![Predicted number of adults aged 20 years and older with moderate to profound LD by CHCP/CHP in NHS GG&C assuming range of prevalence at 3-4 per 1,000 population.](image)

4.2.5 Proxy incidence of LD – inception at or shortly after birth

The age specific prevalence of moderate to profound LD is highest at age 20 years according to the Leicestershire LD register. If we assume that this reflects the inception rate, we could apply this minimum rate of 5.6/1000 to the GG&C birth rate (13,073 births in 2006), to indicate that about 73 newborns and neonates a year, on average, would grow up and have a moderate to profound intellectual
impairment identified at some point. This is a proxy for what might be deemed the *inception at birth* of moderate to profound LD or the *pathological cause* of moderate to profound LD, even though many will not be diagnosed at birth. It is dependent upon the validity of applying Leicestershire data to GG&C.

4.2.6 *Age-specific prevalence estimates of moderate to profound LD from Leicestershire applied to GG&C*

Estimated numbers of adults aged 20 years and above with a moderate to profound LD by age group in NHS GG&C are shown in Figure 2. These age-specific estimates produce a total expected number of adults with the more significant degrees of impairment in GG&C of 3,449. This assumes a distribution across age groups that is similar to that in Leicestershire (and itself based on assumptions, particularly in the 20-29 and 30-29 year age groups), rather than the actual one found in GG&C.

Figure 2: Estimated prevalent number of adults aged 20 years and older with a moderate to profound LD in NHS GG&C area by 10 year age group predicted by the Leicester LD register.

Caution is needed when reading these results, as (a) the ethnic composition of the two populations differs considerably, and we do not know whether or not this effects prevalence of LD, and prevalence of LD may also differ by urban/rural indices. (b) There may also be other demographic and historic health care differences impacting on prevalence, (c) the Leicestershire data may include “ghosts”, given the high death rate of this population, with deaths and migration occurring in between interview dates. This may apply particularly to the younger age groups, (d) the definition of moderate to profound LD as recorded on the Leicestershire register changed between 1999 and 2008, even though the standard definitions (ICD-10, DSM-IV-TR, AAID) have not changed during this time period. Changing definitions significantly impacts on prevalence rates. (e) the data at younger age groups is based on assumptions regarding ability level, as a significant proportion have not been interviewed.

These age specific estimates for adults aged 20 years or older for moderate to profound LD are also applied to the 12 CHPs/CHCPs in GG&C in Table 2.
Table 2: Estimated prevalent numbers of moderate to profound LD by CH(C)P in GG&C based on the Leicester LD register prevalence rates for adults.

The total number predicted for NHS GG&C, population 1,117,810, excluding relevant parts of NL and SL CHCP, would be 3,240 adults aged 20 years and over.

<table>
<thead>
<tr>
<th></th>
<th>Total Pop’n</th>
<th>Age Groups</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td>20 - 39</td>
</tr>
<tr>
<td>E Dunbartonshire</td>
<td>105,460</td>
<td>112</td>
</tr>
<tr>
<td>E Glasgow</td>
<td>123,824</td>
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</tr>
<tr>
<td>E Renfrewshire</td>
<td>89,290</td>
<td>93</td>
</tr>
<tr>
<td>Inverclyde</td>
<td>81,540</td>
<td>98</td>
</tr>
<tr>
<td>N Glasgow</td>
<td>99,954</td>
<td>160</td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>169,590</td>
<td>213</td>
</tr>
<tr>
<td>SE Glasgow</td>
<td>101,476</td>
<td>180</td>
</tr>
<tr>
<td>SW Glasgow</td>
<td>116,580</td>
<td>172</td>
</tr>
<tr>
<td>W Dunbartonshire</td>
<td>91,240</td>
<td>118</td>
</tr>
<tr>
<td>W Glasgow</td>
<td>138,856</td>
<td>281</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1,117,810</strong></td>
<td><strong>1,611</strong></td>
</tr>
</tbody>
</table>

4.2.7 Prevalence of moderate or profound LD by gender

More boys are born with LD than girls\(^{33}\). Among people aged 40 years and over there is no consistent gender difference\(^{29}\). This is because some causes of LD which are genetically determined are specifically associated with male gender (i.e. they are sex-linked), and because the male developing brain is more vulnerable. Cohorts of children and younger adults with LD are about 60% male and 40% female (around 20% excess). This changes in older age, as women typically live longer than men. Hence an equal gender ratio is seen in old age, and at extreme old age there is probably a greater proportion of women than men amongst PWLD. As seen in Figure 3 below, the male:female ratio observed in ascertained LD registers does not reflect a 60:40 rate, probably due to the effects of age. The adult overall percentage of females in the GG&C health check group was 45.1%, in the GG&C LES LD was 43.9%, in the Republic of Ireland was 47.2%\(^{9}\), Northern Ireland 44.8%\(^{9}\), in the Netherlands 45.7%\(^{15}\), in Sydney was 49.4%\(^{5}\), in Finland was 46.2%\(^{16}\) and in Emerson and Hatton’s data was 42.2%\(^{1}\). Figure 6 provides gender information for the city of Leicester.

When the ratio of ascertained prevalence from the LES LD register in 2008 versus Emerson’s estimates in 2004 based on 24 English local authorities is examined, by age group, and by gender, some minor differences are found between the two. It is not possible to say if this is due to a genuine difference between the areas, or bias in ascertainment in one or other of the datasets. It is possible that difference in English and Scottish policy results in a smaller proportion of persons with mild LD in the English data.

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4.2.8 Prevalence of moderate or profound LD by socioeconomic background

The NNA provides a broad analysis of the impact of socioeconomic deprivation and poverty on people with LD and their families (see section on health and social needs). It does not describe the causal relationship between poverty and the development of LD. Mild LD is associated with socioeconomic deprivation and therefore there are many considered arguments as to how we could reduce the prevalence of mild LD, by improving the biological and social environment of the foetus and young child\(^{[32][34]}\).

In the past, publications suggested that socioeconomic background is not causally associated with moderate or profound LD\(^{[36][38]}\) and is therefore less amendable to prevention than in mild LD. However, some studies have been published suggesting that severe LD in ethnic minorities is more common in socially deprived sub-groups\(^{[36][37]}\).

Paradoxically, the tendency for many modern women to delay motherhood to develop their careers could be expected to counteract the overall pressure to decrease inception (incidence at birth) of LD by making severe LD due to Down syndrome (DS), the commonest chromosomal cause of LD, and other genetic abnormalities more common in those privileged social classes where this reproductive strategy is popular. For this reason, the relationship between socioeconomic status and LD may not be as expected as the better off classes experience disproportionately more of the most common chromosomal cause of LD and the poorer classes increasingly benefit from modern medicine, better nutrition and higher uptake of screening programmes. The observed birth prevalence of DS in England has reportedly increased from 0.91 per 1,000 live births in 1995 to 1.04 per 1,000 live births just 3 years later in 1998 despite a constant rate of antenatal diagnosis of 45-46% and greater use of antenatal screening using amniocentesis and chorionic villus sampling\(^{[38]}\). As of 2006, the birth prevalence of Down syndrome in
E&W had risen still further to 1.12 per 1,000 live births and the antenatal diagnosis rate had stabilised for women of all ages at 60%. The number of babies being born live with Down syndrome to mothers aged under 35 is decreasing while the number born to mothers aged 35 and over is rising and the sum total may be a rise in births of children with DS. A disproportionate number will be from more privileged families as the less privileged families still tend to have children at younger ages.

4.2.9 Prevalence of moderate to profound LD by ethnicity

The relationship between ethnicity and moderate to profound LD is unclear. If socioeconomic deprivation has no effect on the prevalence of moderate to profound LD, then the main mediators by which ethnicity might be linked to increased rates of LD would be via consanguineous marriage or biological factors such as iodine deficiency (causing congenital hypothyroidism), which is the commonest cause of LD in the developing world. However, a small number of studies do link socioeconomic deprivation with severe LD in which case socioeconomically deprived ethnic minority groups will have this additional reason to experience from higher prevalence rates of severe LD.

The paper by Roeleveld and others (1997) suggests that prevalence rates of ‘severe mental retardation’ are high (above 10 per thousand) in most developing countries studied (with the exception of the Philippines, Brazil and Sri Lanka) and that prevalence was highest in India at 40 per thousand and Pakistan and Bangladesh tied at about 15 per thousand (Figure 10). Prevalence has also been reported to be higher in indigenous aboriginal children and African Americans, although there may be limitations in the extent to which identification used culturally appropriate methods.

The potential for measurement bias has to be considered in developing countries, versus measuring the prevalence in an immigrant population, from that country to the UK, where some self-selection bias applies. If the extremely high rate in India is valid, this is important given the large numbers of immigrants from the Indian sub-continent in some parts of Glasgow and Leicester city.

In 2001, the Department of Health commissioned and published a report on LD and ethnicity that states that the prevalence of severe learning difficulties in South Asians aged between 5 and 32 is up to three times higher than in other communities, quoting two papers that are based on age-specific rates in three Metropolitan Boroughs in the North of England in 1997. These figures may or may not be accurate, as outlined below. They point out that significant differences also exist between religious groups in terms of diet and lifestyle, socio-economic status and health experience. Different ethnic groups also occupy differential socio-economic positions, with people of Indian origin relatively better off as compared with those of Pakistani, Bangladeshi and African Caribbean origin.

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vii There is some evidence to demonstrate that it is the better off members of an impoverished community that will migrate to the UK from a developing country.

viii According to the CHCP Community Profile for Southwest Glasgow CHCP published in 2008 by the Scottish Public Health Observatory, the percentage of the entire population (116,000) that is from an ethnic minority is just 4.5%. However, specific areas have much higher percentages such as Greater Shawlands (population 45,368) with a percentage of 17%.

ix 11% of the Leicestershire population covered by the LD register is black. This is about 3 times higher than in GG&G where the percentage belonging to ethnic minorities is almost 4%.
In contrast, the Leicester-based researchers found that South Asian and white populations have similar prevalence rates of LD and related psychological morbidity\(^6\). Important differences related to the level of skills and access to user-friendly health and social services; the South Asian LD group studied had less skills for every level of disability and felt less able to access services. The conclusion was that culturally appropriate services for South Asian adults may need to focus on skill development and community care. At that time (2002), there were just 162 ‘south Asians’ on the LD register (97% ascertainment) and 2,029 ‘whites’, so it is inconceivable that the prevalence of LD in Asians might be 3 fold higher in Asians than in Caucasians. This is despite the fact that 11% of the Leicestershire population is ‘black’. Communication with C. McGrother reveals that they are about to publish another study demonstrating a slight excess of LD in south Asians in more recent years thought to be due to migrant healthy worker effect (the least able are left behind in the city of Leicester).

We do not know whether or not the difference in the fraction of the population that is Asian in GG&C (3.375% as of the 2001 census) compared to Leicestershire where 11% are black (Indian 7.2%, Pakistani 2.6% and Bangladeshi 1.3% in 1991), is relevant given the epidemiological evidence demonstrated thus far. There is no reason to believe that the high percentage of Asian people in Leicestershire is causing an inflated prevalence of LD at 3.74 per 1,000. If Emerson’s estimate of a 3-fold excess were correct there would have to be almost 1,000 Asians in Leicestershire with a moderate to profound LD, which would mean that about 850 would be somehow concealed from the LD register, which seems unlikely.

In conclusion, the limited evidence that exists suggests that the prevalence of LD in UK Asians is similar to that of the Caucasian population.

4.2.10 Cohort effects

Different birth cohorts have different prevalence rates. Predicting the sum total effect of different cohort effects on any one cohort is difficult. For example, there have been substantial changes in the prevalence of severe intellectual impairment in childhood by birth cohort\(^\text{4}\) depending on opposing aetiological and prognostic factors that affect the pathogenesis and survival, respectively, of newborns with an LD or the precursor of an LD and therefore the prevalence of LD in any particular birth cohort. On balance, the overall effect of immunisation, improved antenatal and maternity care, improved detection and treatment of metabolic causes of LD, etc is a lowering of birth incidence of causes of LD. Conversely, the survival of very low birth weight infants and maternal smoking and alcohol use might increase incidence. In addition, other more dramatic effects have impacted on prevalence in childhood by increasing survival in childhood. Access to cardiac surgery for infants with DS has improved their survival considerably. Improvements in survival in the oldest PWLD are ensuring that there are disproportionately high increases in older PWLD expected in the next 15 years. A cohort of older people with an LD is working through the system from the surge in births in the 1950s and 1960s (baby boom) who will not be replaced. This is both because of lower prevalence in newborns and because of the lower number of births which steadily declined until 2001. As more people enter each successive age group, however, the rise in older age groups is likely to continue for some time because of better nutrition and living standards, immunisation and medical advances, etc. In Leicestershire, they predict the greatest local rise in people aged 50 years and over\(^{45}\).

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\(^4\) A birth cohort is a group of babies born in the same time period who are subject to the same demographic, medical and social effects.
4.3 Comparison of registers by age

Before considering people with mild LD, it is helpful to compare register information regarding the age distribution of everyone ascertained with LD. The GG&C LES LD register and Brent register has a peak age at 40-49 years, whereas in Leicestershire it is 20-29 years. This is graphed below for PWLD in GG&C, Leicestershire, and from information from Emerson and Hatton, 2004, which is from pooled data from 24 areas of England\(^1\), in Figures 4 and 5. Figure 6 shows the age distribution, by gender, for the city of Leicester (as opposed to the wider area of Leicestershire).

Figure 4: Age distribution of ascertained prevalence for various LD registers and LD surveyed samples between 2002-2008 in England and Scotland.

Figure 5: Ascertained age specific prevalence rates of LD for 3 registers, one north of the Border and two south of the Border.
The Leicestershire data (figures 5 and 6) has the highest prevalence at the youngest age (20 to 29 years), with a decline thereafter. This compares to a peak at 30-39 years for the Leicester city data, and at 40-49 years with decline thereafter in the GG data from the health checks, the GG&C LES LD information, the Brent register, and in Emerson & Hatton’s data from 24 English areas\textsuperscript{(1)} and additionally a reported peak at 35-49 years in the Netherlands\textsuperscript{(15)}, and at 40-64 years in Finland\textsuperscript{(16)}. Table 1 demonstrates that the Leicestershire data shows a higher proportion of persons with mild LD in the younger age groups than in the older age groups. Whilst this more complete identification of persons with mild LD in the younger age groups may contribute to differences, the difference also remains when considering persons with just moderate to profound LD. The distribution differs between the city of Leicester, and Leicestershire. In GG&C there may be a higher proportion of persons with mild LD identified in middle age than at younger age compared with Leicestershire for unknown reasons: it would be exceedingly unlikely that persons with moderate to profound LD are not included on the GG&C LES LD register. With regard to comparisons of the estimated moderate to profound LD group, the Leicestershire data is reliant on assumptions which may, or may not be accurate. The actual number of persons with moderate to profound LD in Leicestershire is similar across the age groups 20-29 years, 30-39 years, and 40-49 years for the persons who had had their ability level assessed. The largest proportion of persons who had not been assessed were in the 20-29 year group, then the 30-39 year group, hence these figures may not be as reliable than for older age groups. A further explanation may be that the demographics are just different in different regions, due to local factors e.g. general population demographics in Leicestershire are unlikely to be the same as those in GG&C, and may impact on birth and death rates of persons with LD. There are ethnicity differences between the area, which may or may not influence rates.
There are theoretical reasons why the GG population with LD may peak at age 40-49, although we do not know for sure. These include (a) primary and secondary prevention. In the 60s, birth rate of LD probably rose, due to survival of very premature babies, and subsequently fell with advances in health care. To understand this better would require analysis of local maternal and neonatal services over this period, which may, or may not, have been similar to other parts of the UK. Other obstetric factors such as screening for congenital hypothyroidism and phenylketonuria have only a trivial impact on overall rates. (b) It is conceivable that persons with LD experience greater health inequalities in GG compared with the general population, than in Leicestershire, resulting in premature death not only at all age groups, but particularly of the most disabled persons with LD and therefore in childhood, and the older frail group. When standardised against general population rates this could account for the distribution. (c) GG has low rates of both migration both in and out (via private care home providers) of persons with LD, other than by family migration by choice, whereas other areas can be one or the other, hence age group prevalence rates can vary depending on these other local factors, e.g. the old NW Thames area was a net exporter out\(^\text{31}\). (d) Regarding Leicestershire, McGrother and Bhauik have previously reported an under-representation of persons from ethnic minority groups, who have a high representation in their general population compared with other areas. There was speculation that is might be due to concealment by families: it is not inconceivable that that might differ by age group. Apparently this has now changed, with slight over-representation. We lack a full understanding of these issues, and possible Check sample was drawn, suggesting differences given the different ethnic compositions of the two areas.

The profile for the Emerson dataset published in 2004\(^{11}\), which is an amalgamation of LD registers from 24 local authorities in England\(^{11}\), is very similar to the GG&C information from which the Health that the efforts to identify PWLD to create such registers around 2004, using various sources, achieved remarkably similar age distributions north and south of the Border. It should however be noted that details of procedures to develop the registers in each of the authorities is not provided by Emerson and Hatton, and nor is any variation in rates ascertained between authorities.

### 4.4 Mild LD

#### 4.4.1 Definition

At mild levels of intellectual impairment there can be difference between impairment as measured by IQ and resulting LD experienced by the person. In childhood, mild intellectual impairment (IQ 50-69) often comes to attention at school, but the impairment may no longer be disabling by adulthood. The resultant prevalence of mild learning disability is even more difficult to measure as it is influenced by so many other cultural and societal factors that determine whether a mild impairment is likely to result in a functional disability. The prevalence of mild intellectual impairment (IQ 50-69) reflects the statistical distribution of IQ in a population and will therefore be in the region of 2.27%\(^{46}\) of the population. This is an average figure and does not equate with the prevalence of mild LD. Additionally, IQ measurement can have a test error of 5 points, as discussed by both DSM-IV-TR and the American Association on

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\(^{11}\) Eric Emerson and Chris Hatton extracted information from locally held LD ‘registers’ on the age and gender of 15,000 people with learning disabilities who are known to services in 24 Local Authorities/District Councils covering a population base of 3.2 million people (7% of the population of England). They then combined this information with 2001 Census data.
Intellectual and Developmental Disabilities, who advise that IQ of 70-75 can indicate intellectual impairment, with the identification of LD depending upon associated limitations in adaptive functioning. This test error greatly influences identified prevalence: whilst 2.27% would be predicted to have an IQ less than 70 according to the normal distribution, a higher figure of 2.50% would be predicted to lie in the range of IQ 70-75. Additionally, the greatest deviation from the normal distribution is at its extreme ends.

Persons with mild intellectual impairment and additional problems such as challenging behaviours, may come into contact with services and so may be more likely to be identified as having mild LD. As education and paediatric services have improved over time, developmental delay in childhood has increasingly been assessed, and support for learning provided in childhood. Consequently, there may be increasingly a greater awareness within primary care of registered patients with mild LD.

Many adults with mild intellectual impairment, will not be identified as having a LD. Children with an IQ just below 70 are likely to require additional support for learning, but most will learn skills over time and as adults a proportion will live independently of support, marry, raise families, be employed, not consider themselves to be disabled, and not wish to, or need to use services designed to meet the needs of adults with LD. Additionally, IQ of 70-75 is a purely arbitrary cut-off point to define intellectual impairment. The vast majority of adults with mild intellectual impairment are not known to learning disabilities services. Nevertheless, this larger group has needs that will not be met by LD services which necessarily tend to focus on people with more severe impairment, in keeping with national policy. In a study that followed-up young people with mild LD in Aberdeen to age 22, only 20% were receiving specialist services although 73% had problems of daily living\textsuperscript{47}, although it should be noted that it included only 143 people with mild LD at age 15, with only 41 (28.7\%) completing the subsequent measures. In a follow-up of the National Child Development Study cohort to age 33, people with mild LD were significantly more likely than their peers to be still living with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress\textsuperscript{48}, but it is worth noting that of 274 persons with mild LD in the study at baseline, only 100 (36.5\%) completed the subsequent measures, due to the challenges presented in research with adults with LD. They reported there were also biases in whom completed, e.g. men, and the results must be interpreted in light of this.

\textbf{4.4.2 Estimated prevalence}

The population prevalence for mild LD varies hugely throughout the world and can reach very high percentages (10-30\%) in poor rural areas and urban ghettos\textsuperscript{49}. It is often assumed that 1 and 3\% of the population has a mild intellectual impairment\textsuperscript{50,51}. In GG&C, the approximate numbers of people with an IQ in the 50-69 range by age group for these two prevalence rates are shown in Figure 7. The total number predicted for NHS GG&C, aged 20 years and above based on the 2006 estimated population of 1,191584, would range from 9,159 to 27,477. Figure 8 draws from the Leicestershire LD register, but note that this includes people with borderline LD and fewer with mild LD than in GG&C.
Figure 7: Estimated prevalent number of people with a mild learning impairment in NHS GG&C area by 10 year age group, assuming that between 1 and 3% of people, regardless of age, experience a mild impairment.

![Figure 7](image)

Figure 8: Ascertained prevalent number of people with a mild/borderline LD in NHSGG&C area by 10 year age group predicted by the Leicester LD register prevalence rates for adults with a mild LD who are in contact with the services, n=730.

![Figure 8](image)

4.5 Ascertained prevalence of LD in GG&C

Table 3 reports estimate prevalent numbers of PWLD by CH(C)Ps, based on a variety of data sources.
Table 3: Estimated and ascertained prevalent numbers of PWLD by community partnership in GG&C based on a variety of data sources. The total population for NHSGG&C is 1,192,241, including relevant parts of NL and SL CHCP.

| Area               | Total Pop’n estimated for mid 2006 (ISD Scotland) | Pop’n aged 16 years and above 2006 | ascer. prev based on TSAY counts of those aged 16+ known to council in 2007 | ascer. prev based on TSAY counts of those aged 16+ known to council in 2008 | ascer. prev. QOF registers in general practice aged 18+ 2007/8 | LES LD register as of Dec ’08 aged 16 years+ | Assumin g ascer. prev. of 3.33/100 0 applied to the 16 yrs+ pop’n | Est. ascer. Prev (mild + mod-prof LD) Leic LD register 2008 20 yrs + | ascer. prev. QOF registers in general practice aged 18+ 2008/9 | Carefirst and Swift/Torex as of March 2009, submitted to QIS 2009 16yrs+ | LES LD Register as of April 2009 16+ |
|--------------------|--------------------------------------------------|-----------------------------------|--------------------------------------------------------------------------|--------------------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------------------------|-----------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------------------------------------------|-------------------------------------------------------------------|
| E Dun              | 105,460                                          | 85,478                            | 390                                                                      | 391                                                                      | 320                                                               | 263                                                             | 282                                                             | 423                                                               | 315                                                               | 390                                                               | 298                                                               |
| E Ren              | 89,290                                           | 71,045                            | 420                                                                      | 359                                                                      | 275                                                               | 254                                                             | 234                                                             | 352                                                               | 280                                                               | 359                                                               | 252                                                               |
| Inver              | 81,540                                           | 66,831                            | 454                                                                      | 444                                                                      | 453                                                               | 317                                                             | 221                                                             | 331                                                               | 485                                                               | 457                                                               | 328                                                               |
| Renfrewshire       | 169,590                                          | 138,451                           | 855                                                                      | 1228                                                                     | 693                                                               | 489                                                             | 457                                                             | 685                                                               | 766                                                               | 1138                                                              | 617                                                               |
| W Dun              | 91,240                                           | 74,623                            | 460                                                                      | 498                                                                      | 421                                                               | 341                                                             | 246                                                             | 369                                                               | 444                                                               | 479                                                               | 369                                                               |
| E G CHCP           | 123,824                                          | 102,036                           | ?                                                                       | ?                                                                       | 794                                                               | 649                                                             | 337                                                             | 505                                                               | 808                                                               | 682                                                               | 717                                                               |
| SE G CHCP          | 101,476                                          | 84,442                            | ?                                                                       | ?                                                                       | 459                                                               | 479                                                             | 279                                                             | 418                                                               | 498                                                               | 383                                                               | 454                                                               |
| SW G CHCP          | 116,580                                          | 95,040                            | ?                                                                       | ?                                                                       | 796                                                               | 673                                                             | 314                                                             | 470                                                               | 803                                                               | 610                                                               | 703                                                               |
| W G CHCP           | 138,856                                          | 119,296                           | ?                                                                       | ?                                                                       | 798                                                               | 639                                                             | 394                                                             | 591                                                               | 813                                                               | 592                                                               | 737                                                               |
| NHSGG&C part of N Lan CHP | 19,113                                       | 15,614                            | Est: 81                                                                | Est. 84                                                                 | 41                                                                | 53                                                              | 52                                                              | 77                                                                | 89                                                                | ?                                                                 | 53                                                                |
| GG&C Total         | 1,192,241                                        | 980,401                           | 5,493                                                                   | 5,851                                                                   | 5,810                                                             | 4,716                                                           | 3,235                                                           | 4,853                                                             | 6,005                                                             | 5,529                                                             | 5,200                                                             |
| Glasgow City       | 580,690                                          | 483,356                           | 2,663                                                                   | 2,671                                                                   | 3,314                                                             | 2,795                                                           | 1,595                                                           | 2,393                                                             | 3,378                                                             | 2,706                                                             | 3,028                                                             |
Appendices 4-6 table a more detailed age and gender breakdown of the 5,200 persons with LD known to the LES LD register as at 18th August 2009. The LES LD register gives a prevalence for LD of 5.3 per 1,000. There is an undercount in the 16-19 year age group, in view of transition with school leaving age being 19 years for many, and the GP LD LES being for adults aged 18+ years, not 16+. The adults included on the LES LD register aged 16 and 17 are therefore only those who are using specialist LD health services.

4.6 Trends in prevalence of moderate to profound LD and ascertained LD

Trends in prevalence are important. Given that total numbers depend on population sizes as well as prevalence rates, the question is “Will we have more people with an LD and if so how many more?” Given that prevalence varies with geography, methodology of data collection, and definitions of LD, comparing time trends with data derived from different localities has limitations. Future predictions of prevalence are extremely difficult to do accurately given the multiple influencing factors, and changing social attitudes which also have an influence. Hence caution is needed in reviewing the following.

In 1996, the prevalence estimates for severe intellectual impairment (equivalent to moderate to profound LD for the purposes of this report) from several different registers was used to demonstrate the rise in age-specific prevalence over the previous 35 years\textsuperscript{[52]}. This analysis demonstrates the marked increase in prevalence for most age groups since the 1960s (Figure 9).

Figure 9: Graph of prevalence of severe intellectual impairment by age group from various UK LD registers obtained from McGrother et al 1996 and McGrother et al 2001\textsuperscript{[52],[53]}.

More recent published literature includes 2 different sets of predictions of future need/demand. One is based on the Leicestershire LD register that attempts to predict future trends of prevalence of moderate to profound LD\textsuperscript{[45],[53]} and the other is based on work from the University of Lancaster that predicts future trends of ascertained and total numbers of adults with LD (of all severities) in England\textsuperscript{[1]}.
In 1999, the Leicestershire researchers used computer simulation using recent age-specific mortality rates from their register and projected an increase in prevalence of 1.05% per annum over the 10 year period from mid 1998 to mid 2008 with the largest increases predicted in the older age groups because of improving survival. Their age-specific projections were calculated and totalled to achieve a predicted number for 2008 of 2,305 adults aged 30 years and above.

In fact, there were 1,970 adults aged 30 years and above estimated to have moderate to profound LD on their register by March 2008, suggesting that the forecast overestimated the numbers. Recent communication with the Leicestershire researchers to clarify this discrepancy reveals the following: the reason the 2008 figure is lower than expected is because the register’s definition of severe intellectual disability was reportedly changed between these two time periods so the two figures are not strictly comparable. Dr C. McGrother reported they are currently undertaking another modelling exercise and that initial findings suggest that the prevalence rate will increase in the future at 1.28% per annum over the 10 year period from 2003-2013 (95% CI 10.4-15.4) although this work has yet to be published. Dr McGrother confirmed the validity of the initial forecast of 1.05% per annum when the 2008 prevalence is recalculated using the original definition.

This forecast suggests that GG&C will accumulate another 34 cases of PWLD with moderate to profound impairment every year (ranging from 2 for East Renfrewshire CHCP and 5 for SW Glasgow CHCP) assuming the Health Check percentage of 61.1%, a baseline ascertained prevalence of 3.1 per thousand and an annual rise of 1.28%. The equivalent figures assuming Leicestershire baseline prevalence of 3.74 per 1,000 for moderate to profound LD and a 1.28% per annum rise would be 41 new cases per annum (ranging from 3 for East Renfrewshire CHCP and 4 for SW Glasgow CHCP).

In 2004, the Institute of Health Research at the University of Lancaster published predictions for ascertained and total prevalence of LD (mild through to profound). Adjusting for ethnicity and mortality rates, they predicted future ascertained and total numbers (Figures 10 and 11) of people aged 15 years and over, by age group. These figures are based on assumptions about the size of the population with LD, and mortality rates which may or may not be accurate. There figures demonstrate almost no increase in the total per capita rates for ascertained prevalence - from 0.48% in 2001 to 0.49% in 2021, but as England’s population is continuing to rise so the absolute numbers of PWLD will rise in the future. Conversely, Scotland’s population is expected to remain just above the 5 million mark for the next 20 years, balancing emigration and immigration, and both birth and death rates.

Overall, Emerson and Hatton’s predicted estimates, adjusted for ethnic composition and mortality rates, suggest modest but sustained growth over the next two decades in both the numbers of people with LD known to LD services (11% over the decade 2001-2011, 14% over the two decades 2001-2021) and the estimated ‘true’ number of people with LD in England (all severities) (15% over the decade 2001-2011, 20% over the two decades 2001-2021). This suggests that there will be a 1.1% and a 0.7% increase per annum in the current decade between 2001 and 2011 and in the current 20 year period from 2001 to 2021, respectively, in numbers of people aged 15 years and above with LD known to services in England until 2021. If these are applied to GG&C, this would suggest 56 additional cases per annum being added to the LES LD register for the entire Board area, (ranging from 3 for East Renfrewshire CHCP and 7 for SW Glasgow CCHP), bringing the total number of PWLD aged 20 years and above on the LES LD register from 5,119 to 5,175 by the end of 2009.

The authors point out that these overall figures mask very marked changes in the age profile of people with LD as demonstrated in Figures 10 and 11 below. These include very little change in the
15-49 year age group identified as having LD, but a marked increase in the 50+ age group. Increased demand in the older age groups is of particular significance for the strategic planning of services since older adults with LD are more likely than younger adults to rely on public funding for supported accommodation.

**Figure 10:** Graph predicting the changes in numbers of people in England with a LD known to services over the 10 year period from 2001-2011 and the 20 year period from 2001-2021, obtained from Emerson and Hatton (2004).

**Figure 11:** Graph predicting the changes in total numbers of people in England with a LD over the 10 year period from 2001-2011 and the 20 year period from 2001-2021, obtained from Emerson and Hatton (2004).
The rise in prevalence of LD has probably been remarkably gradual and steady over the past 3 decades. It reflects, amongst other factors, the gradual rise in life expectancy of PWLD at all ages, but particularly in older age groups. Because of the increasing longevity of older PWLD that has occurred, an increasing proportion of this rising number will be older people with complex co-morbidities to complicate moderate to profound LD.

4.7 Estimating future need for adult social care services for people with LD

Emerson and Hatton recently published estimates of predicted future numbers of young people with an LD entering adult social services as well as the expansion of current numbers of adults with LD expected to continue to require social services over the next 20 years from 2009 to 2026[2]. Emerson accessed the number of children with Special Educational Needs (SEN) associated with LD using the 2008 School Census in England, made assumptions about the percentage (lower, middle and upper estimates) that would be eligible for adult social care services under current criteria applicable to England, and adjusted this for child mortality rates to predict the number of children who would need social services in the future as they entered transition. He combined these predicted estimates of children expecting to enter transition with data from LD registers from 4 English local authorities to estimate current demand by adults with LD for social services, making assumptions about the level of rationing that might be imposed in the future.

Based on this work it suggests that currently (in GG&C in 2009) we have between 3,410 and 3,502 (low and high estimates) people using adult social services for critical, substantial or moderate need (excluding the far more variable numbers of people with mild LD) and that by 2014 this will have risen to a range of 4,338 to 4,856 (the range depending on the percentage of children with SENs and LD who will be eligible for adult LD social services. By 2026, this range is expected to have risen to a range of 6,288 to 7,776.

The estimated number of new entrants to adult social care services with multiple and profound LD predicted for GG&C based on these projections ranges from the current high of 18 per annum to the lowest annual entry of 13, with an average of 15.

4.8 Life expectancy

Life expectancy is the best summary figure of the quality of life and health care experienced by a particular population. It might be useful to know what is the life expectancy of PWLD in GG&C, both to compare the figure at one point in time with other populations with LD in Scotland, the UK and elsewhere; and also to compare with the non-disabled GG&C population; and study the trend over time.

The NNA summarised evidence that the life expectancy for people with LD is lower than for the rest of the Scottish population. For some people inadequate support or environment, or poor quality of healthcare exacerbates what may be a baseline physiologically compromised state, rather than their being a single factor. It is essential that PWLD receive optimal high quality health care to achieve their maximum potential life expectancy. The NNA also makes clear that life expectancy is known to be improving generally for PWLD. If we endeavoured to measure life expectancy for the GG&C

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For example, life expectancy at 5 years of age given that it often takes that long to diagnose the learning impairment, (i.e. at the commencement of school or thereafter).
population of PWLD, and on a serial basis, we would probably find that it was increasing locally as well. To compare with other areas, we would need to measure and compare the slopes of serial measures of life expectancy for NHS GG&C PWLD with those from another demographically similar population. The other way to interpret the life expectancy of the local GG&C population of PWLD would be to compare a single measure at one point in time (e.g. life expectancy at age 10 years in 2008-2010) to that of another population’s figure in which we have statistical confidence (such as the life expectancy for all Scots with a LD for the same period in time). This would tell us how the life expectancy of our local population of PWLD compares to that of a larger less socially deprived population. Ideally, we would need a minimum of 5,000 males and 5,000 females with a moderate to profound impairment to ensure sufficient numbers of deaths in each age-sex grouping. The population size of GG&C is too small to do this.

Alternatively, In order to overcome these difficulties data could be collected over an aggregated period of several years so that sufficient numbers of deaths are obtained in each age-sex grouping. This would require that a system (such as the LES LD register) is in place for several years in succession to link named practice data with death register data as described above. This would provide a summary life expectancy for females with LD, say at age 5 or 10 years, over a period of say 5 years (e.g. 2009-2014, assuming the LES is in place and allows the recording of these deaths in 2009). This would overcome the difficulty but would require waiting another 5 years to produce another summary figure to compare it to (e.g. 2015-2019). If overlapping the periods is considered in order to get an earlier feel for the trend (say by comparing LE over the 4 year period 2009-2012 with the LE over the 4 year period 2011-2014), there is a risk of comparing more similar figures and failing to detect any improvement. Furthermore, there might not be enough deaths, in both genders, in a period of 4 years.

The need for larger populations begs the question of whether we could calculate life expectancy in the LD for all of Scotland. This would provide the statistical confidence but would be a considerable undertaking unless LD register submissions from QOF to ISD centrally were to include the name, CHI number, and date of birth of the PWLD (which it doesn’t at the moment). Life expectancy for all Scots with an LD would be an average figure and would conceal any differences in LE between more and less privileged neighbourhoods, should they exist.

In conclusion, the considerable efforts involved with maintaining high quality datasets required to measure life expectancy, and complete identification and recording of the details of each death in all PWLD in GG&C, may not be warranted by the quality of the information gained, unless ascertainment registers such as the LES LD register achieves a high sensitivity and specificity and is linked to the General Register Office for Scotland register of deaths.

4.9 Down syndrome

DS is important, as it is the commonest single cause of LD (up to 20% of all PWLD have DS). Much of the information below has been informed by the National Down Syndrome Cytogenetic Register and the most recent statistics, relevant as of 15/04/08, were provided by Professor JK Morris\textsuperscript{xii} (NDSCR).

\textsuperscript{xii} The NDSCR is funded by the National Screening Committee in England. NDSCR is part of the research arm of the Centre for Environmental and Preventive Medicine within the Wolfson Centre of Preventive Medicine. The NDSCR has accumulated over 17,000 anonymous records since the Register started in January 1989. It is now probably the largest single dataset on DS and provides an opportunity to search for possible causal factors. It also enables the study of the response of parents and clinical services to the new technologies of screening and diagnosis.
Prenatal screening and diagnosis have expanded dramatically. However, in 1999 44% of all diagnoses were at birth. Prenatal diagnosis is only offered to mothers with a greater risk of having an affected child. The estimation of this risk, previously limited to high maternal age, is now much more precise with the addition of specific ultrasound and/or maternal serum findings. Of all pregnancies with a prenatal diagnosis of DS, 94% of the parents decide to terminate the pregnancy, 5% are live born and 1% are stillbirths or neonatal deaths (1996-1999). A study using the Register data has not identified any evidence of variation in season, by year or by Health Authority area in the rate of DS diagnoses\(^{(54)}\). Further studies are in hand working with smaller populations and also looking at ‘deprivation’ on the incidence of DS.

Maternal age is the only well-recognised associated risk factor for DS such that prevalence at birth increases with maternal age. Mothers below 25 have an average risk of a DS pregnancy of about 1:1600 rising to about 1:340 at 35 and 1:40 at age 43. There have been few advances in the intervening period which offer much hope for primary prevention\(^{(55)}\). The reason for the increased prevalence with age remains unknown, although there are numerous hypotheses. Between 5 and 20% of instances are related to paternal factors.

The trends in diagnosis of DS in England and Wales in 1989 – 97 based on NDSCR data have been reviewed\(^{(56)}\). The updated data is shown below. As similar collated information is not readily available for Scotland, the English data is reviewed here on the assumption that Scottish results would not be markedly different. Data collected by Yorkhill covering GG as part of the Euro-Congenital Anomalies Register is also discussed.

The E&W Register involves anonymous notification of genetic diagnoses of DS to the National DS Cytogenetic Register (NDSCR). The laboratories producing the diagnosis of trisomy 21 (or related changes) provide the genetic details and the date, place of and indications for referral, parental age and family history. The outcome of the pregnancy is requested for all instances where the diagnosis was before birth, and is known for 91% of these. Total registrations to the register increased from 1,144 in 1989 to 1,336 in 1997 (an increase of around 17%). In the same time period, births in England and Wales decreased from 688,000 to 642,000 annually (a decrease of just under 7%).

In 92% of the notified instances where the diagnosis was known before birth, an abortion was performed. 1.9% were miscarried, 1.5% were stillbirths and 5% were live births where the child survived long enough to be discharged from hospital. In the subset of instances where the diagnosis was made after 23 weeks, usually as a result of an ultrasound examination, only a quarter of affected pregnancies were terminated, while in another 23% the child was miscarried, stillborn or died soon after birth.

Figure 12 demonstrates the increase in the numbers identified both before and after birth. Figure 13 demonstrates the increasing percentage of all cases that are identified before birth. These figures indicate an increase in the overall number of registrations, accompanied by a substantial increase in the proportion of registrations in younger women notified before birth. This has not been accompanied by a decrease in the number of children born with DS. Time trends in the number of children born with DS and notified to the register are shown in Figure 14.
Figure 12: Numbers of prenatal and postnatal diagnoses of DS reported to NDSCR, England and Wales, between 1989 and 2006.

Figure 13: Percentage of DS registrations diagnosed before birth in E&W between 1989 and 2006 according to NDSCR.
Figure 14: Total number of children born with DS (excluding stillbirths) and notified to the NDSCR in England and Wales between 1989 and 2006.

Figure 14 shows the number of children diagnosed only after birth combined with children born in whom the diagnosis was already known. It excludes stillbirths. The first red arrow is thought to be due to an increase in the number of births in 1996-1998 that followed a pill scare. The second red arrow reflects a persistent and gradual recent increase in the number of children with DS that are being born as a result of women’s decision to have children at older ages. In summary, the overall result is more babies being born with DS.

When NDSCR rates are applied to the NHSGG&C population, it is estimated that 15 children are born with DS every year in recent years compared to 11 children that were born per annum in 2000. This amounts to an average of 1.5 children per CHP/CHCP per annum. Data obtained from Yorkhill for GG are difficult to interpret because of the fluctuation due to small numbers. The overall trend in numbers of babies born live with DS in GG&C is possibly one of a fluctuating decline for women aged under 35 years and one of a fluctuating increase for those aged 35 years and older in broad keeping with statistics for England and Wales. In 2007, 7 babies were born live with DS in GG, which would suggest 9 were born in GG&C if Clyde has the same birth rate. All of these were in women aged 35 years and older.

These small numbers in GG&C need to be considered in light of increasing life expectancy of PWDS as a result of marked increases in survival rates in the first decade of life as demonstrated by Figure 15[57]. This means they will likely enter adult LD services and present with a range of complex conditions including dementia on average 30 years earlier than experienced by the general population.
In summary, whilst the introduction of antenatal screening programmes for DS has led to an increased rate of termination of pregnancy, birth prevalence for DS is not falling and may be increasing, as more DS babies are being conceived and more are surviving at birth. According to the report on the health check information, 17.7% of PW LD had DS. If this is applied across GG&C based on the LES LD population prevalence, there are an estimated 920 adult PWDS. PWDS also have longer life expectancies than in the previous years. Hence health and social services will continue to be required for PWDS for the foreseeable future, and at all parts of the lifecycle.

4.10 Trends in maternal age in Scotland

In 1967, the fertility rate for Scottish women aged 40-44 years was high at 14.2 per 1,000 women (GROS, 2008). It dropped to 9.6 per 1,000 women in 1971, and is now rising again and approaching 1971 rates. This is a risk factor for genetic causes of LD, including DS, and sensory and physical disabilities (e.g. cerebral palsy).

4.11 Maternal alcohol consumption as a risk factor for LD

Recent publicity\(^{58}\) raises the issue that the binge drinking and excessive consumption of alcohol generally on the part of pregnant women in Scotland may be the cause of mild intellectual impairment and antisocial behaviour in young people via Foetal Alcohol Syndrome Disorders (FASD)\(^{59}\). Italian children seem to develop FASD when their parents consume alcohol more moderately and with meals, so there is concern that West of Scotland children will also be at risk given the more extreme consumption, including binge drinking. Drinking alcohol in the UK tends not to accompany meals and is often done with the express purpose of becoming drunk. There is no reason to believe that this tendency comes to an abrupt end when Scottish women become pregnant.

Hospital admission data for alcohol related disease can be misleading for a number of reasons, hence epidemiologists’ preference for cirrhosis mortality statistics which are less subject to admission bias. These demonstrate that whilst cirrhosis mortality rates are falling throughout Europe, including in
Italy, they are climbing in Scottish men and women, particularly in GG&C (those for Scottish women are depicted in Figures 16 and 17).

Figure 16: Mortality from chronic liver disease, including cirrhosis, age standardised rates among women aged 15-74 years Scotland in context of Southern Europe Compiled by ScotPHO. Source data: WHOSIS (Dec 2004) & GRO(S).

Figure 17: Mortality from Chronic Liver Disease, including Cirrhosis, ASR among women 15-74 years. Directly standardised to Western European population. (Source: WHOSIS & GROS)
Within GG&C, liver disease mortality is not evenly distributed, as we would expect given the inequalities in lifestyle and health. As a council area, rates have been much higher in Inverclyde than in East Dunbartonshire and have climbed far more steeply, as in other socially deprived areas of Glasgow city and parts of Clyde. This provides strong circumstantial evidence that LD due to excessive alcohol consumption during pregnancy is likely to be a problem in socially deprived areas of GG&C.

In conclusion, within Scotland, GG&C has the highest rates of consumption and resulting alcoholic liver disease. Within GG&C, areas of social deprivation experience much higher rates still. Large populations of birth cohorts studied prospectively that include detailed study of maternal behaviour would need to be conducted to assess modern day aetiology of both mild and severe LD and the role of alcohol abuse in particular. Until that evidence is accrued, one might assume that alcohol consumption in parts of Glasgow city, including east Glasgow, is playing an unquantified role in the aetiology of LD. Discussion with paediatricians at Yorkhill hospital revealed a concern about the incidence of FAS in the face of a paucity of research; clinicians admit they find it difficult to raise the issue of the mother’s consumption when a child is born with clinical signs and laboratory evidence of FAS.
5. The health needs of PWLD in GG&C

5.1 Introduction

The health of people with learning disabilities was reviewed nationally by the Health Needs Assessment for People with Learning Disabilities in Scotland Reference Group and related groups and a comprehensive report published in 2004 (NNA). Key points from this report are summarised, updated with more recent publications and reports, and where possible applied to the relevant populations in GG&C to provide estimates of local health and social need. Additionally, this LNA reviews recently published research, local data when available, and has drawn on the expertise and experiences of staff working in the LD service. This report should be read in conjunction with the 2004 NNA. The focus of the study of health needs by the NNA was based on various clinical subgroups based on age or level of ability or on disease processes and this framework is retained for this LNA.

The NNA made it clear that PWLD experience more ill health and therefore have greater health needs than the wider population and that much of their health need is unrecognised and unmet.

5.2 Persons with severe or profound learning and multiple physical disabilities

The following health needs, which are complex and tend to synergistically disable PWLD or cause premature death, when acting in combination, have been described as common:

- epilepsy
- cerebral palsy
- swallowing problems
- sensory impairments
- gastro-intestinal disorders including gastro-oesophageal reflux disease (GORD)
- respiratory problems
- low body weight
- posture and mobility problems
- mental ill-health and problem behaviours

As a result, this particularly vulnerable subgroup experiences increased mortality rates throughout their lifespan (causing markedly reduced life expectancy) but particularly for the youngest and oldest ends of the spectrum. The main causes of premature death tend to be related to the respiratory and gastrointestinal systems (resulting in aspiration pneumonitis), seizures, and infections.
These problems and combination of problems require a heightened awareness of the need for multidisciplinary and multiagency cooperative involvement of many different services and staff, and effective communication within staff teams and across teams and services is typically essential:

- GPs, secondary care hospital consultants, and tertiary specialists.
- LD team specialist health staff including community LD nurses (CLDNs), psychologists, psychiatrists, physiotherapists, occupational therapists (OTs), speech and language therapists (SLTs), dieticians, podiatrists.
- LD Team specialist social work staff including social workers, social care workers and commissioning staff.
- Tier 4 services including acute assessment, complex needs support team, LD epilepsy specialist nurse services, LD pharmacists, ethnic LD service.
- Carers (family and paid).
- Independent providers of support packages in people’s own homes.
- Providers of day centres and other day opportunities.
- Respite care providers.

5.3 Adults with mild LD

This is numerically the largest group of PWLD in GG&C. Some have severe problem behaviours, autism, and health needs associated with their syndromal cause of LD, if they have one. They have a higher prevalence of mental ill-health than do people of average ability. These factors can present a challenge in providing care packages. Furthermore, they can be vulnerable people, relatively unsupported, who can escape the statutory services radar and experience considerable unmet health need, in part related to lifestyle; abuse of a variety of kinds; and problems with friendships and sexual relationships. They probably do not attract as much focused help from health and social services as people who are severely and profoundly impaired with complex health needs. They may use primary care services unsupported by either a carer, so their health needs may remain unmet following a visit to their GP.

5.4 Children and young PWLD (CYPWLD)

Although this LNA is focussed on adults with LD, some attention is directed to children and young people given the importance of issues of transition to adult services. The multi-factorial influences on the health, wellbeing, development and life expectancy described above are particularly critical in children with LD. Poverty and social disadvantage, which is more likely in lone parent and ethnic minority families, impacts negatively on families with a child who has learning disabilities.

The NNA provides a thorough description of the critical aspects of the initial assessment and diagnosis in CYPWLD. It also details the critical aspects of the early intervention in CYPWLD based on international evidence with interesting implications for the Greater Glasgow application of Sure Start, a Scottish version of the American programme Head Start.

- provision of early intervention programmes for children with an LD or other developmental disorders has increased over the past 30 years.
- positive results of these intervention programmes have been reported although there is controversy about the reliability of study findings.
- both the parents and wider family are important in any interventions.
social disadvantage in the family has been shown to be a risk factor for LD in American children\cite{108,109} and predicts the outcome in adulthood of people with mild LD\cite{110}. A systematic review of American early intervention programmes such as Head Start concluded that they are effective in preventing developmental delay and have long term benefits for children from low income families\cite{111,112,113}. A similar intervention programme, Sure Start, was established in the UK in 1997. So far, Sure Start has shown social and emotional benefits to the targeted socially disadvantaged children, via improved parenting, but has yet to demonstrate any improvements in language or cognitive functioning in Scottish children up to three years of age. Methodological problems, including the fact that the target group was widened after the first 5 years of implementation, may make it difficult to actually measure any reductions in the incidence of developmental delay in targeted children.

The NNA details the specific health needs of CYPWLD, including the facts that:

- 20-25% of CYPWLD have epilepsy\cite{114,115}. In GG&C, this would amount to between 250 and 315 CYPWLD in contact with LD services provided by Children and Families Services or Child Development Services. This percentage rises to more than 50% for children with profound LD. Epilepsy is also common in children with cerebral palsy\cite{116}, fragile X syndrome\cite{117} and tuberous sclerosis\cite{118} all of which are independently associated with LD. Epilepsy increases the mortality rates in children with LDs and development disabilities\cite{119}. The epilepsy in children with LDs is likely to be of earlier age of onset\cite{120}, and associated with treatment-refractory seizures\cite{121}, higher seizure frequency\cite{122} and lower health-related quality of life\cite{123}, compared to epilepsy in the general population of children. Children with LDs are at increased risk of visual impairment\cite{124}\cite{125} and hearing impairment\cite{126} which require early detection and correction if they are not to compound the effects of the LD. Cerebral visual impairment is common and typically unrecognised.

- between 31 and 50% of CYPWLD experience a wide range of mental ill-health and problem behaviours\cite{127}\cite{128}\cite{129}\cite{130}\cite{131}\cite{132}\cite{133}\cite{134}\cite{135}, 3-5 times as many as the general population of children/young people\cite{136}\cite{137}. In GG&C, this would amount to between 390 and 625 children and young people with both LD and mental ill health. The associated risk factors are male gender, older age, social disadvantage, family characteristics and the occurrence of significant life events\cite{138}.

- ‘inadequate provision of services for children and young people with LD and mental illness has been demonstrated’\cite{139} and was described in a UK report from the Mental Health Foundation\cite{140}.

5.5 Transition

The NNA describes in detail the critical transition issues for CYPWLD, including the fact that:

- the difficulties involved in partnership working are brought into sharp relief by the difficulties experienced by young PWLD who need to be, but are not always, actively involved and allowed to exercise choice at the time of transition planning, leaving them vulnerable to the loss of protective relationships and friendships.

- young people continue to use services for children well into adulthood or have to manage without an appropriate resource. In addition, poor planning, communication and coordination between childrens’ and adult services - sometimes with disputes over provision and resourcing of services - can leave a young person without the services and supports required to maintain their health, well-being and development.
• Active planning and preparation, in partnership with young PWLDs, their families, support staff and professionals from across agencies, is critical to raising expectations of what can be achieved at the time of transition, bearing in mind opportunities for education, employment and relationships.

Standard 8 of the National Service Framework, published the same year, states that ‘assessment and planning for transition from child to adult services is often unsatisfactory. For many, there is a lack of co-ordination between the relevant agencies and little involvement from the young person. Some disabled young people are not transferred from children’s to adult services with adequate care plans, resulting in their exclusion from adult services. In addition, some disabled young people experience a decline in the services they receive. This can lead to a regression in their achievement and/or deterioration in their condition’.

In GG&C, some adults with severe/profound LD and complex needs as old as 30 years are still being admitted to respiratory, orthopaedic, neurology and rehabilitation wards at Yorkhill hospital, sharing wards with children and adolescents because they, their carers and their hospital consultants are concerned that their care will deteriorate if they are discharged into adult hospital services, from co-located and fully integrated secondary paediatric services with which they grew up from childhood or even birth. Age at death in this group used to be much younger but modern medicine and better standards of living means that they are now living much longer and outgrowing the paediatric wards they are used to occupying. Information from Yorkhill hospital suggests that there are 69 young people (aged 16-25) in GG&C who were admitted to Yorkhill at least once between 1 April 2003 and 1 April 2008.

Excellent guidelines on transition have recently been published that should be used to develop transition strategies, transition care pathways, joint transition teams (consisting of health and social work staff from Yorkhill, LD teams and the relevant adult hospital specialities) for each CYPWLD in transition\(^\text{141}\)

Transitional planning encompasses consideration of a range of needs, including education/day opportunities, College and work, respite care, daily support, and LD team support, and hospital care. LD team members are in a position to actively support transitional processes.

### 5.6 Social deprivation and LD

Normally, social deprivation and ill health are strongly linked in most epidemiological studies of the wider population\(^\text{142}(143)\). Many PWLD are more likely to be living in socially deprived areas\(^\text{144}\). This relates to both the areas that people with LD are born in, and also where the housing association stock is available for rental, for people living in supported accommodation. One could expect that the health of PWLD living in socially deprived areas is more likely to be adversely affected by the adverse circumstances and more impoverished wider environment, although there is some limited evidence that area deprivation impacts on health differently to its influence in the general population\(^\text{145}\), and there are likely to be complex interactions between the influence of families and paid carers for persons living in supported accommodation.

The problems people experience may be further complicated by poverty, long-term familial unemployment, alcohol and drug addiction, sexual or physical abuse in the family and other social problems that have resisted population-based social and economic interventions.
The relationship between social deprivation and LD is a complex one that is hard to quantify using traditional methods. The measures used to categorise social deprivation in the wider population (based on occupation e.g. social class, or census-based data used to describe a geographic area e.g. SIMD, Carstairs’ Depcat) may not be appropriate for persons with LD. Where one lives is often used by policy makers and epidemiologists as a proxy for social deprivation and this may not accurately reflect the socio-economic conditions experienced by a PWLD. PWLD experience considerable and multiple forms of exclusion that often pre-empts their ability to make their own choices about their future, including where they live.

Still other factors that are not as relevant for the wider population, superimpose on social deprivation, to act as additional determinants of health and ill health for PWLD, including:

- Communication needs
- Psychological factors
- Social factors (including adverse experiences in early life and throughout adulthood)
- Experience of discrimination within services
- Exclusion by society at large
- Diagnostic overshadowing
- Comorbidity and polypharmacy
- Multiple life events.

### 5.7 Older PWLD

The NNA details the health needs of older PWLD, including the fact that PWLD are living longer than ever before, which is to be welcomed. It also suggests that the de-institutionalisation of PWLD since the 1970s; the structural determinants of health (including the rising standard of living, improved housing and increasing availability of varied and quality food, etc.); and increasing access to health care, are all impacting positively on their life expectancy. It also means that there will be greater numbers of older PWLD with higher levels of health needs than the general population (a combination of needs that affect the general population, those associated with aging and those needs specifically related to their LD).

#### 5.7.1 Mental health issues, including dementia

- The NNA states the following. About two thirds of older PWLD have an additional mental disorder\(^1\text{46}\)\(^1\text{47}\). This includes attention deficit hyperactivity disorder (ADHD); autism spectrum disorders (ASD); mental illness – recent onset or enduring; problem behaviours persisting through adult life; and acquired dementia. The excess mental disorders in older PWLD are predominantly depression, anxiety, and dementia. In GG&C, where the LD register estimates that we have 527 older people with LD aged 65 years and above, this amounts to 362 older PWLD with a mental disorder.

- The NNA states that dementia is about four times more common in PWLD\(^1\text{48}\)\(^1\text{49}\)\(^1\text{50}\)\(^1\text{51}\). The prevalence of dementia in GG&C for both genders combined according to the QOF register in 2007/8 was just 0.52%. The prevalence of dementia in GG for both genders combined with LD in 2002-4 was 2.22%, confirming the 4-fold excess.

- The NNA states that dementia is particularly common in people with DS (PWDS), about half of whom will acquire clinical dementia in middle or older age, 30 or 40 years before their non-learning disabled peers\(^1\text{52}\)\(^1\text{53}\). The prevalence of dementia in PWDS varies by age: 2% at age 30-39 years, 9.4% at age 40-49 years, 36.1% at age 50-59 years and 54.5% at age 60-69
years\textsuperscript{154}. In NHS GG&C, this would mean that we could expect to have a total of 63 PWDS and dementia aged 50-59 years and 22 aged 60-69 years (as there are fewer people in this older category due to premature death). As the life expectancy of PWDS continues to increase, we should expect this number with LD and dementia to increase\textsuperscript{155}.

- The NNA states, ‘There are advantages to detecting the onset of dementia as early as possible [as] this allows access to cognitive-enhancing drugs for which there is some evidence for effectiveness\textsuperscript{156}\textsuperscript{157}. In addition, it reports that there is ‘a range of biological, psychological, social and developmental approaches designed to improve quality of life and to support carers’ that can be provided by LD teams who ‘advise on assessment, intervention and supports’.

5.7.2 Screening for dementia in PWDS?

Early detection of dementia might be beneficial, but should there actually be proactive screening for dementia? Screening for dementia amongst persons with DS is a controversial point. Whilst drug treatment might be beneficial for clinically-presented dementia, we do not know if it is so for screening-detected dementia.

Neuropsychological assessments are time consuming, and can be fatiguing for people with LD. The research evidence on which are the most useful tools to detect cognitive decline in this population is exceedingly limited, with no longitudinal published data with older people with DS. The largest longitudinal data set has not published raw test scores\textsuperscript{158}; the next largest (57 adults aged 28 and over)\textsuperscript{159} noted that only 45\% could complete the test instruments. Functional assessments are less time-consuming, but can still be viewed as intrusive by some and may raise some sensitivities and anxieties regarding future health problems which are not inevitable. There are significant costs involved in a one-off baseline cognitive assessment and more so for a full screening programme. Even if all psychologists were available for such an exercise, this would mean an extra 33 cases each for an annual programme or 20 in a one-off exercise. Such a detailed assessment would take a number of hours and both would be a significant draw on the psychology resource available from other areas of work. Additionally, diagnosis of dementia requires detection of psychopathology of dementia and exclusion of other conditions that mimic such a presentation e.g. hypothyroidism, onset of sensory impairments. This is complex to undertake, but arguably no more so than for diagnosis of other mental ill-health which also requires comparison of current presentation against previous state.

A recently published report from a working group of the Royal College of Psychiatrists and the British Psychological Society concluded that functional assessments (i.e. skills assessments) might be usefully conducted for young adults with DS, depending upon local service resources and priorities. The report outlines the conflicting and contrasting views on whether or not screening/one-off assessments should be offered. Different LD services in the UK have interpreted the guidance in different ways, with some offering baseline assessments, and others not doing so.

The LD service should help carers to understand the person they support’s strengths and limitations and have some written record of this if they are paid carers. This latter point could be supported through the commissioning process, and is actually relevant to all persons with LD, not just persons with DS. Paid cares should be aware of the issues related to ageing including dementia, and also importantly that decline in skills does not necessarily point to dementia and may be due to a number of factors some of which can be corrected. There is a role for LD teams in encouraging and supporting this. Full assessments should be undertaken if there is any concern about a person’s behaviour, onset of symptoms, a change in personality or decline in skills.
The LD service could consider the practicalities of offering a one-off assessment of functional skills to young adults with DS. Alternatively, this could be incorporated into the assessments of all new referrals to the LD service (DS and non DS) using a valid instrument (e.g. the Vineland Scale), given that such assessments are often performed by clinicians (although at present, just not with an instrument), and for existing case loads, at review appointments. The value of following on from this baseline assessment with repeat testing with a view to diagnosing early dementia is debatable, and GG&C is not resourced at a level to prioritise this over other work.

The RCPsych/BPS guidance advocates that every health authority ensure that there is a multi-agency care pathway for assessment, diagnosis, treatment and support of people who develop, or are at risk of developing dementia, which has been agreed by the Partnership Board or its equivalent. Many CHCP/CHPs in GG&C have ambitious plans to implement dementia screening but that these rarely comply with the guidelines that do exist and tend to involve a variety of different assessment/screening tool, different screening interval, and/or target a different age group. Local LD professionals have worked together to devise a GG&C LD dementia care pathway, but this is not consistent across GG&C.

The subject of dementia in people with LD raises issues about the most-effective way to provide support and care for an increasing group with high dependency needs that will not be well served in traditional nursing home settings for elderly people. For some, their progressive decline will be manageable in their existing home, with increasing levels of support, and advice to their support team. A multidisciplinary assessment, including social work/care management and occupational therapy is essential. For others, a move to new accommodation may be inevitable, in view of unsuitable physical environment of their home, elderly family carers unable to provide highly intensive care when it becomes necessary. If this is likely, consideration is needed as to whether the person gains most from moving early, when they still have some chance of orientating to their new environment and support team, or remaining in their current environment as long as possible. If the person with dementia is only in middle age (particularly relevant for persons with DS) and moving from a family home, should they be move to a supported package with people of their own age, who may not have dementia, or into nursing homes for the elderly, where they may be 20 to 30 years younger than anyone else? These are difficult decisions and require multi-professional input together with the person with LD and their family and paid carers.

5.7.3 Physical ill-health

The NNA stated that physical ill-health is also more common amongst older PWLD, than their similarly aged non-learning disabled counterparts. Higher rates of sensory impairments, thyroid disorders, obesity, non-atherosclerotic heart disorders (including congenital heart disease), mobility impairment, osteoporosis and respiratory problems are superimposed on what are population rates of common age-related disorders such as hypertension, stroke and coronary heart disease. The types of health needs that ageing PWLD experience is also related to their underlying cause of LD. For example, people with homocysteinuria have exceedingly high rates of atherosclerosis, and at much younger than typical age of onset. PWDS have lower rates of hypertension, cerebrovascular disease (including strokes) and ischaemic heart disease than the non-learning disabled aging population \cite{160,161} even though they age prematurely as demonstrated by hair loss, ovarian failure, wrinkling \cite{162} and premature dementia. Whilst they form 15-20% of the LD population, few reach old age if defined chronologically rather than physiologically. Women with DS are found to have lower rates of breast cancer than their non-learning disabled counterparts, even when adjusting for age \cite{163}. Overall, the commonest causes of death in older PWLD are different compared with the general population of the same age bracket. This emphasises that services need to address the
commonest causes of morbidity and premature mortality in PWLD rather than adopt a strategy aimed at maximising uptake by PWLD of services which were aimed at tackling the commonest illnesses in the wider non-disabled population.

The NNA stated that older PWLD live is a diverse range of settings where they are usually in a minority and subject to diagnostic overshadowing; in LD settings their health needs are inappropriately attributed to old age and, conversely, in old age settings, to LD, resulting in a failure to address needs. In addition, older PWLD tend not to report symptoms. For these reasons, there may be indication for a proactive annual health check programme with follow-up of any recommendations made for investigations or treatment.

Following the death of parents, older PWLD often do not have close family supports so can be very dependent on service supports, which need to be robust.

5.8 Carers of PWLD

The report from the health check information shows that 38.1% of PWLD in GG live with a family carer and 45.7% live with paid carer support. Just 10% live independently and 6.3% live in a congregate care setting e.g. a nursing home. The NNA considered family and paid carers of PWLD.

5.8.1 Impact of carers on the health of PWLD

Throughout the document, the NNA comments extensively on the critical role of family and paid carers of PWLD in terms of their impact on the health of PWLD. Family carers play a crucial role in supporting the health needs of their relative with LD. Persons supported by paid carers may be affected by how long the paid carer has known the person, so that they recognise any change in the person; how well information is shared between members of the support team; and between support teams (e.g. supported living and day centres) and how much time the paid carers spend with the person. One study reported that 68% of paid carers felt they had not received sufficient training on the use of medication by clients. ‘There is a role for specialist LD health professionals to contribute their skills by supporting paid and family carers and community workers in health improvement initiatives and also in training to acquire specific skills necessary to maintain health e.g. emergency administration of stesolid for persons with epilepsy, PEG feeds. The caring role can be very demanding, as well as very satisfying.

The NNA highlights:
• The potential for considerable pressures on both family and paid carers of PWLD,
• The considerable expectations in meeting complex health needs placed on carers, and the
• The wide range of training (some of it quite sophisticated) that is needed to fulfil these expectations.
• The NNA highlighted the wide and complex agenda expected of family and paid carers.

The remuneration and training of paid carers are important issues in the overall standard and consistency of the care of PWLD. There are three main sources of training for carers: The Scottish Consortium for Learning Disabilities (SCLD), the LD teams based in the CHCPs/CHPs and the independent sector organisations that provide support/training and/or provide support services on commission. The NNA stated that ‘the SCLD is one of the national centres of excellence in training set up by the Scottish Executive. It has a remit to develop and deliver courses and learning materials
to equip health and social care workers with the values and skills to work in person centred ways in partnership with people with LD and family carers as recommended by *The Same As You?*. Training by LD team staff is limited by the manpower employed in these teams and their competing agenda to directly address the health needs of PWLD and be involved with care management functions. Training of family carers is also provided by some independent sector organisations such as PAMIS, which emphasise health related issues, and has a focus on persons with complex needs. Training is also provided by the independent provider of the service itself.

Staff turnover in provider organisations means that training needs to be offered continually as staff leave the organisation and new staff are employed to replace them. There is variability across provider organisations as to the extent that this is successful. Some senior representatives of provider organisations who employ and manage paid carers express concern about the increasing challenges they face either providing the kind of training that is needed to their staff or arranging for such training as provided by other organisations. This is particularly relevant as they are obliged to make efficiency savings.

The NNA stated that ‘It is essential that employers of support and sessional workers induct and develop their staff: this should include recognition of contributions towards supporting health and enabling health improvement. Commissioners of support packages should specify the need for staff development, including health care responsibilities, within their contracts with providers: they should also maintain robust mechanisms for monitoring these’. There still seems to be concern about the relative lack of specification for health care responsibilities and health promotion activities within contracts with providers in GG&C. This leaves specification and monitoring to the annual review process requiring negotiation and other less formal processes. The role of tier 3 community LD staff in monitoring and reporting to Local Authority partners any education and induction required could be strengthened.

The NNA also highlighted the published evidence on the positive effects on the well-being of families and PWLD, of short respite breaks for people who live with family carers. Many family carers are women and many of whom are aged. The report from the health check information reported that in GG 23% of family carers are over the age of 70. It is important to listen to carers, and respond to the evidence base on the benefits of respite, so PWLD need access to comprehensive health services including respite care when they need them.

### 5.8.2 Health of carers of PWLD

The NNA also describes the health needs of family carers emphasising that the stresses and demands described above can take their toll on those looking after PWLD. It states that ‘A consistent finding is that families with a child with LD are at greater risk of socio-economic disadvantage. Other studies have reported increased rates of stress and depression amongst parents. This highlights the need for adequate provision of welfare rights advice. Some CHCPs/CHPs have little or no access to welfare rights officers, and some LD team staff are unclear if they had been able to maximise their clients’ financial benefits because of their limited skills in negotiating the application procedures for these benefits or because they had no timely access to such qualified officers to help.

That NNA also stated that ‘Both poverty and having a child with LD experiencing problem behaviours or other psychopathology have a negative impact upon the mental well-being of parents’. Carers of people with multiple physical disabilities also acquire musculoskeletal problems associated with moving and handling and other aspects of physical care. This raises the importance of the provision of support from the LD teams, including physiotherapy and OT support.
The NNA refers to published work on the health of family carers based on self-reported ill health. Eighty nine percent of the carers surveyed from the Leicestershire register were female and 17% over the age of 70 years. Female carers were considerably more likely to report depression, gastrointestinal symptoms and musculoskeletal problems while male carers were more 2.7 times more likely to report cardiovascular problems[166].

Little is known about the health of paid carers. Paid carers and family carers may face different challenges and rewards. There are likely to be differences in levels of emotional attachment, a family carer cares 24/7 rather than working shifts, and may be isolated rather than working in a team. Paid carers are of working age, so in general are younger.

5.9 Barriers to access to services

The NNA devoted considerable attention to the fact that PWLD experience barriers to their health needs being met by services, attributing these to a combination of factors affecting access. These should be read in the context of the GG&C findings (see appendix 7 for an excerpt of these factors). These factors, some of which are inter-related, were categorised as to whether they could be attributed to the following:

- Issues relating to the PWLD;
- Health and social work professionals;
- The structure of health and support services.

Most of the issues listed are also relevant in GG&C. Additional factors that might be relevant in some parts of GG&C include:

- Some CLDNs, OTs and social workers in LD teams are spending a lot of time on care management maintenance tasks, funding maximisation, welfare rights, etc. which leaves them with less time for other work. This is particularly so in Glasgow City CHPs where an active decision was taken on this at the inception of the former LD partnership. Increasingly, other staff are also taking on these responsibilities, such as the coordinating role provided by day centre support workers. Care management serves an important function for PWLD, and where the processes are successfully embedded (e.g. East Renfrewshire) teams are delivering this function, and also maintaining the expert skills of individual disciplines. Resources are required for an appropriate skill-mix, including both registered and assistant staff, for appropriate allocation of duties and responsibilities. The needs of the PWLD should be used to determine who is the most appropriate member of staff to deliver the care management function. For example, a community LD nurse might be best placed to be care manager for a person with complex and multiple health needs, a social worker for a person with predominantly social needs, and an assistant might be the most appropriate worker for a person whose health and social and family needs are mostly being well met. It does not seem appropriate for qualified health staff to be manning social work duty rotas.

- There are waiting lists for psychologists, speech and language therapists, and dieticians in some parts of GG&C.

- There are differencing use of eligibility criteria in parts of GG&C, partly due to health and social work staff working to different criteria. The introduction of consistent eligibility criteria across the service might be beneficial. While psychologists have a key role in establishing an individual’s level of functioning (which is not as simplistic as whether someone has LD or not), their expertise in this area should only be called upon when there is significant dubiety about someone’s level of functioning, and not routinely in a mechanistic way to establish individuals’ IQs. The service should be adept at identifying individuals who have clear LD who would benefit
from the services it provides and at working with generic services to support people who do not need a specialist LD service. Clinical psychologists are a highly skilled and therefore not inexpensive workforce, and the development of eligibility criteria should not require highly time consuming tasks such as psychometric assessment to establish LD.

- Recording of health data on clients is of variable quality and completeness, usually not electronically captured and varies by CHP and particularly between Clyde and GG portions of GG&C. Sharing of health information between health and social services continues to be problematic in some areas.

PWLD face innumerable barriers to accessing the NHS, and the LD teams play a crucial role in being able to proactively promote positive health as well as responding reactively to ill health and crises. Their role extends to direct delivery of health and social care, and working more closely and more regularly with colleagues in primary care, and in the acute sector.

Ninety percent of health care is delivered by primary care. The NNA states that the ‘knowledge base [required to effectively operate the same model of care for PWLD who have differing causes of morbidity and premature mortality] does not exist at present in primary health care services in Scotland, for a variety of reasons. It is difficult to see how this capacity can be built within the existing model of primary health care services, given that each GP’s opportunity to gain experience once in practice will be limited. On average, a GP will have only about five persons with LD registered with her / him at any one time, each one of whom will have health needs differing from each other, and typically with lower consultation rates than the rest of the population. This is extremely low volume work compared with other work managed within primary care.” The former LD Partnership rose to this challenge, through the introduction of the Primary Care Liaison Team for a two year period in 2002-2004, and more recently the Board recognised the importance of making reasonable adjustments in supporting primary care to deliver an effective service for PWLD through allocating one the Scottish Enhanced Services Programmes to LD. This LD enhanced service has been highly rated by primary care services and carers, and complements the important work of the LD teams. It would be naïve to believe that primary care could be “skilled-up” to a level where support from the LD enhanced service was not required, or that the specialist skills of the LD teams could be replaced by primary care, and both will be required for the foreseeable future.

NHS GG&C employs 45,000 staff, most of whom rarely see a PWLD and few of whom treat a PWLD frequently enough to develop confidence and expertise. The acute sector in GG&C has introduced training on LD, but there is likely to be a need for ongoing support from the LD teams, particularly when a PWLD is admitted to hospital. Health and support records are being developed by the community LD nurses, for carers to use and take to hospital to inform ward staff.

5.10 Communication

The NNA provides a section on communication difficulties, which are of central importance of this issue of PWLD and those who care for them. Communication difficulties are key to explaining why many healthcare professionals outwith LD specialist services fail to deliver an effective service to PWLD. Most healthcare workers have never had training in the kind of communication methods and techniques that LD health specialists have had and are aware of and able to access.

LD speech and language therapists have a wide variety of skills including the use of ‘Talking Mats’, ‘Total Communication’ and ‘Intensive Interaction’. LD OTs have skills in Sensory Integration, and LD clinical psychologists and psychiatrists all
play critical roles in ensuring that communication is augmented and efforts to respond to health and social needs are effective. LD SLTs also provide an LD audiology service and link with specialist LD audiologists who test hearing in PWLD.

LD SLTs are increasingly involved with working with prisoners and sexual offenders who have learning disabilities where communication is difficult and a major obstacle to treatment and rehabilitation. The Royal College of SLT (RCSLT) is calling for effective SLT services throughout the Justice pathway given the increasing evidence of connection between communication support needs and offending behaviour that is being highlighted by a RCSLT campaign *Locked in and Locked out*. A major document was recently published by the Prison Reform Trust on the experiences of the criminal justice system by prisoners with LD and learning difficulties^{179}.

SLTs are considered an integral part of the multidisciplinary team that responds to autism/ASD in adults according to SIGN guidance on subject^{180}. They are not currently resourced to extend to adults with autism who do not have LD.

The RCSLT position paper on SLT services for adults with LD^{181} published in 2003, describes three levels of service delivery:

- Individual
- Environment
- Community

The evidence base supports tiered SLT services with the levels and associated functions found in the draft table below, kindly loaned by the RCSLT:

<table>
<thead>
<tr>
<th>Specialist</th>
<th>Complex needs:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Assessment of individual</td>
</tr>
<tr>
<td></td>
<td>Develop and directly implement LT ongoing programme including 1:1 / Group therapy, individual centered training staff and carers, develop individualized communication and / or dysphagia resources / equipment provision etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Targeted</th>
<th>Special needs requiring short to medium term support:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Assessment of individual</td>
</tr>
<tr>
<td></td>
<td>Develop and support implementation (short to medium term) of ongoing programme by staff and carers, develop individualized communication and / or dysphagia resources / equipment provision etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Universal</th>
<th>LD Population work (no named clients) – working to the social model of disability;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Developing, via various training strategies and provision of “Inclusive communication” resources, communication accessible communities and cross sector services – including health (public, primary, secondary, tertiary), education (all ages and stages), justice (civil and criminal), leisure and recreation, employment etc.</td>
</tr>
</tbody>
</table>

This LNA revealed waiting lists for these staff in some areas, with inconsistency in this across CHCPs/CHPs. SLTs also have to prioritise dysphagia management.
5.11 Gastrointestinal disorders

The NNA provides a useful description of the common gastrointestinal problems facing PWLD including gastro-oesophageal reflux disease (GORD), *Helicobacter pylori* infection of the stomach, and constipation. These conditions are all painful, and can have longer term sequelae, including oesophageal strictures leading to dysphagia, and cancer. Swallowing difficulties (dysphagia) are covered later in the report in the section on nutrition. The following expands on the identification by the NNA of an increased risk of upper gastrointestinal (GI) cancer (oesophageal and stomach cancer) experienced by PWLD.

An elevation of GI malignancy in PWLD was highlighted by a national report on the subject of cancer and people with LD commissioned by the Department of Health and published by the British Institute for LD in 2001. This apparent increased risk of GI malignancy (oesophageal, stomach, colon and rectum) is based on a small number of studies, for some of which interpretation is made more difficult by the fact that the population changed over the period of study (deinstitutionalisation resulting in the concentration of a more dependent and aging population left behind). Nevertheless, the excess numbers of GI cancers identified by the British studies of the Stoke Park group of hospitals in Bristol are sufficiently high and persistent over time to suggest they are not random or artefacts of methodological flaws. This excess is demonstrated in table 4 by comparing rates and percentages observed in the institutionalised cohort at Stoke Park with those found in Scotland as a whole which is a much larger and statistically more reliable population (monitored by a cancer registration system) (table 4). This excess of GI cancer was found in 3 separate studies of 40, 10 and 10 year periods respectively in the same institutionalised cohort spanning a period of 60 years.

The first study demonstrates that 63% and 47% of all cancer deaths in institutionalised women with LD and men with LD respectively in a 40 year period (from 1936 to 1975) in the hospital were of the GI tract when one would expect to see about 25%. Ten of the 43 GI cancer deaths were of the rectum and colon. Thirty three of the GI cancer deaths were of the oesophagus and stomach, emphasising that in this study most of the excess GI cancer deaths were due to upper GI tract pathology. Although based on small numbers, the percentages of all malignant tumour deaths were considerably higher for all 4 GI sites amongst men with LD and were higher for the oesophagus and stomach for women with LD than their national counterparts for England and Wales. Although all-cause mortality rates were higher for PWLD than their non-disabled counterparts, the cancer death rates were lower for both men and women with LD, and the percentage of all deaths that were due to cancer was very much lower than for their non-disabled counterparts. In conclusion, PWLD in that study had a higher chance of dying in any particular year, but their death was less likely to be due to cancer. If they did have cancer it was more likely to be due to cancer of the GI tract and if affected by cancer of the GI tract it was more likely to be upper GI tract disease in both MWLD and WWLD. The study was of the period 1936-75, when life expectancy was much shorter for PWLD than it is today, and a different pattern of cause of death seen (e.g. tuberculosis causing death before one would expect onset of cancer), so these findings are of historical interest, rather than informing about likely rates of cancer for PWLD today.

The second study covered the same group of hospitals for a further 10 years from 1976-1985. It showed 31 GI cancer deaths occurred (22 in women and 9 in men) making up 58.5% of all 53 cancer deaths, at a time when less than 20% of cancer deaths in Scotland in 1982 were due to cancers of the GI tract, for the same 4 sites. In contrast to the earlier study, cancer death rates have climbed considerably as have GI cancer death rates for both sexes, reflecting the increasing longevity of PWLD in institutions and the fact that they were now living long enough to develop neoplasms.
Eighteen of the 31 GI cancer deaths were of the upper GI tract (stomach and oesophagus). There were 4 additional deaths from gall bladder cancer but no attempt made to interpret rates.

The third study covering the same group of hospitals for a further 10 years from 1986 to 1995 and is complicated by the declining inpatient population\cite{187}. GI cancer deaths remained a high percentage of all cancer deaths in the cohort at 52%. The high death rate which climbed throughout the study period reflects the fact that the least dependent patients were discharged as part of a wider movement to deinstitutionalise PWLD. The high crude cancer death rate is a continuation of the trend seen in the previous study to see higher cancer death rates in this population as they continued to benefit from an increase in life expectancy. There is no reference to gallbladder cancer in this study.

Several explanations have been proposed including:

- The high prevalence of GORD, which is a risk factor for oesophageal cancer, in PWLD, and which is particularly common in people with severe and profound LD, and people with cerebral palsy.
- The increased risk of stomach cancer from high prevalence of infection with *Helicobacter pylori* (a risk factor for stomach ulcers which can cause death in PWLD via perforation) which has been found to be endemic in this population;
- The increased risk of colonic and rectal cancer from chronic constipation which has been found to be endemic in this population, and not helped by immobility and lack of exercise;
- The increased risk of colonic and rectal cancer resulting from consumption of the high fat, high protein, low fibre, low fruit and vegetable diet.

The association of *Helicobacter pylori* and its association with gastrointestinal tract malignancy was explored via a review of all deaths as a result of cancer in the Stoke Park group of hospitals between 1946 and 1996\cite{183}. This retrospective case note analysis over a 50 year period showed death from stomach cancer accounted for up to 48% of all cancer deaths. A further 25 residents had died of perforated stomach ulcers. The authors suggest that high levels of *H. pylori* infection found in institutionalized populations may be instrumental in this higher mortality rate. A recent paper reviews the risk factors for and consequences, diagnosis and management of *H. Pylori* in PWLD, providing useful adaptations to the usual testing and treatment methods as part of a preventative health strategy\cite{188}. Given the considerable amount of evidence for the cost-effectiveness of screening for *H. Pylori* in the general population\cite{189}, it seems reasonable to consider targeted screening in PWLD and signs of dyspepsia, the presentation of which is rarely typical. However, this point is controversial. Many cannot cooperate with the breath test. The treatment is not without drug interactions, and recrudescent rates are high. Given the shared environments eg day centres, shared tenancies, eradication on an individual basis may not be an effective approach. The link between infection and cancer in this population is not certain, and has been challenged by Böhmer, who points out that oesophageal cancer, associated with GORD, can be confused with cancer at the neck of the stomach.

There are few equivalent community-based studies that enable us to assess the epidemiology of GI cancer in PWLD living in the community in modern times. An exception is the population-based study of cancer incidence among PWLD in Finland which is described in more detail in the section on cancer\cite{190}. Although 2,173 PWLD (corroborated by psychological tests) identified from an LD register of 4,013 (general population of 416,973) were followed up for 30 years using the cancer registry, this study is still too small to discern excess or low risks for most, including uncommon, malignancies. Nevertheless, it shows a trend towards cancers of the gastrointestinal system being modestly over-represented (standardised incidence ratio - SIR of 1.2 with a confidence interval (CI) of 0.9 to 1.5). Within this grouping, the only statistically significantly elevated rate was seen for
cancer of the gallbladder. Sixteen cancers of the stomach were observed when 13.7 were expected (SIR of 1.2 with a CI of 0.7-1.9). However, the study is Finnish, and UK studies of cancer incidence may be more relevant when considering public health policy for Scotland.

An exception to the hypothesis that PWLD experience higher than average rates of cancer of the digestive tract is the observed under-representation of GI cancer (oesophagus, stomach, colon and rectum) in PWDS, who may nevertheless be a modestly increased risk of cancers of the pancreas and gallbladder\textsuperscript{191}\textsuperscript{192}\textsuperscript{193} (as well as the known association with leukaemia). Because the distribution of cancers in PWDS is distinct and different from the remainder of the population and from PWLD in general, it is assumed that constitutional protective factors exist\textsuperscript{194}.

Because of an improved awareness of the risk of GORD, the index of suspicion may now be to be higher in modern clinical settings, resulting in more frequent attempts to treat GORD with modern, effective acid suppressants. The report from the health check information suggests there is still considerable GORD that remains undetected; 26.6% of 1,023 PWLD were found to have GORD and more than half of these were newly detected by the health check (15.6%).

The evidence, whilst limited, justifies actively promoting screening for GI cancer in PWLD, using modern testing kits for occult blood that have recently been introduced nationwide in Scotland for those aged 50 to 74 years -The Scottish Bowel Screening Programme is described on their website at: http://www.bowelscreening.scot.nhs.uk/?p=6
Table 4: Stoke Park Group of Hospitals, Bristol, cohort of institutionalised LD patients whose deaths were studied over a 60 year period\textsuperscript{(185)}\textsuperscript{(186)}\textsuperscript{(187)} and compared to Scotland-wide rates in 1982

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total institutionalised pop’n</th>
<th>Total deaths</th>
<th>Crude Death rate from all causes per 100,000</th>
<th>Total deaths from all cancers from 1976-85</th>
<th>Total annual crude death rate from all malignant neoplasms per 100,000</th>
<th>Frequency of deaths from malignant causes</th>
<th>GI deaths (no.) (E, S, C, R)</th>
<th>GI cancer death rate per 100,000 (E, S, C, R)</th>
<th>Frequency of deaths from GI cancer of all malignant causes</th>
<th>Frequency of deaths from GI cancer of all cause deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>820</td>
<td>536</td>
<td>1634.1</td>
<td>30</td>
<td>91.5</td>
<td>5.6%</td>
<td>19</td>
<td>57.9</td>
<td>63.3%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Females</td>
<td>870</td>
<td>589</td>
<td>1692.5</td>
<td>51</td>
<td>146.5</td>
<td>8.7%</td>
<td>24</td>
<td>69.0</td>
<td>47.1%</td>
<td>4.1%</td>
</tr>
</tbody>
</table>

Additional 10 year study from 1976-1985 n=1,051\textsuperscript{(186)}

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total institutionalised pop’n</th>
<th>Total deaths</th>
<th>Crude Death rate from all causes per 100,000</th>
<th>Total deaths from all cancers from 1976-85</th>
<th>Total annual crude death rate from all malignant neoplasms per 100,000</th>
<th>Frequency of deaths from malignant causes</th>
<th>GI deaths (no.) (E, S, C, R)</th>
<th>GI cancer death rate per 100,000 (E, S, C, R)</th>
<th>Frequency of deaths from GI cancer of all malignant causes</th>
<th>Frequency of deaths from GI cancer of all cause deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>620 estimated</td>
<td>129</td>
<td>2080.6</td>
<td>19</td>
<td>306.5</td>
<td>14.7%</td>
<td>9</td>
<td>145.2</td>
<td>47.4%</td>
<td>7.0%</td>
</tr>
<tr>
<td>Females</td>
<td>620 estimated</td>
<td>173</td>
<td>2,790.3</td>
<td>34</td>
<td>548.4</td>
<td>19.7%</td>
<td>22</td>
<td>354.8</td>
<td>64.7%</td>
<td>12.7%</td>
</tr>
</tbody>
</table>

Further 10 years of from 1986 to 1995, n=828, falling to 293 over the decade studied\textsuperscript{(187)}

<table>
<thead>
<tr>
<th>Total study pop’n at start</th>
<th>Total deaths</th>
<th>Crude Death rate from all causes per 100,000 averaged over 10 yrs</th>
<th>Total deaths from all cancers</th>
<th>Total crude death rate from all malignant neoplasms per 100,000 averaged over 10 years</th>
<th>Frequency of deaths from malignant causes</th>
<th>GI deaths (no.) (E, S, C, R)</th>
<th>GI cancer death rate per 100,000 (E, S, C, R)</th>
<th>Frequency of deaths from GI cancer of all malignant causes</th>
<th>Frequency of deaths from GI cancer of all cause deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>828</td>
<td>213</td>
<td>4018.1</td>
<td>29</td>
<td>547.1</td>
<td>13.6%</td>
<td>15</td>
<td>51.7%</td>
<td>7.0%</td>
<td></td>
</tr>
</tbody>
</table>

Scotland – 1982 RGOS stats

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total pop’n in 1982</th>
<th>Total deaths (1982)</th>
<th>Crude Death rate from all causes/100,000</th>
<th>Total deaths from all cancers in 1982</th>
<th>Total crude death rate from all malignant neoplasms per 100,000</th>
<th>Frequency of deaths from malignant causes</th>
<th>GI deaths (no.) (E, S, C, R)</th>
<th>GI cancer death rate per 100,000 (E, S, C, R)</th>
<th>Frequency of deaths from GI cancer of all malignant causes</th>
<th>Frequency of deaths from GI cancer of all cause deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>2,489,700</td>
<td>31,801</td>
<td>1,277.30</td>
<td>7,314</td>
<td>293.8</td>
<td>23.00%</td>
<td>1,668</td>
<td>67.0</td>
<td>22.8%</td>
<td>5.25%</td>
</tr>
<tr>
<td>Females</td>
<td>2,677,100</td>
<td>33,221</td>
<td>1,240.93</td>
<td>6,877</td>
<td>256.9</td>
<td>20.70%</td>
<td>1,687</td>
<td>63.0</td>
<td>24.5%</td>
<td>5.08%</td>
</tr>
</tbody>
</table>
5.12 Mental ill-health and problem behaviours

5.12.1 Prevalence

The NNA provides an excellent summary of the key issues regarding the mental ill health and problem behaviours experienced by PWLD, reportedly with a lifetime prevalence of about 50%. The entire mental health section of the NNA should be read in conjunction with the additional material below.

The first paragraph provides a brief explanation as to why mental health issues are so common in PWLD. It also points out that a significant lack of services for CYPWLD and mental health problems was demonstrated by a UK wide inquiry{195} despite that CYPWLD are at a higher risk of experiencing mental ill-health than other children{196}{197}{198}{199}{200}{201}{202}{203}{204}{205}{206}. Although this report is focused on adults with LD, it is worth highlighting that the north of the Clyde portion of GG&C currently lacks such specialist expertise and capacity to respond to CYPWLD.

The NNA summarises a selection of the studies published prior to 2004 on the prevalence of mental ill-health in PWLD. It states that AWLD experience many of the common mental illnesses including depression{207}{208}, severe anxiety{209}, and delirium{210}, but are also at increased risk of developing schizophrenia{211}, dementia{212}, ADHD{213}, and typical as well as atypical forms of eating disorders and behaviours{214}. Bipolar affective disorder is also considerably more common in PWLD than in the general population. Several recent studies have further corroborated the high prevalence of problem behaviours in this population{215}{216}{217}{218}.

Population-based study in GG has reported a point prevalence of 40.9% (95% CI = 37.8-43.9) for mental ill-health, with problem behaviours being the most common type, followed by autism, affective disorders and then psychotic disorders{219}. The prevalence of mental illness of any type excluding problem behaviours and ASD was 22.4% (table 5 below). Mental ill-health is more common in people the more severe their LD, in women, people living outwith a family home, and who are not immobile. Problem behaviours and other types of mental ill-health often coexist, given the high prevalence of problem behaviours in this population – 22% in GG, of which the point prevalence of aggression was 9.8% (95% CI = 8.0-11.8){220}, and self injury was 4.9% (95% CI = 3.7-6.4){221}. People with DS have a different pattern of mental ill-health, with much higher rates of dementia, but lower rates of other types of mental ill-health, including problem behaviours{222}{223}.

The NNA states that severity of LD influences the psychopathology within mental ill-health{224}; and as mental ill-health prevalence is higher at lower ability levels{225}{226}{227}, there is a diagnostic classification of mental disorders for people with moderate to profound LD{228}. Suffice to say that diagnosing and treating serious mental ill-health in PWLD can be a very difficult task, particularly if complicated by problem behaviour. Problem behaviours and mental ill-health have multi-factorial aetiology, so require time-consuming complex assessments in order to design appropriate care plans. Epilepsy and mental ill-health often co-exist, given that both disorders are common, and psychiatrists require knowledge and skills about both in order to conduct differential diagnoses, given that e.g. problem behaviours and complex partial seizures can present in a similar way, as can depression and anti-epileptic drug side effects. Pharmacological treatments for mental ill-health can lower seizure thresholds, and psychotropic and anti-epileptic drugs interact. In GG, 60.4% of PWLD have problem behaviours, mental ill-health, epilepsy, or some combination thereof.
Table 5: Point prevalence rates of mental ill-health. Excerpt from Cooper et al, 2007.

<table>
<thead>
<tr>
<th>Diagnostic category</th>
<th>Clinical diagnosis (n=1023)</th>
<th>DC-LD diagnosis (n=1023)</th>
<th>ICD-10-DCR diagnosis (n=1023)</th>
<th>DSM-IV-TR diagnosis (n=1023)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Psychotic disorder¹</td>
<td>4.4</td>
<td>3.8</td>
<td>2.6</td>
<td>3.4</td>
</tr>
<tr>
<td>Affective disorder</td>
<td>6.6</td>
<td>5.7</td>
<td>4.8</td>
<td>3.6</td>
</tr>
<tr>
<td>Anxiety disorder²</td>
<td>3.8</td>
<td>3.1</td>
<td>2.8</td>
<td>2.4</td>
</tr>
<tr>
<td>Obsessive compulsive disorder</td>
<td>0.7</td>
<td>0.5</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Organic disorder</td>
<td>2.2</td>
<td>2.1</td>
<td>1.9</td>
<td>1.7</td>
</tr>
<tr>
<td>Alcohol/substance use disorder</td>
<td>1.0</td>
<td>0.8</td>
<td>0.8</td>
<td>0.8</td>
</tr>
<tr>
<td>Pica</td>
<td>2.0</td>
<td>2.0</td>
<td>0</td>
<td>0.9</td>
</tr>
<tr>
<td>Sleep disorder</td>
<td>0.6</td>
<td>0.4</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>ADHD</td>
<td>1.5</td>
<td>1.2</td>
<td>0.5</td>
<td>0.4</td>
</tr>
<tr>
<td>Autism spectrum disorder</td>
<td>7.5</td>
<td>4.4</td>
<td>2.2</td>
<td>2.0</td>
</tr>
<tr>
<td>Problem behaviour</td>
<td>22.5</td>
<td>18.7</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Personality disorder</td>
<td>1.0</td>
<td>0.8</td>
<td>0.7</td>
<td>0.7</td>
</tr>
<tr>
<td>Other mental health</td>
<td>1.4</td>
<td>0.8</td>
<td>0.7</td>
<td>0.4</td>
</tr>
<tr>
<td>Mental ill-health of any type, excluding problem behaviours and autistic-spectrum disorder²</td>
<td>22.4</td>
<td>19.1</td>
<td>14.5</td>
<td>13.9</td>
</tr>
<tr>
<td>Mental ill-health of any type, excluding autistic-spectrum disorder²</td>
<td>37.0</td>
<td>32.8</td>
<td>14.6</td>
<td>14.0</td>
</tr>
<tr>
<td>Mental ill-health of any type, excluding problem behaviours²</td>
<td>28.3</td>
<td>22.4</td>
<td>16.5</td>
<td>15.6</td>
</tr>
<tr>
<td>Mental ill-health of any type²</td>
<td>40.9</td>
<td>35.2</td>
<td>16.6</td>
<td>15.7</td>
</tr>
</tbody>
</table>

1. Includes schizoaffective disorders; 2. Excludes specific phobias.
Assuming the figure of 40.9% applies for the entire GG&C population, this would suggest that there are 2,123 PWLD residing in GG&C with problem behaviours and/or other types of mental ill-health, and 3,140 with problem behaviours, other mental ill-health, and/or epilepsy, many of whom require support from a specialist LD psychiatrist and/or LD clinical psychologist. GG&C employs 17 WTE of these specialists. Comprehensive electronic health data systems do not exist that would enable analysis of the actual patient caseload for each of these specialists.

A considerable additional workload for psychiatrists and psychologists is carrying out mental health assessments in people who present with apparent mental ill health but who do not end up with that diagnosis but for whom one of the following is the primary issue:

- physical ill-health causing psychological or psychiatric signs and symptoms;
- inadequate support from, or breakdown of, support packages;
- issues of decision-making capacity which requires to be assessed;
- vulnerable adults issues which require to be verified and protective legislation implemented.

The report of the health check information showed that 48% of the 1,023 has ‘possible mental health problem requiring further assessment’, corroborating the view that genuine mental ill health workload associated with the 40.9% prevalence figure is expanded by this additional assessment work.

5.12.2 Need for effective community based services

Appropriate community based services need to be in place to support PWLD who have mental health problems including problem behaviours and need to both promote mental health and also respond promptly to relapses so as to prevent further deterioration. This provision consists of a variety of services provided by both the statutory and independent sector described in the various tiers referred to in the national needs assessment (tiers 0-4). If these services do not exist locally or are not adequate, there is a risk of:

- significantly poorer clinical outcomes due to delayed detection and delayed commencement of appropriate treatment.
- failure to design and commission an appropriate, personalised care package that is safe for both client and neighbours.
- breakdown of a care package that was initially successful.
- reliance on costly independent providers who may be located far away, thereby potentially dislocating the client from the support of their friends and relations.
- excessive reliance on psychotropic medication as opposed to psychosocial interventions.
- additional stress for and reliance on family and paid carers.
- self-harm and injury to the client.
- Injury to family, relations, support workers and co-tenants from aggressive behaviour.

The NNA described the kinds of specialist LD services that would be expected to support adequate provision of LD team-based specialist health expertise including LD clinical psychology, CLDN, and specialist LD psychiatry services. This would include tier 4 services that support LD teams (tier 3) when responding to the needs of the ‘low incidence/high complexity’ nature of such cases such as:

- assessment and treatment beds (at a level of 4 per 100,000 population according to The Same as You?, suggesting GG&C should have about 48 such beds for a population of 1.2 million),
• a problem behaviour support team,
• Forensic services for PWLD.

There is a mixed perception of the utility of the out-of-hours service in its current specification. Some CLDNs felt it was not sufficiently proactive in its approach to be either cost-effective or particularly efficacious. Other staff felt it was essential and its disbandment would be problematic. The latter prefer that the LD nurses of various backgrounds on the rota were up-skilled rather than redeployed elsewhere.

The NNA stated that little is known of the long-term outcomes of mental ill-health in adults with LD. Research on this requires prospective follow-up of large samples of similar patients, thus often requiring multicentre studies that collect and aggregate data recorded by a number of healthcare professionals. A considerable amount of reasonably high quality health-related data would need to be collected in similar confidential electronic format to enable aggregation and analysis. Several specialist LD psychologists and psychiatrists expressed concern about the fact that electronic collection of health data within LD teams was under-developed or non-existent in some CHCP settings. The kind of health data that would be helpful to social workers and social work managers in LD teams is very different from the kind of health data that could be intelligently used for research purposes, and service audit.

The NNA highlighted that communication needs and lack of awareness by paid carers and professionals can lead to mental ill-health remaining undiagnosed, and therefore unmanaged, for long periods and that in view of its high prevalence, mental ill-health should always be considered as a possible cause of any change in the behaviour of a PWLD.

5.12.3 Forensic needs

The NNA stated that ‘there is a growing consensus that research should move away from prevalence studies of offending behaviour amongst PWLD, to developing and evaluating effective interventions and services for this group’. This is also needed in other areas for PWLD, as is high quality implementation.

Locally, provision of low and medium secure provision facilities at Leverndale and Rowanbank, respectively, seem adequate to meet demand. Although a small number of staff were interviewed in both settings, less attention was afforded to the GG&C LD forensic service on the assumption that it was better funded per bed and more rigorously organised, out of necessity, than any other part of the LD service. The consequences for an error being made in this part of the service are obvious. However, as this service only accepts people who have been convicted (except in very exceptional circumstances) there is a substantial number of PWLD who demonstrate offending, risky behaviour who need to be managed within the LD teams. This can be quite challenging.

5.12.4 Interventions

The NNS stated that there are ‘recognised difficulties in researching the effectiveness of interventions for people with mental ill-health, problem behaviour or forensic needs’. LD straddles complex boundaries between health and social care; between specialist and generic health services; and between child and adult services. The critical issue of the collection, aggregation and analysis of sensitive health data has already been alluded to. Oliver et al argue that there is a ‘mandatory need for an evidence-based philosophy to underpin the development and maintenance of high quality community services in
the field of LD’ and that this ‘drives the need to build multidisciplinary research capacity and cooperation across agencies and boroughs, to enable questions and issues posed by users, carers and others to be addressed in a systematic and relevant manner, and so educate and inform practice’\(^{(229)}\).

This LNA revealed that LD services staff within LD teams are mostly not involved with research goals, in keeping with their contracts, with the exception of some of the LD specialist clinical psychologists, psychiatrists and allied health professionals (AHPs), who maintain close links with the academic unit and the primary care liaison team. There is also a lack of randomised controlled trials on interventions, and considerably bureaucracy and dogma when conducting research with adults who lack decision-making capacity to consent.

5.12.4.1 Psychological Interventions

The NNA comments on the fact that there have been few studies examining the effectiveness of psychological interventions for PWLD and mental ill-health, other than in perhaps the area of anger management, despite their success for the treatment of mental ill-health in the general population. It is states that ‘models of aggression of relevance to PWLD incorporating cognitive factors are at an early stage of development’ and that ‘there is some optimism for the success of treatment methods for anger informed by cognitive theories’. This work was based on research conducted in Glasgow\(^{(230)}\)\(^{(231)}\)\(^{(232)}\).

Since then Clinical Practice Guidelines have been issued by the British Psychological Society on psychological interventions for severe problem behaviours experienced by PWLD\(^{(233)}\). A review of these guidelines suggests that over the past 10 years there has been a clear change in attitude in terms of the willingness to use psychotherapeutic and other psychological interventions historically used in the general population. A critical overview of the effectiveness of psychotherapeutic interventions for PWLD, including psychodynamic and cognitive-behavioural therapies (CBT), was published shortly after\(^{(234)}\). The available data supports the use of these approaches, although the literature reporting outcomes is limited.

NHS GG&C’s Mental Health Delivery Plan (2006) should apply across the lifespan, across service settings and across all care groups. It therefore needs to be considered how an increase in access can be achieved for individuals with LD, and the Board has formed a central steering group with representatives from a range of care groups including LD. A sensible approach may be to focus on the difficulties for which psychological interventions are appropriate and effective. “The Matrix” (2008) refers to ‘Psychological Therapies’ as a “range of interventions, based on psychological concepts and theory, which are designed to help people understand and make changes to their thinking, behaviour and relationships in order to relieve distress and to improve functioning”. Importantly within LD services, consideraton is needed not only for talking therapies, which are the focus in mental health (particularly CBT for anxiety and depression), but a range of interventions including, CBT, systemic and behavioural interventions as appropriate interventions. In GG&C, the clinical psychologists have developed their own referral guidelines in an attempt to prioritise their service for those people with LD who are most likely to benefit from psychological intervention\(^{(235)}\).

NHS GG&C could helpfully consider the range of competences required to deliver access to psychological therapies, and the extent to which these are available within the current workforce, and the availability of robust governance of these interventions, including training and supervision.
5.12.4.2 Pharmacotherapy

The NNA stated that between 20 and 50% of PWLD are found to be prescribed psychotropic medication depending upon the population studied\(^\text{236}\). In GG, the report from the health check information describes that 23.2% were taking antipsychotic drugs, and 32.6% were taking any psychotropic (excluding antiepileptic drugs). If applies to the whole of the GG&C population this suggest that 1,206 are taking an antipsychotic, and 1,695 any psychotropic drug. Only a proportion of these people are under the care of an LD psychiatrist – the lack of a routine electronic data base to administer the service hinders further analysis.

The NNA stated that:

- the reason for the use of psychotropic medication is often unclear\(^\text{237}\).
- sometimes psychotropic medication is used in the management of problems for which there is little reliable evidence of effectiveness due to lack of research\(^\text{238}\)\(^\text{239}\)\(^\text{240}\).
- a systematic review found that the effectiveness of anti-psychotic medication in the treatment of schizophrenia in PWLD has not been conclusively studied in that RCTs have not been carried out\(^\text{241}\)\(^\text{242}\)\(^\text{243}\).
- there is a need to develop evidence based prescribing given that PWLD experience high rates of mental ill-health.
- the use of anti-psychotic medication for the management of problem behaviours is controversial (in fact, some literature claims that it is the most controversial area of mental health\(^\text{244}\)) and its effectiveness not conclusively studied\(^\text{245}\).
- concerns about the appropriateness of prescription of antipsychotic drugs for PWLD have frequently been raised\(^\text{246}\).

There is some evidence for the use of some psychotropic drugs in selected conditions, including risperidone in children with ASD and serious behavioural disturbances\(^\text{247}\). A review of psychotropic drug use for ASD demonstrates some evidence on selective serotonin reuptake inhibitors, and second generation antipsychotics\(^\text{248}\).

There are additional reasons why everyone, including LD psychiatrists, wish to reduce the use of anti-psychotic drugs:

- the risk of debilitating side effects associated with neuroleptics e.g. weight gain, tardive dyskinesia, excessive sedation, and in particular, the risk of cardiac events,
- the need for administration by carers,
- a recent RCT suggests that risperidone and haloperidol are not effective in the management of aggression in PWLD who do not have a confirmed mental illness\(^\text{249}\).

Some limited debate has taken place in the literature on the merits\(^\text{250}\)\(^\text{251}\) or otherwise of withdrawing PWLD and problem behaviours from antipsychotic medication. The Department of Health in England appears to have endorsed the principle\(^\text{252}\). Those against have cited the benefits of thioridazine\(^\text{253}\) and the problems following its discontinuing in order to adhere to guidance from the Committee of Safety of Medicines regarding the risks of cardiac events. A recent letter pointed out that it is no easy task to withdraw these medications after decades of exposure\(^\text{254}\).
We do not know if, and to what extent, there is an excessive reliance on the use of antipsychotic medication in GG&C, above that for which there is a clear clinical indication. Occasionally, some persons with problem behaviours are prescribed psychotropic medication as a treatment trial, if there are diagnostic complexities and an underlying mental illness is suspected, but cannot be formally diagnosed. Decisions with regard to continuing or withdrawing can be difficult if treatment was initiated by a GP without a comprehensive initial assessment and they seem to help.

5.13 Epilepsy

5.13.1 Prevalence

The NNA, which highlights the difficult clinical issues involved with managing epilepsy in PWLD, should be read in conjunction with the additional material below.

The NNA stated that the prevalence of epilepsy among PWLD of all severities was around 25%, providing a number of references, in comparison to 0.4%-1% in the general population. This more recent review of the literature suggests that prevalence in PWLD varies more considerably between 18 and 32%, depending on the population surveyed and the methodology. A recent study based on 40 general practices in Wales provides one of several estimates in the published literature at the lower end of the spectrum at 18%. The estimate at the high end of the range was obtained from a study of institutionalised PWLD and encephalopathy. Another recent study suggested that 26% of all people on Leicestershire LD register had epilepsy.

The prevalence of epilepsy in GG from the report of the health check information described a prevalence of 34.1%, with a gradient across ability levels ranging from 24.1% in people with mild LD, 32.0% moderate LD, 35.4% severe LD, and 59.3% in people with profound LD. This was consistently higher when compared at each level of ability than the prevalences on the Leicestershire LD register, suggesting this is not just an issue of ascertainment of mild LD. This equates to 1,773 PWLD and epilepsy in GG&C, and is at the high end of previous estimates. No explanation is immediately available as to why GG might have a high prevalence of epilepsy in its ascertained population of PWLD, other than social deprivation, for which parts of Glasgow City are well-known. A higher prevalence of epilepsy is associated with markers of deprivation and recent evidence suggests that the incidence of epilepsy may be up to twice as high in socioeconomically deprived populations. A local audit of patients diagnosed with epilepsy in a single general practice in southwest Glasgow LHCC published in 2005 revealed a prevalence of 1% which suggested that the prevalence of epilepsy generally can be considerably higher in socioeconomically deprived parts of Glasgow and that some cases of epilepsy might be missed by routine data collection systems normally used to calculate prevalence. If epilepsy is more common in GG generally, which is a view shared by the neurologists who manage epilepsy in that area, it is possible that more of them are on the LES LD register because of mild LD. Cohort effects, due to year of birth, are considered important in defining prevalence of epilepsy.

In 2004, a needs assessment reviewed LD services in Argyll and Clyde Health Board area for adults over 20 years of age with LD who also have epilepsy. It was able to identify 347 adults with epilepsy amongst its total adult population ascertained to have LD giving an estimated prevalence of
epilepsy in adult PWLD of 29%. The total adult population of A&C health board area was 316,963 in 2004 and included Argyll and Bute which had a population of 70,527 aged 20 and above at that time. Argyll and Bute had a higher prevalence of epilepsy at 40%.

Regardless of the cause of the high prevalence in GG and in Argyll and Bute (which is now part of NHS Highland area), there is no doubt that it is an important health care issue. Additionally, it appears to not be optimally addressed at present in GG&C. According to the SIGN guideline on epilepsy, 2003 diagnosis of epilepsy should be by an accredited epileptologist who is often a consultant neurologist or LD psychiatrist or neuro-pharmacologist who spends a specified percentage of sessions working with epilepsy, and a service should provide a multidisciplinary service (including neurologist, LD psychiatrist, neuro-radiologist, LD epilepsy specialist nurses, and ideally GPs with a special interest in epilepsy). The adult LD service does not often have to diagnose epilepsy as onset is usual in childhood. Where a PWLD does present with a possible first seizure, the most appropriate course of action is the first seizure clinic, which provides a rapid service with appropriately staff, able to undertake the full differential diagnosis which is outwith the competency of most LD psychiatrists. Conversely, the need for longer term management of epilepsy is very prevalent in the adult LD population, and the LD service has a responsibility to meet these needs.

The recent report on epilepsy in England, published by the All-Party Parliamentary Group on Epilepsy (APPG), assumed that 20% of all people with epilepsy have LD\textsuperscript{[269]}, however it would appear that this is higher in the GG&C population. This fraction is important when calculating the percentage of epilepsy specialist nurses practising nationwide, and locally at board level, who should be specialising in LD. However, the percentage of all people with epilepsy in the community who also have an LD is estimated to be around 32% in the GG&C population, assuming that not everyone with mild LD is on the LES LD register. This suggests that one out of every 3 epilepsy specialist nurse (ESN) should be an LD ESN.

The report of the health check information revealed that 23.8% and 5.1% of the 1,023 people had had contact with a psychiatrist and psychologist, respectively within the previous 12 months. According to this information, there are almost 20% of PWLD who have epilepsy and no other co-morbidity. At present they are not routinely receiving care from LD psychiatrists in GG&C. This means that there are 1,019 adults aged 20 years and older with LD in GG&C who have epilepsy and who would not normally qualify to receive the input of an LD psychiatrist to treat their epilepsy. The Venn diagram (figure 18 below) uses information from the report of the health check information to show the overlap of epilepsy, mental ill-health, problem behaviours, and physical disabilities.

The adults on the LES LD register are those that are recognised to have LD, and hence are the group that will be referred to LD services when their GPs make referrals, if there are LD services available. Some epilepsy is managed in primary care, but many of these individuals would benefit from secondary care working together with primary care.

Currently, the LD Epilepsy Specialist Nurses comprise only 1.85 WTE. They only cover GG and therefore they are currently responsible for three quarters of the GG&C population. This is an inequity in the service, but given the current organisation of epilepsy services in GG&C and the small WTE, it will not be able to address it without organisational change in other parts of the service, and a properly developed care pathway for PWLD who have epilepsy.
Figure 18: Prevalence of significant disabilities in the adult population with LD in GG (%) (provided by Prof Anna Cooper) applied to the GG&C ascertained numbers of PWLD on the LES LD register (numbers) n=5,200 to predict the numbers in each co-morbidity category.

(A) Mental ill health (excluding specific phobias)  
12.7% (660)  
5.5% (286)  
3.7% (192)  
6.2% (322)  
6.9% (359)

(B) Epilepsy  
19.6% (1,019)  
5.7% (296)

(C) Problem behaviours

(D) No disability 39.6% (1836)

5.13.2 Who should provide specialist epilepsy services to PWLD?

Shona Robinson reportedly told Epilepsy Scotland, and was quoted saying in their journal, Learning Disability Practice: “In relation to people with epilepsy who may also have LD, there appears to be a need for better integration of services for this group of people. SIGN guidance emphasises the importance of a multi-disciplinary approach and the role of CLDN. I would expect NHS boards to take this into account in their planning of services”. (Learning Disability Practice, September 2005).

An unpublished questionnaire survey carried out by J. Dolman and M. Scheepers was carried out recently in England (66% response rate) that revealed that 47% of LD services offer a specialist epilepsy service\(^{270}\). There are many reasons why a mainstream epilepsy service for the general population is often inadequate for PWLD (Table 6).
Table 6: Listing of reasons why mainstream epilepsy services may not be suitable for PWLD.

Excerpt from jointly produced document prepared for NHSGG&C in April 2009 by N. Simpson and A. Corp².

<table>
<thead>
<tr>
<th>Diagnostic complexity</th>
<th>Misdiagnosis more common because communication problems make it harder to diagnose non-epileptic paroxysmal disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Comorbidity with mental ill-health more common.</td>
</tr>
<tr>
<td></td>
<td>Care by proxy – reliance on observation and reporting from care staff.</td>
</tr>
<tr>
<td>Complexity of epilepsy</td>
<td>Multiple coexisting seizure types more common</td>
</tr>
<tr>
<td></td>
<td>Rare syndromes arise more often</td>
</tr>
<tr>
<td>Chronicity</td>
<td>Onset may be early in childhood and persistent into adulthood.</td>
</tr>
<tr>
<td></td>
<td>More often lifelong</td>
</tr>
<tr>
<td>Complexity of service context</td>
<td>Patients more often unable to use a clinic setting and investigation procedures appropriately (autism, ADHD, challenging behaviour)</td>
</tr>
<tr>
<td></td>
<td>Treatment more often needs to involve assessment of decision-making capacity</td>
</tr>
<tr>
<td></td>
<td>Treatment decisions more often by proxy (via carers)</td>
</tr>
<tr>
<td>Complexity of treatment</td>
<td>Treatment more often needs to take account of treatment for mental ill health (&amp; other conditions) and polypharmacy of antiepileptic drugs is common.</td>
</tr>
<tr>
<td>Response to treatment</td>
<td>More often refractory</td>
</tr>
<tr>
<td></td>
<td>More frequent adverse effects and drug interactions</td>
</tr>
</tbody>
</table>

This LNA found that LD specialist services, including LD psychiatrists, are best placed to look after PWLD and epilepsy, but that in GG&C, they are not presently equipped to do this, in terms of organisation and in some cases the need to update skills through CPD. The rigorous criteria for a specialist epilepsy service have been itemised in the paper described above. These include: training in the management of epilepsy; continuing education in the management of epilepsy; the equivalent of at least one session per week in epilepsy management as part of their workload, peer review of practice; and regular audit of diagnosis.

Current provision in GG&C cannot continue because of clinical governance issues, among them the fact that the LD epilepsy specialist nurses based at the former GLDP lack clinical supervision and are facing unreasonable demands in relation to the workload quantified above.

5.13.3 History of poor standards in the care of epilepsy throughout the UK

Many reports over the last 55 years have criticised epilepsy care standards, with the most recent report published two years ago by the APPG. This report expressed the concern of the APPG about the evidence of non-implementation of the NICE Guidelines, which was presented to them in oral and written evidence ‘time and again’. The main reasons given by witnesses for non-implementation of the Guidelines was the absence of any plan (national, regional or local) to address poor levels of knowledge
in the clinicians managing the care of many people with epilepsy. They also described a critical shortfall in clinicians and nurses specialising in epilepsy, and the fact that the treatment gap had not been addressed by the development of clinical networks to make the best use of such expertise as was currently available. The report makes clear that the situation is even more difficult for PWLD and epilepsy because both groups of medically qualified specialists who have, or who could be additionally trained to have, the expertise required to diagnose and treat epilepsy in PWLD, i.e. the neurologists and the LD psychiatrists, are not necessarily able to prioritise these patients.

Given their workloads most neurologists do not have the understanding of the complex and subtle issues around epilepsy in PWLD; the time to explore these issues; nor, as a result, the aptitude for developing LD-sensitive services\(^\text{[272]}\). They may be more likely to take at face value inaccurate reports and descriptions of seizure activity provided by family and paid carers, not identify the gaps in information (e.g. from day centres) or prescribe solutions and treatments that may not take into account the wider context experienced by a particular learning disabled client.

In addition, studies show that the mean proportion of people with epilepsy with LD who achieved seizure-control was between 22 per cent and 32.8 per cent, which is significantly below the proportion of the general population with epilepsy. It is possible that lack of access to the epilepsy specialist service may contribute to this poor outcome, and the apparent underutilisation of investigations.

Many guidelines and initiatives have been produced to try to improve this situation, such as the Chief Medical Officer's report on improving services\(^\text{[273]}\), the new GP contract\(^\text{[274]}\), guidance from the Scottish Intercollegiate Guidelines Network\(^\text{[275]}\), Royal College of General Practitioners' guidance (which is the NICE guidance referred to above), and The National Service Framework for Long-term Conditions\(^\text{[276]}\).

5.13.4 Nature of poor standards in the UK

Key criticisms have been summarised as: lack of systematic follow-up; inappropriate use of investigations; patients seen in hospital by medical staff who are not neurologists; inappropriate drug combinations; non-adherence to treatment; poor communication between primary and secondary care; poor communication with patients; and sparse patient knowledge\(^\text{[277]}\). The APPG report provides a particularly sobering description of poor standards that result in mis-diagnosis, suboptimal care, unnecessary seizures, avoidable deaths, and consumption of drugs that are not needed (needless expenditure). If we apply the sums estimated for England to GG&C, this amounts to 3 avoidable deaths, 530 people living with unnecessary seizures, and 568 people taking drugs they do not need each year.

5.13.5 Historical recommendations to employ epilepsy specialist nurses

Several reports recommended employing epilepsy specialist nurses to address some of these issues. The Clinical Standards Advisory Group\(^\text{[278]}\) found that while only a minority of adults had seen an epilepsy specialist nurse, 74% of those who had done so thought that they helped them to cope better by providing information and advice, extra support and being easier to talk to. Stokes et al (2004) advocated that epilepsy specialist nurses become an integral part of epilepsy care, supporting epilepsy specialists and generalists. If the APPG advice to employ 920 ESNs for England is heeded, this would mean employing 7 WTE epilepsy specialist nurses for LD in GG&C, based on the size of our population and the calculation that 32% of people with epilepsy also have an LD.
Unlike epilepsy in the wider population, epilepsy in PWLD is often refractory to treatment, particularly in people with severe or profound LD. A key specialist role for epilepsy specialist nurses is to help people to live with their seizures. This includes using risk assessments, personalised care plans and protocols, and distinguishes epilepsy management in the non-LD population in whom it is easier to control and where such additional documentation and processes are not required or are not as extensive. Reliance on the family or paid carer being able and willing to report on the client’s ongoing health status and health needs and provide the prescribed care is not necessary for most people without LD. For PWLD who also have epilepsy, the quality of that form of ‘care by proxy’ determines their prognosis given the life-threatening nature of refractory epilepsy and risk of sudden unexplained death in epilepsy (SUDEP), and carers do need support.

5.13.6 Community LD teams may protect PWLD who have epilepsy

One of the unpublished findings of the National Sentinel Clinical Audit of Epilepsy-Related Death\(^{279}\) was that, of the 22 PWLD who had died and where complete case note ascertainment was possible, only one (less than 5%) was known to their local LD service\(^{280}\). It seems reasonable to assume that more than 5% of PWLD who have epilepsy in the UK, a group that is at particular risk of SUDEP, are in touch with their local LD service and that therefore community LD services are in some way protective. Evidence from this LNA would suggest that some LD teams are in a better position to be able to offer this kind of protection than others, particularly if they possess in-house expertise (e.g. an LD psychiatrist with an interest in epilepsy) and have solid links to specialist and mainstream epilepsy services. In the Cornish service looking after about 800 people with epilepsy and LD, the rate of SUDEP is indeed considerably lower than expected\(^{281}\). There are a number of possible reasons for this including better AED compliance where medication is administered by carers (paid or family) than is perhaps found in the wider community of people with epilepsy, with or without LD, who may have to manage their own regimes. Also, PWLD with carers are less likely to experience seizures unwitnessed or without access to first aid, thereby increasing their chance of being resuscitated. The UK is known for having some of the best LD epilepsy services in the western world because they are community-based, delivered at home with meticulous follow-up from specialist nurses and pay special attention to risk assessment and rescue medication protocols. GG&C should strive to emulate this.

5.13.7 The challenge ahead

Epilepsy is a major health need for the population with LD. Epilepsy services in GG&C are currently ad-hoc, variable and poorly organised. This cannot be allowed to continue. There is compelling evidence to suggest that the specialist LD service has a key role to play in the management of epilepsy, together with the expertise at the Neurological Institute at Southern General Hospital, and supporting the persons own primary care team and paid and family carers. Epilepsy management is one of the core competencies for accreditation as an LD psychiatrists, so if more expert support is made available, together with ongoing CPD, the workforce should be fit for purpose. LD nurses are also trained in epilepsy, and with support from the LD epilepsy specialist nurses and CPD there is a clear role for the area teams in working with clients with epilepsy as a component of a stepped model of care, supporting, and being supported by, the LD epilepsy nurse specialists, LD psychiatrists and the mainstream neurologists. A care pathway should be devised, with consideration of the roles to be played by all key disciplines, and how best to integrate these. Medical leadership is needed from the LD psychiatrists to work with the LD epilepsy nurse specialists, CLDNs, and neurology, to devise the care pathway and its
implementation, involving all these disciplines. This will require a job plan change for one of the LD psychiatrist to devote some sessions to become an expert in epilepsy, to work with the Southern General Hospital, and to support the Consultants in LD psychiatry in developing their epilepsy work, and also the nurses. Several of the Consultants are interested in developing this area of work.

5.14 Autism spectrum disorders

The remit for this LNA did not include autism and autistic spectrum disorders, but these disorders are more common in adults with LD. Hence some brief additional material is worth highlighting.

The NNA provides estimates, based on an MRC report published in Britain in 2001\textsuperscript{282}, of ASD (20 per 10,000 children), which would be expected to be associated with LD, and ASD (40 per 10,000 children), which would not be associated with LD. The combined prevalence of ASD would therefore be 60 per 10,000 children, one third of which have LD. In the same year, the Public Health Institute for Scotland published a comprehensive needs assessment for ASD in Scotland that made a number of recommendations aimed at improving services, which were accepted in principle by the Scottish Executive\textsuperscript{283}. As of 2009, most of these recommendations have not been implemented in many parts of Scotland including GG&C, where diagnostic services that exist in GG do not extend to the Clyde. A nationwide monitoring system set up in eight year old children in the USA suggested very similar prevalence rates for ASD in 2001 (6.7 per 1,000 children) and in 2002 (6.6 per 1,000 children) or approximately 1 in 150 children\textsuperscript{284}. According to a recent MMWR report, this prevalence rate is still accepted as valid in the United States\textsuperscript{285}.

A survey by the Office of National Statistics of the mental health of children and young people in Great Britain found a prevalence rate of 0.9% for ASD or 90 in 10,000. These were not differentiated into subtypes\textsuperscript{286}. A year later, a study of children aged 9-10 years from the South Thames region was published. The results showed a prevalence rate of 38.9 in 10,000 for childhood autism, and 77.2 in 10,000 for other ASD, giving an overall figure of 116 in 10,000 for all ASD. In this study very few children were identified with Asperger syndrome. The authors acknowledged that some children in mainstream schools who did not have a statement of special educational would have been omitted, and stated that the prevalence estimate should be regarded as a minimum figure\textsuperscript{287}.

There is little information regarding the prevalence of autism in adults. One English survey of adults living in private households has reported a prevalence of 1.0% (95% CI 0.3% to 1.7%) for ASD in adults\textsuperscript{288}.

The recent MMWR report of the American monitoring network described above suggests that the prevalence of additional cognitive impairment in the children with ASD was 58% in girls and 42% of boys. However, estimates of the proportion of people with ASD who have LD vary considerably, and it is not possible to give an accurate figure. It is likely that over 50% of people with ASD have an IQ in the average to high range, and a proportion of these will be very able intellectually.

Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD
may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.

The NNA stated that studies have reported that 10-30% of people using LD services for adults have an ASD. The extent to which LD teams in GG&C impose eligibility criteria varies, which might also impact on the numbers with autism using services in different parts of GG&C.

Views differ both locally and nationally as to whether LD services should offer a service for adults with severe ASD who do not have LD. Some consider that the skills within LD services are such that they are well placed to offer a service, depending on appropriate resourcing; other consider this to be inappropriate, as such persons do not really “fit”. Some adults with autism who do not have LD do require health services, and it is the responsibility of NHS GG&C Board to provide for them. Clarification on which service should lead is needed, together with an awareness of the associated significant resource implication.

### 5.15 Sensory impairments

The NNA reported that studies on the prevalence of sensory impairment in PWLD ranged from 12.3% to 47% for hearing, and 19% to 63% for vision. The report on the health check information described 26.9% for hearing impairment and 47% for visual impairment. In addition, a further 3.5% were referred for further investigation for a possible previously unrecognised hearing impairment (not including impairment due to impacted cerumen), and 13.0% were referred for further investigation of a possible previously unrecognised visual impairment. Impacted cerumen, which can impair hearing was found in 26%. The outcomes of these referrals were not checked in this LNA. Cerebral visual impairment is thought to be extremely common in PWLD, especially more severe LD, but there is little published literature from which to quote rates.

The NNA emphasised that it is possible to assess vision and hearing in persons with profound LD, provided there is access to special equipment and expertise. It highlights that many visual impairments are not assessed, and that spectacle provision is often inadequate. The NNA highlighted how impaired hearing impacts upon communication and development as well as on quality of life in other ways, highlighting the need for sensory assessments early in life, and at repeated intervals during adult life. It also noted the demands on paid carers and that visual impairments including cerebral visual impairment and hearing impairment tends to be frequently unrecognised or under-reported by carers.

### 5.16 Respiratory disease

The NNA stated that diseases of the respiratory system are the commonest cause of death for people with LD and that this differs from findings for the general population. The development of effective antibiotics had a major impact on the life expectancy of PWLD. Recent studies of mortality demonstrate an increasing role for vascular and malignant causes. The causes of death for older PWLD (aged 40 years and above) are more similar to those of the older members of the general population, highlighting that if a PWLD achieves older age, they acquire ischaemic heart disease and cancer\(^{[289]}\); life expectancy of PWLD is higher for those with milder LD.
Three provisos need to be considered when reviewing mortality studies:

- The main cause of death on the death certificate will often be respiratory or cardiac in origin, as they are often the final common denominator of other underlying conditions. One study rightly identifies the causes of death in a population-based study by 3 criteria: primary, immediate and contributing\(^{190}\). When characterised in this fashion, the commonest cause for both primary and immediate is vascular causes. The commonest contributing cause is disturbances of mental health,

- Deaths are sometimes arbitrarily characterised as ‘unavoidable’, ‘avoidable’ or ‘preventable’ and this is often subjectively determined\(^{290}\),

- The proportion of all deaths due to various causes is not the same as the standardised mortality ratio (SMR) for that cause of death, which reflects the cause-specific rates in the general population. An important example is highlighted by a recent study from Finland where although the SMR is highest for respiratory causes, which are much lower in the general Finnish population, the commonest single cause of death in that cohort of PWLD was vascular in origin (myocardial infarction, cerebrovascular disease (stroke), congenital heart disease and pulmonary infarction)\(^{190}\). In an Australian study, the largest single proportion of deaths and the highest SMR were both apportioned to respiratory causes\(^{291}\).

Aspiration causing asphyxia and aspiration pneumonia are more commonly implicated as causes of death in younger PWLD than in the wider population. Contributing factors include:

- Neurodevelopmental pathologies that affect swallowing.
- Susceptibility to infection.
- Higher prevalence of GORD.
- The effects of drugs (e.g. antiepileptic drugs) that affect swallowing and protection of the airway.
- Postural problems that make the airway vulnerable e.g. cerebral palsy.
- Genetic predisposition to muco-ciliary anomalies that may predispose to lung disease e.g. DS

The risk of SUDEP is also a problem for with PWLD and epilepsy. SUDEP is thought to involve sudden cessation of the respiratory centres in the brain following a seizure or is thought to occur post-seizure as a result of high circulating levels of adrenaline which trip the heart into ventricular tachycardia and then life-threatening fibrillation. These two scenarios highlight the need for carers to understand the need to re-position the person if they stop breathing to trigger the respiratory control centre in the brain, or administer basic resuscitation.

The report from the health check information described 6.0% to have asthma. The QOF prevalence for asthma for both genders combined in GG&C was similar at 5.28% in 2007/8.

Smoking related conditions such as chronic bronchitis and lung cancer have been of low incidence in PWLD because of their lower smoking rates. Cancer registration data does not identify whether a person has a LD so it is currently not possible to measure cancer rates. The report of the health check information described 5.8% compared to a QOF prevalence for Chronic Obstructive Pulmonary Disease of 2.26%. The reason for this doubling of point prevalence is not known, but may reflect chronic respiration infection from aspiration and muco-ciliary pathologies.

The prevalence of smoking was just 10.2% in PWLD in 2002-4 according to the report of the health check information, compared with a Greater Glasgow board area prevalence for both sexes of 35% in 2003 according to the Scottish Health Survey\(^{292}\).
Studies of mortality in PWLD in institutions report the lower risk of death from lung cancer in PWLD. The 10 year follow-up at Stoke Park group of hospitals found that just 2 cases of lung cancer were identified in a total of 29 cancers and 213 deaths\(^{(187)}\). The population based study in Finland identified 17 lung cancers over a 30 year follow-up in PWLD when 27.6 were expected. All 17 were observed in the moderate/mild severity sub-group (22.4 expected) and none in the severe/profound subgroup, reflecting the smoking prevalence in the two subgroups. In Finland, people with less severe LD and who tend to live independently in the community have smoking rates that approximate that of the general population. Given that smoking causes more than 90% of lung cancer and that smoking prevalence tends to be lower in PWLD, it is expected that lung cancer rates will continue to be lower in PWLD as a whole. However, amongst PWLD with mild LD in Greater Glasgow, smoking prevalence is higher (17% or about half of that of the general population in Greater Glasgow) and we should expect to see some cases. Other characteristics about which we have little or no information will also determine the risk of lung cancer in PWLD, including how many cigarettes are smoked per day, age of onset of smoking, depth of inhalation, use of home-rolled cigarettes, use of filter-less cigarettes, etc.

### 5.17 Cardiovascular disease

Hypertension is a problem for some PWLD\(^{(293)}\). The prevalence of hypertension in GG&C for both genders combined according to the QOF register in 2007/8 was 12.4%. The prevalence in PWLD in GG for both genders during 2002-4 according to the report on the health check information was 9.7% with an additional 9% having raised blood pressure readings on three recordings during the health check, so requiring follow up, and a further 5.6% having borderline raised recordings. This LNA has not followed up the outcomes of these referrals to primary care.

Cardiac disease is the second most common cause of death, after respiratory causes, amongst people with LD in some studies (14%-20%)\(^{(294)}\); these studies include both problems related to congenital heart disease and ischaemic/coronary heart disease (CHD). Rates may be increasing, due to increasing life spans, and possibly increasing exposure to lifestyle risk factors\(^{(295)}\)\(^{(296)}\)\(^{(297)}\). The general population prevalence of CHD in GG&C for both genders combined according to the QOF register in 2007/8 was 4.46%. The percentage of adults who reported ever having CHD was 8.4% and 7.3% in GG and Scotland, respectively, according to the Scottish Health Survey in 2003. The prevalence of CHD in PWLD in GG for both genders during 2002-4 according to the report on the health check information was only 1.8%. The differences in the age distribution of the PWLD and the general population should be noted, but it seems that PWLD in GG&C are not yet at high risk. This would also suggest that PWLD are not subject, to the same extent, to the priority causes of morbidity and mortality targeted by government health improvement programmes such as *Keep Well*. The lower prevalence of smoking is a key factor, together with premature death due to other causes. There is no local data available to suggest whether or not age-specific rates of CHD are climbing in PWLD in GG&C, but overall rates may rise as life expectancy of PWLD improves. CHD incidence and mortality rates in the wider population are decreasing in Scotland, and other cohort factors such as improving standard of living and care and treatment may resist the impact of increasing risk factors in PWLD.

The prevalence of heart failure (normally mostly a consequence of CHD) in GG&C for both genders combined according to the QOF register in 2007/8 was 0.89%. The prevalence of heart failure in PWLD in GG for both genders during 2002-4 (n=1,023) according to the report on the health check
information was 1.3%, and might be more likely to be the result of right-sided failure resulting from congenital heart disease and primary pulmonary disease.

The prevalence of stroke and TIA in GG&C for both genders combined according to the QOF register in 2007/8 was 2.0%. The prevalence of stroke and TIA in PWLD in GG for both genders during 2002-4 according to the report on the health check information was 2.1% (1.8% for stroke and 0.3% for TIA), similar to that for the general population, despite lower smoking rates, and may be a consequence of unhealthy diet, raised blood pressure, lack of exercise and obesity.

People with DS are an exception; there is remarkable resilience to atherosclerosis in DS\(^{(298)}\). This is possibly due to the cystathionine beta synthase gene's location on chromosome 21, which is over-expressed in DS, as DS is due to trisomy 21. This leads to decreased homocysteine, and so reduced arteriosclerosis. As DS adults are atheroma free\(^{(299)}\), with low blood pressure\(^{(299)}\) and low vascular dementia rates, CHD and stroke/TIA. However, the remainder of PWLD are not protected and should take part in tailored health promotion initiatives to improve all the risk factors, with carer support.

The prevalence of atrial fibrillation in GG&C for both genders combined according to the QOF register in 2007/8 was 2.0%, compared to 0.2% according to the report on the health check information. Atrial fibrillation is common in older populations who experience chronic CHD, so this lower rate was expected.

### 5.18 Cancer

The epidemiology of cancer in general in PWLD remains poorly studied and poorly understood. This is because the only valid way to study cancer epidemiology is to compare tumour type-specific, age standardised cancer registration rates or standardised registration ratios, by gender. For this one needs a near complete ascertainment cancer registry with information about associated LD or linkage between LD registers and cancer registers. Although Scotland has one of the best cancer registries in the world, the data collected does not include LD. Now that there is a LD LES register for GG&C, record matching may be possible in future, although large samples and long periods of follow-up (decades) would still be required. In the past, researchers compromised by examining relatively large samples of PWLD living in institutions. The methodology precludes calculation of age-specific rates and therefore age-standardised rates, but enabled measurement of the proportion of all cancer deaths or all deaths due to each tumour type or perhaps crude cancer death rates per thousands of per years of observation. Examples of these included the 4 studies related to the Stoke Park group of hospitals in Bristol. However, studies using routinely collected mortality data under-enumerate cancer incidence or misrepresent tumours or risk factors and are therefore a crude if not more accessible methodology, and more so in the institutionalized LD groups, due to failure to detect/investigate underlying disease and recording of the final cause of death (e.g. bronchopneumonia).

These studies to date suggest that:
- Cancer incidence and mortality was probably quite low in PWLD in the past because PWLD did not live long enough to develop it, instead succumbing at younger ages to epilepsy, aspiration pneumonia, tuberculosis, other infection, or congenital heart disease\(^{(300)}\). Also PWLD did not smoke or use alcohol to the same extent as the general population.
The proportion of all deaths due to cancer in Scotland is about 27% whereas for PWLD reports have ranged from 5-18%\(^\text{[301]}\).

Cancer incidence and mortality is rising as infectious causes decline with improving living conditions and the advent of antibiotics and life expectancy continues to rise\(^\text{[302]}\).

In older PWLD, cancer incidence might be approaching that of the general population for many tumour types\(^\text{[301]}\).

Cancer incidence in PWLD may rise if more PWLD lead unhealthy lifestyles in the community e.g. smoking\(^\text{[301]}\).

PWLD living in the Stoke Park group of hospitals in Bristol experienced a disproportionate proportion of all cancer deaths attributed to the GI tract, including oesophageal, stomach, colon and rectum\(^\text{[185],[186],[187]}\); almost the largest group was oesophageal\(^\text{[183]}\).

The population of women with LD may be less likely to be sexually active\(^\text{[303],[304]}\), and so at reduced risk of cervical cancer. However, some women with LD are sexually active out of choice and others due of abuse, and so some individual women are at risk.

PWDS experience higher rates of leukaemia, testicular tumours and liver cancers than does the wider population\(^\text{[305]}\). The Finnish study also confirmed the higher rates of leukemia and germ cell tumours in PWDS demonstrated in earlier studies. However, PWDS appears to demonstrate lower rates of solid tumours\(^\text{[306],[307]}\).

Women with LD appear to have similar rates of breast cancer as the female general population\(^\text{[301]}\), with the exception of women with DS who seem to be protected from breast cancer, a solid tumour\(^\text{[307]}\).

The Finnish study demonstrated statistically significantly reduced risks of lung cancer, prostate cancer, and cancer of the urinary tract, and modestly raised risks of cancer of the gallbladder and thyroid gland in PWLD\(^\text{[301]}\). There was also a modest excess of upper GI cancers with 21 observed when 16.1 were expected, in keeping with the evidence from Stoke Park. In people with severe to profound LD, cancer of the brain was also more common than expected. Finland has different health patterns to the UK, with very high rates of CHD mortality, so the cancer data may or may not apply to PWLD in GG.

PWDS experience low rates of many solid tumour neoplasms (benign and malignant) including that of the breast and gastrointestinal tract. The latter has been attributed to the increased natural production of superoxide dismutase type I\(^\text{[308]}\) (an enzyme that acts as an antioxidant) due to the tumour suppressor gene on chromosome 21\(^\text{[309],[310]}\) (SIM-2) being over-expressed, and the role of the genes Dscr1 and Dyrk1a, also located on chromosome 21. These genes are also over-expressed. The protein DSCR1 acts by suppressing signalling by the angiogenesis promoting vascular growth factor (WEGF). Dscr1, together with Dyrk1a limit angiogenesis by reducing the activity of the calcineurin pathway, thought to be the mechanism of reduced cancer incidence\(^\text{[311]}\).

The prevalence of cancers (all types) in GG&C for both genders combined according to the QOF register in 2007/8 was 1.03%. The prevalence of cancers (all types) in PWLD in GG for both genders according to the report of the health check information was 1.8%. However, comparisons are not valid, as they are not tumour specific, age-standardised incidence rates, and the health check report includes cancer survivors who have been treated in the past.

The literature on cancer care to PWLD is growing, and addresses palliative care and end of life issues, the importance of families and relationships, best methods for sharing diagnoses, bereavement tools to
assess needs, involving PWLD in death and dying research and preventing unnecessary hospital admission via support from community LD services\textsuperscript{312}.

5.19 Metabolic and endocrine disorders

The prevalence of hypothyroidism in GG&C for both genders combined according to the QOF register in 2007/8 was 2.8%, and according to the report of the health check information was 6.1% for GG adults with LD in 2002-4. It is well established that thyroid disorders are more common in PWDS\textsuperscript{313}.

The percentage of adults (both genders combined) who reported ever having diabetes diagnosed by a doctor was 4.0% in GG in 2003, according to the Scottish Health Survey. This had risen from 1.5% in males and 1.5% in females in 1995, confirming the rise in rates over that 8 year period. The prevalence of diabetes in PWLD in GG for both genders during 2002-4 according to the report of the health check information was higher at 5.1%, with a further 4/1,023 found to have hyperglycaemia and a further 15/1,023 glycosuria, and were referred to their GP for further investigation (the outcomes of these investigations were not checked in this LNA). So, more than 5.1% of the adults with LD in GG had diabetes. The higher rate is not surprising, given the high rates of obesity; high level of antipsychotic drug use (29-49%) contributing to weight gain, inducing hyperglycaemia and worsening other metabolic cardiovascular risk factors; low cardiovascular fitness levels; high levels of sedentary behaviour; and probably some undiagnosed mitochondrial disorders. PWDS have an increased rate of type 1 diabetes, but this has little impact on overall prevalence of diabetes in the population with LD.

The prevalence of chronic kidney disease in GG&C for both genders combined according to the QOF register in 2007/8 was 2.59%. We do not have equivalent information for PWLD in GG&C. Prevalence might be higher due to significant health risks and complex health needs\textsuperscript{314}, or lower in view of the earlier age of death of PWLD. A recent initiative aimed at developing information materials specifically for this group of patients highlights the need for additional effort, time spent with patient and the creation of LD-specific information leaflets and tools for virtually every relevant topic\textsuperscript{315}.

Osteoporosis and fractures are thought to be more common in PWLD. A number of risk factors for osteoporosis are more common amongst PWLD (both risks for failure to build bone strength in early life, and subsequent loss of bone strength). These include inability to weight bear, immobility, poor diet, being reliant on carers to get outside (so going into the sunshine less), living in congregate care settings, use of antiepileptic drugs, earlier age of menopause for women with DS), and some rare syndromes associated with low levels of sex hormones. There are added complexities in determining the best means of investigation and care, as a large proportion of the high risk groups may not be able to cooperate with dexascaning to measure bone density, and are also the high risk group for gastro-oesophageal reflux disorder, so standard treatment with biphosphonates is problematic, and even treatment with Vitamin D and Calcium is not straight forward, if blood or urine cannot easily be checked to ensure hypercalcaemia does not occur, and if people cannot swallow tablet preparations. A working group in GG&C is currently developing an osteoporosis care pathway.
5.20 Oral and dental health

The NNA described the important issues and the common nature of oral and dental health in PWLD. The LNA found that many PWLD depend on the Dental Hospital because general dental services are not readily accessible to PWLD particularly in some areas. Satisfaction with the Dental Hospital services has previously been reported to be high in GG (this finding is referred to in the NNA). The commonest operation recorded as being performed on PWLD, according to the report on the health check information was full dental clearance/multiple tooth extraction.

5.21 Nutrition

The section on nutrition from the NNA should be read in conjunction with this LNA section.

The NNA states that there is a need for detailed, multidisciplinary assessment of swallowing and feeding problems to minimise secondary conditions such as dehydration, aspiration and respiratory infections. This is critical if the most vulnerable sub-group of PWLD are to survive and thrive. It also highlights the need for speech and language therapists; when they are in short supply they will be fully occupied with the paramount task of addressing the dysphagia, rather than the communication issues.

The NNA states that the reported prevalence of obesity varies from 10-56% depending upon the population studied, and methodology (which often is non-random samples), with higher prevalence in women. The NNA stated that PWLD generally are more likely to be overweight or obese than the general population. This observation was also reported from the health check information for PWLD in GG, although they were less likely to be overweight and more likely to be obese or morbidly obese than their non disabled GG and Scottish counterparts. The NNA stated that PWLD with profound LD or multiple disabilities, including physical disabilities such as cerebral palsy, are more likely to be underweight and this was also demonstrated by report from the health check information.

5.21.1 Prevalence of obesity

The NNA describes some rare genetic causes of overweight in PWLD such as Prader Willi syndrome (which is a starvation model i.e. people with PWS are always hungry). However, the essential cause is the same as in the wider population; PWLD with overweight or obesity are taking in more calories than they require for their basal metabolic rate and their level of activity, and need to cut back on their intake of calories and/or increase their activity levels.

BMI or Quetelet’s index was devised for the general population and assigns people to one of 5 WHO categories\(^{316}\). It may not be suitable for some PWLD with different body proportions, although this has not been subject to study. Waist measurement has been advocated as an alternative to BMI since 1995 by some researchers\(^{317}\). It can be used in some PWLD who are unable to stand for height measurement and have contractures, although similar practical problems can exist for some people, and it might not be suitable for people with syndromes associated with short stature. There is very little reported experience of the use of waist circumference measurements, in LD clinical or research settings, and no clear guidance on how waist circumference measurement could guide the targets for weight loss interventions. Within published clinical guidelines and the Glasgow Weight Management Service the use of weight,
and BMI, is the primary method of assessing weight status. It would be premature to change current practice without strong evidence that waist circumference is a more reliable, valid and practical measure, in people with and without LD. However, it is possible that a reliance on BMI may result in lack of recognition of people with the greatest degrees of underweight, as for some of them BMI cannot be calculated due to being unable to stand and having severe contractures, precluding measurement between bony prominences.

According to the report on the health check information, a BMI was available for 92.5%, of whom 30.5% had a BMI that was either obese or morbidly obese compared to 24.2% of their Scottish equivalents (Scottish Health Survey) and 22.8% of their non-disabled GG counterparts. The proportion of PWLD who were of acceptable weight or overweight was lower than in their GG and Scottish counterparts. The likelihood in PWLD of being obese or morbidly obese is inversely related to the degree of the LD, in keeping with previous studies.[318][319](36.7% with mild LD compared to 16.6% with profound LD). The likelihood in PWLD of being underweight is directly proportional to the degree of LD (2.1% with mild LD compared to 16.0% with profound LD). Additionally, there is a clear gradient across level of ability, for each of underweight, acceptable weight, overweight, obese, and morbidly obese, with the exception of obesity which is marginally more common in people with moderate LD than mild LD. Obesity/morbid obesity was more common in people with mild, moderate or severe LD when compared with the Scottish general population. The BMI of 77 (7.5%) people was not measured; typically this was due to lack of ease of availability of mobile scales.

5.21.2 Structural causes of overweight and obesity

Achieving weight control or weight reduction is difficult to achieve by health improvement initiatives based on health education. The basic paradigm that a change in knowledge will change attitude which will result in a change of health-related behaviour has not been validated over the past 20 years for many areas of health promotion and particularly in the area of weight control. A change in the wider environment may be required that makes it easier to take exercise or incorporate physical activity in daily living and makes it more difficult to obtain high-calorie low fibre food. These modern structural factors impinge on PWLD in the same way as they do on the non learning disabled population. Fundamental changes are needed in society’s attitude toward the way people spend their leisure and work time; the physical environment and its conduciveness to taking exercise; and the relative cost and availability of obesogenic food and drinks.

5.21.3 Role of carers

As described by the NNA, PWLD may not be in a position to make informed choices about their diet or activity levels, and carers have a critical role to play in helping PWLD understand the choices they should have. There may be examples were poor diet is thought by carers to be a choice made by the person with LD, but if the person does not receive information or guidance about healthy choices, it is hardly an informed decision. Other considerations include:

- carers might be concerned that withdrawal of the sensory and social pleasure of eating might follow attempts at weight reduction,
- the ethical difficulties of altering the diet of someone unable to give informed consent,
- the client or their carer might decline to accept advice to lose weight from a healthcare professional,
where PWLD with problem behaviours are given inappropriate food to influence their behaviour\(^{(320)}\).

There is a role for LD team staff in educating and supporting carers who are struggling with these issues. It takes more work and innovative thinking by carers, to come up with imaginative ways to incorporate physical activity into the daily life of the PWLD in their care, and the challenge this presents should not be underestimated. This is not easy, and support for carers is essential. One pilot study of a walking intervention involving adults with LD has been published and reported that participants increased their levels of physical activity and physical fitness, and reduced their percentage body fat\(^{(321)}\). This suggests a role for carers in encouraging such approaches.

### 5.21.4 Existing guidance on obesity

NICE published evidence-based guidelines aimed at preventing or managing obesity in adults in 2006\(^{(322)}\). They make it clear that there is a paucity of intervention studies specific to PWLD. The NICE guidelines suggest a multicomponent intervention for weight loss, comprising dietary change with a 600kcal deficit diet, physical activity and incorporated behavioural approaches to support lifestyle change.

‘Fighting Fit’ is a pan-Manchester programme. Their view is that weight reductions in obese PWLD may be effective if the effort is pan-community wide and taken seriously by senior management\(^{(323)}\). They found reductions of one BMI per annum on a sustained basis in selected populations of PWLD and obesity or morbid obesity\(^{(324)}\). This achievement falls short of NHS Health Scotland advice to health agencies to support organisations that are likely to achieve a target reduction of 5-10% of obese people’s original body weight\(^{(325)}\). However, Fighting Fit was designed as a healthy lifestyle intervention - not a weight loss intervention, and it does not follow NICE guidelines for a weight loss intervention - which is why some of the participants who received the intervention were actually of normal weight to start with. Local inter-disciplinary research is underway in Glasgow to evaluate the impact on BMI/waist measurement of interventions in PWLD with obesity and co-morbidity, in conjunction with an adapted form of the Glasgow Weight Management Service.

### 5.21.5 Underweight

The prevalence of underweight may be higher than reported, as some of the 77/1,023 who did not have their BMI measured may have had severe contractures precluding measurement between bony prominences to estimate height. The lack of mobile scales precluded other measurements, so firm conclusions cannot be drawn.

A study from the Leicestershire LD register presents standardized morbidity ratios for weight categories for adults over 25, using general population data from the Health Survey for England, 1998\(^{(326)}\). It found that the difference in rates between the LD and general populations was much greater for the underweight category than for obesity, as whilst obesity is more prevalent amongst PWLD, it is relatively common in the general population. So, underweight affects vulnerable PWLD far more often than it does the general population and specialist LD dieticians and SLT are the main source of expertise. The complexity of raising BMI in people with severe LD who are underweight requires the
intervention of a dietician because many require special feeding arrangements or personalised therapeutic dietary advice.

5.21.6 Selection of relevant published literature

A case control study of obesity in adults with DS from the Leicestershire LD register revealed that the prevalence of overweight and obesity was statistically significantly more common in women with DS than in non-DS, LD controls from the same register who were matched for gender, age and living arrangements\(^{327}\). The prevalence of overweight, but not obesity, was statistically more common in men with DS than their non-DS, LD controls. The controls were not matched for level of LD which is a limitation of the paper.

A review of the published evidence on the prevalence and determinants of obesity in PWLD\(^{328}\) concludes that obesity has been shown to make a ‘significant contribution to the reduced life expectancy and increased health needs of PWLD’, based on four published sources. Two of the sources provide evidence of relatively modest although statistically significant contributions to excess morbidity\(^{329}\) and mortality\(^{330}\) respectively, resulting from obesity. This was non-malignant GI disease (mainly GORD), ‘cardiovascular disease’ (types not specified), and psychiatric illness (anxiety, depression and behavioural problems). The direction of these statistical associations is not clear as the studies were cross-sectional. The excess mortality cited was a standardised mortality odds ratios of 1.83, causing 211 deaths out of 17,958 recorded on death certificates in PWDS (compared to 5,199 deaths due to aspiration, pneumonia or influenza; 5,066 deaths due to congenital heart defects, and 1,619 deaths due to seizures). The statistical significance reflects the large sample size. As previously described, reliance on death certification data has limitations. A third study assessed blood lipids in PWLD and demonstrated that PWLD have higher total cholesterol and total LDL than the general population if they lived in group homes or with their family\(^{331}\). The fourth source highlights the high prevalence of obesity in people with mild LD and in PWDS and that obesity is a risk factor for diabetes and cardiovascular disease in the general population\(^{332}\). PWDS, however, are extremely resilient to atherosclerosis, although obesity might theoretically impact on their mobility (particularly relevant given the high level of dementia in middle age), arthritis, and be a further risk factor added to their constitutional predisposition to chest infections.

Although obesity is common in PWLD and is a risk factor for type II diabetes and cardiovascular disease including hypertension and coronary artery disease in the general population, the impact of obesity on these life-threatening diseases in PWLD, and therefore their life expectancy, is not clear. Moran et al.\(^{333}\) suggests that the impact of obesity on the lives of PWLD is ‘thought to be greater than the impact on those in the general population. The disadvantages associated with impaired cognitive function are compounded when an individual is perceived to be unattractive, have lower stamina, and have higher risk for illness, traits often associated with obesity’. Population strategies aimed at reducing the prevalence of obesity in PWLD should perhaps also address these quality of life issues.

5.21.7 Intervention studies in obesity

A review article presented the current evidence as of 2006 on the effectiveness of interventions for obesity in adults with LD. It provides an encouraging number of references describing improvements in BMI in obese PWLD. These include approaches that emphasise: dietary change, behavioural
approaches, education on nutrition, interventions specific to genetic syndromes e.g. Prader Willi syndrome, and physical activity. Interventions have been delivered and seen to work, in the short-term, in terms of respectable reductions in mean BMI, in both one-to-one and group-based settings. The conclusion, as with the non-disabled population, is that the best results are achieved by a multi-component approach combining dietary change, increased physical activity and a behavioural approach that bears in mind the PWLD and the context in which they are living. There is a considerable literature on the role and benefits of involving carers in these interventions. The evidence regarding long-term effectiveness of weight loss intervention for adults with LD is less robust. The authors point out that the apparent lack of longer-term effect raises the issue of the sustainability of the intervention approach. Multi-component interventions seem most likely to be successfully assimilated into participants’ lives after treatment ends, and locally, there is considerable interest in providing tailor made local interventions of this kind.

5.21.8 Risk factors for obesity in PWLD

The risk factors for being overweight and obese, in PWLD, have been shown to include:
- being female,
- milder levels of LD,
- having certain genetic syndromes such as Down Syndrome, Prader Willi syndrome, etc.
- living independently or in supported community accommodation (as opposed to living in an institution where mean BMIs tended to be lower),
- taking medication (antidepressants, antipsychotics and anti-epileptics),
- unhealthy eating habits/unbalanced diet,
- physical inactivity,
- contributing social factors such as friendship, social opportunities and significant life events, and
- obesogenic influences in the wider environment that impact on the general population and that are now impacting on PWLD (ubiquity of inexpensive fast foods and processed foods).

It has been argued that a clearer understanding of these determinants is required in order to design effective intervention and prevention strategies, and that current tendencies to generalise the findings from obesity research in general population to PWLD is on its own, insufficient. A key factor is carers.

5.21.9 Secondary physical co-morbidity

The rising prevalence of type II diabetes in Scotland has been attributed to the so-called epidemic of obesity in Scotland. The percentage of adults (both genders combined) who reported ever having diabetes diagnosed by a doctor was 4.0% in Greater Glasgow in 2003, according to the Scottish Health Survey. The prevalence of diabetes in PWLD in GG for both genders during 2002-4 according to the report on the health check information was slightly higher at more than 5.1%. Another risk factor that is associated with obesity in PWLD is hypertension\textsuperscript{[334]}. Prevalence of diagnosed hypertension was lower in PWLD in GG, during 2002-4 according to the report, than observed by the QOF hypertension register for the general population but there might be considerable under-diagnosis in PWLD as indicated by the numbers of PWLD with raised or borderline readings at the health check. This LNA has not checked the diagnosis outcomes from these raised findings, so it is difficult to assess how much higher overall prevalence of hypertension was in PWLD in Greater Glasgow. The prevalence of coronary artery
disease from the report of the health check information is low (1.8%), likely to be due to low smoking rates. The extent to which obesity is impacting on mobility, arthritis and chest infections is not known.

5.21.10 Obesity in PWDS

People with DS have shorter life expectancy than the general population, or PWLD in general. Common causes of death include congenital heart disease, infection, and dementia. Despite their high rate of obesity, PWDS experience very low rates of hypertension, coronary heart disease, and cerebrovascular disease (including stroke) This is possibly due to the cystathionine beta synthase gene's location on chromosome 21, which is over-expressed in DS, as DS is due to trisomy 21. This leads to decreased homocysteine, and so reduced arteriosclerosis. They also experience low rates of many solid tumour neoplasms (benign and malignant) including that of the breast and gastrointestinal tract. The latter has been attributed to the increased natural production of superoxide dismutase type 1 (an enzyme that acts as an antioxidant) due to the tumour suppressor gene on chromosome 21 being overexpressed, and the role of the genes Dscr1 and Dyrk1a, also located on chromosome 21. The extent to which obesity is well tolerated or contributes to other aspects of their health such as mobility, arthritis, GORD, and chest infections is not known.

5.21.11 Weight interventions for PWLD in GG&C

Obesity and morbid obesity appears more common than it is for non-learning disabled Scots generally, particularly women. Whilst commoner in people with mild LD, this is also the case for people with moderate and severe LD. Some people with mild LD will be able to access existing services in GG&C, but existing weight loss services are not geared towards the needs of people with more severe LD. This is a local service gap. Evidence-based approaches advocated by NICE guidelines need to be adapted for PWLD and their carers given the possibility that cardiovascular disease rates could start to rise in PWLD; given other undesirable consequences of obesity including the symptoms of obesity, arthritis, GORD, and gall bladder disease, etc., and given the quality of life issues described above.

5.21.12 Constipation

According to the report of the health check information, the prevalence of constipation in PWLD in GG for both genders during 2002-4 was 31.7% and this includes 7.4% of the total sample having constipation that was previously unidentified. Constipation is a risk factor for irritable bowel syndrome, haemorrhoids and colonic cancer. Whilst poor mobility and psychotropic drugs contribute to this, constipation reflects a low fibre diet, which is linked with obesity. Carers should be offered advice on acceptable and palatable ways to increase fibre levels.

5.22 Mobility, balance, co-ordination and footcare

The national needs assessment provides a summary of the relevant issues surrounding these important areas. It stated that “In order to maximise quality of life and prevent secondary morbidity, children with learning disabilities and mobility problems, or people whose mobility changes require detailed assessment and management by specialist services. Access to specialist physiotherapy, specialist occupational therapy and wheelchair services is essential.” Generic physiotherapy and OT have a role
to play in working with people with milder LD, but are not sufficient to provide for the needs of people with more severe LD who are particularly affected by problems of mobility, balance and coordination, and who present with more complex problems.

Depending on need, PWLD may require aids and environmental adaptations, functional assessments, and risk assessments, much of which is carried out by LD Occupational therapists. The latter are also involved with developing meaningful activities bearing in mind physical limitations, and assessing occupational performance and activity. The increasing numbers of PWLD who develop dementia also benefit from the input of LD OTs in adapting their environment. Specialist wheelchair provision is also important.

The NNA highlights the importance of postural management for people with multiple physical disabilities in preventing deformities, joint problems, breathing or feeding difficulties, pain, discomfort and major difficulties in moving and handling. In GG&C provision of postural management clinics or full postural management programmes for PWLD is not comprehensive although the LD physiotherapists have been trained to provide it. This lack of local service persists despite the published evidence of benefits.

Hydrotherapy and rebound therapy are also in limited supply, although rebound therapy is being expanded in GG&C. The evidence base for using hydrotherapy is limited, and applied to select client groups rather than adults with LD, but a systematic review of the evidence that does exist shows positive results\(^\text{(335)}\).

The report on the health check information shows that impaired mobility and quadriplegia affected 24.2% and 6.4% in GG respectively.

A ‘Sports and Leisure Facilitator’ was created jointly between the Inverclyde LD physiotherapist, Inverclyde Leisure and Inverclyde Council Community Services to respond to the increasing number of referrals for overweight and obesity in PWLD. Resourced by the Health Initiative Funding, the 18 month pilot created a wide variety of enjoyable physical activities for PWLD in a range of settings in Inverclyde.

5.22.1 Podiatry

The NNA section on foot and toenail problems also reflects the importance of healthy feet in the overall health and wellbeing of PWLD and the fact that PWLD have a higher incidence of foot problems than the general population. The report of the health check information demonstrates that the podiatrist is the healthcare professional most commonly in contact with a PWLD – 55% had seen a podiatrist at least once within the past 12 months, a prevalence of contact that exceeds even that with the GP (53.7%).

5.23 Sleep disorders

This LNA learned little to add to the section on sleep disorders. Sleep disorders impact on carers as well as the PWLD.
5.24 Haematological disorders

The NNA provides a succinct summary of the key issues on this important area. It summarises the fact that PWLD are at increased risk of experiencing all the haematological issues of the wider population (side effects of drugs, polypharmacy, anaemia from blood loss or poor nutrition) in addition to the fact that some of them are at increased risk of serious blood dyscrasias because of the genetic cause of their LD. This section highlights the need for high quality carers with appropriate training to remain vigilant of possible unseen problems.

5.25 Infection

The NNA highlighted the high susceptibility of many PWLD to infections by virtue of their genetic constitution and predisposition to GORD and swallowing problems leading to aspiration pneumonia. It also lists several of the infections that are more likely to affect PWLD in group settings. Many effective diagnostic tests, treatments, vaccines and immunoglobulin products are now available to prevent, diagnose or treat most of these infections. LD staff need to be aware of the fact that they can access advice and support from the Public Health Protection Team at NHS Greater Glasgow and Clyde Board HQ during office hours and outwith office hours (Gartnavel Royal switchboard 0141 211 3600).

5.26 Sexual health

The NNA provides a realistic summary of the issues surrounding this important area including that:

- Sexual health needs of PWLD have been largely overlooked.
- PWLD have similar sexual health needs to all other people.
- Nevertheless, PWLD are vulnerable may be subject to sexual abuse.
- There are important issues regarding protection and the capacity of PWLD to consent to sexual intercourse.
- It remains important for PWLD to have opportunities to discuss, make choices about and enjoy their sexuality.
- PWLD need accessible information about sexuality and sexual health to enable informed choices.
- Sex education initiatives for PWLD and training for carers have been developed that can help the development of positive self-esteem for PWLD.
- Women with LD have additional sexual and reproductive health needs.
- Greater focus has been placed on supporting PWLD (both men and women) in their role as parents.
- Whether through voluntary or involuntary sexual activity, PWLD can be at risk of sexually transmitted diseases.

It behoves service planners to ensure that a GG&C sexual health strategy exists to optimise the delivery of Sexual and Relationship Education and related services to PWLD. It needs to be developed in a systematic and evidence based fashion and implemented safely, ethically, consistently across the Board area. SCLD offer a 2 day course on the subject, which covers a range of aspects including the legal framework surrounding relationships and sexuality, the concept of taking positive risks, and signs and
indicators of abuse. Many useful materials are also available from the SCLD website, including a recently published review of all available materials in Scotland[336].

5.27 Accidents

The NNA describes some of the evidence to suggest that PWLD are highly susceptible to accidents. Several examples were found locally during this LNA, highlighting the responsibility held by carers of PWLD. Training paid carers is extremely important, and there is a role for the LD teams in this, and the need for rigour in the commissioning, monitoring and regulation of care packages. The collection of health information around accidents in PWLD is limited and needs extending to inform any future new policies.

5.28 Adverse experiences and abuse

The NNA provides a section on the abuse of PWLD, including references that focus on the potential for abuse within support services. It refers to the “corruption of care”, to describe what takes place in many institutional settings, including but not exclusively long-stay hospitals[337]. Wardhaugh and Wilding describe 8 propositions or ‘elements in systems of organisation’ which they see as playing a part. Proposition 3 states that ‘Particular pressures and particular kinds of work are associated with corruption care’. They shed light on the possibility that corruption of care might also be allowed to take place in the kinds of care packages we are currently commissioning, even though they are firmly placed in the community and far removed from the institutions of old, and even though they can cost considerable sums of money to commission. Overwork, limited resources, lack of supervision, limited expertise, training and resources can all contribute. PWLD who have limited ability to communicate are unable to report any neglect or abuse they might be experiencing and there is no way of actually measuring the scale of this problem.

5.29 Health promotion and health lifestyles

The NNA starts by making the point that a key focus of health promotion should be enabling informed choice for people with LD, including choices that directly affect health and well-being, such as eating or activity patterns, on the grounds that initiatives promoting empowerment and enabling choice will lead to health improvement. However, this LNA questions if there is an excessive emphasis by many carers on respecting the choice and rights of the PWLD to the detriment of complying with a duty of care to protect from risky activities such as smoking or unhealthy eating and drinking habits.

Possession and understanding of knowledge required to underpin a healthy choice is essential. Accessing and interpreting information has become a more complex task in recent times and requires the ability to discern where vested interests may compromise the reliability of so-called facts. The critical concepts of informed choice, consent and capacity become blurred and it is assumed that many PWLD are able to make informed healthy choices, that many non-LD people are having difficulty making. Despite record levels of investment in health education budgets in Scotland, prevalence of smoking has declined only very slowly and has actually risen in some sub-groups, alcohol intake is still rising,
sedentary lifestyles are more widespread and the prevalence of obesity and type II diabetes are rapidly climbing. There is a need to move on from health promotion approaches that rely simply on education and assume that changes in attitude and behaviour will follow. Healthier choices need to be made easier and unhealthy choices need to be made more difficult. The increasing emphasis on public health protective approaches applies equally to PWLD in that society needs to make it easier for PWLD to make healthy choices and make it harder to make unhealthy choices, in the interests of the PWLD, on the grounds that they may not be able to make an informed choice.

There needs to be a balance between respecting the choice of the PWLD and discharging a duty of care to protect the PWLD from unhealthy choices. This involves information, providing a range of attractive healthy options, explaining the positive advantages of a healthy choice and the disadvantages of an unhealthy choice, etc. The NNA stated that family carers and paid carers have an important role to play and that health promotional training should be available for carers as well as training and accessible resources for use with PWLD. This is critical, and the challenge of addressing it is underestimated.

5.29.1 Obesogenic diet

Obesity and morbid obesity are more common in PWLD compared to both the wider Scottish population and the GG population in 2003. Several studies have confirmed the high prevalence of overweight and obesity in PWLD generally, as has been described in the section on nutrition. The NNA confirmed that unhealthy nutritional practices observed in the wider population are also observed in PWLD. It also argued that other social factors, other than nutritional knowledge, such as living environment, friendships and social activity in health promotion are important determinants of diet thereby emphasising the need to consider the needs of an individual within the wider context of their life. This highlights the critical need to create care packages that suit the client with LD.

Given the large numbers of PWLD in GG&C, their high absolute prevalence of combined overweight, obesity and morbid obesity, the expectation that the trend of rising prevalence of obesity seen for non LD population is also affecting PWLD and will continue to rise, and the fact that there is little evidence that the state intends to impose stricter controls on the advertising, pricing and availability of fast food from high street outlets and junk food available from supermarkets and corner shops - there is no area of health promotion in the field of LD that justifies a pan-population approach more than the area of obesity. Structural determinants of obesity need to be addressed for PWLD. Carers and day service providers of PWLD need to be targeted given the central influence they have over the client. In addition, high quality materials need to be created, and interventions appropriate for PWLD should be developed, trialed, and implemented for this population.

It is unlikely that LD services could ever be expanded sufficiently for its health professionals to deliver personalised, multi-professional interventions for all. It will be important that work is undertaken in partnership between the LD service and GG&C’s health promotion services, reserving multi-professional interventions by the LD service for highly selected groups.

5.29.2 Physical inactivity

The NNA stated that people with LD have levels of physical activity below those recommended for health promotion, that there are recognised barriers to exercise and recreation opportunities for PWLD
and that providing a range of opportunities and enabling people to make positive choices about their own lives may be a more successful strategy in improving physical activity levels than prescribing activity programmes. The LNA suggests that day services need to be developed in creative ways to enable a range of additional meaningful activities, including pleasurable physical activity, to be made available for PWLD both during the day and in the evening. This may also provide a sound distraction to PWLD from comfort eating. However, only a proportion of PWLD use day services. A recent study summarises the barriers to participating in physical activity experienced by PWLD, including:

- absence of consistent policy guidelines creating inequity across services, e.g. time spent in physical activity while using day services;
- insufficient residential staffing (paid carers) and resourcing to support physical activity;
- personal finance and budgeting.

NHS GG&C has a physical activity action plan for disabled people, which can be drawn upon for PWLD.

5.29.3 Alcohol and drugs

According to the report on the health check information, 3.4% drink more than 7 units of alcohol per week; 1.3% drink >14 units/week. There was no record for 0.6%. This is much lower when compared to Scottish wide consumption in 2003 when, according to the Scottish Health Survey, 20.4% of Scottish adults (men and women combined) consumed more than the recommended weekly limits of 14 units for women and 21 units for men. In 2003, 23.8% of adults in Greater Glasgow consumed more than the recommended weekly limits of 14 units for women and 21 units for men. Although abuse of alcohol by PWLD is not common, there is no service that is aimed at treating PWLD who do abuse alcohol, and existing community alcohol services may not be able to provide a suitable service. The same point is relevant for PWLD who use recreational drugs. Although only 0.6% used recreational drugs (there was no record for 0.4%), they can be very challenging to work with.

5.29.4 Smoking

The prevalence of smoking was just 10.2% in PWLD in 2002-4, according to the report on the health check information, compared to a GG board area prevalence of 34.7% and a Scotland-wide prevalence of 28.4%, for both sexes aged 16-64 years, in 2003, based on the Scottish Health Survey. The prevalence of smoking in PWLD is inversely related to the level of LD. Seventeen point four percent of those with mild LD in GG were smokers which is still half of those in all Scottish adults combined, which suggests that adults with mild LD in G have not taken up the habit to the same extent as in some published studies in Finland where equivalent prevalence rates of smoking equalised. GG&C smoking cessation staff have addressed the needs of PWLD in their latest anti-smoking strategy.

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xiii This was revised in 2009 bearing in mind changes to units such that 28.5% had consumed more than the weekly recommended limit.

xiv This was revised in 2009 bearing in mind changes to units such that 31.2% had consumed more than the weekly recommended limit.
5.29.5 Vaccination

The NNA stated that PWLD are less likely to be immunised against tetanus, poliomyelitis and influenza than are the general population. There is no routine way to assess uptake of primary immunisation schedule vaccines such as tetanus and polio in the GG&C population with LD. The very high uptakes for the population overall suggests this may not be an issue. Alternatively, it may be that PWLD have not received all of the prescribed vaccines. Routine assessment of uptake of primary schedule immunisation from existing datasets is currently difficult and may require ad hoc audits on a practice-by-practice basis. Five doses of diphtheria, tetanus and polio vaccines should have been given by the time of school leaving to ensure long-term protection through adulthood. Individuals with a LD who have not completed the five doses should have their remaining doses at the appropriate interval. Where there is an unclear history of vaccination, adults with LD should be assumed to be unimmunised. A full course of diphtheria, tetanus and polio should be offered in line with advice contained in the relevant chapters of the Green Book. The primary vaccination schedule can be viewed at:

www.dh.gov.uk/en/Publichealth/Healthprotection/Immunisation/Greenbook/dh_4097254

Illness related to the flu virus is very unpleasant at best (influenza infection) and fatal at worst (predisposing to pneumonia and sepsis) in physically vulnerable patients, and many PWLD will qualify as physically vulnerable because of postural, respiratory, cardiac and neurodevelopmental problems. Pneumococcus causes serious infection of the blood, lung, middle ears and the meningeal space etc and affects the young, the elderly, and people with underlying chronic diseases. All PWLD aged over 6 months should be receiving influenza vaccine if they have an underlying chronic condition as described in the Green Book on Immunisation or if they are older than 65 years. All PWLD aged over 2 years should be receiving pneumococcal polysaccharide vaccine (PPV) if they have an underlying chronic condition as described in the Green Book on Immunisation or if they are older than 65 years. Chronic conditions that are particularly relevant in PWLD include congenital heart disease, Type 2 diabetes requiring treatment or dietary control, asthma, bronchiectasis, etc. All children in Scotland are now routinely vaccinated with pneumococcal conjugate vaccine (PCV) as part of the routine primary schedule and this should also apply to children that are subsequently identified as having LD. Greater effort should be made to ensure that they are vaccinated as per guidance the same as the wider population. Routine assessment of uptake of flu and pneumococcal immunisation can be difficult from existing datasets and may require ad hoc audits on a practice-by-practice basis. Vaccination against human papilloma virus (HPV) has recently been introduced for young women, and should equally be made available for young women with LD.

5.30 Health screening and health needs associated with specific causes of LD

The NNA stated that inclusion of PWLD in all health improvement policy will not happen automatically; it will need additional, specific actions. Additionally, given the considerable evidence of unmet health need in PWLD, which is different in overall profile (including the commonest killers) to that of the general population, and limited resources, it behoves service planners to selectively promote the uptake by PWLD of services deemed evidence-based and cost-effective on the basis of them being relevant. Further information of cervical screening is provided below. It is important to be mindful of the possibility of perversely increasing inequalities as general population screening priorities will not be the same as for population with LD, due to the different profile of health needs.
Some public health programmes, particularly when they are being piloted, such as Keep Well, are not suited to PWLD for a number of reasons. With relatively small sample sizes of tens of thousands, the number with LD is too small to allow any judgement, statistically, on whether the primary prevention scheme had any impact on the health of PWLD. Furthermore, Keep Well is aimed at CHD, which is not a common illness or cause of death in PWLD. The additional cost and effort involved with adjusting such programmes to make them appropriate for PWLD may not be justified. Given the large number of health issues that relate specifically to PWLD, a screening process which focuses on those specific issues, and that is delivered by staff with appropriate training, seems more appropriate than shoe-horning PWLD into a screening programme that was designed to tackle the commonest cause of death in the wider population. Whether the existing community-based services that support initiatives such as Keep Well, including the Glasgow Weight Management Services, can reasonably be made effective to respond to PWLD and overweight/obesity needs to be demonstrated: work between LD services and the Glasgow Weight Management Services is in progress.

5.30.1 Screening for GI cancer

Other newly introduced programmes such as foecal occult blood (FOB) testing for gastrointestinal cancer should immediately include PWLD because of their relevance. Gastro-intestinal cancer appears to be more common in PWLD, as discussed above.

5.30.2 Cervical screening

The incidence of cervical cancer in women with LD is unknown; there are no published studies specifically of the incidence; and cancer registration records do not routinely record whether the patient has LD. Published studies of cancer incidence in PWLD demonstrated raised rates of GI cancer and leukaemia as described above, but none of cervical cancer, although the studies are limited by their size. An audit of cervical cancer for NHS GG over a 3 year period (1993-95) revealed no women with LD. LD nursing staff in GG&C who contributed to this LNA recalled three cases of cancer of the cervix. Cancer of the cervix is an uncommon condition and there were only 295 cases in Scotland in 2005. The Scottish Government predicts that the current decline in incidence will continue such that by 2016-20, there will be 42.8% fewer cases in Scotland, estimating just 48 cases in GG&C per annum. This would suggest less than 1 woman with LD would be diagnosed with cervical cancer in GG&C per annum if the risk was the same as for the general female population, which it probably is not.

Cancer of the cervix is associated with a sexually transmitted disease, in particular the HPV. Infection with the HPV alone is insufficient, and there are a number of risk factors that determine the outcome, including smoking and multiple sexual partners. Sexual activity is probably less common in WWLD of moderate to profound severity than the general population, as is smoking, so the overall risk of cervical cancer is lower. Women with LD are at increased risk of sexual abuse, but its extent is unknown.

Low incidences of cervical abnormalities in women with LD have been found ranging from an incidence rate of 2.8 per 1000, through 8 per 1000 to 20 per 1000. These findings suggest that cervical abnormalities in women with LD can and do exist, although they are much lower than reported incidence rates of cervical abnormalities in the general population of 69 per 1000 and 156 per 1000. A considerable fraction of cervical abnormalities do not go on to form cervical cancer.
Many studies show low uptake of cervical screening amongst women with LD ranging from 10-30% compared to upwards of 80% in the general female population, the implication being that this inequality in access to a preventive service is no longer considered acceptable. According to the report on the health check information, uptake of cervical screening in women with LD in GG during 2002-4 was also low, and for women with LD who might be considered at a higher risk due to being sexually active i.e. women using contraception, or who have had a pregnancy, it was 44.8%. Uptake of cervical cancer screening in GG women generally, in 2003-4, was 82.1%.

Several papers have described the complex medical, ethical, social and legal issues that must be carefully considered to address cervical screening and other gynaecological care procedures and treatments in women with LD. Others have described the difficulties involved with cervical screening in WWLD including providing reasons why primary care staff including GPs might not feel able to carry out the procedure. Some women with LD will not be able to comprehend the procedure, some may not cooperate with the procedure, and some might find it intrusive.

Unknown sexual abuse may be considered a reason to justify promoting cervical screening in all women with LD. However, a more reasonable approach would be to consider each woman’s circumstances on an individual basis, with discussions between the primary care team and the woman and/or her carer (depending upon her ability level).

All women with LD should be routinely invited for cervical screening so that they and their carers have an opportunity to make the decision as to whether to take up this preventive measure. Women in the higher risk categories should be encouraged to have the procedure. It follows that it is very important that women with LD and their carers are provided with the additional information, materials, time and other allowances required to assimilate that invitation. For some women, there is a role for the CLDN in supporting this preparatory work, as well as for carers. Recent guidance, in response to the requirements of the DDA 1995, from the NHS Screening Programme, entitled Equal Access to Breast and Cervical Screening for Disabled Women advocates screening where possible and provides 30 pages of detailed specification about how to approach this sensitive topic. Screening is not appropriate for some women with LD.

5.30.3 Breast screening

The incidence of breast cancer in women with LD, as for cervical cancer, is not systematically known as cancer registration records do not routinely record whether the patient newly diagnosed with cancer has an LD. It would be worth considering introducing a requirement to record LD on SMR6 cancer registration records, despite the considerable practical and ethical considerations that would needed.

The few studies suggest that breast cancer occurs in women with LD with a similar or lower incidence and mortality compared to that of the general population. Thirteen percent of deaths were caused by breast cancer in the cohort study at the Bristol Stoke Park hospitals. A population-based study in Western Australia linked the records of LD clients of the Disability Services Commission with the State Cancer Registry. For 2,370 women aged 25 years and over between 1982 and 2000, there were 20 cases of breast cancer observed over 31,148.4 person-years, whereas the expected number of cases based on cancer rates in the general population would be 45 (SIR 0.44, 95% CI 0.27-0.68). This lower

xv This can be downloaded from http://www.cancerscreening.nhs.uk/publications/cs2.pdf.
incidence is despite the nulliparous tendency of women with LD which increases risk. The study probably under-represent breast cancer risk as it did not take age into account - women with LD live less long and breast cancer is commoner in older women.

Women with DS are an exception, and several studies show their mortality from breast cancer is approximately 10 times lower than in the general female population. PWDS have a lower incidence of many solid tumours. Just 9 deaths from breast cancer have been observed from studies combined of women with DS compared to hundreds of cases of leukaemia\textsuperscript{186}\textsuperscript{301}\textsuperscript{363}. The Australian study described above observed no cases of breast cancer among the 247 women with DS (3,020.4 person-years) in the cohort, although 4.4 were expected\textsuperscript{362}. A Danish study linked 1,278 women with DS to the Danish Cancer Registry and identified no cases of breast cancer\textsuperscript{364}. Additionally, tissues from PWDS may be more vulnerable to ionising radiation and particularly x-rays\textsuperscript{365} which may contribute to the high rate of leukaemia observed in many studies\textsuperscript{364}. Hence there is a reduced benefit:risk ratio on mammography for women with DS.

Cancer of the breast is the commonest cancer in women in Scotland with 3,998 new cases and 1,114 deaths in 2005. In GG&C there were 4,318 incident cases between 2001-2005; an average of 864 cases per annum. Of these, more than half (58%) presented at the age of 60 and above and more than a third (35%) presented at age 70 years or older. With the exception of women with DS, it seems reasonable to assume the risk in women with LD is the same as that of the general female population of the same age. The incident burden of disease may increase in future as a result of the increasing longevity of women with LD, and the increase in alcohol intake (a risk factor for breast cancer).

National statistics in England for 1998–1999 indicated that the breast screening uptake figures for women with LD were 40% compared to national targets of 70%. In GG the report on the health check information found that uptake was 42.1% for eligible women with LD, compared with a 71.8% uptake of eligible women in general in the 2003-6 round, demonstrating a remarkable consistency in differential uptake between LD and non disabled women across the UK. A small number of studies lead to a consensus is that uptake/invitation is lower than in the general population\textsuperscript{366}\textsuperscript{367}\textsuperscript{368}\textsuperscript{369}.

Associated physical disability and physical problems such as scoliosis, spasticity, etc means that locality-based mammography services are not suitable for some women with LD and attendance at large secondary care centres may be frightening.

Questions have recently been raised about breast screening in general, and that women are still not given enough, or correct, information about the potential harms of breast screening\textsuperscript{370}.

As women with LD do get breast cancer, and the NHS formally endorses breast screening, it is important that all women with LD in the age range are offered breast screening and that they, and their carers, are provided with the additional information, support and time required to assimilate that invitation and undergo the procedure. There will be a role for CLDNs in supporting this for some women, and recent guidance on screening in women with disabilities should be applied, in order to minimise any stress and discomfort, and to ensure that this sensitive issue is managed in an ethical manner. However, CLDNs and screening practitioners need to be aware of the less favourable benefit : risk ratio for women with DS so that they can consider less frequent mammographic screening, unless
there is a strong family history. Breast awareness information should be available for women with LD and also for carers.

5.30.4 Health checks

There is a growing, although still limited, body of evidence to suggest that health checks should be offered to adults with LD, to check for health problems that are common in this population, which often remain undetected through standard service provision, and for which there are effective interventions once detected. The rationale is the different disease profile in the population with LD compared with the general population, with generic screening services designed for the majority general population, rather targeting the needs that are the priority for the minority group with LD. The numerous reasons for poor service access for adults with LD (appendix 7) suggests a role for health checks. A detailed review on the health check literature has been produced by academics at the University of Lancaster, which recommends that they should be regularly provided to the population with LD. England and Wales allocated £22million for two years from 2008 to introduce annual health checks as a GP directly enhanced service. There is not yet any data evaluating these investments. In contrast to England and Wales, Scotland has not introduced health checks for adults with LD into the GP contract, and provision across Scotland varies and is locally determined.

There is evidence to suggest health checks are effective when delivered by GPs or specially trained LD nurses. In an uncontrolled study, 181 of 374 adults with LD had a health check with their GP, and a high level of unmet health need was identified. Thirty-nine had a repeat health check 16-39 months later, and 36 had at 31-54 months later, with additional unmet health need identified. The authors recommended that health checks should be offered on an annual basis, as the population's health status is unlikely to be static. In GG, a non-randomised controlled study investigated 50 people with LD who were first to have the local health check, matched on gender, age, and ability with 50 adults who received treatment-as-usual, as they were not in the areas offered the intervention. After one year, the intervention group had more health needs identified and met, and more health monitoring and health promotion needs met, and the intervention was inexpensive. In an Australian cluster-RCT with 453 adults in 34 clusters, GPs delivered a health check and found modest benefits in detecting health needs in the intervention group compared to controls one year later. A second Australian cluster-RCT combined a health advocacy tool with the GP-delivered health assessment, randomised 272 participants, and found no additional benefits from health advocacy. A pooled analysis also combined the three controlled studies and reported benefits.

GG&C has offered a detailed one-off health check to adults with LD, gathering information to provide a background summary of relevant past health information and ability level, as well as health needs and disabilities at the time of the health check. The question now the programme is complete is – should repeated health checks be offered, and if so, by whom, and how often? Local research is investigating this, but will not provide an immediate answer. Debate about this between the LD service, the LD primary care liaison team and primary health care services might be useful.

5.30.5 Syndrome specific screening

There are thousands of different genetic causes of LD, each with differing related health problems. Some of these might warrant routine screening e.g. thyroid problems in people with DS. The low
prevalence of the syndromes means that this can only be undertaken at an individual level. A prompt for this could be included in future health check programme.

5.31 Polypharmacy, drug interactions and adverse reactions

This LNA has outlined how PWLD experience a high level of co-morbidity and multiple-morbidity. Numerous drugs may be prescribed and needed because of co-existing conditions, or prescribed through lack of review of repeat prescriptions. The common problems experienced by this population – mental ill-health and epilepsy – are treated with drugs that both interact, and impact on efficacy of the other drug. PWLD may be more sensitive to side effects of medication than neurotypical people. The evidence base specifically for PWLD is limited.

PWLD may metabolise drugs differently from the general population. Within the LD population, there is greater variation in the physical stature and physiological functioning among individuals than in the wider population. Such factors may result in different electrolyte levels, blood drug levels and therefore drug efficacy; mediated by different volumes of distribution, different renal and/or hepatic capacity, and different pharmacokinetics. The nature of the damage in the brain or changes in the brain structure that have given rise to LD may result in altered sensitivities to a drug or changed effects of a drug. For some PWLD, there are also genetic differences. All of the above provides prescribers with challenges in determining the optimum dose. The combination of multiple health problems, communication needs and reporting difficulties probably makes polypharmacy and adverse drug reactions and interactions more common in the LD population.

Given the above, the LD pharmacy service is clearly important, and provides a full clinical pharmacy service to the assessment and treatment units, and support to the LD teams in GG. There is a service gap in that there is no equivalent service for Clyde. It would be anticipated that extending the clinical pharmacy service for LD to provide a GG&C wide service would be beneficial for service users and would inform other professionals on the best pharmacological choices and modes of delivery.
6. Description of LD services in NHS GG&C

6.1 Introduction

The GG&C LD service comprises a large and heterogeneous collection of predominantly community-based, tiered, specialised and supra-specialised services. The service aims to support the health and social needs of PWLD to enjoy optimum health and meaningful lives in the community, by:

- providing direct specialist health and social services,
- facilitating access to mainstream primary, secondary, and tertiary NHS services; social work, housing, education, and other local authority services; and tertiary education and employment opportunities,
- providing advice, support and training for provider organisations and carers,
- commissioning appropriate care packages.

Provision of these services is the responsibility of the LD service which is jointly managed by NHS GG&C and local authorities, who employ a multidisciplinary, integrated workforce. Specialist health services are provided by the NHS. The voluntary sector offers a wide range of community-supported living options.

6.2 Management of the GG&C LD service

The GG&C LD service forms a key part of services provided by the GG&C Mental Health Partnership and GG&C CH(C)Ps. Strategic direction is derived from:

- the LD Way Forward Planning Group, which is attended by CH(C)P LD Service leads/heads of mental health and senior clinicians. This group is chaired by the director of the Mental Health Partnership and meets every 2 months;
- the Health Reference Group which drives the health improvement agenda for PWLD in acute and primary care settings. Chaired by the director of the Mental Health Partnership, its quarterly meetings are attended by senior representatives from CH(C)P’s; the Local Medical Committee; acute care; and health improvement services.

A tier 4 steering group was established in 2008 to manage a review of tier 4 services across NHS GG&C. The tier 4 steering group reports to the Way Forward Planning Group. Additionally, on 1 April 2010 the former Glasgow LD Partnership was dissolved and CH(C)P’s subsumed the responsibility for local staff management, strategy and performance.
6.3 Structure of the GG&C LD service

The GG&C LD Service operate at five levels from tiers 0 to 4, as described in the NNA.

**Tier 0**  Community resources and support, housing and support packages, education and learning, employment, public health initiatives, and policy development.

**Tier 1**  Primary health care services, directly accessed services, and paid and family carers.

**Tier 2**  Generic secondary (outpatient, inpatient and tertiary) health services accessed via primary health care services, and paid and family carers.

**Tier 3**  Specialist LD services provided by local authorities, NHS GG&C, the independent sector, and paid and family carers.

**Tier 4**  Supra-specialist (tertiary) LD services provided by local authorities, NHS Scotland, the independent sector, and paid and family carers.

This LNA report focuses on services provided within tiers 3 and 4.

6.4 Tiers 3 and 4: LD professionals

The following description does not include employees of child, nor forensic services. The Mental Health Partnership (LD service) and GG&C CH(C)Ps employs professionals from the following disciplines:

- LD psychiatry. 10 WTE Consultants (a headcount of 11, with some working part-time) plus two non-Consultant career psychiatrists.
- LD psychology. There has recently been a shortage of clinical LD psychologists, with vacant posts and staff-turnover. There are no psychology assistants.
- LD SLT. 12.2 WTE SLTs/support workers (at all grades).
- LD physiotherapy. 16.55 WTE LD physiotherapists/assistants, with high case loads.
- LD occupational therapy. 15.7 WTE, plus, in GG, 3.4 WTE artform workers (OT, technician grade).
- LD dietetics. 6.1 WTE.
- LD podiatry. 3 WTE, working in GG only, plus mainstream podiatry sessions in Clyde (estimated at 3-4 WTE).
- CLDNs. 54.2 WTE (a headcount of 58), plus 10.2 WTE (a headcount of 11) unregistered posts. Due to agreements resulting from the closure of Lennox Castle Hospital, no new graduate nurse has been recruited within Glasgow CHP for over a decade. Vacancies, when filled, have been from the pool of seconded or redeployed staff resulting from agreements with 3rd sector provider agencies. Consequently the workforce is ageing, with significant numbers of staff eligible for retirement in the next 5 – 10 years. In some teams there has been role-blurring, including filling in on social work duty rotas.
- Local area co-ordinators. 9.2 WTE (6.6 WTE in Clyde, 2.6 in GG; headcount of 13). The distribution is inequitable across the service, but the function and source of funding also varies across the service.
- LD pharmacists. 2 part-time clinical pharmacists and a full-time clinical technician, accountable to the Mental Health Pharmacy, which is part of the Pharmacy Prescribing Support Unit (accountable to the Board of NHS GG&C). The service is for GG, with no equivalent service for Clyde.
6.5 Tier 4 services

6.5.1 NHS in-patient/residential assessment & treatment services

The inpatient assessment and treatment services is a provision for PWLD who have mental ill-health which cannot be safely or effectively managed in their own home. For people with complex needs and/or moderate to severe LD, if they need to be admitted, their needs are typically best met by the LD units. Some people with mild LD access a service from general adult psychiatry admission units, often with support from LD psychiatrists and LD staff working from the LD teams; sometimes this is not possible because of the vulnerability of the PWLD, or because specialist knowledge or skills are needed to devise/deliver their care plan.

The service model is based on a person centred holistic approach and is delivered in a multi-disciplinary way, with 24 hour LD nursing, and dedicated Consultant LD psychiatry. Multi disciplinary input is provided on a follow through model, i.e. psychology and AHP input is provided from their tier 3 community LD team. There are 42 beds across NHS GG&C:

<table>
<thead>
<tr>
<th>LONGER STAY NHS TREATMENT</th>
<th>8 (2 x 4 bed accommodation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Netherton, Anniesland, Glasgow</td>
<td></td>
</tr>
<tr>
<td>Overtoun Court, Rutherglen</td>
<td>8(2 x 4 bed accommodation)</td>
</tr>
<tr>
<td>Waterloo Close, Kirkintilloch</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SHORT STAY ASSESSMENT &amp; TREATMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overtoun Court, Rutherglen</td>
</tr>
<tr>
<td>Waterloo Close, Kirkintilloch</td>
</tr>
<tr>
<td>Blythswood House, Renfrew</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

6.5.2 Complex needs support team

The service aims of the CNST are to: prevent placement breakdown, manage crises in conjunction with the out-of-hours service, provide specialist support and training to carers, facilitate admission, and/or change care packages. The CNST is multi-disciplinary, and aims to support tier 3 services by working to: provide practice leadership and training to prevent problems arising; detect problems within services early; and provide specialised long-term support. Emphasis is placed on safe, effective and sensitive risk and behavioural management with a multi-disciplinary/multi-agency setting.

CNST staff provision for GG (2009) comprises: 1 WTE SLT, 0.7 WTE clinical psychologist and 2.0 WTE clinical nurse specialists. No CNST provision is available in the Clyde area.

6.5.3 Complex needs out-of-hours nursing service

The LD out-of-hours nursing service is an integral part of the crisis response service, co-ordinated through tier 4 Complex Needs Services. Its two main areas of support are proactive activity for other tier 4 or CH(C)P services, reacting to contact from service users, care providers, carers, NHS 24, or social
work standby services. This can assist individuals and carers to effectively manage a crisis and alleviate the need for hospital admission.

Out-of-hours staff provision for GG (September 2008) comprised: 4 WTE healthcare assistants and 5 WTE LD specialist nurses. No out-of-hours provision is available in the Clyde area.

**6.5.4 LD epilepsy specialist nursing service**

The epilepsy specialist service is for PWLD who have complex epilepsy. It provides specialist nursing assessment, treatment and care planning to augment existing epilepsy and LD services.

Epilepsy specialist service staff provision for GG (2010) comprises: 1.8 epilepsy specialist nurses. No specialist epilepsy provision is available for the Clyde area. A key recommendation of the needs assessment for PWLD and epilepsy in Argyll and Clyde, 2004, was to develop an epilepsy specialist nurse service.

**6.5.5 Tier 4 service review**

GG&C’s Mental Health Partnership is redesigning its LD Tier 4. Detailed work has been carried out to design a model for the future, taking into account the predicted future needs of the population and current identified areas for improvement.

The redesign aims to:
- improve the care pathway for people with LD who require in-patient admission because of mental ill-health;
- improve patient flow by developing robust interfaces between Tier 3 (local community LD services) & Tier 4, providing alternatives to admission, shorter lengths of stay when admission is necessary, and mechanisms which reduce the possibility of delayed discharge;
- provide the right care, in the right place at the right time dependant on the presenting needs of the individual;
- provide person centred approaches which promote positive health outcomes and recovery and reduce the usage of distant out of area placements.

Two stages are proposed:
- **Stage 1**: Creation of an acute admissions service on one of the Board’s existing mental health hospital sites, and the retention of a community based assessment & treatment service in line with the current model and national policy.
- **Stage 2**: A longer term shift in the provision of longer stay NHS care to a robust range of community social care alternatives, and the development of the current complex needs community service to cover the entire Board area, with a focus on crisis and complex case management to prevent hospital admission where possible and support discharge. This includes review of CNST and the out-of-hours nursing service.
6.6 Tier 3 services

Thirteen ‘community LD teams’ are based in CH(C)Ps across GG&C.

Within the three sectors of Glasgow city CHP (North East, North West, and South) the term Area LD Team (ALDT) is used. There are eight ALDTs across Glasgow City CHP, each reporting to one of three adult services managers, who is a member of the CHP sectors management team. The ALDT’s provide a fully multidisciplinary, integrated healthcare and social service.

Outwith Glasgow city, there are five community LD teams: the LD Service (LDS) at West Dunbartonshire CHCP; the Integrated LD Team (ILDT) at East Renfrewshire CHCP; the Joint LD Team (JLDT) at East Dunbartonshire CHP; the Community LD Team (CLDT) at Inverclyde CHCP; and the Renfrewshire LD Services (RLDS) at Renfrewshire CHP.

The LD teams vary considerably in their composition (such as access to AHPs), management structure, the degree of integration between health professionals and social workers, use of eligibility criteria, and access to IT systems. The diversity of the LD teams does not appear to have derived from any overarching planned nor coordinated strategy or operation.

- Operation within the Glasgow City ALDTs includes:
  - use of a single shared assessment tool and a single data-recording system, to capture all social data and health data concerning service users,
  - merging of policies and procedures between social and health services staff,
  - matrix management structures where social workers might be accountable to a health professional and healthcare professionals might be accountable to a social worker,
  - the requirement for social workers, CLDNs and occupational therapists to potentially take on care management responsibilities; similarly social workers may be required to take on health roles, such as referral to both specialist and mainstream NHS services.
- East Renfrewshire ILDT operates a fully integrated service model, but does not utilise a single data recording system. Care management responsibilities are fully embedded, and successfully carried out by healthcare staff.
- Healthcare and social services for the RLDS, JLDT, CLDT and LDS are co-located but apply an intermediate degree of integration, with separate policies and procedures.

The NNAs refers repeatedly to tier 3 services and specifically describes the functions and responsibilities of LD teams to provide specialist services that are unlikely to be available at tiers 0-2.

6.6.1 Health data recording in community LD teams

The Glasgow City CHP sectors use the CareFirst data recording system, which is standardised to enable routine data analysis. This is consistent with the data sharing protocol agreed in 2005 (GLDP, 2005). Data recording systems used by the other CH(C)Ps vary (table 7 below).
Table 7: Data recording system usage in NHS GG&C

<table>
<thead>
<tr>
<th>CHP/CHCP</th>
<th>Healthcare collection system</th>
<th>data</th>
<th>Social services collection system</th>
<th>data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasgow City</td>
<td>CareFirst</td>
<td>CareFirst</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renfrewshire</td>
<td>TOREX/Continuum</td>
<td>SWIFT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>East Renfrewshire</td>
<td>No specific system</td>
<td>CareFirst</td>
<td></td>
<td></td>
</tr>
<tr>
<td>East Dunbartonshire</td>
<td>CareFirst</td>
<td>CareFirst</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inverclyde</td>
<td>TOREX/Continuum</td>
<td>SWIFT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>West Dunbartonshire</td>
<td>Limited use of CareFirst</td>
<td>CareFirst</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

East Dunbartonshire and Glasgow City both use CareFirst, though the systems do not interface. With the East Dunbartonshire system LD health staff record health information in health-related sections specifically created within CareFirst. The system allows the number of people with LD with additional dementia, epilepsy, mental illness, autism and other conditions to be identified, and exceeds capabilities in other CHP/CHCPs. It also records minimum standard data on follow-up visits.

Tailored data collection systems that both protect confidential health data, and enable audit, evaluation and research into LD service provision and health outcomes, are required across GG&C.

6.6.2 Care management

Health care staff act as care managers in Glasgow City CHP, and in some parts of Clyde. The varied and complex processes involved in care management are described in guidance documents produced by the six councils covered by NHS GG&C. Care management tasks can be time consuming, and impinge on other health care and social case work responsibilities and interventions.

The degree to which healthcare professionals take on care management roles varies. East Dunbartonshire JLDT preclude healthcare professionals from involvement in such tasks, West Dunbartonshire LDS involving healthcare professionals (CLDNs but not OT) in care management, and Renfrewshire LDS is increasing CLDN involvement in care management. East Renfrewshire CHCP ILDT has some restrictions on healthcare staff acting as care managers, with CLDNs and OTs taking this roles only for people with complex health needs (which also limits cases to less than 6 per professional). This is further discussed on page 57 of this LNA.

6.6.3 Allied health professionals and psychology/psychiatry support to tier 3

There are a variety of service provision and accountability arrangement for allied health professionals, particularly within the former GG boundary:

- In GG, AHPs each have two and usually more lines of accountability (line management accountability within an ALDT and professional accountability within and across areas). AHP leads can cover either a geographic area (individual or aggregated), the AHP professions as a whole, or an individual AHP professional area.
- In Renfrewshire CHCP, the LD team employs all their staff in a partially integrated locality team that consists of professionals from all health and social work disciplines.
• In Inverclyde, the LD team employs all disciplines of healthcare professionals who work jointly with their social work counterparts.
• East Renfrewshire CHCP employ their own psychiatrist, but rely on professional staff based at Blysthwood House in Renfrewshire CHP and The Wedge or Berryknowes Team within the S Glasgow CHP sector to provide AHP and psychology support.
• West Dunbartonshire CHCP employ their own social work and health professionals, including AHP, psychology and psychiatry. However, LD specialist podiatry is provided by the NW Glasgow CHP sector for the east side of West Dunbartonshire (i.e. the Clydebank half).
• East Dunbartonshire employ their own health and social work professionals, and LACs but also receive AHP, psychology and psychiatry support from the NE Glasgow CHP sector.

6.7 The primary care liaison team

The LD primary care liaison team has a primary function of supporting general practices and the extended primary health care team to ensure accessible, equitable and responsive services for PWLD. The service is managed by the Nurse Consultant in LD. It has funding from the Scottish Enhanced Service Programme (GP contracting). There are obvious advantages of having the service embedded within General Practice, such as ownership, shifting the balance of care etc. Work streams include supporting the LES LD register, and its further development as an information system, GP and practice training, provision of accessible person centred health promotion materials, service development to meet health check outcomes, and development of access to community based health improvement services. This is discussed further on page 58 of this LNA.

6.8 LD forensic services

The forensic directorate provides in-patient LD services: medium security at Rowanbank Clinic (6 beds) in the north of Glasgow, low security and close supervision at Leverndale (8 beds) and Dykebar Psychiatric Hospitals (8 beds) on the south side of the city. Additionally community based care is provided in GG, and under development in Clyde.
• Medium secure LD. Holly Ward in Rowanbank Clinic provides medium secure admission, assessment, continuing care specialist treatment and rehabilitation for up to six men.
• Low secure and close supervision. Whitehouse and Campsie are 4 bedded in-patient close supervision units, established to provide step-down units from The State Hospital. They are located on the Leverndale site and provide close supervision and rehabilitation.
• Bute Ward, on the Dykebar Hospital site is an 8 bed low secure unit initially established as a step-down unit from The State Hospital by a consortium by 4 Health Boards (Argyll & Clyde, Lanarkshire, Ayrshire & Arran and Dumfries and Galloway). They provide multi-disciplinary slow stream rehabilitation aiming at community resettlement. From 2010 the unit will reduce bed numbers, cater solely for the South Clyde catchment area and relocate to Leverndale Hospital.
6.8.1 Community forensic LD services

The Glasgow forensic community LD team covers the ALDTs, CNST and LD units across the GG area of NHS GG&C. The team has both male and female clients, many of whom are subject to Scottish Government restrictions, involved with the Care Programming Approach, subject to MAPPA arrangements and considered to be in the severely ‘at risk’ category. A similar service is currently under development for the South Clyde area of NHS GG&C.
7. **Recommendations**

“People with learning disabilities are individuals. They should be valued for their differences, respected as citizens, supported to speak for themselves and make their own choices. They should not experience discrimination, abuse, harassment or exclusion from the community, of which they are a full part.” (NNA, 2004). It is essential that this value-base underpins all service organisation and delivery, and that the following evidence-based recommendations are in addition to rather than in place of it.

7.1 Information and planning

1. There is limited local information regarding the local trends in prevalence of LD, and the proportion of people with mild LD, and with moderate to profound LD, and their associated needs. The population demographic is changing, with an increase expected in the 50+ age group with complex needs. Consideration should be given to using and resourcing the LES LD register to underpin and support an observatory function, to inform future service planning.

2. Clinical information systems should be improved to better capture electronically the distribution of activity data across the service, and basic clinical and social information on service users, for the proportion of people on the LES LD register who use the LD services. This is high priority. The information system should be appropriate for service delivery, monitoring, audit, evaluation, and health services research. Privacy arrangements, and the potential for deposit in the safe haven (at the Robertson Centre for Biostatistics, for NHS GG&C R&D, West of Scotland node of the Scottish Academic Health Sciences Collaboration) should also be considered, to maximise the use of information, including planning data.

7.2 Protocols and care pathways

3. The provision of services for PWLD who have epilepsy should be reviewed and is high priority. A care pathway should be developed by all the relevant component parts, including, at a minimum, LD psychiatry, epileptology/neurology, LD epilepsy nurse specialists, CLDNs. A Consultant LD psychiatrist should be identified as a lead for epilepsy for LD psychiatry, and job plans changed accordingly. A review of training/CPD needs on epilepsy in the LD service should be undertaken, so that all staff can rise to this challenge with confidence.

4. Several adults are still using paediatric and childrens services into their 20s and 30s. Arrangements for transitional planning should be reviewed jointly with child health services, and a joint protocol devised and implemented in each CHCP/CHP. This should also address better data capture from children’s services for transitional planning and adult care and support.
5. Linked to NHS GG&C’s dementia heat target work stream, the local protocol for dementia and PWDS should be reviewed, to improve greater consistency across the GG and the Clyde areas. Neuropsychological testing for individuals with DS should be offered on an individual basis when clinically indicated, rather than routinely.

6. All new referrals to the LD service, regardless of the cause of their LD or reason for referral should have a brief assessment of their skill and abilities, using a standard instrument, to inform assessments and the development of appropriate care plans; and to provide information for any future contacts with the service. All tier 3 staff should be competent in such assessments; and if not, should access training to develop this competence.

7. All PWLD with dysphagia should be assessed by a specialist practitioner and this should include a safety assessment and an accessible management plan. The National Patient Safety Agency has developed a resource set which provides a serried of documents and supporting material based on best practice which can be adapted for local use. NHS GG&C should develop a protocol based on best practice, to be implemented Board-wide.

8. NHS GG&C should demonstrate meaningful family and paid carer involvement in service delivery and design. Paid and family carers can have very important roles to play, and the LD teams and tier 4 services have an important role in supporting them in this. To ensure proper engagement with carers, meaningful participation should ensure their voices are clearly heard.

9. There is some suggestion that eligibility criteria for the LD service might differ in parts of GG&C, partly due to health and social work staff working to differing criteria. Clinical Psychologists should not be used in any other than exceptional decisions regarding service eligibility for tier 3 services. Agreed criteria across CH(C)Ps is recommended and is high priority. This should include consideration of eligibility criteria for people with ASD.

10. Much work has been undertaken to improve the experience of using secondary care services for PWLD. The wide dispersion of secondary care across GG&C, and the level of in-patient admissions is such that a dedicated LD hospital liaison care service could not be resourced in an effective way. Further work to develop a standard CH(C)P out-reaching of CLDNs into acute sector services when indicated is recommended.

11. LD team staff should be made aware of all health services that are relevant for PWLD, including the Special Needs Dental Service. Compilation of local directories should be considered.

7.3 Professional roles, service organisation, and operational management

12. Contracting with support providers is mainly a Local Authority responsibility. Ideally, contracts should routinely require support workers to work with health services and health professionals to optimise health, and this should be robustly monitored. Given turnover of support workers, carers need to routinely have a record of a person’s health needs and their skills and abilities, for comparison purposes should these needs change in future, as well as to help new staff in the delivery of care and support. Tier 3 community LD staff have a role in working with care providers to
achieve these aims, and they should be linked to support providers. The monitoring and reporting role of community LD staff should be strengthened to improve the overall standard and consistency of health care supported in social care settings.

13. Clinical Psychology services are an essential component of the specialist LD service, and GG&C has a strong tradition of delivering high quality clinical psychology services. Clinical psychology is unequally distributed across the service, and has been subject to high staff-turnover. It is recommended that the reasons for this are reviewed, and consideration given to whether the skill mix of staff is optimum.

14. Care management or an equivalent function is essential. It has embedded in some CHCPs/CHPs successfully. Successful care management requires an understanding of the distinct skills that each discipline can mobilise, so that these can be matched to individual needs of the person with LD. Following the review of organisational restructures, some staff reported a blurring of professional roles with the potential for skill-loss, and hence a GG&C wide review of care management is indicated, and is high priority. This should be linked to any current review of professional roles including that of CLDNs staffing the social work duty rota.

15. Across GG&C CLDNs are an essential component of the specialist LD service. The demands placed upon them are potentially high whilst the level of resource is finite. The CLDT workforce is ageing and the only new graduates within community services in recent years have been to the primary care liaison team. There may also be a role for assistant practitioners working under supervision of registered nurses. A review of skill mix of the CLDN nurse workforce is recommended, and is high priority.

16. The current LD AHP management and reporting mechanisms are confusing and lack consistency across the service. Given the small number of AHPs in the service, this introduces inefficiencies in what are essential services. This should be reviewed and is high priority.

17. Due to the very high rates of mental ill-health and problem behaviours experienced by PWLD, it is recommended that training is provided for CLDNs and other professionals in the service so they can more effectively contribute to the stepped model of care. It is recommended that training and supervisory arrangements are put in place to grow competencies to deliver access to psychological therapies.

18. Work to improve the interface between LD AHPs, and primary and secondary care is recommended.

19. The clinical pharmacy service for LD should be extended to provide a GG&C wide service.

20. LD staff should work within NHS GG&C’s equality scheme; impact assessment process; communication, support and language plan and accessible information policy. Procedures should be in place to ensure new staff are made aware of these specific processes/policies as well as all other operating procedures and policies, through their induction.
7.4 Strategy and planning

21. A strategic review of standardisation and consistency of function and processes across tier 3 services is recommended. This should include recommendations made in the LNA, and the management structures and lines of accountability for the LD teams. Current changes in the Glasgow CHP and Mental Health Partnership mean the timing of this is optimum now.

22. The review of tier 4 should be completed.

23. This LNA was commissioned by the Way Forward Planning Group. The Health Reference Group has also provided direction for the service. At Board level, LD sits within the disabilities planning framework. It is recommended that arrangements for planning and strategic direction for LD services are reviewed, including accountability for implementation of the LNA recommendations.

7.5 Health promotion, screening and health improvement

24. The LD primary care liaison team provides an important function to support primary care, complementing that of the LD teams. It has been highly rated in evaluations by primary care and service users/carers. The low volume of LD work in individual practices compared with other pressures, means that the primary care liaison team continues to be needed. Future workstreams should add a focus on PWLD who are high risk for repeated hospital admission. It is recommended that it should additionally be developed to provide improved information services, for example, through work with the safe haven.

25. LD dieticians should focus individual management efforts on PWLD who are underweight. Obesity is a major issue in this population, with secondary health sequelae and quality of life implications. There is not the resource to address it by LD dieticians, and considerable progress has been made by the Glasgow weight management service together with professionals from the LD service to better address the needs of PWLD who are obese, using multi-component interventions. LD dieticians have an important role in this, and LD physiotherapists bring important expertise. This work needs to continue and may need to further adapt as improved information becomes available from intervention trials for PWLD.

26. Health promotion initiatives in Scotland and in GG&C have been designed on the basis of the needs of the general population. They do not address the most important issues for the population with LD, although will be relevant and should be offered and accessible for some PWLD. Where relevant, review of accessibility is recommended.

27. With the possible exception of PWDS, screening for gastro-intestinal cancer is as relevant, or more relevant, for PWLD as for the general population, and should be equally made available and actively promoted to PWLD in the prescribed age-range, and their carers.

28. Health screening for mammography should be encouraged for all women with LD in the prescribed age range, with the exception of reluctant women with DS who should be assessed as to their risk on
an individual basis (e.g. family history of breast cancer), in view of the overall reduced risk for breast cancer in DS. Cervical screening should be offered to all women; effort should then be focussed on those at higher risk who should be encouraged and supported to take the procedure. Such decisions should be properly informed, and it is recommended that CLDNs are made familiar with the risks and potential benefits so they can offer advice, education and support, along side that of expert services such as the Sandyford clinic. Immunisation against human papilloma virus should be equally made available to all girls with LD, to the same extent as it is for the general population.

29. Health promotion initiatives should focus on the issues most relevant for the population with LD. Syndrome specific health screening is highly relevant for some people, but cannot be offered on a population basis. Health checks are now funded as part of the routine primary care service in England and Wales, but not yet in Scotland. The programme of detailed baseline health checks has been offered to the GG&C LD population across the service. It is recommended that consideration is now given as to how GG&C should respond to the need for shorter, repeat health checks, which might also include a prompt on syndrome specific screening, and in particular, who should offer these and how often.
### Appendix 1: Recent studies measuring the prevalence of LD in adults.


<table>
<thead>
<tr>
<th>Author</th>
<th>Age group</th>
<th>Geographical area</th>
<th>Sample size</th>
<th>Method of ascertainment</th>
<th>Definition of LD</th>
<th>Prevalence per 1,000 LD (per 1,000)</th>
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</thead>
<tbody>
<tr>
<td>Beange, 1996(5)</td>
<td>20-50 years</td>
<td>Australia</td>
<td>104,584</td>
<td>Population based administrative (including primary care) survey. Interviewed by a psychologist</td>
<td>IQ&lt;70 on psychological testing</td>
<td>1.12 2.19 combined</td>
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<tr>
<td>McGrother, 2002(6)</td>
<td>20+ years</td>
<td>Leicestershire</td>
<td>2,256</td>
<td>Population based administrative prevalence in 1991. Individual interviews by non-clinical worker of adaptive behaviour</td>
<td>Dependency on specialist services with adaptive behaviour problems associated with moderate, severe or profound impairment</td>
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<tr>
<td>Felce, 2004(7)</td>
<td>&gt;16 years</td>
<td>Wales</td>
<td>2,360,700</td>
<td>Population based administrative survey</td>
<td>Known to local authorities as in receipt or in need of LD service</td>
<td>4.3</td>
</tr>
<tr>
<td>Noorbala, 2004(8)</td>
<td>15+ years</td>
<td>Iran</td>
<td>35,014</td>
<td>Population based survey using random cluster sampling. Semi-structured interview by GP</td>
<td>Evident LD as assessed by GP</td>
<td>14.0</td>
</tr>
<tr>
<td>McConkey, 2006(9)</td>
<td>19+ years</td>
<td>Ireland</td>
<td>3,961,701</td>
<td>Population based administrative survey using the National LD database</td>
<td>Known to have LD meeting ICD-10 criteria, or else in receipt or in need of LD service</td>
<td>2.2 4.14 combined</td>
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<tr>
<td>Bailey, 2008(10)</td>
<td>19+ years</td>
<td>Northamptonshire</td>
<td>984</td>
<td>Identification via multiple sources, including health, social services, independent sector and voluntary organisations. Individual interviews by a psychiatrist of adaptive behaviour</td>
<td>Adaptive behaviour scores &lt;12 years on the Vineland Scale</td>
<td>0.5 2.3 combined</td>
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</table>
## Appendix 2: Recent studies measuring life span prevalence of LD.


<table>
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<tr>
<th>Author</th>
<th>Age group</th>
<th>Geographical area</th>
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<th>Method of ascertainment</th>
<th>Definition of LD</th>
<th>Prevalence per 1,000</th>
</tr>
</thead>
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<tr>
<td>Larson, 2001</td>
<td>Lifespan</td>
<td>USA</td>
<td>202,560</td>
<td>Non-institutionalized population, household survey. National Health Interview Survey 1987-1994 with follow-up disability interview for possible cases</td>
<td>Mental retardation reported as the primary cause of limitations in basic activities or for seeking services</td>
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<tr>
<td>Arvio, 2003</td>
<td>Lifespan</td>
<td>Finland</td>
<td>341,227</td>
<td>Population based administrative survey in 1995</td>
<td>IQ&lt;70 and using ID services</td>
<td>4.3</td>
</tr>
<tr>
<td>Fujiura, 2003</td>
<td>Lifespan</td>
<td>USA</td>
<td>202,560</td>
<td>Non-institutionalized population, household survey. National Health Interview Survey 1994/1995 with follow-up disability interview for possible cases</td>
<td>Mental retardation reported, or if mild intellectual disability, generalised learning difficulty or specific learning disability was associated with activity limitation or need for formal support</td>
<td>12.7</td>
</tr>
<tr>
<td>Van Schrojenstein</td>
<td>Lifespan</td>
<td>Netherlands</td>
<td>1,142,679</td>
<td>Population based administrative survey including primary care. Case files of identified persons examined for evidence of LD</td>
<td>IQ&lt;70-75, manifest before 18 years plus related limitations in two or more skill areas</td>
<td>6.4-7.0</td>
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<tr>
<td>Westerinen, 2007</td>
<td>Lifespan</td>
<td>Finland</td>
<td>36,053</td>
<td>Data combined from eight national registers using social security codes</td>
<td>ICD-10 definition of LD derived in routine practice</td>
<td>7.0</td>
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<tr>
<td>Wullink, 2007</td>
<td>Lifespan</td>
<td>Netherlands</td>
<td>15987,075</td>
<td>Two methods of extrapolation from GP research database and LD care service records</td>
<td>IQ&lt;70-75 and impaired adaptive behaviour (= definite LD), or person attended a special school/uses specialist LD services/or an adult unsuccessful at primary school (= unconfirmed LD)</td>
<td>6.4-7.0</td>
</tr>
<tr>
<td>Allgar, 2008</td>
<td>Lifespan</td>
<td>UK</td>
<td>218,551</td>
<td>Administrative survey including primary care</td>
<td>Significantly reduced ability to understand new and complex information and a reduced capacity to cope independently (including autism and cerebral palsy)</td>
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</table>
### Appendix 3: Recent studies measuring prevalence of LD in children.


<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Age group</th>
<th>Geographical area</th>
<th>Sample size</th>
<th>Method of ascertainment</th>
<th>Definition of LD</th>
<th>Prevalence per 1,000</th>
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</thead>
<tbody>
<tr>
<td>Stromme, 1998(19)</td>
<td>Medium age 10.8 years</td>
<td>Norway 30,037</td>
<td>Birth cohort 1980-1985. Ascertainment via educational and health services for children with ID, followed by psychometric evaluation</td>
<td>IQ&lt;70 (various tests used; not a standard battery)</td>
<td>3.5</td>
<td>1.5</td>
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<tr>
<td>Croen, 2001(20)</td>
<td>4-12 years</td>
<td>USA 4,590,333</td>
<td>Birth cohort 1987-1994. Identification via Developmental Service register</td>
<td>Physician or psychologist established significantly subaverage intellectual functioning, concurrent with related limitations in at least 2 adaptive skills areas</td>
<td></td>
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<tr>
<td>Bradley, 2002(21)</td>
<td>14-20 years</td>
<td>Canada 225</td>
<td>Population based survey in 1994. Identification via service registers followed by psychological assessment</td>
<td>IQ&lt;75 on Weschler Adult Intelligence Scale-revised, or Weschler Intelligence Scale for Children-Revised or Palmer scale of Mental Tests</td>
<td>3.5</td>
<td>3.6 combined</td>
</tr>
<tr>
<td>Christianson, 2002(22)</td>
<td>2-9 years</td>
<td>South Africa (rural) 6,692</td>
<td>Population based survey in 1993-1996. All households screened using the Ten Questions Questionnaire followed by paediatric neurodevelopmental assessment</td>
<td>GIQ&lt;80 measured by the Griffiths Scale of Developmental Assessment</td>
<td>29.1</td>
<td>6.4 combined</td>
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<tr>
<td>Heikura, 2003(23)</td>
<td>11.5 years</td>
<td>Finland 9,351</td>
<td>Birth cohort 1985-1986. Individual assessments</td>
<td>IQ&lt;70 on most recently administered psychometric test or developmental assessment (various tools used)</td>
<td>7.5</td>
<td>1.7</td>
</tr>
<tr>
<td>Leonard, 2003(24)</td>
<td>&lt;16 years</td>
<td>Australia 240,358</td>
<td>Birth cohort 1983-1992. Identified by record linkage of multiple sources</td>
<td>IQ&lt;70 on testing, or has a condition known to be associated with LD or clearly documented as having LD</td>
<td>10.6</td>
<td>1.4 combined</td>
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<tr>
<td>El-Hazmi, 2003(25)</td>
<td>&lt;18 years</td>
<td>Saudi Arabia 60,630</td>
<td>Population based survey, Specially designed screening questionnaire followed by clinical assessment and psychological testing</td>
<td>IQ&lt;70 on Weschler Intelligence Scale for Children or Stanford Binet Intelligence Test</td>
<td>2.6</td>
<td>6.3 combined</td>
</tr>
<tr>
<td>Author</td>
<td>Age group</td>
<td>Geographical area</td>
<td>Sample size</td>
<td>Method of ascertainment</td>
<td>Definition of LD</td>
<td>Prevalence per 1,000</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------</td>
<td>-------------------</td>
<td>-------------</td>
<td>-----------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Gustavson, 2005(26)</td>
<td>6-10 years</td>
<td>Pakistan</td>
<td>1,476</td>
<td>Birth cohort 1984-1986. Individual paediatric, psychology and social work assessment</td>
<td>IQ&lt;69 (assessment tools unspecified)</td>
<td>62 11 combined 73</td>
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<tr>
<td>Eapen, 2006(27)</td>
<td>3 years</td>
<td>United Arab Emirates</td>
<td>694</td>
<td>Population based survey. Denver Developmental Screening Test followed by clinical diagnostic interview</td>
<td>Functional limitations in two or more adaptive skill areas as determined by clinical assessment</td>
<td>24.4</td>
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</table>
Appendix 4: Ascertained number of PWLD in NHS GG&C Board area, by age and gender

<table>
<thead>
<tr>
<th>Age group</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>16-19</td>
<td>55</td>
<td>26</td>
<td>81</td>
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<tr>
<td>20-24</td>
<td>315</td>
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<tr>
<td>25-29</td>
<td>276</td>
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</tr>
<tr>
<td>30-34</td>
<td>230</td>
<td>171</td>
<td>401</td>
</tr>
<tr>
<td>35-39</td>
<td>265</td>
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<td>474</td>
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<tr>
<td>40-44</td>
<td>352</td>
<td>261</td>
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<tr>
<td>45-49</td>
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<td>50-54</td>
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<td>55-59</td>
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<td>85+</td>
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<td>18</td>
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</tr>
<tr>
<td>Total</td>
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<td>2272</td>
<td>5200</td>
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## Appendix 5: Ascertained number of PWLD in NHS GG&C Board area, by CH(C)P

<table>
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<th>CH(C)P</th>
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<th>Female</th>
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<td>East</td>
<td>417</td>
<td>300</td>
<td>717</td>
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<tr>
<td>East Dunbartonshire</td>
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<tr>
<td>East Renfrewshire</td>
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<td>120</td>
<td>252</td>
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<tr>
<td>Inverclyde</td>
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<td>Renfrewshire</td>
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## Appendix 6: Ascertained number of PWLD in CH(C)P, by age

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<th>Age group</th>
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<th>East Dunbart</th>
<th>East Renfrew</th>
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<td>1</td>
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<td>3</td>
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<tr>
<td>Total</td>
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<td>298</td>
<td>252</td>
<td>328</td>
<td>417</td>
<td>53</td>
<td>617</td>
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<table>
<thead>
<tr>
<th>Age group</th>
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<th>South West</th>
<th>West</th>
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Appendix 7. Excerpt from NNA on the factors affecting access by PWLD to health and social services

Issues related to the PWLD, and requiring services to make reasonable adjustments:

- Communication needs.
- Problem behaviours.
- Multiple coexisting health needs.
- Some types of health needs are distinct to PWLD and not experienced by the general population (e.g. some types of self injury, behavioural phenotypes).
- Low expectations of services due to previous bad experience of services.
- High tolerance of pain associated with certain causes of LD may result in carers not being aware of health need.

Health and social work professionals:

- Attribution of a person’s additional health needs to their LD.
- Presence of inappropriate stereotypes and negative assumptions about a person’s ability to maintain health and quality of life.
- Lack of pre-registration training in working with PWLD.
- Inexperience in working with PWLD, and low level of contact leading to difficulties in gaining experience.
- Lack of post-registration training in working with PWLD.
- Knowledge, skills, and attitudes.
- Lack of confidence, fear, and feeling de-skilled.
- Lack of recognition of the contribution to personal knowledge and experience of family carers to their family member’s needs and behaviour.

The structure of health and support services:

- Inflexible appointment systems.
- Short appointment times.
- Reliance on a person’s ability to read e.g. appointments, information sheets, leaflets and consent forms.
- Reactive, rather than proactive delivery of health care e.g. reliance on the individual seeking help, rather than routinely offering it.
- Physical barriers.
- Poor co-ordination and exchange of information between services and agencies.
• Ineffective communication and planning between services and agencies at times of transition.
• Exclusion from services that may be beneficial on the basis of a person having LD e.g. services for older people or physical disability services.
• Institutional discrimination e.g. protocols to access treatments for dementia being based on average ability levels of the general population.
• Recording and sharing of health information within teams of paid support workers e.g. staff shifts, staff turnover, new and agency employed workers.
• Lack of healthcare training and education for family carers and paid carers to enable health promotion and identification of health needs.
• Limited availability of information from the person’s past.
• Limited information about available services.
• Limited availability of independent advocacy.
• Unclear complaints procedures.
• Lack of accountability of NHS Boards to explicitly address and report the needs of PWLD.
• Lack of systems in place to identify and record the number of PWLD and their health needs, to inform service delivery and planning.
• Limited quantity and quality of research supported to lead to developments for health improvements.
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