



A Health Needs Assessment of Adults with Learning Disabilities, Aged 18 or Over in Devon

Author: Fiona Tolley, Consultant in Public Health

Sponsor: Dr Virginia Pearson, Director of Public Health

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1. Foreword

- 1.1 This report has been produced in response to comments from the public and professionals made during consultation on the Devon Joint Strategic Needs Assessment earlier this year.
- 1.2 Adults with learning disabilities are people first, who should be valued and respected for their differences, who have the same rights as other citizens to healthcare, but who have particular health needs. Their health needs should be met by mainstream health services. Reasonable adjustments might need to be made to accommodate their needs, which often include communication difficulties. There is evidence, nationally and locally, that people with learning disabilities suffer from the inverse care law and are not able to access mainstream services whether this is in respect of general health promotion, disease prevention, screening or treatment.
- 1.3 Just under 3,000 people are recorded on GP registers in Devon as having a learning disability and adult care services currently support just over 2,000 people with learning disabilities. The prevalence of people with a severe learning disability is set to rise by around 1% each year due to longer life expectancy (especially those with Down's syndrome), with more children and young people with complex and multiple disabilities surviving into adulthood, the rise in the reported number of school aged children with autistic spectrum disorder and the greater prevalence of learning disability in some minority ethnic groups.
- 1.4 Diagnostic over shadowing is a term used by the Disabilities Rights Commission (Disabilities Rights Commission) and others to describe the tendency healthcare professionals have to attribute to symptoms and behaviours associated with illness to the learning disability, and for the illness itself therefore to be over looked and routine investigations not being undertaken. This can be a particularly problematic when someone with a learning disability is in pain and can only communicate distress through behaviour such as screaming or biting.
- 1.5 In addition to the priorities for action outlined in Devon's Joint Strategic Framework for Health and Social Care, detailed in Appendix 3, consideration needs to be given to improving local public health intelligence through the anonymised sharing of the results of health checks.
- 1.6 There is a need to raise awareness and understanding amongst all healthcare professionals of the particular health needs of people with learning difficulties. This is necessary to ensure that 'reasonable adjustments' are made in order to facilitate better engagement with healthcare services and maximise the health benefit. A comprehensive programme needs to be put in place to raise awareness and should include induction and on-going professional development opportunities facilitated by service champions.
- 1.7 Commissioners and providers should review organisational equalities and diversity policies to provide assurance that 'reasonable' adjustments are being made.

- 1.8 Commissioners need to develop a range of quality standards and tools (audits, metrics) to ensure the current inequalities in access to mainstream services are addressed, health outcomes for this vulnerable client group improve and the existing health inequalities gap is narrowed. The scope of the Joint Strategic Commissioning Manager could be reviewed using the framework of the tiered service model described in this report. Reports on agreed performance measures and audit findings should be reported to the Devon Health and Social Care Learning Disability Partnership.

2. Executive Summary

- 2.1 People with learning disabilities have greater health needs than the general population. They are more likely to experience mental illness, and are more prone to chronic health problems such as epilepsy, cerebral palsy and other physical and sensory disabilities. People with learning disabilities are at a higher risk of premature death and four times more likely to have a preventable cause of death.
- 2.2 The prevalence of people with a severe learning disability is set to rise by around 1% each year in part due to longer life expectancy (especially those with Down's syndrome), with more children and young people with complex and multiple disabilities surviving into adulthood, the rise in the reported number of school aged children with autistic spectrum disorder and the greater prevalence of learning disability in some minority ethnic groups.
- 2.3 There is a need to improve equality of access for all people with learning disabilities to primary care, community and specialist health services including palliative care.
- 2.4 Health outcomes can be improved by:
- regular comprehensive and individualised health checks, the provision of appropriate treatment and follow up in the right environment
 - the use of Health Action Plans will enable the client and their carer to take better care of their needs
 - the identification of 'learning disability 'champions' in each Practice Based Commissioning Consortia to support awareness raising, training, audit and sharing of best practice and ensuring effective networking with Community Learning Disability Teams and acute liaison nurses
 - improved access to public health promotion programmes such as weight management, physical activities, and screening programmes
 - strengthening joint commissioning arrangements, the co-ordination of care, the pooling of budgets and the sharing of information (qualitative and quantitative) in order to:
 - target resources to meet needs

- reduce the need for hospitalisation because when community support breaks down
- enhance opportunities for client and carer engagement in choice, service development / re-design and contract monitoring.

3. Introduction

Purpose of Health Needs Assessment

- 3.1 The National Institute for Health and Clinical Excellence describes a health needs assessment as a “systematic method for reviewing the health needs of a particular population, leading to agreed priorities and resource allocation, which will lead to improved health and reduced health inequalities”.
- 3.2 This report will focus on the health needs of adults with learning disabilities, aged 18 years and over.

Legal Framework

- 3.3 The overarching framework of the Human Rights Act, the Disability Discrimination Act relating to the access to and provision of equal treatment, the treatment of people who lack capacity (Mental Capacity Act) and support for carers (the Carers Act) summarise the context for commissioning and delivering health care whether it is in primary care, community services or NHS foundation trusts.
- 3.4 A Joint Committee on Human Rights report¹ concluded that it is regrettably still necessary to emphasize that adults with learning disability have the same rights as everyone else and the NHS is required to ensure this is the case in relation to all aspects of healthcare.
- 3.5 Core standards within Standards for Better Health (C07e) challenge discrimination, promote equality and respect human rights and (C18) enable all members of the population to access services equally and offer choice in access and treatment equitably are the basis for assessing NHS organisations in relation to equality. In 2006, a Disabilities Rights Commission formal investigation² into the health inequalities facing people with learning disabilities identified how mainstream primary care services are failing to properly include and meet the general health needs of people with learning disabilities.

Definition of Learning Disabilities

- 3.6 People with learning disability are people first, who should be valued and respected for their differences. They have the same rights as any other citizen but evidence would suggest that these rights are frequently ignored.

¹ ‘A life like any other: Human rights of adults with Learning Disabilities’, Joint Committee on Human Rights 2008

² Equal treatment: closing the gap. Disability Rights Commission London 2006

- 3.7 The White Paper, Valuing People³ defines learning disability as meaning the presence of:
- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with
 - a reduced ability to cope independently (impaired social functioning)
 - which started before adulthood, with a lasting effect on development.
- 3.8 Whilst the International Statistical Classification of Diseases and related health problems tenth version (ICD-10) uses the term 'mental retardation' this is considered to be discriminatory and government reports now use the term learning disability. For the purposes of this health needs assessment the term learning disability will be used throughout. Degrees of learning disability are conventionally estimated by standardised intelligence tests which can be supplemented by scales assessing social adaptation in a given environment. These measures provide an approximate indication of the degree of learning disability. The diagnosis will depend on the overall assessment of intellectual functioning by a skilled diagnostician.
- Mild Learning Disability (F70): Approximate IQ range 50–69 (in adults, mental age from 9 years to under 12 years). Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships and contribute to society.
 - Moderate Learning Disability (F71): Approximate IQ range 35–49 (in adults, mental age from 6 to under 9 years). Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community.
 - Severe Learning Disability (F72): Approximate IQ range 20 – 34 (in adults, mental age from 3 to under 6 years), likely to result in continuous need of support.
 - Profound Learning Disability (F73): IQ under 20 (in adults, mental age below 3 years), results in severe limitation in self care, continence, communication and mobility.
- 3.9 Intellectual abilities and social adaptation may change over time and, however poor, may improve as a result of training and rehabilitation. It is important therefore to note that the diagnosis should be based on current level of functioning and focus on the level of support required.

³ Valuing People: a new strategy for learning disability in the 21st century. London, Department of Health 2001

4. Background

National Policies

- 4.1 The consistent theme in a number of UK national policies⁴ aiming to improve quality of life for people with learning disabilities focus on:
- citizenship
 - empowerment
 - having choices in making decisions
 - having the same opportunities as other people
 - having the same rights as other people
 - promoting social inclusion.
- 4.2 Valuing People³ in 2001 made reference to the four key principles of rights, independence, choice and inclusion and reinforced the need to ensure the Human Rights Act and the Disability Discrimination Act applied equally to all people with learning disabilities, in order to improve their life chances. The main objective for the National Health Service (NHS) is to enable people with learning disabilities to access a health service designed around their individual needs with additional support and reasonable adjustments where necessary.
- 4.3 In 2006 another White Paper Our Health, Our Care, Our Say⁵ reinforced the key role of the services provided by healthcare professionals working in community settings, and that Practitioners with Special Interests (PwSIs) and NHS specialist staff have in the delivery of community services. The need for comprehensive annual health checks for people with learning disability is described alongside developing community based arrangements. Good practice guidance, produced June 2007⁶ aims to provide practical support to commissioners for the provision of more specialised services closer to home with the emphasis on the role of PwSIs. This should be considered in the context of Practice Based Commissioning Consortia and across Devon as a whole.
- 4.4 Valuing People Now⁷ sets out the direction of travel and delivery priorities for the provision of services for adults with learning disabilities over the next three years. The priorities focus on personalisation, what people do during the day, better health, access to housing and making sure change happens.
- 4.5 Concerns have been raised as to how people with learning disability access healthcare and a number of actions to address this are described. These include:

⁴ Meeting the health needs of people with learning disability -guidance for nursing staff 2006

⁵ Our Health, Our Care, Our Say - a new direction for community services January 2006

⁶ Commissioning Specialist Adult Learning Disability Health Services Department of Health Oct.2007

⁷ Valuing People Now from progress to transformation Department of Health December 2007

- initiatives to ensure the NHS meets its obligations in relation to human rights and disability discrimination
 - a new primary care service framework to support primary care trusts in commissioning comprehensive health checks and better primary care access for people with learning disability
 - new good practice guidance on health action planning
 - good practice guidance on commissioning specialist adult learning disability health services⁶
 - local action for Primary Care Trusts to ensure acute healthcare is properly meeting the needs of people with learning disability
 - clear statements in the next NHS operating framework about delivery in relation to learning disability.
- 4.6 In July 2008 a report of an independent inquiry⁸ chaired by Sir Jonathon Michael was published. The report quotes from the Joint Committee on Human Rights report¹ “*public authorities should never be allowed to treat their duties towards adults with learning disabilities under the Human Rights Act 1998 and the Disability Discrimination Act (including their positive duties under Disability Equality Duty) as optional*”.
- 4.7 Sir Michael's report makes a number of recommendations aimed at the Department of Health, pre and post registration training, commissioners, providers and inspectors and regulators. Whilst the Government has yet to respond to this report the recommendations for commissioners and providers are outlined in Appendix 1.
- 4.8 Another report⁹ published in June 2008 highlighted the fact that the health of the most disadvantaged has not improved as quickly as that of the better off. The report makes specific reference to the findings within the Disability Rights Commission report² “...” *people with learning disabilities often receive a poorer level and quality of service from the NHS*” and that improvements in this area are likely to improve the health outcomes for other groups at risk of health inequalities. The report⁹ includes four key areas where NHS action is required including: using primary care to reduce inequalities, commissioning services in partnership to reduce inequalities, creating services that reach out to people and using NHS service to actively promote equality, including prison health.

Regional Ambitions

- 4.9 The draft strategic framework¹⁰ for improving health in the South West reinforced the rights of people with learning disabilities, described the rising prevalence, the evidence of health inequalities and outlined the key

⁸ 'Healthcare for all, report of the independent inquiry into access to healthcare for people with learning disability' July 2008

⁹ Health in-equalities: progress and next steps'. Department of Health June 2008

¹⁰ Draft Strategic Framework for improving health in the south west 2008/09 to 2010/11 NHS South West May 2008

components of an effective service for people with learning disabilities of any age, see below:

- a care co-ordinator to ensure health screening, early identification
- assessment of health needs, choice of treatment and care options and specialist intervention where necessary
- engaging and involving service users and carers in decisions about their care
- timely assessments for carers, in order to ensure adequate support for identified needs
- a focus on the delivery of outcomes that are agreed with the service user, carer and / or advocate.

4.10 Five ambitions for the South West were articulated and the mechanism for delivery of these regional ambitions were described, see below:

- all general practices maintaining a register of people with a learning disability and using the information to meet health needs
- the provision of information and support in accessing mainstream primary health care, mental health services and acute hospital care
- ensuring a comprehensive range of specialist learning disabilities services are available to people in their local community or as close to home as possible
- ensuring that people with learning disabilities and their families and carers are enabled to fully contribute to the planning and delivery of health services
- ensuring all relevant NHS staff are trained to work with people with learning disabilities and have the skills to deliver care for them
- addressing health inequalities in current NHS provision in the South West by requiring all providers of NHS care to review their disability, equality and diversity strategies to ensure that these have taken full account of the needs of vulnerable groups including people with learning disabilities
- a full response to the national Independent Inquiry into the health care of people with learning disabilities when it reports later in 2008
- supporting close working with Local Authorities as the lead agency for learning disability services (in Devon this is seen very much as a joint approach).

4.11 Appendix 2 summarises how the proposed ambitions¹⁰ will be achieved across the South West.

Local Strategies

- 4.12 The joint five-year strategy for health and social care¹¹ in Devon includes a number of intentions for addressing the health and social care needs of people with a learning disability. The strategy reflects national policy and regional ambitions to ensure there are local plans in place to address personalisation, choice, equality, better health experiences and improved health outcomes (see Appendix 3).
- 4.13 The Adult and Community Services Directorate “Joint Commissioning Strategy Adults with a Learning Disability 2008-2013” describes the changes required to improve services in Devon and reflects a partnership approach between the Adult and Community Services Directorate of Devon County Council, Devon Partnership NHS Trust and Devon Primary Care Trust and their commitments to joint commissioning (see Appendix 4).
- 4.14 The Devon Health and Social Care Learning Disabilities Partnership has produced a business plan¹² that sets out the main priorities and development intentions for the current financial year. In relation to improving health and emotional wellbeing in its widest sense four priorities have been described, see below:
- improved access to mainstream health services
 - designing and delivering specialist health services
 - providing effective adult protection and timely responses to Safeguarding Adult alerts
 - ensuring all service users receive annual reviews.
- 4.15 The Adult and Community Services Directorate highlights a further four areas for action¹³ covering physical health, mental health, specialist health care provision and commissioning.

5. Demography and Population Projections

- 5.1 The GP-registered population of Devon Primary Care Trust totalled 755,601 as of 30th June 2008, of which 386,043 were female and 369,558 were male. A graphical representation further breaking the population down by sex and age band is shown in Figure 1 along with a second graph, Figure 2, showing population projections up until 2029.

¹¹ The Way Ahead five years of improvement 2008-2013 Health and Social Care in Devon - Devon County Council Devon Primary Care Trust 2008

¹² ‘From ‘Service user’ to Citizenship, a business plan for Learning Disabilities services in Devon’ 2008/09 Devon Health and Social Care Learning Disabilities Partnership

¹³ Draft Strategy for Health Delivery for People with Learning Disabilities 2008, Devon Health and Social Care Learning Disability Partnership

Figure 1: Population Pyramid, Breaking the Population Down by Sex and Age Band

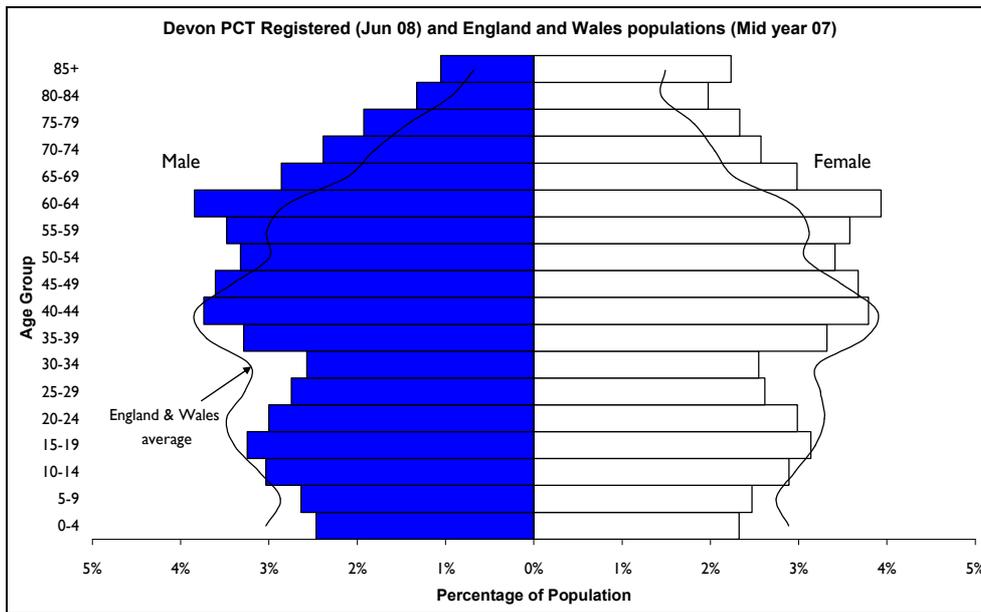
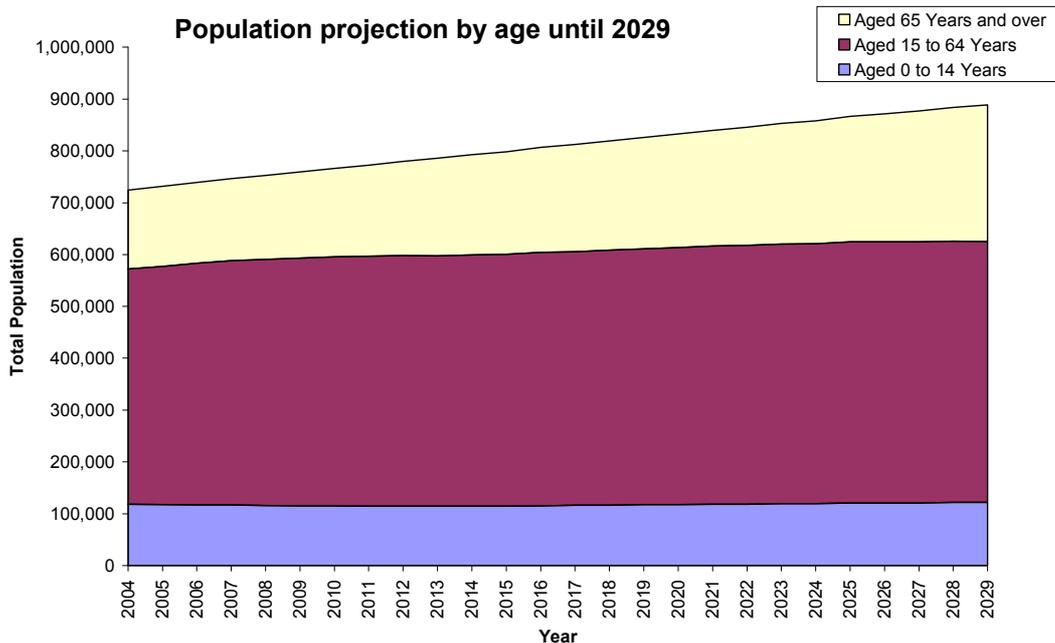


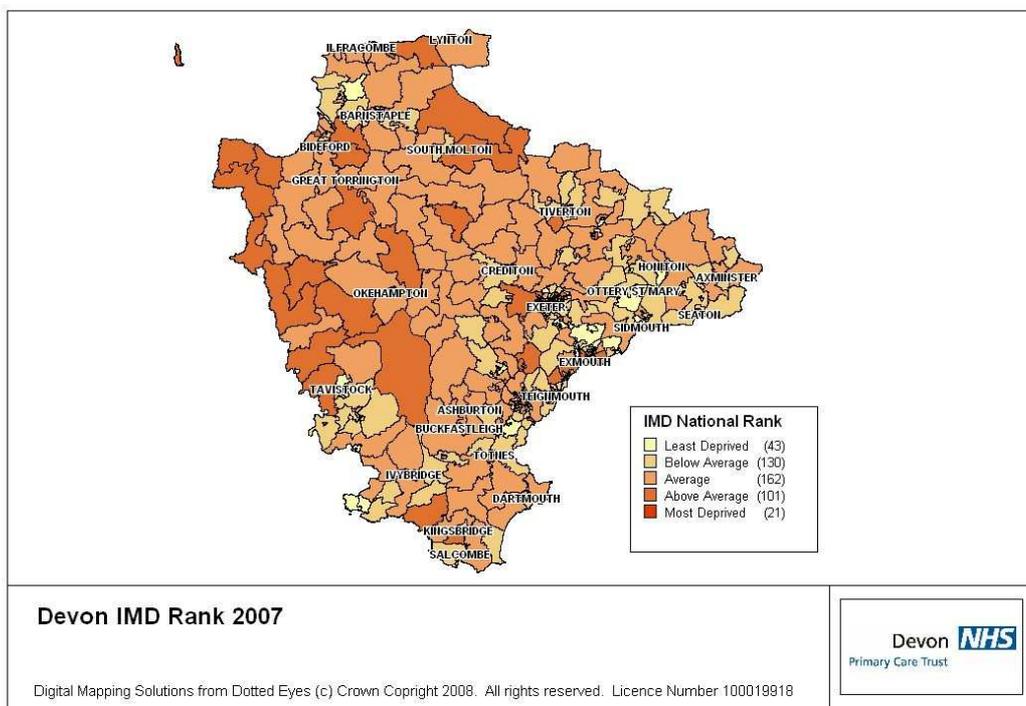
Figure 2: Graph Showing Population Projections by Age up Until 2029



- 5.2 Projections for the population change across Devon between 2006 and 2031 suggest that the overall population will increase from 741,000 to 967,900. The 0 to 14 years and 15 to 64 years age groups are forecast to increase by around 20% with larger increases, of 75% and 85%, being anticipated in the over 65 years and 75 years population.
- 5.3 By 2031, forecasts suggest that there will 270,500 people over the age of 65 years and 146,600 over the age of 75 years. In addition to considering

population, it is also important to consider indicators of deprivation, which is shown Figure 3 below, where dark areas indicate higher deprivation.

Figure 3: Map Showing Indicators of Multiple Deprivation in Devon



- 5.4 Deprivation across Devon is on the whole low, with East Devon and South Hams being the most affluent areas. There are 21 areas across Devon in the most deprived 20% nationally and 43 areas in the most affluent 20%.
- 5.5 Although deprivation is low, there are localised pockets of significant deprivation in areas of Exeter and North Devon.

6. Prevalence, Epidemiology and Burden of Disease

- 6.1 Estimates of the prevalence of learning disability vary reflecting differences in definition. Whilst the Department of Health suggests about 2.5% of the UK population has a learning disability Emerson and Hatton in 2004 suggested an estimate of 3% of children and 2% of adults fall into the category overall.
- 6.2 The prevalence of severe learning disability in the general population is expected to rise by 1% per annum for the next 10 years and to grow overall by over 10% by 2020. Factors affecting this include:
 - longer life expectancy, especially for people with Down's Syndrome
 - more children and young people with complex and multiple disabilities surviving into adulthood

- a rise in the reported number of school age children with autistic spectrum disorder
 - more learning disability in some minority ethnic groups of South Asian origin
- 6.3 There will be a growth in the complexity of disabilities partly due to improvements in maternal and neonatal care, but also adverse effects on foetal development as a result of alcohol misuse, rising teenage pregnancies and increase of prevalence amongst some ethnic groups.
- 6.4 Severe learning disability is relatively evenly spread in the population, however mild to moderate learning disability is linked to poverty and rates are higher in deprived and urban areas. Rates may also be higher in areas where large learning disability institutions existed which are pertinent to parts of Devon.
- 6.5 Whilst these figures could be interpreted for a General Medical Services doctor with a list size of 2,000 as about 6 patients with severe learning disabilities and about 44 with mild to moderate learning disabilities rates do vary widely between practices.
- 6.6 The Quality and Outcomes Framework provides GP practices with incentives for producing a register of patients with learning disabilities. This information can be broken down by Practice Based Commissioning Consortia group and is shown in Figure 4.
- 6.7 To note, Newton Abbot practices have not yet officially signed up to a consortia and at the moment are commissioning individually.

Figure 4: Table of Practice Based Commissioning Consortia Groups

Market Town	Population	Register Size
Exeter Commissioning Group	138855	448
Mid Devon Consortia	112827	424
Newton Abbot Consortium (Provisional)	41657	165
North Devon Commissioning Consortia	163548	572
South Devon Commissioning Partnership	72006	386
South Hams Commissioning Consortium	57472	199
Teignmouth Grouping	22444	91
Wakeley (East Devon)	71632	176
West Devon Commissioning Consortium	25560	92
Woodbury, Exmouth, Budleigh	48897	179

- 6.8 In order to commission effectively we need to be able to understand and forecast future demand. The websites www.pansi.org.uk (Projecting Adult Needs and Service Information System (18-64)) and www.poppi.org.uk (Projecting Older People Population Information System (65+)) calculate estimates for a range of information around learning disabilities. This information is shown in Figures 5, 6, 7 and 8.
- 6.9 The following statistics shown in Figure 5 come out for an overall learning disability baseline for Devon which can be further broken down to lower tier local authority districts.

Figure 5: Table of Projecting Adult Needs and Service Information System and Projecting Older People Population Information System Estimates: Age Group Predicted to have a Learning Disability

Age group predicted to have a learning disability	2008	2010	2015	2020	2025
Projecting Adult Needs and Service Information System Estimates for Devon					
18-24	1,802	1,860	1,862	1,758	1,782
25-34	1,860	1,977	2,336	2,480	2,435
35-44	2,470	2,402	2,218	2,365	2,735
45-54	2,349	2,476	2,714	2,661	2,471
55-64	2,457	2,459	2,418	2,695	2,931
Total	10,938	11,174	11,548	11,959	12,354
Projecting Older People Population Information System Estimates for Devon					
50-59	2,376	2,397	2,661	2,896	2,822
60-69	2,115	2,236	2,329	2,313	2,593
70-79	1,518	1,557	1,797	2,181	2,268
80+	916	956	1,062	1,236	1,510
Total	6,925	7,146	7,849	8,626	9,193

6.10 Figure 6 shows breakdowns for moderate or severe learning disability (hence in greater need of services especially residential care) and Down's syndrome, and can also be broken down to lower tier local authority districts.

Figure 6: Table of Projecting Adult Needs and Service Information System and Projecting Older People Population Information System Estimates: Age Group Predicted to have a Moderate or Severe Learning Disability

Age group predicted to have a moderate or severe learning disability	2008	2010	2015	2020	2025
Projecting Adult Needs and Service Information System Estimates for Devon					
18-24	412	426	430	409	420
25-34	399	425	502	533	523
35-44	620	603	558	594	688
45-54	525	555	608	595	556
55-64	530	529	524	585	632
Total	2486	2538	2622	2716	2819
Projecting Older People Population Information System Estimates for Devon					
50-59	521	525	583	639	628
60-69	400	422	435	432	483
70-79	198	204	236	287	293
80+	88	91	100	116	140
Total	1207	1242	1354	1474	1544

- 6.11 Information from Devon GP registers suggest there are just under 3,000 adults with a learning disability but practice registers are known to normally only record people with more severe learning disability. Estimates for Devon suggest the adult population with learning disability known to the learning disability service to be within a range of 2267-3407. Modest predictions of sustained growth over the next two decades in the numbers of people with learning disabilities known to learning disabilities services is estimates to be 11% over the decade 2001-2011 and 14% over the two decades 2001-2021.
- 6.12 On average 35 children have been identified with either a severe or profound multiple learning disability who will transfer to learning disability services each year for the next four years. It has also been estimated that 110 service users are living with carers over 70 years of age and this figure is likely to grow as both people with learning disabilities and their carers live longer.
- 6.13 Figure 7 also obtained from the Projecting Adult Needs and Service Information System and Projecting Older People Population Information System website provides estimated for the numbers with Down's Syndrome.

Figure 7: Table of Projecting Adult Needs and Service Information System and Projecting Older People Population Information System estimates: Age Group Predicted to have Down's Syndrome

Age group predicted to have Down's syndrome	2008	2010	2015	2020	2025
Projecting Adult Needs and Service Information System Estimates for Devon					
18-24	41	43	43	41	41
25-34	47	50	59	62	61
35-44	63	61	56	60	69
45-54	63	67	73	71	65
55-64	68	68	67	74	81
Total	282	289	298	308	317
Projecting Older People Population Information System Estimates for Devon					
50-59	54	54	60	66	64
60-69	18	19	20	19	22
70-79	2	2	2	3	3
80+	0	0	0	0	0
Total	74	75	82	88	89

- 6.14 The Down's syndrome estimates are based on the numbers of people with Down's syndrome recorded on the Sheffield Learning Disability Case Register, October 2007.
- 6.15 The learning disability estimates are based on prevalence rates in a report by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University, entitled Estimating Future Need / Demand for Supports for Adults with Learning Disabilities in England, June 2004.

Down's Syndrome and Dementia

- 6.16 The prevalence of dementia in people with Down's syndrome is estimated as:

- 17.7% in people aged 50-54 with Down's syndrome
- 32.1% in people aged 55-59 with Down's syndrome
- 25.6% in people aged 60 and over with Down's syndrome

6.17 These prevalence rates are taken from a Dutch study of 506 people in the Netherlands with Down's syndrome, aged 45 years and over, during 1999 to 2003, A Coppus et al¹⁴. These prevalence rates have been applied to the numbers of people aged 50 and over predicted to have Down's syndrome giving the estimated number of people with Down's syndrome predicted to have dementia in Figure 8 below.

Figure 8: Estimated Number of People in Devon with Down's Syndrome Predicted to have Dementia (by Age Groups)

Estimated number of people in Devon with Down's syndrome predicted to have dementia (by age groups)	2008	2010	2015	2020	2025
50-59	13	13	14	15	15
60+	5	5	6	6	7

6.18 The population predictions, for Devon, are based on ONS population projections of the total 50 and over population - these figures should be treated cautiously as they are estimates only, based on the above local analysis, and may be subject to local variation.

Other Co-morbidities Found in People with Down's Syndrome

6.19 Almost half of all people with Down's syndrome have congenital heart problems, a higher rate than the rest of the population, a higher risk of developing Alzheimer's disease, a higher risk of gastro-intestinal problems and cancer. They have high rates of oral complications – mouth deformities and gum problems.

Co-morbidities Found in People with Learning Disabilities

6.20 There is considerable evidence that the health of people with a learning disability is much worse than the population as a whole.

6.21 Figure 9 compares incidence/mortality within the UK Learning Disability population and the UK population. Mortality from gastrointestinal cancer and coronary heart disease is illustrated along with incidence from epilepsy and dementia.

¹⁴ Dementia and mortality in persons with Down's syndrome, A Coppus et al . Published in the Journal of Intellectual Disability Research, October 2006.

Figure 9: Table Comparing Incidence / Mortality within the UK Learning Disability Population and the UK Population

Problem	UK population	Learning Disability population
Gastro-Intestinal Cancer (mortality)	25%	48%-58%
Coronary Heart Disease (mortality)	19%	14%-20%
Epilepsy (incidence)	0.4%-1.0%	22%
Dementia (incidence)	5.7%	21%

- 6.22 There are higher levels of gastrointestinal cancers roughly double the population rates and other gastrointestinal problems such as high levels of Helicobacter Pylori, Gastro Oesophageal Reflux Disease (Gastro Oesophageal Reflux), constipation, incontinence and Coeliac disease. People with learning disabilities experience over a third more eating and swallowing problems than the general population, either caused by neurological problems or structural abnormalities.
- 6.23 Approximately a third of people with learning disabilities have epilepsy (20 times higher than the general population) and often more difficult to control. Mental ill health is also more common in people with learning disabilities and 15% of people with learning disabilities may present with 'challenging' behaviour.
- 6.24 Hypertension, obesity and low levels of physical activity are all risk factors for ischaemic heart disease. The cognitive impairment that lies at the heart of learning disabilities, means that all these health risks are more difficult for individuals to self manage or make informed choices.
- 6.25 Respiratory disease is the main cause of death in people with learning disabilities and they are more prone to repeat chest infections as a result of aspiration, reflux and /or lung abnormalities.
- 6.26 Sensory impairments (such as sight and hearing problems) that may not be referred on, or if referred on, might then lead to difficulties during the testing procedures, reinforcing the need for reasonable adjustments and specialist support.
- 6.27 Physical disabilities: up to a third of people with learning disabilities have associated physical disabilities, most often cerebral palsy, at risk of postural deformities, mobility problems, and hip dislocations. People with learning disabilities present with osteoporosis at an earlier age than the general population and have more fractures.
- 6.28 Dental issues/oral hygiene - People with learning disabilities are more likely to have tooth decay, loose teeth, gum disease and higher levels of untreated disease.

Carers

- 6.29 Nationally, data from the 2001 Census indicated that 18% of carers look after someone with both a mental and physical ill health including a learning disability. It is estimated that there are approximately 72,400 carers of all ages in Devon. People who care for someone with a learning disability need to have their own health needs assessed and met.

- 6.30 People with learning disability can have more difficulty in identifying and describing their symptoms apart from navigating the healthcare system effectively. In view of their caring role and their expert knowledge, not the least on how to communicate with the person they care for, more attention needs to be given in supporting carers to have an active role in supporting those people with a learning disability, in order to maximize their benefit from a healthcare intervention.

7. Health Inequalities

- 7.1 The Disability Discrimination Act 1995) makes it illegal to provide services, or facilities to a disabled person (including those with learning disability) on terms which are unjustifiably different from those given to other people. However, in the health sector, there is some evidence of unequal treatment patterns and diagnostic overshadowing.
- 7.2 Diagnostic over shadowing is a term used by the Disabilities Rights Commission (Disabilities Rights Commission) and others to describe the tendency healthcare professionals have to attribute to symptoms and behaviours associated with illness to the learning disability, and for the illness itself therefore to be over looked and routine investigations not being undertaken. This can be a particularly problematic when someone with a learning disability is in pain and can only communicate distress through behaviour such as screaming or biting.
- 7.3 The health of people with a learning disability is much worse than the population as a whole. One third have a sensory impairment, around a fifth have a physical disability and a quarter will suffer from some form of mental ill health during their life. People with a learning disability are also more likely to be obese, develop epilepsy and have a higher mortality rate and greater morbidity in relation to treatable conditions.
- 7.4 People with a learning disability need special consideration to make sure that they get the same access as others to all aspects of healthcare. Staff need access to education and training to raise their awareness of the specific needs of people with learning disabilities to ensure that their health needs are not missed because a physical or mental ill health is thought to be an inevitable part of the learning disability.

8. Evidence of Effectiveness

Annual Health Checks

- 8.1 There have been three controlled trials regarding annual health checks, all have found unmet health needs, and consensus expert opinion is that annual health screening should be undertaken moving towards a systematic approach. The Royal College of General Practitioners web site (www.rcgp.org.uk) currently gives six examples of annual health check models. The Devon Primary Care Trust Directly Enhanced Service

recommends using the Cardiff Health Check for People with a Learning Disability (see Appendices 5 and 8).

National Institute for Health and Clinical Excellence Clinical Guidelines

- 8.2 Devon Primary Care Trust (Primary Care Trust) is committed to ensuring that there is a systematic process for planning, implementing, monitoring and evaluating National Institute for Clinical Excellence guidelines. The Primary Care Trust accepts that National Institute for Clinical Excellence guidance represents good clinical practice and effective use of resources. The process includes the commissioning and the provider arms of the Primary Care Trust.
- 8.3 Clinical guidelines pertinent to improving health and quality of life in people with a learning disability include:
- National Institute for Clinical Excellence clinical guideline 20 Oct 2004
The epilepsies : diagnosis and management of the epilepsies in adults in primary and secondary care
 - National Institute for Clinical Excellence Clinical guideline 42 Nov 2006
Dementia supporting people with dementia and their carers in health and social care.

National Service Frameworks

- 8.4 National Service Frameworks are evidenced-based long-term strategies for improving specific areas of care. They set national standards, identify key interventions and put in place agreed time scales for implementation. There are a number of National Service Frameworks covering the major causes of ill health and mortality such as cancer, coronary heart disease, mental health, long-term conditions including neurological conditions and diabetes. When implementing these frameworks locally, commissioners and providers must ensure that the care and treatment of people with learning disabilities is no different to the care and treatment of the rest of the population albeit some 'reasonable adjustments' may have to be made.

Other Good Practice Guidelines, Department of Health

- 8.5 Good practice guidance was published in October 2000 for both breast (nhsbsp publication no 46) and cervical (nhscsp publication no 130) screening programmes, to ensure women with learning disabilities achieved the same level of access to services as other eligible women in the general population. The Public Health Directorate in Devon plan to undertake a health equity audit on the cervical screening programme to establish the local uptake and coverage for women with a learning disability and to take action where necessary.

Professional Bodies

- 8.6 The Royal College of Nursing¹⁵ has published guidance for professionals caring for people with learning disabilities. This covers specific health needs,

¹⁵ Meeting the needs of people with learning disabilities -guidance for nursing staff Royal College of Nursing London 2006

specialist services, supporting access to services and signposting to a range of other resources. Commissioners should review the current arrangements across Devon to ensure best practice across all commissioned secondary care in Devon.

Practitioners with a Special Interest and / or General Practitioners or Pharmacists with a Special Interest

8.7 Practice based commissioning consortia should consider the value in identifying clinical champions in each Practice Based Commissioning Consortia area to raise the profile of the health inequalities that currently exist in this client group, and support and endorse the actions necessary to narrow the gaps in terms of improving health outcomes and access to mainstream healthcare. Clinical champions could work across Practice Based Commissioning Consortia areas to share good practice in terms of awareness raising, training, professional development, audit and the ‘reasonable adjustments’ that need to be made to enable people with learning disability maximize healthcare appointments and treatment. For example, Torbay Hospital has developed a system that signals when someone has a communication need using their Integrated Health Care System. This alerts staff that the patient has communication difficulties and special arrangements need to be put in place (see Appendix 9).

Special Interest groups

8.8 Information for lay people and professionals can also be found on the web and the Foundation for People with Learning Disabilities www.learningdisabilities.org.uk has a number of useful good practice guidelines, including supporting family carers as they get older.

9. Current Commissioning

9.1 Devon County Council and Devon Primary Care Trust have appointed a Joint Strategic Commissioning Manager for adults with learning disabilities and there are a set of priorities for delivery outlined in the local strategies; (see Appendices 5 and 6).

9.2 The Joint Strategic Commissioning Manager reports to an Assistant Director who is also a joint appoint between the local authority and the NHS with the specific brief to lead on joint commissioning. A summary of the joint strategic commissioning manager role, all to happen in a joint context crossing organisational structures and cultures and encouraging a more joint perspective and practice is detailed in Figure 10. The role focuses on individual patient / user experience, shared underlying values and effective use of organisational and other resources.

Figure 10: A Summary of the Joint Strategic Commissioning Manager Role

Need to be aware of	Wider context – National, regional, good wheels being invented
	External Drivers – Performance Indicators, legislation, guidance,

	some case law
	Internal drivers – policies, projects, initiatives in both organisations, financial and other pressures
	Local situations, Joint Strategic Needs Assessment, user/carer/patient experiences, structures, operational practice and pressures
Need to influence	Development of plans / policies / strategies - may be active in some.
	Operational practice
	Perception and ownership of how various above factors connect
Need to do	Check some performance reporting
	Communicate and report in order to effect the above.

- 9.3 Current commissioning arrangements are complex and issues relating to Continuing Health Care requirements also need to be considered. An agreement and operational protocol for NHS continuing healthcare is in place between Devon Primary Care Trust and Devon Adult and Community Services (see Appendix 6).
- 9.4 Adult and Community Services is the lead agency and employs some workers in the Devon Health and Social Care Learning Disabilities Partnership.
- 9.5 The Devon Health and Social Care Learning Disabilities Partnership as unifying entity acts as Commissioner, (e.g. buying residential, nursing, residential support and domiciliary care) with some in-house and provider services and some health provision (e.g. therapy services). Devon Health and Social Care Learning Disabilities Partnership's role as per the partnership agreement provided delegated financial authority and provision of health and social care and included more strategic commissioning.
- 9.6 Devon Primary Care Trust commissions specialist services from Devon Partnership Trust. This is managed and delivered by the Devon Health and Social Care Learning Disabilities Partnership.
- 9.7 The separation of financial and operational management across Devon Partnership Trust, Adult and Community Services and Primary Care Trust has raised some concerns around how decisions which need to balance professional and financial accountability and priorities are made.
- 9.8 Both Adult and Community Services and Devon Partnership Trust have (different) performance indicators received by Devon Health and Social Care Learning Disabilities Partnership to focus on. There are also additional performance indicators required from the Primary Care Trust.

Issues to consider:

- finding ways to generate local information qualitative and quantitative from available and other data. The National Indicator Set and Key Lines of Enquiry suggest increasing the weighting for patient / user / carer perspectives in this. Local engagement through both 'Links' and the Devon Health and Social Care Learning Disabilities Partnership Board groups would seem to have potential for this

- time to revisit the partnership agreement (Appendix 6) including how decision processes are framed to align financial and operational decisions. The benefits or otherwise of pooled budgets could be considered in this process
- to review the scope, authority and accountability, budget managed by the joint strategic commissioning manager within the tiered framework described below.

9.9 NHS Scotland published a report¹⁶ which described a tiered approach to care for people with learning disabilities (see Figure 11 below)

Figure 11: Table Showing NHS Scotland Tiered Approach to Care for People with Learning Disabilities

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 their supporting services including third sector and family carers.
Tier 2	Generic secondary (outpatient, inpatient and tertiary) health services accessed via primary health care services, and their supporting services including third sector and family carers
Tier 3	Specialist learning disabilities services provided by Local Authorities, the NHS and the independent sector, including third sector and family carers
Tier 4	Supra-specialist (tertiary) learning disabilities services provided by Local Authorities, NHS, and the independent sector, including third sector and family carers

9.10 This model may be of use when considering current and future commissioning arrangements such as those that are:

- truly integrated and joint - including high volume and low cost, high cost but low volume (individual patient placements or complex cases)
- those led by practice based commissioning consortia
- those currently commissioned by the local authority or health separately

Tier 1 - Primary Care:

9.11 Access to health services for most people is achieved through primary care in the first instance.

9.12 There are two additional learning disabilities specific contracting arrangements:

- the Quality and Outcomes Framework requires practices set up a register of patients with a learning disability and provide crude numbers. The

¹⁶ People with Learning Disabilities in Scotland - a Health Needs Assessment Report - summary NHS Scotland Feb. 2004

existing Quality and Outcomes Framework registers do not differentiate learning disability by severity, but it is generally felt that GPs are recording the more severe end of the spectrum of learning disability as these people are easier to indentify (see Appendix 7 for the national definition)

- Directly Enhanced Services: Changes related to learning disability were introduced for 2008/09. Practices will be expected to provide an annual health check to patients on the local authority learning disability register. To participate in this Directly Enhanced Service, practices need to attend a multi professional education session run by their Primary Care Trust. Practices will get £100 for every health check. Devon Primary Care Trust is encouraging the use of the Cardiff Health Check tool (see Appendices 5 and 8 for the full details).

Tier 2 - Secondary Care

9.13 It is not currently possible to systematically and routinely interrogate Hospital Episode Statistics data to quantitatively determine variations in treatment or health outcomes for people with learning disability compared with the rest of the population.

9.14 Acute liaison nurses have been appointed following recommendations in Valuing People³. Their role aims to proactively assist people with learning disabilities aged 18 and older to achieve the maximum benefit during their time attending or in hospital. This includes ensuring reasonable adjustments have been made during planned visits (out patient appointments and elective admissions), care plans, risk assessment and consent are addressed and currently there is some limited support during working hours to Accident and Emergency as well as signposting and referring on. Nurses record their activity and this information will be helpful to start to measure changes in outcomes for clients entering hospitals. In Torbay, the acute liaison nurse has supported approximately 350 episodes of care each year although this is considered to represent less than 40% of the potential activity required.

9.15 Common problems encountered by the liaison nurse:

- consent – ensuring that the Mental Capacity Act (2005) is adhered to
- negative assumptions about the health outcomes or ability of people with a learning disability to have various medical procedures done
- diagnostic over shadowing – the health professional is unable to see past the learning disability
- carers not being respected as vital information holders or being left to do nursing care
- identification of patients with a learning disability and understanding what a reasonable adjustment is.

9.16 To overcome these issues the liaison nurse has:

- become a holder of specialist knowledge concerning the mental capacity act

- supports Mental Capacity Act training sessions with the hospital
- training to all staff groups is available on request – often following complaints
- lead training to National Vocational Qualification students on a regular basis
- supported the development and implementation of the recognition of specific requirements form
- supported the development of a draft admission policy to be agreed and launched to affect elective, emergency and outpatient admissions (to yet be agreed and launched)
- supported the development of a draft carers protocol (to yet be agreed and launched).

9.17 An example of good practice already exists in Devon at Torbay Hospital, and is referred to in Sir Jonathon Michael's report.⁸ This is the development, with input from staff, clients and lay people, of a system of identifying (patient profiles or recognition of specific requirements) and supporting patients, described in Appendix 9. An alert is recorded in the patient's medical notes to help identify the patient has a learning disability and special needs. The aim is to eventually have the profile accessible electronically, although it should be noted that profiles are not intended to replace health action plans.

9.18 Whilst there is no hard research evidence on the effectiveness of the role of acute liaison nurses they are valued by clients, carers and professionals alike.⁸ Commissioners should review the capacity, within current contracting arrangements, of these posts to ensure equitable access to their specialist support across all secondary and tertiary care providers. It should be noted though that it is the responsibility of all mainstream services to meet the needs of any vulnerable group.

9.19 Whilst good practice locally is to be celebrated it is interesting to note an observation by the Torbay acute liaison nurse that in Torbay Hospital it is felt that *"there is still a long way to go until it could be said that people with a learning disability have the same access to health care as the general population"*.

Tier 3/4 Specialist Services and supra-specialist services (forensic)

9.20 The scope of this health needs assessment has not included details of current commissioning arrangements (budgets, volumes or specific quality standards) for specialist services. Specialist providers are represented on the Devon Health and Social Care Learning Disabilities Partnership. Good practice guidance⁶ is available from the Department of Health and this is aimed at Primary Care Trust and Local Authority Commissioners and Learning Disability Partnership Boards. The guidance covers specialist community health staff, specialist teams including their role in supporting mainstream health services in their delivery of good quality health care for people with learning disabilities as well as in-patient and forensic services.

10. Performance Metrics

- 10.1 In addition to reporting on Quality and Outcomes Framework and the Directly Enhanced Service for learning disability there are other key performance measures. Currently there are different indicators centrally monitored by different bodies.
- 10.2 There is no indicator pertinent to learning disabilities in Vital Signs that underpin the Operating Framework for the NHS as either a national requirement or a national priority for local delivery.
- 10.3 There are two specific ones, within the adult health and wellbeing and tackling exclusion and promoting equality block, for local action in the new Performance Assessment Framework for local authorities and local partnerships.
- Proportion of adults with learning disabilities in settled accommodation (NI145 PSA 16)
 - Proportion of adults with learning disabilities in employment (NI146 PSA16).
- 10.4 NI146 'the Proportion of adults with learning disabilities in employment' has been signed off locally as a three year Local Area Agreement. Reports against this target will inform local Partnership Boards of progress being made in this key area.
- 10.5 Supporting people has developed outcome based contracts, partly based on the five outcomes in 'Every Child Matters'. Data is available for learning disability clients receiving long term housing related support. Data is provider generated, based on annual samples (50% for learning disabilities) of service users and is available by age, gender, ethnicity and reason outcome not achieved.
- 10.6 Other relevant indicators within the same block in the Performance Assessment Framework could include:
- people with a long term conditions supported to be independent and in control of their condition (NI124)
 - end of life care: access to appropriate care enabling people to be able to choose to die at home (NI129)
 - people supported to live independently through social services (all adults (NI136 PSA18).
- 10.7 Care 1st version 6, a social care performance monitoring data base is beginning to include health staff activity as well as social care activity. There are therefore a number of potentially helpful indicators that can be used as proxy measures of improvement in the health and wellbeing of people with learning disabilities. Work is in hand to determine the baseline from which local targets can be set in the future.

- 10.8 Reporting against these targets will inform the Devon Health and Social Care Learning Disabilities Partnership of progress being made in these key areas.

11. Recommendations

Existing Priorities

- 11.1 Priorities for action to improve the quality of life for people with learning disabilities that have already been agreed are detailed in Appendices 2, 3, and 4. The mechanisms of reporting and to whom, need to be made clear so progress can be effectively monitored across partnerships. A number of small audits have been undertaken locally and support the national picture of inequalities. It is not clear how the audit programme is prioritised, or the role of the Devon Health and Social Care Learning Disabilities Partnership in determining the work plan. One of the outcomes of these audits has been in improving care pathways for example in audiology.
- 11.2 In determining the needs of people with learning disabilities the needs of their carers must also be assessed and addressed particularly where the carer's health and wellbeing is at increased risk.

Joint Strategic Commissioning Manager

- 11.3 To review the scope, authority and accountability, budget managed by the joint strategic commissioning manager within the tiered framework described in section 9.

Intelligence

- 11.4 Local intelligence on the health needs of people with learning disabilities could be improved if there is agreement across all parties that data gathered from the annual health checks can be anonymised, shared and analysed to inform commissioning decisions. There is a need to move towards a common comprehensive screening tool that is electronically compatible with GP systems. A number of different health screening tools exist and can be found on the Royal College of General Practitioners web site. In Devon the preference is to use the Cardiff Health Check tool and this has been linked to the newly agreed Directly Enhanced Service, but as yet is not readily available on all of the existing GP systems, see Appendices 5 and 8.

Service Champions

- 11.5 To identify a cadre of practitioners who will champion the needs of people with learning disability in their area possibly Practice Based Commissioning Consortia in order to support awareness raising, training, audit and sharing of best practice. It would be useful if these individuals were supported to network with acute liaison nurses where they are in post.
- 11.6 Much emphasis has been placed on the role and responsibility of primary care professionals primarily that of the general practitioner. It is important to ensure effective local networking with members of the Community Learning Disability Teams in order to maximise skills and learning available in the

community in particular in relation to communication skills. Awareness raising, education and skills development needs to include those services that primary care might routinely refer on to such as dentistry, optometry, audiology and dietetics.

- 11.7 The scope and capacity of the acute liaison nurses needs to be reviewed to ensure equitable provision across the district general hospitals in Devon.

Training

- 11.8 A joint programme of induction and ongoing training needs to be developed to raise the profile of the specific health needs of people with learning difficulties and what reasonable adjustment to organisational systems need to be put in place. Training needs to cover the reasonable adjustments that should be considered within primary care, secondary care and mental health.

Audit

- 11.9 Where there is paucity of intelligence a joint audit programme needs to be agreed and implemented to provide assurance of improvement in access the health care, an audit on access to the cervical screening programme has already been agreed.
- 11.10 Audits of Health Action Plans could provide a useful multi-disciplinary learning experience leading to improved outcomes for people with learning disability over time. Resources to support such as audit programme need to be realised.
- 11.11 Results of audits, where routine data and intelligence is currently not available should also be reported so that strategic leads are kept informed.

Equality and Diversity

- 11.12 People with learning disabilities and their carers will benefit if commissioners and providers review their equality and diversity strategies and policies to ensure they comply with the legal framework that exists.

Performance Monitoring

- 11.13 Regular reports on progress against a number of national indicators (once baselines have been established) will help inform improvements for people with learning disabilities. Thought needs to be given as to how this information will be made available to clients and their carers.

12. Conclusions

- 12.1 This report has been produced in response to comments from the public and professionals made during consultation on the Joint Strategic Needs Assessment earlier this year.
- 12.2 Just under 3,000 people are recorded on GP registers in Devon as having a learning disability and adult care services currently support just over 2,000

people with learning disabilities. The prevalence of people with a severe learning disability is set to rise by around 1% each year in part due to longer life expectancy (especially those with Down's syndrome), with more children and young people with complex and multiple disabilities surviving into adulthood, the rise in the reported number of school aged children with autistic spectrum disorder and the greater prevalence of learning disability in some minority ethnic groups.

- 12.3 Adults with learning disabilities, are 'people first' who have the same rights as other citizens to healthcare and who have particular health needs. Their health needs should be met by mainstream health services, with 'reasonable adjustments' made for their particular problems, including communication difficulties. There is evidence that people with learning disabilities suffer from the 'inverse care' law and are not as able as the general population to access mainstream services whether this is in respect of general health promotion, disease prevention, screening or treatment. Robust local data however is scant.
- 12.4 Diagnostic over shadowing is a term used by the Disabilities Rights Commission (Disabilities Rights Commission) and others to describe the tendency healthcare professionals have to attribute to symptoms and behaviours associated with illness to the learning disability, and for the illness itself therefore to be over looked and normal investigations not being undertaken. This can be a particularly problematic when someone with a learning disability is in pain and can only communicate distress through behaviour such as screaming or biting.
- 12.5 There is a need to raise awareness and understanding amongst all healthcare professionals of the particular health needs of people with learning difficulties. For these professionals to appreciate and put in place those 'reasonable adjustments' that need to be made in order to facilitate better engagement with healthcare services thus maximising health benefit. There is a need to provide at induction and on-going professional development opportunities, the training and support staff need to provide effective interventions within mainstream services.
- 12.6 Commissioners need to develop their intelligence and the range of quality standards, metrics and tools (training, audits) to ensure the current inequalities in access to mainstream services are addressed, health outcomes for this vulnerable client group improve and the existing health in-equalities gap is narrowed.
- 12.7 A number of additional recommendations have been made to enhance the priorities already agreed. This report has been amended and updated to reflect comments received during a two week period of consultation, 19th November to 5th December 2008.

13. Acknowledgements

- 13.1 The Public Health Directorate of Devon Primary Care Trust has led in the production of this health needs assessment.

- 13.2 The author of the report is indebted to a number of people from Devon County Council's adult health and social care services directorate, staff from Devon Primary Care Trust and others in neighbouring areas across the south west region. All have so freely given up time and offered support, advice and expertise. They are listed below:

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- 13.3 The final report and recommendations reflects their inputs.

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Recommendations from Sir Jonathon Michael Inquiry July 2008

Commissioners

Primary care trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment. They should consult with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations and use the information to inform the development of Local Area Agreements.

Providers

There is a clear legal framework for the provision of equal treatment for people with disabilities and yet it seems clear that since services are not yet being provided to an adequate standard. It is important to understand the reasons why, and the action to take. The Inquiry therefore recommends:

- All health care organisations, including the Department of Health, should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.
- All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services. This should include arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on Patient Advisory Liaison Service from all client groups including people with learning disabilities.
- Section 242 of the National Health Service Act 2006 requires NHS bodies to involve and consult patients and the public in the planning and development of services, and in decisions affecting the operation of services. All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.
- Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.

APPENDIX 2

Extracts from NHS SW Strategic Ambitions for the South West in relation to people with a learning disability

The five proposed ambitions for the South West are:

1. Full implementation of Valuing People: a new strategy for learning disability for the 21st century.
2. Each person with a learning disability will be supported to have greater choice and control over their care. The support will be included in a personal care plan by 31st March 2009.
3. Each person with a learning disability will have full access to the physical and mental health care they need. The health care is to be based on a comprehensive annual health check, included in a personal health plan and checked by a primary care professional by 31 March 2009.
4. All people in NHS-provided accommodation are to be housed in accommodation of their choice, with the appropriate level of care and support by 31st March 2010; not applicable in Devon.
5. People with a learning disability will have the same access to screening for breast and cervical cancer as everyone else. Screening rates will be increased year-on-year, towards the same uptake rate as the general population of 80% by 2013.

The improvements for people with a learning disability will be achieved by:

1. All general practices maintaining a register of people with a learning disability and using the information to meet health needs.
2. The provision of information and support in accessing mainstream primary health care, mental health services and acute hospital care.
3. By ensuring a comprehensive range of specialist learning disabilities services are available to people in their local community or as close to home as possible.
4. By ensuring that people with learning disabilities and their families and carers are enabled to fully contribute to the planning and delivery of health services.
5. By ensuring all relevant NHS staff are trained to work with people with learning disabilities and have the skills to deliver care for them.
6. By addressing health inequalities in current NHS provision in the South West by requiring all providers of NHS care to review their disability, equality and diversity strategies to ensure that these have taken full account of the needs of vulnerable groups including people with learning disabilities.
7. By providing a full response to the national Independent Inquiry into the health care of people with learning disabilities when it reports later in 2008.

8. By supporting close working with Local Authorities as the lead agency for learning disability services (in Devon this is seen as joint working with the Primary Care Trust and the Local Authority).

Extract from the Way Ahead: Five years of Improvement 2008-11, Devon County Council and Devon Primary Care Trust

For people with learning disabilities we intend to support positive futures with a health and social care system that values people, promotes true inclusion and improved life experiences, and actively works against the discrimination and health inequalities that are still too often experienced by people with learning disabilities

We will achieve:

- person-centred plans for everyone with a learning disability who accesses health and social care support and wants a plan, to increase choice and control by 2009
- appropriate healthcare, with everyone with a learning disability having access to an annual health assessment that is checked by a primary care professional by 2009
- evidence of a year-on-year increase in screening rates, for example breast and cervical screening, towards the same uptake rate as the general population of 80% by 2012
- an increase in the number of people helped to live at home, reaching national leader status for all adult care services by 2013
- an increase in the number of people with a learning disability who are helped into employment between 2008-2011
- evidence of commissioning for equality and value within all contracts by 2010

Extracts from Joint Commissioning Strategy Adults with a learning disability 2008-13

The key areas of social care commissioning development in Devon will include:

- the ongoing development of individualised budgets which will be a major step in enabling adults with a learning disability to have more control over their lives
- the use of a Resource Allocation System (RAS) to ensure that resources are allocated equitably and provide value for money
- offering more support to carers through the reconfiguration of respite/short break services giving carers a break how and when they need it
- development of the market place to ensure a wide range of provision that provides choice and flexibility
- reduce expenditure on residential care to fund investment in individualised supported-living options
- increasing employment opportunities

Health Care development will focus upon physical, mental, and specialist health care and long term health care and monitoring. Commissioning issues will include the case management and contracting and monitoring of individual complex care packages, and developing a commissioning framework to develop long-term care provision.

Future change of direct, or 'in house' services will fall into two key areas – the development of services, and achieving independence as a provider organisation.

Increasing service user choice and control through the personalisation agenda will continue to shape further developments of both the nature of provision, and how it is arranged.

The need to adopt new ways of working will be addressed through a workforce project to ensure that the workforce is sufficiently prepared and supported to meet the challenge of change.

Cardiff Health Check for People with a Learning Disability

Date Name
 Marital status Ethnic origin
 Principal carer Age Sex
 Address

Weight (kg/stone)..... Height (meters /feet)
 Blood Pressure Urine Analysis
 Smoke (per day) Alcohol (units per week)
 Body Mass Index Cholesterol/
 (weight in kg / height in m2) Serum lipids

Immunization - People with learning disability should have the same regimes as others and the same

contra indications apply. (please circle)

Tetanus in last ten years?	Yes	No
If no has tetanus been given?	Yes	No
Has influenza vaccine been given?	Yes	No
Is Hepatitis B status known?	Yes	No
Result?		

Cervical screen – people with a learning disability have same indications for cervical cytology as others.

Is a smear indicated? Yes No
 If yes when was last smear?/...../..... When is next due?/...../.....
 What was the result?

Mammography – this should be arranged as per local practise.

Has mammogram been performed. Yes No

CHRONIC ILLNESS - Does your patient suffer from any chronic illnesses.

Diabetes	Yes	No
Asthma	Yes	No

SYSTEMS ENQUIRY – the answer to these will not always be available.

Respiratory cough	Yes	No
Haemoptysis	Yes	No
Sputum	Yes	No
Wheeze	Yes	No
Dyspnoea	Yes	No

Cardiovascular system

Chest pain	Yes	No
Swelling of ankles	Yes	No
Palpitations	Yes	No
Postural nocturnal dyspnoea	Yes	No
Cyanosis	Yes	No

Abdominal

Constipation Yes No
 Weight loss Yes No
 Diarrhoea Yes No
 Dyspepsia Yes No
 Melaena Yes No
 Rectal bleeding Yes No
 Faecal incontinence Yes No
 Feeding problems Yes No

C.N.S. – for epilepsy see overleaf

Faints Yes No
 Parasthesia Yes No
 Weakness Yes No where

Genito- urinary

Dysuria Yes No
 Frequency Yes No
 Haematuria Yes No
 Urinary Incontinence Yes No
 If Yes has M.S.U. been done Yes No
 Would you consider other investigations? Yes No

Gynae

Dysmenorrhoea Yes No
 Inter menstrual bleeding Yes No
 PV discharge Yes No
 Is patient post menopausal? Yes No
 Contraceptives Yes No
 Other.....

EPILEPSY Yes No

Type of fit
 Frequency of seizures (fits/month)/
 Over the last year have the fits Worsened Remained Improved
 the same

Antiepileptic medication

Name	Dose/frequency	Levels (if indicated)

Side effects observed in the patient

.....

BEHAVIOURAL DISTURBANCE.

Behavioural disturbance in people with a learning disability is often an indicator of other morbidity. For this reason it is important to record it as it can point to other morbidity.

Aggression Yes No
 more than once less than very

	a month		once a month		infrequently
Self injury	Yes		No		
more than once a month			less than once a month		very infrequently
Overactivity	Yes		No		
more than once a month			less than once a month		very infrequently
Other					
more than once a month			less than once a month		very infrequently

PHYSICAL EXAMINATION

General appearance

Anaemia	Yes	No
Lymph nodes	Yes	No
Clubbing	Yes	No
Jaundice	Yes	No
Hydration	Yes	No

CARDIO VASCULAR SYSTEM

Pulsebeats/min Blood pressure
Heart sounds S.O.A. Yes No
(describe)

RESPIRATORY SYSTEM

Respiratory ratebreaths/min
Breath sounds Yes No
Wheeze Yes No
Tachypnoea Yes No
Additional sounds Yes No
(describe).....

ABDOMEN

Masses	Yes	No
Liver	Yes	No
Spleen	Yes	No
PR indicated	Yes	No
Results		

CENTRAL NERVOUS SYSTEM – It is often difficult and not relevant to perform a full neurological examination, however, people with a learning disability are particularly prone to abnormalities

in vision, hearing and communication – a change in function would suggest further investigation is necessary

VISION

Normal vision	Minor visual problem	Major visual problems
Is the carer/key worker concerned?	Yes	No
When did the patient last see an optician?/...../.....	
Is there a cataract?	Yes	No
Result of Snellen chart		
Any other data		

HEARING

Normal hearing	Minor hearing problem	Major hearing problem
Is the carer/ key worker concerned?	Yes No	
Does he/she wear a hearing aid?	Yes No	
Any wax?	Yes No	
Does your patient see an audiologist?	Yes	No
Other investigation		

COMMUNICATION

Does your patient communicate normally?	Yes	No	
Does your patient communicate with aids?	Yes	No	
Does your patient have a severe communication problem?	Yes	No	No
Does your patient see a speech therapist?		Yes	No

MOBILITY

Is your patient fully mobile?	Yes	No
Is your patient fully mobile with aids?	Yes	No
Is your patient immobile?	Yes	No
Has immobility been assessed?	Yes	No

DERMATOLOGY

Any abnormality?	Yes	No
Diagnosis		

BREAST

Any lumps?	Yes	No
Any discharge?	Yes	No
Nipple retraction?	Yes	No

OTHER INVESTIGATIONS

Are there any further investigations necessary?	Yes	No
If yes please indicate		

SYNDROME SPECIFIC CHECK - Certain syndromes causing learning disabilities are

associated with increased morbidity (information can be found in the education pack provided) for this

reason it is important to record:

Is the cause of learning disability known?	Yes	No
If yes, what is it?		

Has the patient had a chromosomal analysis?	Yes	No
Result?		

Is the degree of learning disability?

	mild	moderate	severe	profound
Is a formalised IQ test available?			Yes	No

If yes, what were the results?

If your patient has Down's syndrome he/she should have a yearly test for hypothyroidism.

Has this been done?	Yes	No
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OTHER MEDICATION

Drug	Dose	Side effects	Levels (if indicated)

THANK YOU

APPENDIX 6

Devon Primary Care Trust and Devon Adult and Community Services - NHS Continuing Health Care Agreement and Operational Protocols for NHS Continuing Healthcare

Purpose	<p>Devon Primary Care Trust intends to exercise its legal duties in relation to NHS Continuing Health Care through its contractual framework with service providers. This Protocol applies to all service providers setting out the requirements of those organisations in relation to NHS Continuing Health Care. It has been agreed with Devon Adult and Community Services.</p> <p>This protocol relates to individuals of 18 years and over who may be eligible for NHS Continuing Health Care. It addresses:</p> <ul style="list-style-type: none">• the processes for determining eligibility for NHS Continuing Health Care in Devon• the roles and responsibilities of key health and social care staff• how Devon Primary Care Trust will arrange and fund care in a way that reflects the choices and preferences of individuals and balances the need for the Primary Care Trust to commission safe and effective care that makes best use of its resources <p>The application of this protocol will provide transparency and consistency in decision making in order to ensure that decisions taken:</p> <ul style="list-style-type: none">• are robust, fair, consistent and transparent• are based on the objective assessment of the individual's clinical need, safety and best interests• have regard for the safety and appropriateness of care packages to those involved in care delivery• involve the individual and their family wherever this is possible• take into account the need for the Primary Care Trust to allocate its financial resources in the most cost effective way• support choice to the extent possible in the light of the above factors <p>This agreement will be effective from 1st August 2008. It must be used within the context of the principles and guidance in the National Health Service Continuing Healthcare National Framework implemented on 1st October 2007.</p> <p>The following organisations have agreed the protocol and will jointly review it in 12 months:</p> <p>Devon Primary Care Trust Devon County Council</p> <p>Signed :</p> <p>Date:</p>
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1. Context	
	In June 2007 the Department of Health published a National Framework for NHS Continuing Healthcare and in October 2007 issued Directions making the National Framework and associated tools mandatory for health and social care. This framework applies to all adults over 18 years.
Definition for NHS Continuing Health Care	<p>"NHS Continuing Healthcare" means a package of care arranged and funded solely by the health service for a person aged 18 or over to meet physical or mental health needs which have arisen as a result of disability, accident or illness.</p> <p>Individuals assessed as having a <i>primary health need</i> are eligible for NHS Continuing Health Care and are entitled to have that care provided by the NHS. Individuals not eligible for NHS Continuing Health Care are entitled to an assessment by adult social care. Eligibility for social care services is determined using Fair Access to Care Services eligibility criteria. Individuals not eligible for NHS Continuing Health Care may be eligible for NHS-funded Nursing Care from the Primary Care Trust. The framework precludes joint funding of NHS Continuing Health Care cases.</p>
Key National Documents	<p>The key documents relating to the National Framework are:</p> <ul style="list-style-type: none"> • the National Framework for NHS Continuing Healthcare and NHS funded nursing care June 2007 • the Decision Support Tool September 2007 • the Fast-Track tool September 2007 • the Checklist September 2007 • the NHS-funded Nursing Care Practice Guide October 2007 • the National Health Service (Nursing care in Residential Accommodation)(England) Directions 2007 • the Delayed Discharges (Continuing Care) Directions 2007 • the NHS Continuing Healthcare (Responsibilities) Directions 2007
Web Address	<p>All the above are available at the Department of Health web-pages via this link: http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/index.htm</p> <p>The Department of Health FAQs pages on NHS Continuing Health Care are at: http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH_079276</p>

2. Legal Context	
Joint Duties	<p>The National Framework sets out the main responsibilities for the NHS and Local Authorities in respect of NHS Continuing Health Care and explains the influence of key court cases.</p> <p>In accordance with current legislation and the National Framework, access to and eligibility for an assessment must be based on an individual's needs and not their current legal status, current funding arrangements or anticipated funding outcomes.</p>
NHS Duties	<p>The Primary Care Trust is responsible, in consultation with the Local Authority, for deciding whether the assessed needs of an individual require the provision of health care services.</p> <p>The NHS Act 2006 requires that the Primary Care Trust promotes a comprehensive health service on behalf of the Secretary of State and that it does not exceed its financial allocation.</p> <p>The Primary Care Trust must take reasonable steps to ensure that an assessment for NHS Continuing Healthcare is carried out in all cases where it appears to the Primary Care Trust that there may be need for such care.</p> <p>The duties of the Primary Care Trust are set out in sections 2 of the NHS Continuing Healthcare (Responsibilities) Directions 2007 and the Delayed Discharges (Continuing Care) Directions 2007.</p> <p>In summary the Primary Care Trust must ensure that:</p> <ul style="list-style-type: none"> • a NHS Continuing Health Care assessment is carried out where it appears to the Primary Care Trust that there may be a need for such care • the individual and, where appropriate, carers and friends are consulted • a Multi-Disciplinary Team undertakes an assessment • the Decision Support Tool is completed following the assessment • the completed Decision Support tool is used to inform the decision as to whether the individual has a primary health need • the decision is recorded and shared with the individual and / or family / carers where appropriate. • where an individual is not found eligible, to advise the individual of the rights for review of the decision.
Acute Trust Duties	<p>Acute Trusts must consider whether a person may be eligible for NHS Continuing Health Care and, if it considers there is a need for such care, take all reasonable steps to ensure that an assessment is carried out before making a referral to the Local Authority under s2 Community Care (Delayed Discharges etc) Act 2003.</p>

Local Authority Duties	<p>The National Framework sets out the legal duties for the Local Authority and is an important source of information. Each Local Authority will:</p> <ul style="list-style-type: none"> • assess a person who appears to be in need of community care services (community care services include residential accommodation, domiciliary and community-based services for persons who by reason of age, illness or disability are in need of care and attention <i>which is not otherwise available to them</i>) • decide if a person's needs require provision of community care services • notify the relevant Primary Care Trust if it becomes apparent that the person has needs which may fall under the National Health Service Act 2006, and invite them to assist in the making of the assessment (see section 47(3)(a) of the National Health Service and Community Care Act 1990)
Fair Access to Care Services	<p>Fair Access to care services guidance can be accessed via : http://www.devon.gov.uk/index/socialcare/assessment-and-eligibility/facs-policy-adults.htm</p>
Primary Health Need Concept	<p>To assist in deciding which treatment and other health services it is appropriate for the NHS to provide under the National Health Service Act 2006, and to distinguish between those and the services which Local Authorities may provide, under section 21 of the National Assistance Act 1948, the Secretary of State has developed the concept of “a primary health need”. Where a person’s primary need is a health need, the NHS is regarded as responsible for providing for their needs and so they are eligible for NHS Continuing Healthcare. The decision as to whether this is the case should look at the totality of the relevant needs. The following characteristics of need and their impact on care may help in the determination:</p> <ul style="list-style-type: none"> • Nature: the type of needs, and the overall effect of those needs on the individual, including the type (“quality”) of interventions required to manage them • Intensity: both the extent (“quantity”) and severity (degree) of the needs, including the need for sustained care (“continuity”) • Complexity: how the needs arise and interact to increase the skill needed to monitor and manage the care • Unpredictability: the degree to which needs fluctuate, creating difficulty in managing needs, and the level of risk to the person’s health if adequate and timely care is not provided <p>Each of these characteristics may, in combination or alone, demonstrate a primary health need, because of the quality and/or quantity of care required to meet the individual’s needs.</p>
Consents	<p>Consent should be obtained from the individual being assessed including confirming whether they are willing for other family members or representatives to</p>

	be involved. Asking about consent, and recording the outcome, is embedded in the Devon health and social care assessment documentation and processes.
Mental Capacity Act	Guidance in relation to persons who lack capacity to consent can be found in the National Framework. The Mental Capacity Act (MCA) 2005 is now in force, requiring full involvement of individuals in the decisions that affect them, whether or not they have the mental capacity to make the decisions themselves. Further details of the MCA and MCA code of practice are available via this link: http://www.devon.gov.uk/mentalcapacityact.htm
What to do if an Individual Cannot Make an Informed Choice?	If an individual does not have the capacity to make an informed choice the most cost effective, safe care available will be delivered based on an assessment of best interests and in conjunction with any advocate, close family member or other person who should be consulted under the terms of the Mental Capacity Act 2005.
Section 117	<p>A patient who has been detained under Section 3 of the Mental Health Act 1983 will be eligible for Section 117 aftercare until they are discharged from their aftercare.</p> <p>Section 117 is a freestanding duty that is distinct from the Primary Care Trust's obligations to provide NHS Continuing Health Care.</p> <p>Nothing in Section 117 gives a local authority power to provide services which would otherwise be the responsibility of the NHS. This means that the application of the National Framework for NHS Continuing Health Care ("Continuing Health Care") remains relevant as a means of determining whether the aftercare provided should be funded by the Primary Care Trust or the Local Authority.</p> <p>If a person in need of aftercare is assessed as eligible for Continuing Health Care then the Primary Care Trust will be responsible for the full aftercare package i.e. both health and social care. This guidance can be used to determine S117 funding but will be paid from budgets as currently no S117.</p> <p>If a person in need of aftercare is not eligible for NHS Continuing Health Care then the Individual becomes the joint responsibility of the NHS and Local Authority for the provision of after care services until such time as they are satisfied that the person is no longer in need of such services.</p> <p>There are no powers for the Local Authority to charge for services arranged or provided under s117.</p>
Joint or Transferred Arrangements	<p>Individuals subject to joint or transferred arrangements e.g. S75 NHS Act 2006 (previously S31 Health Act 1999) or S256 NHS Act 2006 (previously S28a NHS Act 1977) are entitled to an assessment to determine their primary need in the same way and with the same priority as individuals not subject to those arrangements.</p> <p>This operational guidance excludes:</p> <ul style="list-style-type: none"> • individual Patient Placements placements – see separate criteria • placements where treatment is the primary purpose

3. Individual Choice / Preferences and Patient Safety	
When might choice, preferences and patient safety arise?	<p>This section should be used to inform practice and decision making where an individual wishes to exercise choice in relation to where or how their care is arranged. It covers both community and care home settings. It will be of particular use where for example:</p> <ul style="list-style-type: none"> • an individual wishes to have their care needs met in their own home and the complexity of care and associated risks and safety raise serious concerns about the viability of doing this • an individual wishes to have their care needs met in their own home and the cost to do so exceeds the cost of meeting those needs in a care home • an individual chooses a care home that is more expensive than the Primary Care Trust would normally expect to pay to meet the needs and risks of the individual the individual's assessed needs for care and support
General Considerations for Decision-Making Regarding Choice, Preferences and Safety	<p>In arranging care to meet the assessed needs of an individual the Primary Care Trust must be mindful of its overall responsibilities to provide health care for the whole population within its available resources.</p> <p>The Primary Care Trust must demonstrate that it has:</p> <ul style="list-style-type: none"> • acted fairly and reasonably in the particular circumstances • not imposed a <i>fixed limit</i> on the cost of care • considered each individual according to the assessment facts • met the individual's needs within available resources <p>The decision about whether to arrange community or care home based care must be a rounded one based on the balance between sustainability of the package of care, safety for individuals, their families and service provider(s), the cost of the care and an individual's preference. This will require the Primary Care Trust considering the proposed package taking into account the individual's assessed needs, the acceptable standards of living, the nature and extent of the needs and the relative cost balanced against the relative benefit and relative need for that benefit.</p> <p>The consideration of the needs of the individual must be a consideration of that individual's total needs. In addition to a person's healthcare needs this must include a review of the psychological and social needs and the impact on the home and family life</p> <p>Cost alone cannot be used in the first instance to deny community based care packages. Cost parameters may be used as a guide but must <i>not</i> be applied rigidly.</p>
NHS Obligations	The NHS does not have an absolute obligation to meet individual choice and preferences and is not subject to specific directions on choice of accommodation

	<p>in the same way as the Local Authority. The Choice Directive on accommodation is not binding on the Primary Care Trust in the same way as the Local Authority.</p>
<p>“Reasonable” requirements</p>	<p>The Primary Care Trust is obliged to arrange or provide services that it considers necessary to meet all <i>reasonable</i> requirements. In the context of <i>care homes</i> for NHS Continuing Health Care the Primary Care Trust is obliged to provide for the cost of providing accommodation, care and support necessary to meet the assessed needs of the individual. The Primary Care Trust is not obliged to provide for the cost of providing accommodation if the individual is living in the <i>community</i> but it should fund services that are required directly as a result of the individual's health need.</p> <p>The Primary Care Trust is not obliged to fund services of a domestic or family nature e.g. cleaning, gardening, cooking, childcare simply because, due to the patient's health need, the patient is no longer able to fulfil those requirements themselves.</p>
<p>Considerations for Arranging Care in a Person's Own Home</p>	<p>Devon Primary Care Trust will take account of the following issues when considering a request to deliver a complex care package in a person's own home:</p> <ul style="list-style-type: none"> • Care can be delivered safely to the individual. This will take account of risks to the individual, the staff or other people living in the house. A formal risk assessment will be undertaken by a trained person to determine risk and safety issues. The risk assessment will include: <ul style="list-style-type: none"> ○ the availability of equipment including telehealth and telecare and home adaptations ○ the appropriateness of the physical environment ○ the availability of appropriately trained carers and/or staff to deliver care when it is required • the acceptance by the Primary Care Trust and those involved in providing the individual's care of any identified risks • the individual's acceptance of the risks and potential consequences of receiving care • the individual or his/her family and/or carers agreement to comply with the steps required to minimise such identified risks to those involved • the individual's General Practitioner agrees to provide primary medical support • it is the individual's preferred choice • the suitability and availability of alternative arrangements • the extent of an individual's needs • the cost of providing the care at home in the context of best value and the costs of usual care

	<ul style="list-style-type: none"> • the cost effectiveness, clinical effectiveness and quality of care that can be provided • the relative cost of providing the package of choice considered against the relative benefit • the psychological, social and physical impact on the individual • the individual's human rights and the rights of their family and/or carers including the right of respect for home and family life • the willingness and ability of family members or friends to provide elements of care where this is a necessary/desirable part of the care plan and the agreement of those persons to the plan • a full range of options for care have been considered in partnership with the individual and their family carer as appropriate. This should include clear written evidence that individual choices, safety and risks have been fully discussed • how care and support is arranged to address individuals needs relating to age, gender, ethnic group, religion, disability, culture, disability and/ or personal relationships
<p>Considerations for Arranging Care in a Care Home</p>	<p>Whilst the Choice Directive is not binding on the Primary Care Trust, the emphasis on individual choice is good and reasonable practice. When considering whether a less expensive care home is a genuine alternative to a more expensive placement the Primary Care Trust should consider the following:</p> <ul style="list-style-type: none"> • the individual's wishes and/or that of their family/carer • the psychological, social and physical impact on the individual • the availability of alternative care home placements • the suitability of the option of choice and the proposed alternatives • the location of the alternative care home – proximity to individual's home, family and other support networks • potential risk to the individual's health if changes are made to current arrangements • practical and legal issues resulting if a person refuses to move
<p>Top Up Fees and Optional Extras</p>	<p>All NHS Health Care is free at the point of delivery; where an individual has been assessed as eligible for NHS Continuing Health Care there is no provision for “top-up” fees for individual contributions to fund assessed needs. However, a person does have the right to decline NHS services and make their own private</p>

	<p>arrangements if they wish to do so. Where a person has been assessed as eligible for NHS Continuing Health Care they cannot chose not to accept the decision and return to Local Authority/NHS-funded nursing care funding.</p> <p>Individuals can choose to pay a first party or third party top up but only for <i>optional extras</i>. Optional extras include non essential services which a care home resident has chosen but was not obliged to include in their care package to meet their assessed needs and risks. The NHS must assure itself that these services are non essential to the care and support of the individual and that they do not fall within its statutory responsibilities given the circumstances of the individual case.</p>
Right of Appeal	The appeal process set out in the National Framework and local policy is applicable if the patient wishes.
4. Referrals and Assessment	
	<p>Where, following assessment or review, health or social care staff consider an individual may have a primary health need the following process should be followed.</p> <p>This section should be read alongside Single Assessment Process/Care Programme Approach guidance.</p> <p>In this context integrated teams are Complex Care Teams (Older People/ Older People Mental Health/Long Term Conditions/Physical Disability/Sensory), Network team (Adult Mental Health), integrated joint teams (Learning Disability).</p>
What is the Multi Disciplinary Team?	A “multi-disciplinary team” is defined in the Directions as consisting of at least two professionals from different healthcare or social care backgrounds. Typically this will be a nurse and a case manager, but should extend to those professionals involved in the care of the individual and must include the views of the individual and or their family / appointed representative where appropriate.
How to Refer for a Multi Disciplinary Team Health Needs Assessment	<p>All normal referral routes apply. Where following the completion of a Single Assessment Process contact assessment and NHS Continuing Health Care Needs Checklist it is considered that a Multi Disciplinary Team Health Needs Assessment is required, a referral shall be made to the Multi Disciplinary Team. The referral should include as a minimum:</p> <ul style="list-style-type: none"> • Single Assessment Process contact assessment • NHS Continuing Health Care Needs Checklist • a request for a Multi Disciplinary Team Health Needs Assessment to ascertain whether the individual has a primary health need • confirmation of whether a fast track assessment is required • confirmation that the complex care team has communicated with the individual/family the outcome of its assessments and the decision to refer the individual to the Multi Disciplinary Team

	<p>Where other Single Assessment Process /Care Programme Approach or other specialist assessments have been completed these should be shared with the relevant integrated team.</p> <p>Please refer to Panel Guidance for details of next steps</p>
Integrated Teams	Staff who work in an integrated health and social care team should nominate one member of the team to lead and co-ordinate on behalf of the Multi Disciplinary Team team, the assessment, monitoring and review the processes.
Deciding on the case Manager	<p>This team member will be referred to as the <i>case manager</i> and should be chosen on the basis of being the most appropriate person to undertake this role – not on the basis of organisational or professional boundaries. It is a requirement that:</p> <ul style="list-style-type: none"> • everyone being assessed/reviewed for Continuing Health Care requires a case manager • the case manager could be employed by the NHS or Adult and Community Services • where Adult and Community Services staff undertake this role there MUST be a named health worker in place to contribute to the assessment, monitor and review as required by the case manager
What is the Role of the Case Manager?	<p>The case manager will ensure:</p> <ul style="list-style-type: none"> • the Health Needs Assessment is completed as part of the Multi Disciplinary Team assessment - building on assessment information that is already recorded to avoid duplication and ensure proportionate practice. The health worker will play a key role in the assessment, monitoring and review of individuals • the Decision Support Tool is completed by the health care worker • co-ordination of specialist assessments as identified by the Multi Disciplinary Team • communication with the individual/family • a recommendation is made to the relevant manager • where required the Joint Agency Panel is sent the relevant documentation as set out in the Panel process • arrange NHS directly provided services where this is the agreed plan
What is the Health Needs Assessment?	<p>The Health Needs Assessment <i>is not</i> a decision making tool to determine eligibility for NHS Continuing Health Care. It is part of the Multi Disciplinary Team assessment which comprehensively evidences an individual's total health and social care needs.</p> <p>The Health Needs Assessment should detail both physical and psychological</p>

	<p>needs, the specific interventions needed to meet them and whether these interventions should be carried out by a professional, a formal carer or an informal carer</p> <p>To ensure proportionate assessment practice and to avoid duplication of users / patients, staff should use the Health Needs Assessment to build on the overview / Care Programme Approach / specialist assessments. If the information is already recorded, that information should be cross referenced and not repeated within the Health Needs Assessment domains.</p>
What are the Outcomes of the Assessment?	<p>The outcomes of an assessment are:</p> <ul style="list-style-type: none"> • the individual has a primary health need and remains eligible for NHS Continuing Health Care • the individual does not meet the criteria for NHS Continuing Health Care. The Primary Care Trust may still have a responsibility to effectively contribute to that person's health needs and should assess whether the individual is eligible for NHS-Funded Nursing Care in accordance with the NHS-Funded Nursing Care Practice Guide (DoH, 2007) • the needs are within the power of the Local Authority. In these circumstances they may be offered social care services, subject to Fair Access to Care services, which may result in means-tested charges being applied, or they may self-fund <p>The Practice Manager/Team Leader will also be responsible for agreeing Adult & Community Services packages within the banded rates for care homes and their authorised, delegated levels for all other cases.</p> <p>All Continuing Health Care cases will be authorised via the Panel Process. Fast Track cases are the exception to this.</p> <p>See separate Panel Guidance.</p>
Joint Health and Social Care Panels	<p>Please refer to separate Panel Guidance.</p> <p>The Practice Manager and Community Matron (Older People/Physical Disability) and the Team Leaders (Adult Mental Health and Learning Disability) are responsible for assuring the quality of assessment and decision-making of the Multi Disciplinary Team.</p> <p>Once Panel authorisation has been agreed, the Multi Disciplinary Team will then arrange for the care package to be procured as set out below.</p>
5. Care Plan and Procuring	<p><i>This section must be used alongside the Devon Primary Care Trust Choice, Preferences and Patient Safety Policy and Operational Guidance.</i></p>
Who is Responsible for Arranging and	<p>When a person is assessed as eligible for NHS Continuing Health Care the Primary Care Trust is responsible for arranging appropriate care and ensuring case management support is provided to the individual. The case manager will</p>

Procuring Services?	undertake this role as set out.
Care Planning Responsibilities	<p>The case manager will undertake this role as set above.</p> <p>The care plan must establish the review date and be shared with the individual, service providers and others as required.</p>
Broker Service	<p>Devon Primary Care Trust has in place arrangements with Devon County Council for a broker service to arrange and procure services to meet the needs of individuals eligible for NHS Continuing Health Care (the "Broker Service").</p> <p>Devon Primary Care Trust and Adult and Community Services have agreed:</p> <ul style="list-style-type: none"> • the Broker Service will be used to procure and arrange services from the 3rd and independent sectors on behalf of the Primary Care Trust using agreed prices/pricing tool • there will be a standard broker service and a personal broker service • the Broker will enter into contracts with the service providers using the Primary Care Trust agreed contract format unless otherwise agreed • the Broker will send all relevant details to the service provider including a copy of the care plan and assessments • case details and review dates will be held on Care First 6 • invoices and Payment to providers will be made through the Local Authority payment system <p>Note: the Broker service will not arrange NHS directly provided services. This is the role of the case manager.</p>
What Details are Sent to Broker?	The assessment and care plan must be sent to the Broker service for services to be procured on behalf of the Primary Care Trust. These forms will be shared with the service provider.
When to use the Broker Service	<p>Where care is arranged with independent and / or third sector service providers it will be arranged through the <i>Broker Service</i>. <i>Such care must not be arranged in any other way. Clinical staff must not directly arrange care with providers other than in exceptional circumstances such as end of life care and other Fast Track situations.</i></p> <p>The <i>standard</i> Broker Service will arrange care where this is a call off a block contract or pre placement agreement. This can be for community based or care home services.</p> <p>The <i>personal</i> Broker Service will arrange services where there is no fixed price contract (no block contract or pre placement agreement). This may be community based or care home services.</p>

NHS Direct Provider Services	<p>Where there is a mix of care between the NHS directly provided services such as Primary Care Trust provider, NDHT or Devon Partnership Trust, the case manager will arrange the NHS directly provided services and refer to the Broker Service to arrange the independent and third sector services.</p> <p>End of life care will be arranged in this most timely manner taking account of the individual's circumstances.</p> <p>The limits to care packages as described below must be adhered to in both these circumstances.</p>
Broker Service Guidance	<p><i>The following is a guide only for staff and not to be rigidly applied.</i></p> <p>Each case must be assessed on the basis of its individual needs, risks, patient safety and expressed choices/preferences.</p>
Arranging Fixed Price contracts	<p>For care homes where there is a fixed price contract the local authority banding system will be used. Where an individual's needs and risks are particularly complex an agreed tolerance level above this banding rate may be applied. The outcomes of the Decision Support Tool should be used to inform decision-making on any additional funding above the banded rate.</p> <ul style="list-style-type: none"> • one domain recorded as severe, together with needs in a number of other domains, or • a number of domains with high and/or moderate needs <p>An additional 10% may be paid above the Local Authority band 3 Nursing Home rates where an individual has:</p> <ul style="list-style-type: none"> • a level of priority needs in any one of the four domains that carry this level; or • a total of two or more incidences of identified severe needs across all care domains
Arranging Community Based Packages	<p>As a guide the maximum weekly cost for the community based care packages should not exceed the cost of a care home per week using the above approach. However, decision making must be based on a combination of needs, safety and risks rather than on set cost caps.</p> <p>Where community based care packages are above the upper cost parameter guide this cannot be used to deny community based support in the first instance. Case managers will need to discuss all such cases with their manager.</p> <p>Any care packages above the upper cost parameter guide will require budget holder approval before they can be arranged. <i>The Broker Service must not accept such cases without the agreement of the case managers.</i></p> <p>The process of budget holder approval should not add delays to the care package being agreed and arranged.</p> <p>The case manager must record any differences of view and the service user/ representative must always be informed of their right to make a complaint/ appeal</p>

	<p>if they remain unhappy with the decision</p> <p>The cost of care arranged by the personal Broker Service will be determined on a case by case basis using the agreed process for this service.</p>
<p>Roles and Responsibilities</p>	<p><i>The Case Manager Must:</i></p> <ul style="list-style-type: none"> • involve, negotiate and agree with the individual and their family about issues of choice, safety and preferences in terms of where and how care is arranged. This is not a function of the Broker Service • ensure individuals and families are fully aware that individuals may not meet NHS Continuing Health Care criteria at subsequent reviews • co-ordinate assessments including specialist and risk assessments • arrange Devon Primary Care Trust and Devon Partnership Trust direct provided services • record outcomes of assessments, decisions and negotiations with family • liaise closely with the nominated health worker and ensure the assessment's risks are shared with them • set a review date • ensure the accountable manager - line manager and the Deputy Assistant Director for the relevant locality who has decision making authority -is fully briefed where individual choice is assessed as compromising patient or service provider safety or where the cost of doing so exceeds the general cost parameters set out in this policy • ensure the appropriate process for authorisation of spend is followed • provide the Broker Service with care plan, assessment details , panel requirements which should clearly set out where (care home/ community based) and how care is to be arranged, any special assessed needs or risks to individual or service provider that require consideration – without this, care cannot be arranged or costs agreed • undertake reviews – use <i>Devon NHS and Adult and Community Services Operational Protocols for NHS Continuing Healthcare</i> • enter all case details and assessment on to Care First 6 in a timely and accurate manner following agreed procedures <p>The Broker Service will:</p> <ul style="list-style-type: none"> • receive the care plan from the case manager • use the cost of a care home placement suitable to meet the assessed needs of

	<p>the individual as an indicative guide for setting up community based services unless the care plan clearly evidences and stipulates there are additional assessed needs that require additional care and support and this has been agreed by the Deputy Assistant Director</p> <ul style="list-style-type: none"> • use the banding system as set out above as an indicative guide for setting up care home placements • use the personal Broker Service approach for relevant cases • negotiate and arrange care with service providers • notify case manager of service providers or send 3 options to case manager of potential service providers for personal brokered services • input to Care First 6 • ensure individual/family/service providers have copy of care plan <p>Note: the broker service is not responsible for deciding on cost of care where this is outside the indicative guidance parameter or for negotiating with family</p>
<p>6. Review Process</p>	
<p>What are the Review Arrangements?</p>	<p>The first review of eligibility should be undertaken within 3 months and annually thereafter, or more frequently, if there is a significant change in the individual's health needs. Individuals with palliative care needs will have their care reviewed more frequently in response to their medical condition.</p> <p>The review will be undertaken using the Health Needs Assessment and any other specialist assessments as required.</p> <p>Where the case manager feels the person may no longer be eligible for NHS Continuing Health Care they will complete the checklist to support their decision making.</p> <p>The NHS responsibility to provide or commission care is based on the needs of the individual being primarily for healthcare and therefore is not indefinite. In some circumstances an individual's needs might change and therefore so might their eligibility for NHS Continuing Healthcare.</p> <p>The case manager must ensure that the individual and their family are clear that the reassessment can therefore lead to a change in how care is arranged and provided.</p>
<p>What are the Outcomes of a Review?</p>	<p>The review may result in either an increase or a decrease in support offered based on the assessed need of the individual at that time.</p> <p>The outcomes of a review are:</p> <ul style="list-style-type: none"> • the individual has a primary health need and remains eligible for NHS

	<p>Continuing Health Care</p> <ul style="list-style-type: none"> the individual's condition may have improved or stabilised to such an extent that they no longer meet the criteria for NHS Continuing Health Care. The Primary Care Trust may still have a responsibility to effectively contribute to that person's health needs and should assess whether the individual is eligible for NHS-funded Nursing care in accordance with the NHS-funded Nursing Care Practice Guide (Department of Health, 2007). If their needs are within the powers of the Local Authority, they may be offered social care services subject to Fair Access to Care Services, which may result in means-tested charges being applied or they may self fund care <p>Where a review, together with the completed Checklist, indicates the individual may no longer be eligible for NHS Continuing Health Care the case manager will confirm their findings with the nominated health worker. If it is agreed that the person is no longer eligible for NHS Continuing Health Care they will refer the person for a NHS-funded Nursing Care assessment and community care assessment unless this has already been undertaken jointly as part of the review.</p> <p>The specialist nurse assessors within the NHS Continuing Health Care team will moderate random selected review cases and quality assure selected cases.</p>
<p>Withdrawal of Care</p>	<p>Where a review is carried out on an individual receiving NHS Continuing Health Care in their own home and the review determines that the package of care is no longer feasible then an alternative package will be discussed and agreed.</p> <p>There may occasionally be circumstances where the individual declines to accept alternative suitable provision and a suitable package acceptable to the individual and the Primary Care Trust cannot be identified. This may result in the Primary Care Trust issuing a <i>Withdrawal of Care Notice</i> where safety of the individual and/or those people involved in providing care is likely to be compromised without such action or a material increase in support is required and, as a result of this increase, the Primary Care Trust considers that the cost of providing the care in the individual's home is no longer appropriate.</p> <p>Where the review identifies, or the Primary Care Trust otherwise becomes aware that an action to reduce risks to the service or the individual has not been observed and such failure may put those individuals providing care at risk or may significantly increase the cost of the package then the Primary Care Trust will take the necessary steps to protect the individual and staff involved with a view to ensuring the safety of all concerned. This may result in the Primary Care Trust issuing a <i>Withdrawal of Care Notice</i> where safety is likely to be compromised without such action.</p>
<p>7. The Department of Health Tools Fast-Track Pathway</p>	
<p>What is Fast Track tool?</p>	<p>The Fast Track tool should be used for those individuals who have a rapidly deteriorating condition, which may be in a terminal phase, with an increasing level of dependency. It is for use within the guidance of the National Framework for NHS Continuing Healthcare.</p>
<p>Who can</p>	<p>The tool may be used by a senior clinician such as a ward sister, Consultant or</p>

<p>Complete it?</p>	<p>GP, the relevant consultant or nurse specialist/consultant to outline the reasons for the fast tracking decision. This may be supported by a prognosis if available, but strict time limits are not relevant for end-of- life cases and the responsibility rests with the assessor to make a decision based on the relevant facts of the case.</p> <p>It can be used in any setting and its purpose is to fast track an individual for NHS Continuing Healthcare provision.</p>
<p>What Should be the Outcome of the Fast Track Assessment?</p>	<p>Correctly identified individuals who meet the Fast Track requirements should receive the care they need without delay. They may need NHS Continuing Healthcare funding to enable their needs to be urgently met (e.g. to allow them to go home to die or to allow appropriate end of life support to be put in place). The Fast Track Tool needs to be accompanied with the personal information section of the contact assessment.</p> <p>A full assessment should follow as appropriate. In most cases the Primary Care Trust will fast track these individuals care, however if there is disagreement between the statutory agencies please refer to the “Without Prejudice” section.</p>
<p>8. NHS Continuing Health Care Needs Checklist</p>	
<p>What is the Checklist?</p>	<p>The Checklist is a Department of Health tool to help health and social care staff identify individuals who may be eligible for NHS Continuing Health Care and to decide whether there is a need for a comprehensive Multi Disciplinary Team and Health Needs Assessment.</p>
<p>Who/when should it be completed?</p>	<p>It can be used by a variety of people in a variety of settings. The checklist can be used by hospital discharge, a nurse in an individual’s home, and Adult Social Services workers carrying out a Community Care Assessment.</p> <p>For example:</p> <ul style="list-style-type: none"> • where an individual has been assessed, or is being funded by Adult and Community Services either in a care home or their own home • where the NHS currently funds an individual and a review of their needs indicates that they may no longer be entitled to NHS funding • when planning hospital discharge <p>Referral for consideration for NHS Continuing Health Care is not an indication of the outcome.</p> <p>This should be clearly communicated to individuals and their representatives by the person completing the checklist.</p> <p>Whoever uses the Checklist needs to be familiar with it and be aware of the principles set out in the National Framework.</p>
<p>What are the Outcomes of Completing the</p>	<p>For all new cases a full consideration for NHS Continuing Health Care will be undertaken if:</p>

<p>Checklist?</p>	<ul style="list-style-type: none"> • 2 or more ticks in A • 5 or more ticks in B • 1 tick in A and 4 in B • 1 tick in A on one of the boxes marked with an * <p>In these circumstances, a referral will be required to the integrated team for a Multi Disciplinary Team Health Needs Assessment assessment.</p> <p>For all reviews where any of the above are met the person will be deemed eligible for NHS Continuing Health Care.</p> <p>Where the above indicators have not been met a full consideration of NHS Continuing Health Care is not normally required</p>
<p>9. Decision Support Tool</p>	
<p>What is the Decision Support Tool?</p>	<p>The Decision Support Tool supports the application of the National Framework for NHS Continuing Healthcare and consistent decision making in line with the “<i>Primary Health Need Approach</i>”.</p> <p>It helps to set out the evidence in a detailed needs based format and clarifies the evidence used to make professional judgements and recommended outcomes. The tool should be applied following a comprehensive Multi Disciplinary Team assessment of an individual’s care needs.</p> <p>The Decision Support Tool is <i>not</i>:</p> <ul style="list-style-type: none"> • another assessment. It is a decision support tool applied against previous assessments • a decision <i>making</i> tool. Rather it supports professional judgement and decision making • a substitute for professional judgement
<p>Who Completes the Decision Support Tool?</p>	<p>The decision Support tool will be completed by a health care professional of the Multi Disciplinary Team who is <i>trained and skilled in the National Framework policy, the Devon Protocols and the Decision Support Tool national guidance</i>. This will have been agreed by the Multi Disciplinary Team at the start of the assessment.</p> <p>The lead nurses within Primary Care Trust NHS Continuing Care team will offer advice and guidance on the most complex cases. They will also provide mentoring for those who are using this tool for the first time and will set up moderation approach to assure consistency of approach.</p>
<p>Outcome of Decision Support Tool</p>	<p>The completed Decision Support Tool should result in the following:</p> <ul style="list-style-type: none"> • a Primary Health Need <u>is</u> established and the recommendation is for

	<p>NHS Continuing Healthcare</p> <ul style="list-style-type: none"> • a Primary health need <u>is not</u> established, however, NHS funded nursing care and social care needs are established • other Care needs identified and either the local authority or NHS or contribution from both organisations is required • the person will self fund their care. <p>The Decision Support Tool advises that eligibility for NHS Continuing Healthcare would be <i>expected</i> for anyone found to have:</p> <ul style="list-style-type: none"> • 1 Priority need in any domain, or • 2 or more Severe needs. <p>People <i>may</i> have a primary health need if they are found to have either:</p> <ul style="list-style-type: none"> • 1 Severe need together with needs in a number of other domains, or • a number of domains with high and/or moderate needs. <p>People with needs falling entirely in Low needs or No Needs are likely to be ineligible for NHS Continuing Healthcare.</p>
<p>Who Checks this?</p>	<p>The manager of the integrated team should check all the documentation to ensure the agreed processes have been followed and recommendations are clearly recorded and evidenced regarding eligibility for NHS Continuing Health Care.</p>
<p>What happens to the form?</p>	<p>A preliminary recommendation should then be recorded on the Decision Support Tool. The Decision Support tool should be sent to the joint agency panel together with relevant assessment documentation, and if completed, the Checklist. The joint-agency Panel have a decision-making function as to whether the person is eligible for NHS Continuing Health Care as they have a primary health need.</p>
<p>10. Joint Agency Panel</p>	
<p>The Decision Making Process</p>	<p>This section must be read alongside the Panel guidance and terms of reference.</p> <p>There will be 2 panels in Devon with a pre panel requirement at team level.</p>
<p>Pre Panel</p>	<p>For complex cases where Multi Disciplinary Team recommendation is for Continuing Health Care or for Adult and Community Services eligible cases for care home or equivalent cost community based packages there will be a team level pre panel screening. This will be undertaken by Community Matrons, Practice Managers and Team Leaders who are required to:</p> <ul style="list-style-type: none"> • review the evidence to support Multi Disciplinary Team recommendation about eligibility for either NHS or Adult and Community Services funded care

	<ul style="list-style-type: none"> • seek further clarification/assessments, if required, to support recommendations • evidence involvement of individuals, family, carers and key practitioners and clinicians as required • adult and Community Services Practice Managers will authorise all packages of care within their authorised levels and/or within care home banded rates for Broker Service to arrange • refer all Continuing Health Care cases to the Area Joint Panel once all above checks have been made
<p>Generic, Area Joint Agency Panel</p>	<p>Cases must have this level of scrutiny before referral to the Area Joint Agency Panel.</p> <p>There will be one for each of the 3 Areas (North/Torridge; South Hams/ West Devon/Teignbridge; Exeter/Mid/East)</p> <p>These panels will be held once per week and include a joint agency membership. Details will be input to CareFirst 6 direct and so there will be no separate recording processes for Panel.</p> <p>This Panel will be chaired by an AD or their Deputy. The purpose of the Panel will be:</p> <ul style="list-style-type: none"> • to validate the recommendations re FACS eligibility • to agree funding for Adult and Community Services funded cases that are beyond the authorisation levels of the Practice manager • to validate the recommendations re all Continuing Health Care eligibility • to agree funding for all NHS funded cases • to refer to county panel for funding decision for cases in excess of agreed price point or banding level • to ensure the individual family/carers are informed in writing of the outcome of Panel with clear rationale and a copy of the Decision Support Tool • to ensure MDT members are informed of the outcome of Panel <p>The Panel have the following eligibility decisions options available:</p> <ul style="list-style-type: none"> • eligible for NHS Continuing Health Care fully funded by Primary Care Trust • not eligible for NHS Continuing Health Care – fully funded by Adult and Community Services or self funder • not eligible for full NHS Continuing Health Care but for NHS Funded Nursing care and either Adult and Community Services funding or self funder

	<ul style="list-style-type: none"> • eligibility not agreed – refer to disputes resolution
Generic County NHS Continuing Health Care Panel	<p>There will be one county panel for NHS Continuing Health Care decision making about funding for these cases.</p> <p>This Panel level will be chaired by the Deputy Chief Executive of the Primary Care Trust</p> <p>The purpose of the panel will be:</p> <ul style="list-style-type: none"> • to agree funding for all NHS funded cases • to resolve disputes in conjunction with the Director of Adult and Community Services <p>Note: For cases to come to this level it is a requirement that managers have fully addressed and confirmed the eligibility for NHS Continuing Health Care. This panel will focus on funding requirements only.</p>
	<p><i>In accordance with the National Framework, paragraph 63, the decision-making should not exceed 2 weeks in most cases.</i></p> <p>In addition to the management role, Panel core membership will be:</p> <ul style="list-style-type: none"> • NHS Clinical lead for service area • ASC practice lead for service area • Primary Care Trust Lead nurse from NHS Continuing Health Care Team • Panel administrator
11. Disputes	
Dispute Resolution Process Between NHS and Adult and Community Services	<p>Devon Primary Care Trust and Adult and Community Services are committed to avoiding disputes wherever possible. Experience shows that commissioning additional assessments and carrying out, or reviewing the assessments jointly, through our integrated teams can resolve most differences.</p> <p>For cases where there is a dispute between NHS bodies or between Local Authority and Primary Care Trust about responsibility, the local dispute resolution process will be used. Disputes should not delay the provision of the care package. The protocol below sets out how funding will be handled during the dispute.</p> <p>Where the locality joint-agency Panel is unable to reach a decision or agreement in a case, the information should be referred to the Devon Resolution Panel. In this Panel, the Chief Executive and Director of Adult and Community Services will reach a conclusion about responsibility where Locality Panels have been unable to decide.</p> <p>For further details see Annex H – Resolution Panels</p>

<p>Dispute Resolution Process Between NHS and Individuals</p>	<p>Devon Primary Care Trust will deal promptly with any request to review decisions about eligibility for either NHS Continuing Healthcare or NHS-funded Nursing Care.</p> <p>The local resolution process will be to set up a Primary Care Trust review panel.</p> <p>Once local procedures have been exhausted, the case should be referred to the SHA.</p>
<p>Funding Arrangements for Disputed Cases</p>	<p>Devon Primary Care Trust and Adult and Community Services have agreed there should be no delay in the provision of services to individuals due to disagreements on the assessment recommendation or outcome of the decision on eligibility. There will be no unilateral withdrawal of existing funding arrangements without the agreement of the other party.</p>
<p>Living in Own Home</p>	<p>Anyone in their own home, or care home funded by the local authority must continue to be financially assisted by the Council until the dispute is resolved.</p>
<p>In Hospital / Funded by Primary Care Trust</p>	<p>Similarly, anyone in hospital, or funded by the Primary Care Trust must remain funded by the Primary Care Trust until the dispute is resolved.</p> <p>Devon Primary Care Trust and Devon Adult and Community Services agree to adopt a “Without Prejudice” approach to such situations whereby the final outcome of the dispute will be backdated to the time of the original funding request. This means that if the Council has continued to fund an arrangement that subsequently is decided to be NHS Continuing Healthcare, the Primary Care Trust funding should be backdated to the date that the Council gave notification to the Primary Care Trust and the individual should be reimbursed any charges that they have paid during this interim period.</p> <p>Similarly, where a Primary Care Trust has continued to fund an arrangement that subsequently is decided to have been a local authority responsibility, the Council will reimburse the relevant Primary Care Trust to the date of notification.</p> <p>Placements in care homes will be made within the current Local Authority banding levels. Third and first party top-ups cannot be entered into without the agreement of the Primary Care Trust because this could jeopardise subsequent contracting for care services.</p>
<p>12. Timeframes</p>	
<p>What is the Timeframe for Completing the Assessment and Decision Making?</p>	<p>Either following a new referral, or a review by either agency, which triggers the need to undertake a Health Needs Assessment this will be responded to within 3 working.</p> <p>The National Framework requires ‘<i>most decisions regarding eligibility for NHS Continuing Health Care funding will be made within 2 weeks</i>’ of the receipt of the original referral by the Primary Care Trust.</p> <p>Where this is not possible the Primary Care Trust will clearly advise the individual of the likely date that the decision will be made and this should not normally extend to more than <i>4 weeks</i>.</p>

	<p>Where this timeframe is exceeded the Primary Care Trust will record this on the Primary Care Trust risk register and ensure that the individual concerned is kept fully informed of the progress of the assessment and of their right to complain.</p>
<p>Performance Framework</p>	<p>Management information will be provided to Primary Care Trust SMT and Adult and Community Services SMG as set out in the performance requirements and will include financial as well as activity and outcome details. It will include key data requirements set out in this protocol.</p> <p><i>Reference detailed separate guidance</i></p>

Learning Disabilities: Quality and Outcomes Framework

Learning disability indicator 1 *Changes to the General Medical Services Contract 2008/09* 101 - Rationale for inclusion of indicator set

People with learning disabilities are amongst the most vulnerable and socially excluded in our society. It is estimated that there are approximately 20/1,000 people with mild learning disabilities and 3-4/1,000 people with severe and profound learning disabilities in the UK. Over the past three decades, almost all the long stay beds for people with learning disabilities have closed, and virtually all patients with learning disabilities are now living in the community and depend on GPs for their primary health care needs.

Learning Disability 1.1 Rationale

The idea of a learning disability register for adults in primary care has been widely recommended by professionals and charities alike (See *Treat Me Right*, Mencap, 2004; www.mencap.org.uk). The creation of a full register of patients aged 18 years and over with learning disabilities will provide primary care practitioners with the first important building block in providing better quality and more appropriate services for this patient population.

Learning disability is defined in *Valuing People* (and 'The Same as You') as the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood (18 years), with a lasting effect on development.

The definition encompasses people with a broad range of disabilities. It includes adult with autism who also have learning disabilities, but not people with a higher level autistic spectrum disorder who may be of average or above average intelligence. The presence of an Intelligence Quotient below 70, should not, in isolation, be used in deciding whether someone has a learning disability. The definition does not include all those people who have a "learning difficulty".

For most people, there is no difficulty in reaching a decision whether they have a learning disability or not. However, in those individuals where there is some doubt about the diagnosis and the level of learning disability, referral to a multidisciplinary team may be necessary to assess the degree of disability and diagnose any underlying condition. Local learning disability teams have expanded and these, working along with Primary Care Organisations, have provided expertise and data about and for people with learning disabilities. Learning Disabilities nurses from the community learning disability team are thus likely to know the names of patients and the practice with whom they are registered and may also be able to assist in the construction of a primary care database (see Martin and Martin. *Journal of Learning Disabilities*, 2000; 4(1): 37-48).

Learning Disability 1.2 Reporting and Verification

Practices report the number of patients aged 18 years and over on its learning disability register and the number of patients with learning disabilities as a proportion of total list size.

Further information:

Valuing People: a new strategy for learning disability in the 21st century. London, Department of Health, 2001.

www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf

'The Same as You?' Scottish Executive (2000)

www.scotland.gov.uk/topics/health/care/VAUnit/TheSameasyou

NHS Health Scotland; *Health Needs Assessment Report: People with Learning Disabilities in Scotland* (2004)

www.healthscotland.com/uploads/documents/LD_summary.pdf

Northern Ireland Strategy on Learning Disability

www.rmhdni.gov.uk/ *Learning Disability Strategy Section 7 Guidance on Service Principles and Service*

Responses, Welsh Assembly Government, 2004

www.wales.nhs.uk/sites3/Documents/480/SP_response_guide-e.pdf

www.bild.org.uk/05downloads.htm#bfs

Public Health Institute of Scotland's Autistic Spectrum Disorder: Needs Assessment Report (2001) www.scotland.gov.uk/Publications/2006/02/28094616/0

Devon Primary Care Trust Directed Enhanced Service Specification - Learning Disabilities

Introduction

1. There is good evidence that patients with learning disabilities have more health problems and die at a younger age than the rest of the population.
2. The existing Quality and Outcomes Framework registers do not differentiate Learning Disability by severity. There are estimated to be 240,000 people with moderate to severe Learning Disabilities in England known to social services. The Directly Enhanced Service is designed to encourage practices to identify those patients with moderate to severe Learning Disability as defined by the same criteria used by the local authority.
3. The pre-requisites for taking part in the Directly Enhanced Service are as follows:
 - practices will have liaised with the Local Authority to share and collate information, in order to identify the people on their practice Learning Disability register with moderate to severe learning disabilities
 - a practice providing this service will be expected to have attended a multi-professional education session (refer to paragraphs 13 to 15 for further information). The minimum expectation of staff attending will include the lead general practitioner (GP), lead practice nurse and practice manager/senior receptionist. Practices may also wish to involve specialist Learning Disability staff from the community learning disability team to provide support and advice.
4. The total investment available for this two-year Directly Enhanced Service in England is £22m per year for 2008/09 and 2009/10.

Details of the Directly Enhanced Service :

5. Practices will be expected to provide an annual health check to patients on the local authority Learning Disability register. Practices are recommended to use the Cardiff health check protocol or a protocol as agreed locally with the Primary Care Trust.
6. Further information on the Cardiff Protocol is available at:
http://www.rcgp.org.uk/PDF/clinical_Welsh_Health_Check_newA.pdf
7. As a minimum, the health check should include:
 - a review of physical and mental health with referral through the usual practice routes if health problems are identified:
 - health promotion
 - chronic illness and systems enquiry
 - physical examination

- epilepsy
 - behaviour and mental health
 - specific syndrome check
 - a check on the accuracy of prescribed medications
 - a review of coordination arrangements with secondary care
 - a review of transition arrangements where appropriate
8. Health checks should integrate with the patients' personal health record or health action plan. Where possible, and with the consent of the patient, this should involve carers and support workers. Practices should liaise with relevant local support services such as social services and educational support services in addition to learning disability health professionals.

Payment and Validation:

9. Payment will be based on a report to the Primary Care Trust at the end of each year (31 March) on the number of patients on the health check register who have received the health check. *Prior to that date, the Primary Care Trust will require notification from Practices of forecasted 08/09 annual activity costs (by end of February each year) to ensure that payment can be processed by 31st March. Practices will receive balancing payments in April.*
10. Once a practice has agreed the health check Learning Disability register with their Primary Care Trust, it will receive a £50 aspiration payment for each patient on the register.
11. The reward for each health check will be £100.
12. The cost of aspiration payments will be deducted from payments made for the health checks. If practices do not complete enough health checks to fund the full cost of their aspiration payment, the Primary Care Trust will recover any overpayment made as result, in line with normal practice.

Multi-Professional Education Session – Training for Primary Healthcare Staff:

13. Further information regarding training for primary healthcare staff, together with good practice examples, is available on the Valuing People website at: <http://valuingpeople.gov.uk/dynamic/valuingpeople144.jsp>
14. A framework for the content that the training should include is:
- understanding of learning disabilities
 - identification of people with learning disabilities and clinical coding
 - understanding of the range and increased health needs associated with learning disabilities

- understanding of what an annual health check should cover
 - information that should be requested prior to an annual health check
 - understanding of health action plans
 - understanding and awareness of 1:1 health facilitation and strategic health facilitation
 - ways to increase the effectiveness of health checks
 - overcoming barriers including:
 - communication needs
 - using accessible information and aids
 - physical access
 - social and cognitive attitudes
 - values and attitudes
 - collaborative working including:
 - working in partnership with family carers
 - the role of the community learning disability team
 - the role of social care supporters
 - the role of other health care professional and services
 - experiences and expectations
 - consent
 - Disability Discrimination Act and the Disability Equality Duty
 - resources – local contacts, networks, practitioners with special interest and
 - information
15. The training should be provided by the strategic primary health care facilitator for people with learning disabilities (where Primary Care Trusts have invested in this support) and / or members of the local community learning disability team (this may need to be commissioned via the local specialist NHS trust) in partnership with self advocates (as paid co-trainers). Each Primary Care Trust should use their internal procedures to approve the content of the training for their locality using the framework provided as guidance.

South Devon Healthcare Foundation Trust's System to Support Patients with Specific Requirements and Disabilities

Background

The report "Improving the Life Chances of Disabled People" (Department of Health Strategy Unit, 2005), delivers the vision of a social model of disability equality. It states that: "by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society".

The Code of Practice actively promotes equality of opportunity for disabled people and makes an important distinction between 'impairment' and 'disability'. Impairment is defined as "an injury, illness, or congenital condition that causes or is likely to cause a long term effect on physical appearance and / or limitation of function within the individual that differs from the commonplace". Disability is described as being "the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers".

Over the last 12 months South Devon Healthcare Foundation Trust has taken the lead to define systems and processes to capture the information regarding any special needs identified by patients

Defining Key Stakeholders

A small group of key stakeholders from across the community initially gathered to review existing processes and share best practice. It was quickly identified that although some information was gathered by various organisations, it was not shared on an IT system and tended to only be used by a specific service.

The group tasked the Health Records/PAS Manager to explore the options for capturing information within the current Referrals Index on PAS. As this interfaces with a multitude of systems community wide it seemed a sensible option to record the data which could then be shared with other system users.

The group also wished to standardise where possible the information being gathered. This information was collated into a form which started to create the information to capture patients' specific requirements. This was driven forward by Kerra Morgan, Integrated Health Care System Data Quality Analyst, Katy Welsh, Learning Disabilities and Nikki Henderson from Torbay Mencap. Considerable time was spent researching information, signs and symbols, all of which moulded the Specific Requirements form into its current format.

As a provider of services, South Devon Healthcare Foundation Trust has been actively working with members of the Disability Awareness Action Group which has a membership from groups. Representation from patients from:

- Torbay Deaf Club
- SPOT (Torbay Mencap)
- Carers support

- PAL's
- Patients with wheelchair disabilities
- The 'Blind Club'
- Disability Liaison teams

All involved were a great support taking time on numerous occasions, defining the information that patients would wish to be captured in relation to their specific requirements which can be used by health professionals during the course of the patient journey.

Patient Profiles

The current patient profiles used by the learning disabilities teams have also been revised and included within the new specific requirements form. Katy Welsh, Learning Disabilities liaison nurse has taken the lead to update information relating to all patients who have a patient profile.

This information has then been double checked against the PAS system to ensure the patient record is flagged accordingly. This piece of work captured the most up to date information and validated against the IT system using the patients NHS and Hospital numbers. Where errors in demographic data had been recorded these were fed back to the teams.

Copies of the latest profiles have been replaced in the AE department at Torbay Hospital and also in the medical case notes. A copy of all of the 550 + forms has been taken and is being loaded into the new records archiving system 'WinDIP' which it is hoped will be available to staff across the community when a server is available to share the data through a URL via the trusts intranet home page. This will allow access to vital information 24/7 community wide.

The Recognition of Specific Requirements Form

The form has been divided up into sections: Sensory, Physical, Learning Disability and Additional Support requirements. It allows patients to highlight these needs visually either through information held within the patients record, a notice placed above the patients bed (see Figure 1) during an admission or by the use of a yellow specific requirements card (see Figure 2) which can be shown during an outpatient visit.

It is the responsibility of the Practitioner who is most directly involved with the patient (or their carer) to ensure that they are given the option of having their specific requirement flagged. The form is then returned to the Medical Records Manager to be placed within the case notes, scanned into 'WinDIP' and for updating on the PAS Referrals Index.

Sharing information electronically

An enhancement to the existing PAS system has added a further details screen to the Patient Referrals Index. This allows the data capture of information detailed on the specific requirements form to be recorded, as well as recording the person who

has given permission and the date the permission has been provided. A free text box is also available for additional information to be recorded if required.

In adding this information to PAS the Integrated Health Care System team will also cascade the update to other system managers and staff who manage separate types of records. This will ensure the information is shared with as many staff as possible.

Publicising the New Process

Katy Welsh, Tanya Drew and Nikki Henderson are launching the form within their teams and are also planning to have a stand during the International Disabilities day at Torbay Hospital.

Sue Holton will be including the form within the new 'Guidelines for the Support of Carer's of Patients with a Disability' and will launch this to the modern matrons and nursing teams within the coming months. Sue will also be looking to incorporate the information held on the yellow notice (Figure 1) above the patient's bed into the new wipe boards so that the information can be shared and reviewed for all patients.

The use of the form is also being incorporated into the new 'Standard Operating Procedures' being written for clerical staff. The Training department are also supporting the process by training all the Outpatient Receptionists and Ward Clerks at the introduction of the form and amendments to the PAS system. This will be undertaken by trainers floor walking the various areas and updating staff. It is aimed that when the yellow specific requirements card (Figure 2) is shown to the receptionists that they will book any follow up appointment required for the patient after the patients consultation. This will save the patient being inconvenienced having to locate interpreters to be available at a future date to negotiate further appointments for the patient over the telephone.

Andrea Phare (GP Liaison Team) and Sian Faulkes (Senior Business Analyst) are also working with GPs and teams within Torbay Care Trust to raise the use of the forms.

RECOGNITION OF SPECIFIC REQUIREMENTS

Patient ID Label or
 Patient Name:DOB:...../...../.....
 Hospital MRN No:
 NHS Number:

Do you require an Interpreter?
 Do you have a Carer?
 Is your Carer in attendance?

Do you have a Red Book?
 Do you have a Yellow Folder?
 Do you require assistance after discharge?

I have a specific requirement as indicated below:

SENSORY

	Deaf	<input type="checkbox"/>	Hard of Hearing	<input type="checkbox"/>
	Lip Reading British Sign Language User Lip Speaker Required Hearing Dog	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Deaf in one ear only (Left) Deaf in one ear only (Right)	<input type="checkbox"/> <input type="checkbox"/>
	Book an Interpreter Usher required	<input type="checkbox"/>	Hearing Aid	<input type="checkbox"/>
		<input type="checkbox"/>	Left Ear Right Ear Both Ears	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	Blind	<input type="checkbox"/>	Partial Loss of Sight	<input type="checkbox"/>
	Reads Braille Guide Dog Manual Interpreter Usher Required	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Blind in one eye only (Left) Blind in one eye only (Right) Glasses / Contacts Large Print Audio Description Prosthetic Eye	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	Communication	<input type="checkbox"/>		
	Problem with speech Use communication aids	<input type="checkbox"/>		

PHYSICAL

	Unable to Walk	<input type="checkbox"/>	Difficulties with Walking	<input type="checkbox"/>
	Motorised Wheelchair Manual Wheelchair	<input type="checkbox"/> <input type="checkbox"/>	Motorized Wheelchair Manual Wheelchair Unable to walk long distances Falls	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	Paralysed one side	<input type="checkbox"/>	Walking stick	<input type="checkbox"/>
	Left Right	<input type="checkbox"/> <input type="checkbox"/>	Left Right Both	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>



LEARNING DISABILITY

Would you like to bring any additional support requirements to the attention of staff about how they

- Do you have a Learning Disability? Please Tick
- Please contact the Liaison Nurse Please Tick
- Do you have a Life Story Book? Please Tick
- Do you have a Patient Profile on file at Torbay Hospital? Yes No
- If no, does a Patient Profile need to be completed? Yes No

If Yes, a Patient Profile does need to be completed, please refer to Appendix A of this form.

Is there anything that you need extra help with?
eg. difficulties with communication or assistance required with Activities of Daily Living (ADL's)

In order for us to care for you properly during your hospital stay, we would like your permission to put your specific requirements information on the Patient Administration System (PAS), your hospital notes, and above your hospital bed.

I agree to having a card with the symbol indicated above being placed on the outside of my hospital medical record: Yes No

I agree to having a sign with details of my specific requirements placed above my bed if I am admitted to hospital: Yes No

Please inform a member of staff if you wish to withdraw your permission at any time.

Signed by Patient: _____ **DOB:** ____/____/____

Print Name: _____ **Date:** _____

Witness to signature: _____ **Date:** _____

I am the patient's main carer, and I agree that flagging specific requirements information is important to patient care, and I agree on behalf of the patient that a card with the symbol indicated above can be placed on the outside of the patient's hospital medical record:	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am the patient's main carer, and I agree that flagging specific requirements information is important to patient care, and I agree on behalf of the patient that a sign with details of the patient's specific requirements can be placed above the patient's bed if the patient is admitted to hospital.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Please inform a member of staff if you wish to withdraw your permission at any time.		
Signed by Carer/Parent on behalf of patient: _____	Date: _____	
Print Name: _____	Date: _____	
Witness to signature: _____	Date: _____	

After completion please file in the patient's health record in the Allergies and Special Conditions Section - if permission is withdrawn please cross through form and remove sign from notes/bed.

After completion please file in the patient's health record in the Allergies and Special Conditions Section - if permission is withdrawn please cross through form and remove sign from notes/bed.

RECOGNITION OF SPECIFIC REQUIREMENTS

Background

On occasion we will care for patients whose individual needs will require further arrangements to be made to ensure their needs can be addressed.

The Recognition of Specific Requirements form allows us to highlight these needs visually either through a card on the medical record and/or a sign placed above the bed. Permission must be sought prior to using any of these visual triggers.

Scope

The group of patients whose needs may be met in this way will include the following disabilities:
Sensory, Physical, Mental Health, Hidden Disabilities, Learning Disability

Responsibility

Permission must be sought during the following encounters with patients: Outpatient, Pre-assessment, Inpatient (both emergency and elective). It is the responsibility of the Practitioner who is most directly involved with the patient (or their carer) to ensure that patients are given the option of having their specific requirements flagged.

If patients agree to their requirement being flagged the procedure below must be followed:

1. Specific Requirement discussed and form given
2. Ensure form is signed
3. Ensure form is filed in the notes in the Allergies & Special Conditions Section
4. Where an ICP is in use the form will remain within the ICP until Discharge, it should then be removed from the ICP and filed in the Allergies & Special Condition section
5. Tick the appropriate boxes on the ICP
6. Place a special requirements card in the plastic message carrier the front of the case notes and annotate accordingly on the inside leaf. Also place sign above bed during inpatient/daycase stays.

The flagging of Specific Requirements must be discussed and agreed with the patient or carer/parent at each subsequent admission/outpatient episode. If the patient withdraws their permission, the specific requirements card must be removed from the notes, the sign above the bed must be removed and a line drawn through the permission form.

The procedure will be audited during regular casenote audits, if the Specific Requirements form is not contained within the casenotes displaying a specific requirements card, the card will be removed.

This procedure will be reviewed in / / .

PATIENT PROFILE

Patient ID Labeler Patient Name: DOB: .../.../..... Hospital MRN No: NHS Number:	Preferred Name:
Communication	
Mobility	
Personal Hygiene	
Eating and Drinking	
Continence	
Sleep Pattern	
Favourite Objects	
Risks	
Behaviour - including reaction to pain	
Medical Conditions - including known allergies	
Administration of Medication	

Signature:Signature of NOK / Main Carer:

Date Profile Completed:

Learning Disability Service use only (THIS MUST BE COMPLETED IN ORDER TO KEEP DATABASE UP TO DATE)

Area: Teignbridge / South Hams / Torbay (delete as appropriate).

Community Nurse / Main Carer:

Should you require any further information contact:

THE LIAISON NURSE (TOH) on 01803 654992 or THE WILLOWS OUTREACH TEAM 01626 206419 for advice

Please ensure that one copy of this Patient Profile is forwarded to the Supervisor, Accident and Emergency, one copy is forwarded to the Team Leader, Health Records Library to be filed in the patient notes and one copy is forwarded to the relevant Learning Disability Team.

Figure 1

South Devon Health Community 

This patient has a Specific Requirement

To support this patient through their health care journey, please ensure that all further appointments are booked following their consultation.



Chief Executive

Figure 2

South Devon Health Community 



This patient has a Specific Requirement

Hearing Sight

Physical Additional Support Needs

Please refer to patient casenotes for further information