JOINT SERVICE AND COMMISSIONING STRATEGY FOR PEOPLE WITH A LEARNING DISABILITY IN DUDLEY

INTRODUCTION

The Joint Service and Commissioning Strategy for learning disabilities sets out the
commissioning intentions of the Council and the PCT in respect of specialist services
for people with learning disabilities. All community services should be accessible to
people with a learning disability and there is a wider responsibility on all Council and
NHS services to be considering how well they are serving people with a learning
disability.

HOW WE COMMISSION SERVICES

- 2. Dudley Council and Dudley PCT aim to jointly develop services for people with a learning disability. The Dudley Learning Disability Partnership Board sets the local strategic direction for services.
- 3. There are a number of sub groups of the Board that undertake more detailed work in specific areas. These report to the Partnership Board.
 - Involving People (Advocacy; communication; PCP; public information; website; complex needs)
 - Carers
 - Housing
 - Health
 - Opportunities, Jobs and Learning (to include Day Services)
 - Diversity and Relationships
 - Keeping Safe
 - Joint Commissioning Group
- 4. The Joint Commissioning Group brings together officers from the Council and PCT to implement the strategy agreed by the Board and to co-ordinate their commissioning activity.
- 5. The Council has held the lead commissioning role since the late 1990s, though this is not recognised in a S31 Agreement. The Council commissions all care and support services whilst the PCT retains responsibility to provide specialist health services and to ensure access for people with a learning disability to mainstream primary and secondary NHS provision.

SCOPE AND PURPOSE OF THE JOINT SERVICE AND COMMISSIONING STRATEGY

- 6. The Service and Commissioning Strategy explains how the Council and the PCT plan to develop services to people with a learning disability who come within the commissioning responsibilities of the two authorities.
- 7. This agenda is shaped at a national level by the Valuing People White Paper and its

- revision, Valuing People Now, which was published in January 2009. There is also the wider national direction for all adult care services set out in the White Paper "Our Health Our Care Our Say" (2006) and the more recent concordat "Putting People First" (2007). There are also a number of other key documents that we have taken into account; some of these are referenced at appropriate sections.
- 8. Central Government is in the process of a national consultation on the future shape and funding of adult care services and that the results of this will be published in a Green Paper in 2009.
- 9. The local priorities for learning disability services were set out in the Joint Strategy 2005 2008, approved by the Dudley Learning Disability Partnership Board. This Strategy has now reached the end of its term
- 10. The direction of local service development is clear and confirmed through the publication of Valuing People Now in January 2008 and through the wider social and health care policy context.
- 11. The Strategy also takes account of the local **Joint Health and Social Care Commissioning Framework** and the **Joint Strategic Needs Assessment (JSNA).** This sets out the broader context in which we are commissioning learning disability services.
- 12. The **PCT Strategic Plan** picks up some of the key health issues identified in the JSNA and sets out the key goals for health improvement in the borough. These are:-
 - Goal 1 Tackling Obesity
 - Goal 2 Reducing Alcohol Misuse
 - Goal 3 Improving Mental Health Well Being
 - Goal 4 Providing Systematic and Targeted Prevention
 - Goal 5 Providing Care at the appropriate setting
 - Goal 6 Developing and implementing our Urgent Care Strategy
 - Goal 7 Managing Long Term Conditions
 - Goal 8 Improving Patient Quality and Outcomes
 - Goal 9 Strategy to Improve Patient Experience
 - Goal 10 Championing Innovation and Excellence
- 13. As citizens of the borough, people with a learning disability should benefit from these key goals. Later in this strategy we make reference to specific ways in which people with a learning disability are supported to access general health services.

The Joint Service and Commissioning Strategy addresses two key issues:

- What services do people with a learning disability and their families want.
- How can we develop services that meet these requirements within the resources available?
- 14. In order to address these two key issues we need to identify the following:
 - The sources of information that help us to understand what people want.
 - The current services and how we fund them, sometimes referred to as "mapping the market"
 - The strengths and weakness of current services in relation to what people want the "gap analysis"
 - The actions we need to take to try and reduce the gap between what is currently available and what people want and need.
 - This Joint Strategy is therefore divided into four sections to reflect these four areas.

WHAT PEOPLE WANT

- 15. There are a number of sources of information that help us to determine what people want. These may be summarised as:
 - Defining the population for whom our services are provided
 - Being aware of what people have said they require at both a national and local level.
 - Using information from the individual care management and person centred work
 - Talking with people in groups and listening to representatives of service users.
 - Listening to carers, both family carers and those who provide care through their work.
 - Trying to find out why sometimes things go wrong and what could be done differently.

The learning disability population.

- 16. The learning disability population of Dudley needs to be viewed in the context of Dudley borough.
- 17. Dudley is a large metropolitan borough council located in the Black Country and some nine miles west of Birmingham. Rather than being dominated by one centre, Dudley is composed of a number of townships b- Dudley, Sedgley, Brierley Hill, Stourbridge and Halesowen, each with its own identity and culture.

18. The total population is 305,300 (2006 mid year estimates) and the adult population is 237,205. The age composition is as below.

18-19yrs	6505
20-29	33,900
30-39	42,300
40-49	43,300
50-59	39,600
69-69	33,800
70-79	24,300
80 plus	13,500

- 19. Dudley has an ageing population with people over 60 and those over 80 representing an increasing proportion of the total.
- 20. "Workless" people are a higher proportion of the Borough's working age population than in the West Midlands as a whole or nationally.
- 21. Dudley's economic base has undergone dramatic restructuring during the past 25 years. Dependence on manufacturing has reduced, whilst the service sector has grown. It is relatively reliant on low-pay, low skill jobs in retail and distribution. (Economic Strategy 2008)
- 22. Multiple deprivation is concentrated in a small number of neighbourhoods, a fact that tends to obscure the problem in a Borough that otherwise may appear to be relatively affluent. (Local Area Agreement)
- 23. The White Paper "Valuing People" (2001) defined learning disability as including a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) combined with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development.
- 24. Learning disabilities has traditionally been categorised as a continuum from mild/moderate to severe, and profound. Valuing People suggests that people with mild to moderate learning disabilities will usually be able to live independently provided they have the right support, whilst people with severe to profound will need significant assistance with daily living.
- 25. IQ levels have been equated to the differing levels of learning disability with mild being in the range 70 50, moderate 49 35, severe 34 20 and profound below 20.

- 26. The relative strengths and weakness of any individual are much more important. As with all people an individual's abilities are unlikely to be at a uniform level, and it is important that assessments and services draw out the strengths of each person and design support system that builds on these.
- 27. National prevalence rates suggest that approximately 25 people in every 1000 have a mild to moderate learning disability, and that between 3 and 4 in every 1000 have a severe or profound learning disability. A high proportion of Council and PCT resources are targeted at people with severe learning disabilities, as people with this degree of disability will usually require intensive services in order to lead a safe and healthy lifestyle.
- 28. Studies suggest that there will be an increase in the prevalence of severe learning disabilities of around 1% per annum. (Valuing People) This is a reflection of:
 - a. Increased life expectancy, especially amongst people with Down's Syndrome. Overall, the number of adults with learning disabilities aged over 60 was predicted to rise by 36% between 2001 and 2021 (Foundation for People with Learning Disabilities)
 - b. An increase in the number of children with autistic spectrum disorder identified
 - c. Children with complex needs surviving into adulthood
 - d. A greater prevalence amongst some minority ethnic populations of South Asian origin.
- 29. On this basis, the numbers of adults with severe learning disability in Dudley is likely to rise from 934 (the current number on Dudley Special Needs Register) to 1031 in the next 10 years.
- 30. It has to be acknowledged that there is a difference between the population of people with a learning disability served by the PCT and that served by the Council, although there is a very significant group of people who receive services from both the Council and the PCT. One of the key differences in the approach between the Council and the PCT is through the application of eligibility criteria. Council services operate within the context of **Fair Access to Services** criteria that aims to target resources at people with the highest social care needs. These are usually people with severe learning disability. The PCT as part of the NHS operates on the basis of meeting clinical need and therefore will provide services to people who do not necessarily meet Council eligibility criteria and may in some case have a mild/moderate learning disability with additional health care needs such as a mental health or autistic spectrum disorder.
- 31. The main source of data is the **Dudley Special Needs Register**, **(SNR)**. This register is a voluntary register on which people who use health and social care services for people with a learning disability can agree to have their personal details recorded. The vast majority of people do agree to have their details placed on the register.
- 32. The SNR also provides data on the numbers of people living with older carers.

Clearly, as the life expectancy of people with learning disability increases, we can expect an increase in the number of older people with learning disabilities living with even older family carers. In many cases it is the infirmity or death of a family carer that determines when someone requires full time care and support funded by the Council.

- 33. As people with a learning disability and their carers get older, the likelihood that they will need to be supported outside of the family home greatly increases. Approximately 40% of people aged 40-49 are still living in the family home. This declines to 29% for people 50-59 and reduces to 11% for people in their 60s. However, it is interesting to note that 70% of people are living with their family in the age group 20-29 and that this falls to 53% in the next age group of 30-39, representing a 17% difference and one of the largest changes between the different age groups.
- 34. These statistics would suggest that if the same proportion of people continue to live with their families over the next ten years an additional 80 people will require alternative accommodation and support during that time. This does not take account of younger people who by reason of very high levels of care needs or family breakdown will also require alternative accommodation and support. Neither does it take account of the changing expectations of families; families may not accept in the future that they should continue to be lifelong carers for their son/daughter.
- 35. Another indication of the potential future demand for care and support outside of the family home is the number of people with a learning disability living with older carers. The SNR shows that 120 people are living with a family carer in the age range 60 69; 82 people are living with a carer 70 79; 35 are living with a carer 80 89; and two people have a carer who is over 90. These figures need to be seen in the context of a significant growth in the proportion of older people in the general population of Dudley. The proportion over 65 is expected to rise by 24% and that over 85 by 52%. (Local Area Agreement)
- 36. We also need to have regard for the younger people who will be transferring from Children to Adult services. The CTLD establishment includes two transition social workers. Their role is to identify young people who meet the eligibility criteria for learning disability services and assess their needs. From their work we are able to identify the following numbers of young people who will require some support from the CTLD and Learning disability services:-
 - 2009/1014
 - 2010/11 13
 - 2011/12 16
- 37. Most young people who may require adult care funding for either residential or supported living services as they are unlikely to be able to live with their families will require services that are skilled in supporting people with difficult and challenging behaviour and autism.
- 38. Our services need to reflect the diverse ethnicity of the borough. Dudley has a

relatively small Black and Minority ethnic community, currently estimated at 7.5%. (LAA). The largest group is of Pakistani origin (over 2%), followed by Indian (around 1.6%), Caribbean, African and other black groups (1%), and people of mixed race (just over 1%). (Census 2001)

- 39. The distribution of the BME population is such that there are strong concentrations within certain neighbourhoods, pushing local proportions as high as 50% for the Pakistani and Indian Communities. (LAA)
- 40. A total of 86 people with a learning disability are identified as coming from a BME community. This represents 8.6% of the SNR population. These figures may underestimate some of the ethnic group numbers, particularly those of Pakistani origin.
- 41. There are only three clusters of more than 5 people identified. These are:-

Mixed race – 10 African Caribbean - 15 Pakistani- 35

It is interesting to note that the majority of African Caribbean people (9) are in residential care whilst only 2 people are in residential care from the Pakistan community.

Views and wishes of people with a learning disability.

- 42. Over the past few years we have been getting better at asking people with a learning disability and those that support them, how they want to live their lives. This is true both at a national and local level. We still can do a lot more, but we do have a good deal of information about peoples' hopes for the future.
- 43. Generally these expectations are much the same as for most people in our society. They want a comfortable and safe home, money to buy the things they want, to feel useful in what they do during the day, to be helped to keep healthy and safe. People with a learning disability also want to play a full and active part in their local community.
- 44. Above all people want to have choice and control over their lives. Whilst most people may have the same basic aspirations, everyone is different and will want to have their own way of life.
- 45. Our services need to deliver support that enables people to lead their own individual lifestyle and upholds their individual human rights.
- 46. "Valuing People" (2001) and "Valuing People Now" (2009) summarise recent government policy for people with learning disabilities. As both were produced following extensive consultation with people with learning disabilities, they provide a broad overview of what people want (as well as the views of other stakeholders).
- 47. Valuing People set out a vision based on the four main principles of rights, independence, choice and inclusion

- 48. Valuing People Now builds on Valuing People. Valuing People Now sets out the Government's strategy for people with learning disabilities for the next three years. The strategy sits within the context of the transformation agenda for adult social care, set out in Putting People First. There are strong links with other national strategies and initiatives such as, Aiming High for Disabled Children, the Carers'Strategy, the consultation on No Secrets, Local Involvement Networks (LINks) and the forthcoming Adult Social Care Workforce Strategy, and Dementia Strategy.
- 49. Valuing People Now identifies six priorities for 2009-2010:
 - to raise awareness of *Valuing People Now* across national and local government, private and voluntary sectors, and within wider society
 - to have an effective Learning Disability Partnership Board operating in every Local Authority area
 - to secure access to, and improvements in, healthcare, with Strategic Health Authorities and Primary Care Trusts (PCTs) responsible for, and leading, this work
 - to increase the range of housing options for people with learning disabilities and their families, including closure of NHS campuses
 - to ensure that the Personalisation agenda is embedded within all local authority services and developments for people with learning disabilities and their family carers, and is underpinned by person centred planning
 - to increase employment opportunities for people with learning disabilities
- 53. In addition, Valuing People Now sets out key policy objectives for 2009–12

All people with learning disabilities and their families will:

- benefit from Valuing People Now;
- have greater choice and control over their lives and have support to develop person centred plans;
- get the healthcare they need and the support they need to live healthy lives;
- have an informed choice about where, and with whom, they live;
- have a fulfilling life of their own, beyond services, that includes opportunities to study, work and enjoy leisure and social activities;
- be supported into paid work, including those with more complex needs;

- have the choice to have relationships, become parents and continue to be parents, and will be supported to do so;
- be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities;
- have the opportunity to speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it;
- be able to use public transport safely and easily and feel confident about doing so; and
- be able to lead their lives in safe environments and feel confident that their right to live in safety is upheld by the criminal justice system.

For services:

- Leadership, delivery and partnership structures are put in place that will make sure the outcomes set out in this strategy are delivered.
- Effective commissioning in a way that best supports the right outcomes for people with learning disabilities and their families is ensured.
- The workforces across services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the *Valuing People Now* priorities for all people with learning disabilities.
- Learning disabilities will have a clear position in the new performance frameworks for the NHS and local authorities, and there will be a comprehensive range of data sets and reporting mechanisms.
- 50. Over the past few years we have conducted other consultations on health, housing and the activities available to people.
- 51. The Learning Disability Specialist Health team have ensured that clients have been involved at many levels within Dudley to secure their views on the health services in respect of:
 - What they want from the health staff they meet with The Blooming Health consultation gained a wealth of information as to what helped and hindered the clients.
 - The way they want health staff to improve their support The Keep me Healthy and Blooming Health events drew out clients' views, and resulted in the making of the DVD for GP surgeries on what makes a good consultation with your doctor.
 - The type of support they need from the nurses a group of clients talked with Wolverhampton University and the nurse training programme.

- Their Health Screening folder and how they want it changed Clients attended a focus day to discuss what they liked and what they wanted to change.
- 52. Health projects have also been evaluated, for example looking at the issues to be addressed to improve breast screen for women with learning disabilities. The evaluation involved talking to women with learning disabilities about their experiences and therefore getting direct feedback on the service.

Information from individual reviews and person-centred plans.

- 53. This is becoming a valuable source of information at a local level. A summary of each review outcomes is now passed to the Commissioning Unit. These show that in respect of outcomes achieved over the past 12 months:
 - 66% of people had outcomes regarding health issues and promotion of healthier lifestyles.
 - 50% of people had outcomes focussed on social interaction and maintaining close relationships.
 - 43% of people had outcomes relating to their current accommodation.
- 54. There has been an increase in setting target outcomes for the next 12 months in the areas of promoting independence, communication development, support for carers, and community involvement. There is also an increase in the number of outcomes relating to the potential change of accommodation for people.
- 55. Useful person-centred plans have been undertaken in situations where people have faced significant change in their lives, for example through the closure of a residential care home or resettlement from hospital. Planning has led on to people having a more personal service and with greater control and security in where they live. Person-centred plans are therefore being used to help shape the development of services at an individual level but we need to extend this opportunity to many more people.

Representative Groups.

- 56. **Dudley Voices For Choice** (a local self advocacy group) is supported to provide a service user input to a number of planning forums. In particular they have representatives on the Dudley Partnership Board and a number of the sub groups.
- 57. The involvement of service users helps all involved to keep easy to understand communication high on the priority list for all services. This may take the form of a provider brochure that explains the service available, or an accessible form of tenancy agreement that helps people understand their rights and responsibilities when renting a property.
- 58. **Apna Group** is a local self advocacy group for people from black and minority ethnic communities. Members of the group take part in the Learning Disability Partnership Sub Group looking at black and minority issues. A male and a female bi lingual development worker support the group with funding from the British Institute

of Learning Disability. 11 men attend the male group and 8 women the female group.

59. Lesbian and gay people: the recent Learning Disability Joint Review recommended that the Council and PCT ensure that the needs of lesbian, gay, bisexual and transgender people are explicitly addressed in commissioning strategies. As a first step a new field has been created on the Special Needs Register to capture data about this group. We will then analyse the data to inform commissioning of services for this group.

Listening to Carers

- 60. Family carers are also represented on the Partnership Board. This includes a representative from the black and minority ethnic communities.
- 61. Family carers, especially older carers, have often seen great changes in services. They are frequently concerned about the continuity of service and the impact that change may have on the relative for whom they provide care and support. It is imperative that we take this perspective into account when developing or changing services. Often the key issue is can we demonstrate to family carers that service changes will be beneficial to their relative, and this is very good practical test for service development.
- 62. Paid carers are also a very significant source of information, both at an individual commissioning level and when considering wider developments.
- 63. **Ehsas** (means "understanding") Carers group is a group of family carers of children and adults with severe learning disabilities. The majority of the carers are from the Pakistani community. A bi lingual Support Worker funded from Children's Services supports them. The group holds regular meetings, a drop in, and information events. It also facilitates carers training events delivered by local health and social care professionals.
- 64. The needs of carers and the support available to them is set out in the **Dudley Carers Strategy (2007 -2012)**. There has been consultation on this Strategy with carers and feedback highlighted a number of issues which included:-
 - Carers often feel that their role is not recognised
 - Carers assessments are very important but some staff do always understand their purpose.
 - There needs to be more evaluation of different types of "breaks" for carers

Complaints and concerns

- 65. The Council and the PCT complaints procedures are used to investigate issues raised when people make complaints or raise concerns.
- 66. Where the complaint investigation highlights issues in relation to the operation of a service provider, these will be passed to the Commissioning Unit. The Commissioners will want to see a clear plan of how these issues will be addressed

by the provider and will monitor progress. Where this applies to a Commission for Social Care Inspection (CSCI) regulated service we will work with the Inspectors to monitor progress.

Safeguarding

- 67. The most fundamental requirement of any service must be that it provides a safe service to the people who use it. This should not be confused with a service that does not allow people to take risks. Risk taking is an essential part of individual development and is present in all aspects of life. However, the safe service will have undertaken a risk assessment and agreed with all concerned what actions will be taken to mitigate a particular risk.
- 68. We have clear procedures for investigating allegations of abuse. (Safeguard and Protect, Dudley Multi Agency Policy and Procedure for the Protection of Vulnerable Adults 2008)
- 69. During 2007-08 the Community Team for Learning Disability carried out investigations into 69 adult protection referrals out of a total of 231 for all client groups.
- 70. A 'Keeping Safe' sub-group of the Partnership Board has been set up to review safeguarding issues for people with a learning disability.

Health care needs

- 71. National studies have shown that people with a learning disability are likely to have greater health needs than the general population. Four times as many people with a learning disability will die of preventable causes as compared with the general population. They are also 58 more times likely to die before the age of 50. (Healthcare for All)
- 72. There are number of conditions that are more common in people with a learning disability:-
 - Physical disability-approximately a third of people with learning disabilities have an associated physical disability, most often cerebral palsy (Healthcare for All)
 - Sensory Disabilities are more prevalent, and often less well managed, than in the general population. (Healthcare for All)
 - Epilepsy approximately a third of people with learning disabilities have epilepsy (at least twenty times the rate in the general population) and more have epilepsy that is hard to control(Healthcare for All)
 - Obesity one in three people with a learning disability is likely to obese as compared with one in five of the general population. (Closing the Gap)
 - Heart disease between 40 -50% of people with Down's syndrome have congenital heart disease. (Healthcare for All)
 - Pre- senile dementia and dementia this occurs four times as frequently in older

people with a learning disability as compared with the general older population. People with Down's syndrome are at particular risk of developing this condition. (Alzheimer's Society)

- Mental ill health and challenging behaviour-Mental ill health is more common among people with learning disability. For example, the prevalence of schizophrenia (3%) is three times that of the general population.
- Around 15% of people with learning disabilities display challenging behaviour (though estimates vary) (Healthcare for All)

CURRENT SERVICES AND EXPENDITURE

73. The combined expenditure of the PCT and the Council on learning disability services is in excess of £32.5. The largest proportion, nearly £14M, currently funds people in residential care. The next largest spend, £5.7M supports people living in their own homes and the third largest spend, £4.6M, provides specialist health services. The Council spends £3.4M providing day services for people in the community.

Accommodation and support.

- 74. Residential care is therefore a very significant element in the total services in Dudley. Currently 210 people live in a variety of forms of residential care within the borough boundaries, whilst a further 63 live in homes outside of the borough. However, 27 of these out of borough placements are very close to the borough boundaries in neighbouring Black Country authorities, or on the southern or western fringes of the West Midlands conurbation. 53 of the people in residential care are funded by other Councils; the NHS Specialist Services Agency funds some specialist placements and some of the placements within the borough are funded by other local authorities, although the individuals may receive support from the PCT Specialist Health services.
- 75. Residential care covers a wide range of provision from larger homes of 30+ people to homes that are registered for 1 or 2 people. The costs of residential care also vary greatly from around £400 per week to over £3,500 per week. All residential services are "spot purchased" by the Council from up to 20 providers within the borough and over 30 different providers outside of the borough. In most cases where it has been agreed that the PCT will contribute to the cost of a placement the Council re-charges the PCT having paid the full amount to the provider. However, there are one or two situations where for historical reasons the PCT makes a direct payment to providers of residential care.
- 76. A total of 196 people who are supported to live in the community. Supporting people to live in their own home also covers a very wide spectrum of need. Some people are supported by being part of a network where people are encouraged to support one another and receive only occasional advice and support on an individual level. Other people require regular and frequent visits on a daily basis. Many people with severe learning disabilities require 24 hour constant support, some on a two members of staff to one person ratio at times during the day.
- 77.94 people with a learning disability receive housing related support from the

- Supporting People fund. Their needs are recognised in the Supporting People Strategy, and there are some schemes, for example the Adult Placement Scheme that has a high proportion of the costs met by this funding.
- 78. There are a variety of living situations. Many people will live on their own in a flat or house whilst others choose to share a property with two or three other people. Some people live in accommodation that has been specifically designed to meet their needs; others live in standard Council or Housing Association accommodation. Nearly all rent the accommodation with only one or two people owning or having a share in the ownership of the property in which they live.
- 79.17 people live in a family placement, that is where a family has been approved as 'adult placement carers' to offer accommodation and support to a person with a learning disability. The individual has a licence agreement with the family and the placements are regulated and supported through the Council's adult placement scheme which is regulated by Commission for Social Care Inspection (CSCI).
- 80. There are a small number of people who present very complex needs and require expert assessment in order to find the right placement. The PCT provides inpatient facilities at Ridge Hill to undertake this work. Two places are specifically designated as re-integration beds and these are to support the return of individuals with very complex needs from out of borough placements. There are 5 beds for assessment and therapy.
- 81. Currently there are three people living in a NHS Campus facility a house owned and staffed by the PCT. Central Government decided that such services should be closed by 2010 and work is currently in hand to provide alternative accommodation and support for the three people that will give them more choice and control over their lives.
- 82. In order to try and reduce the number of people being admitted to residential care in an emergency situation we have established an emergency support service. This is run be a domiciliary agency and enables professional carers to support a person with a learning disability in their own home in the circumstances where for example a family carer has suddenly been admitted to hospital.

Day activity and employment

- 83. As with accommodation based services, these cover a very wide spectrum of need and activity. The services included various employment related training and support organisations, day centres, community based supported activities and some domiciliary support that provides activity for individuals in their own home or in the community and which also supports family carers.
- 84. In respect of employment the Council has employed a job coach through funding obtained through the **Local Area Agreement** (LAA for three years. The Adult Community and Learning team in the Council is also managing "Workmate" a Big Lottery funded scheme to promote employment of people with a learning disability and people with mental health needs particularly within the Council and the NHS. A further Big Lottery bid is being made for a project called "Groundswell" which will focus on training and work in garden design and maintenance.

- 85. There are a number of other schemes available to people with a learning disability which are run by independent organisations, some of which receive funding from the Council and some which are independently funded.
- 86. The largest provider of day services is the Council which operates three large day centres at Lower Gornal, Amblecote and Stourbridge; two other centres have closed in the last three years. The Council's Cabinet has agreed a plan to re-provide Lower Gornal with a smaller centre, which will be an integrated facility and will cater for people with complex needs to reduce the need for residential placements. PULSE (People Using Local Services) provides community based activities. A total of 330 people use these services during an average week.
- 87. There are a number of much smaller independent organisations which the Council spot purchases a variety of individual support services for people. The Council also makes Direct Payments to 34 individuals to enable them to purchase their own support. In some cases people may also be eligible to funding from the **Independent Living Fund** (ILF). In these situations people make their own arrangements to purchase support from whichever individual or organisation they choose.

Support for family carers

- 88. Nationally, it is estimated that 60% of adults with learning disabilities live with their family. (Valuing People) The figures from the Special Needs Register show that in total just over 45% of the people known to our services live with a family carer. Support for carers is therefore of great importance.
- 89. Carers will receive advice and support from members of the Community Learning Disability Team, and many other professionals employed by the PCT. There is also a specific carers forum for carers of people with a learning disability. In addition they will receive support through the borough wide carers support network which is open to all carers whoever they support. Ehsas carers support carers who look after people from the BME community
- 90. Many carers are supported through the provision of respite care. This is provided through a 15 bed facility in a central location in the borough, and through 2 beds at the PCT service at Ridge Hill for people who meet the criteria for NHS care. In addition there is a respite bed in a residential facility in the southern part of the borough and through short term family placements.

Specialist Health Services

91. Since the planned closure of the learning disability residential services within the PCT, the Specialist Health Service has been gradually developing into a multidisciplinary team of clinicians and support staff which are now able to provide support within the community to clients with the most complex of physical and mental health needs. These include, psychiatry, psychology, speech and communication

therapists, occupational therapists, physiotherapists, and a health facilitation team. The most recent developments have been the introduction of a small Dysphagia service, which is already overwhelmed with referrals and the long awaited provision of a dedicated Dementia service. Partnership working is gradually expanding to bring in other health and voluntary sector services. These include Dental, Physiotherapy, Audiology and end of life care

- 92. The service is based at the Ridge Hill Centre where facilities include a hydrotherapy suite, therapy, training and consultation rooms.
- 93. These services provide direct health care for people and also support and advice to other providers to assist them to meet the needs of the people they support.
- 94. The Service proposes to operate a tiered model of care as follows:
- 95. Level 1 Promotion and Well being: Development of accessible health promotion materials, improved access, targeting/including people who have a learning disability in local mainstream initiatives to reduce health inequalities and promote healthy lifestyles.
- 96. Level 2 Self Care: Ensuring accessible information and appropriate support to people who have a learning disability (and their families and carers) to enable effective self care. This is currently achieved through Speech and Language team support which needs to be maintained and expanded to meet growing needs. Ensuring effective liaison with public health to ensure the needs of this client group are recognised and supported
- 97. Level 3 Universal Primary & Community Services: Clear systems to identify people who have a learning disability in GP practice lists and chronic disease registers needs to continue to be developed. Routine annual health checks with recall systems and access to all mainstream screening programmes. Clear understanding within primary and community services of issues relating to mental capacity for people who have a learning disability, and timely and effective best interests decisions.
- 98. Level 4 Specialist Community Services: Ensuring all people who have a learning disability have equitable access to all generic specialist community services when a specific health need has been identified.
- 99. Level 5 Acute & Tertiary Care: Continuation, development and strengthening of liaison and advisory links between Learning Disability Specialist Health Service and Community Learning Disability Nurses and Acute Service staff, generic community nursing and palliative care teams.
- 100. Services will work across more than one tier to ensure that patients' needs are met. Effective referral and communication between services will ensure that patients receive the right care from the right professional at the right time. Service specifications will record responsibility for onward referral across agreed care pathways. Payment mechanisms will be used to embed care pathways and implement specifications.

- 101. The specialist services seek to ensure that within primary care the fact that National Service Frameworks for various forms of screening apply to people with a learning disability and also promote health action plans for individuals. Examples include breast and cervical screening. The health facilitation team has been able to explain to health colleagues the needs of people with a learning disability and arrange longer appointments, where necessary.
- 102. The Trust's End of Life Co-ordinator has been working with the Specialist Health team to develop the application of the Liverpool Care Pathway and the Gold Standard to meet the needs of this client group. The Co-ordinator has been working with surgeries to ensure they are putting patients with learning disabilities on to these pathways with some success.
- 103. Recent work undertaken with the public health department, health facilitation and psychology has been around a sexual health needs assessment of some of the clients with a learning disability in Dudley.
- 104. The specialist health services provide a wide range of training programmes to support local learning disability services. These include training in specific conditions such as epilepsy, how to work with people who have challenging behaviour and communication of various forms.

GAP ANALYSIS - STRENGTHS AND WEAKNESS OF EXISTING SERVICES

- 105.In looking at the strengths and weakness of our current services we need to consider the following:
 - •Do the current services deliver good quality and value for money?
 - •Is our current expenditure on services in line with the identified needs of the people with a learning disability in Dudley?
 - Are there gaps where there are no appropriate services or the service provision is insufficient?

Pressure on existing resources

- 106. The analysis of need suggests that the pressure on existing financial resources will increase over the coming years. In brief this will include:
 - An increase in the numbers of people with severe learning disability and greater life expectancy.
 - Higher expectations of more individual lifestyles of people with learning disability.
 - More complex needs and higher health care needs as people live into older age.
 - Greater identification of people with autistic spectrum disorders.
 - Because of greater complexity individual care costs are higher.
- 107. Dudley Council and PCT acknowledge the pressure on resources and have agreed

to maintain current levels of expenditure on this client group over the next few years. The Council has invested growth monies as follows:

2005-06 £0.327m 2006-07 £1.3m 2007-08 £1.0m 2008-09 £1.9m 2009-2010 £1.2m

- 108. The Council takes VFM in the services we both purchase and provide very seriously. Information contained within the CIPFA Learning Disability Benchmarking Club for 2006/07 shows that spend per head of population in Dudley on learning disability services in 2006/07 was higher than the average spent by Metropolitan Authorities at £62.20.
- 109. The spend on Learning Disability at Dudley, when compared with other authorities as a percentage of spend on major adult client groups, is in the top quartile and this has been the case for the period covered in this commentary. This position is partly historic due to the high number of residential placements as a result of hospital closures in the borough some 20 years ago.
- 110. The number of clients supported per head of population in nursing and residential care is in the top quartile of Metropolitan Authorities. The gross cost per week showed Dudley to have higher than average costs for our own provision and average costs for these purchased from the private sector. However, most of the in-house provision has since been re-provided.
- 111. Nationally, pressures on budgets have tended to result in tightened eligibility criteria and some reductions in services (Tell it Like It Is). Dudley is one of the few Councils in the country that continues to provide services to people with moderate needs, as well as critical and substantial, under Fair Access to Care.
- 112.It is yet to be seen as to whether the introduction of personal budgets through a resource allocation system will reduce financial pressures. There may well be a greater expectation that people will use their benefits to meet some of their support costs.
- 113. The Council and PCT are therefore keen to explore models of provision that addresses the individual requirements of people with a learning disability but can also deliver on a cost effective basis. Both organisations have joined the In Control pilot.
- 114. Whilst there has been some acknowledgement by Central Government of the increased costs of community care for people in NHS Campus provision by making some additional revenue and capital available this only amounts to some £131,000 additional revenue for Dudley spread over the next three years.
- 115.People who need secure or semi secure accommodation are funded through the regional NHS Specialist Support Agency. Individual patient funding does not follow the person if they are rehabilitate back to their home area. This therefore puts an additional strain on local PCT and Council budgets as often such people require

- high levels of care and support if their rehabilitation is to be successful.
- 116. Valuing People Now signalled that there will be a transfer of funding from PCTs to Councils to meet social care needs whilst PCTs retain responsibility for funding specialist health services.

Accommodation and support.

Residential care

- 117. The residential care sector is regulated by CSCI and also subject to contract monitoring by the Council. CSCI now produce a summary of the quality rating for each regulated service purchased by the Council. Only one residential home for people with a learning disability within the borough has a 0 rating.
- 118.In addition CSCI provide a break- down of the ratings (poor to excellent) for the key outcomes that are assessed during inspections. This shows areas of strength and weakness which are not immediately apparent from the overall star ratings for the whole service.
- 119.CSCI has published a report detailing the key areas for improvement. This is based on inspections up to 30th September 2007. Areas highlighted for improvement were, quality assurance, adult protection, service user plans, training and medication. On the positive side standards around relationships, social inclusion and personal support were rated as good. Services also appear to be performing well in meeting standards regarding activities and daily life.
- 120. The Commissioning Unit has examined inspection reports published since October 2007 and there appears to be improvements in the areas highlighted. The Commissioning Unit monitors providers and takes account of issues raised in CSCI reports. The aim of contract monitoring is to work with providers to improve quality but also to acknowledge good practice.
- 121. Contract monitoring confirms the variable quality of residential care provision, although nearly all services achieve at least an adequate level of quality.
- 122. There is a wide variation in costs, but this mainly reflects the varying needs of the people placed and the very different settings in which residential care is provided. Within the last year the Council has adopted the use of the **care cost calculator**, a costing tool that has been developed nationally with the support of Local Authority Regional Improvement and Efficiency Partnership.
- 123. This tool takes account of the many different components that make up the residential care fee. In particular it looks at the hours of individual care a resident requires and builds this into the cost. The tool is being used to negotiate individual fees when a person is placed in residential care or to look at a revised fee where it is felt that there has been a substantial change in the needs of an existing resident. Indications from the use of the calculator is that most current residential fees come within the tool's predicted range.
- 124. Many people with a learning disability in Dudley want to have the security enjoyed by most other citizens of having a secure tenancy or owning their own home. The

- Government has recognised that concern and from this year will require Councils to declare how many people they support in settled accommodation.
- 125.It is therefore of concern that Dudley still spends such a significantly greater proportion of its combined budget on residential care as compared with other forms of accommodation and support. In this sense our expenditure is not in line with our understanding of the needs and wishes of people with a learning disability.
- 126. Even with this high level of expenditure on residential care it is not always possible to find an appropriate placement for people with severe learning disability and particular complex needs. This can result in placements outside of the borough.
- 127. Senior managers in DMBC meet with the Provider Forum and the West Midlands Care Homes Association on a regular basis. We have signalled our commissioning intent i.e. some residential care provision is needed as part of the range of services, but the policy direction is to place in supported housing as the preferred option. Providers have therefore been encouraged to develop more supported housing options. We have worked successfully with some providers to change their approach e.g. Halas; Grazebrook, and by negotiation on individual cases. Others are more reluctant to diversify.

Supported Living

- 128. Supported living situations are only regulated by CSCI if the person being supported requires the care and support of a registered domiciliary care agency. This will be required if the individual requires personal care as defined by the CSCI. Whilst there are a number of registered agencies operating within Dudley, only 4 are specialists in providing services to people with a learning disability. Of these two have a significant capacity to provide care having come into the borough following a tender exercise to re-provide the accommodation and care for 35 people living in the local NHS hospital.
- 129. As with residential care CSCI provides information on how well registered domiciliary agencies are meeting national standards. However, these figures are for all agencies operating in Dudley. The Commissioning Unit has looked at the reports for the small number of specialist learning disability providers and this shows that for most standards they are achieving near national average on most assessed area except for complaints and privacy, and exceeding the national average on staff supervision.
- 130. Dudley is already successful at helping adults with a learning disability (18 − 64 years) to live at home with a score of 5 on the Performance Assessment Framework. (C30) Our admissions to residential care for recent years are also at a similar rating on the PAF (C73). This would suggest that we have been successful in reducing the numbers of people (18 − 64) being admitted to residential care and the reason for higher numbers in residential care is based on historical patterns of care.
- 131. Our policy of moving towards a greater use of supported living has enabled more

- than 70 people to move into their own homes from long-stay hospitals, care homes and their family carers' home during the last three years. However, we face a number of issues if we are to significantly change the pattern of spending and move to greater support for people in their own home.
- 132. We have not yet succeeded in moving a significant proportion of the 200+ people in residential care into supported housing.
- 133. We are reluctant to do this by simply re-badging homes as supported housing, and the Alternative Futures case would in any case suggest that this would not be legal.
- 134. In many cases the cost of an individual care and support package is greater than equivalent residential costs. Individual support will only be more cost effective where individuals have been "over provided" in residential care -in other words they do not need 24 hour constant care and support.
- 135. The supply of suitable housing is not always easy to find. Whilst many people can live in standard mainstream housing, others, because of complex needs, require housing designed or adapted to their requirements.
- 136. Shared accommodation is one approach to reducing care and support costs, but as tenants people have the right to choose who they live with. An initial compatible group may cease to be so if people fall out or move on and strangers are introduced.
- 137. The grouping together of individual units of accommodation may overcome some of these issues, but availability is still an issue.
- 138. The number of registered care and support providers able to fully meet the needs of people with a learning disability needs to be increased to provide a greater range of provision.
- 139. The contraction of the local residential care market needs to be managed so that the interests of all residents are taken into account.
- 140. The provision of specifically designed or adapted properties often requires capital injection in order to make rents affordable. The alternative is that some providers of both housing and support will try and recover housing costs through care costs.

Day activity and employment

- 141. Day and employment services are not regulated by CSCI. Measures of quality and effectiveness are therefore judged against contractual standards and outcomes where these apply to external services. There are no agreed standards for Council provided day services.
- 142. Nationally there has been a clear directive on supporting people with a learning disability into paid employment. This has now been further emphasised by the introduction of a new performance indicator looking at the number of people with a learning disability known to the Council who are in paid employment.
- 143. Dudley has a number of organisations providing work related training and the

- number of people actually in paid employment is increasing, the overall number remains low. If people are able to make a valuable contribution on a voluntary basis employers need to be challenged to convert such positions into paid work.
- 144. Valuing People Now has suggested that we need to move away from day service modernisation to thinking about how each person arranges their own personalised service with an individual budget, to build up a pattern of daily activity that meets their requirements and that of their families. At this stage it is difficult to judge how many people will, in those circumstances, opt to continue to purchase a service from Council centres.
- 145. Day activity services need to respond to a wide spectrum of need and it is particularly important that the needs of people with very complex needs are fully catered for. Currently the Council day centres have the facilities to provide much of the care that is required for people with complex needs with the support of the PCT special health services.
- 146.It has however become increasingly difficult to arrange an extensive range of activities in the community, which require a higher staff ratio, while at the same time maintaining a service from the centres for people with increasing dependency needs. The 330 people receiving day opportunities include 123, who live in residential care homes. Many of them were until recently receiving five-days-per week day care, but the maximum entitlement for those in residential care has recently been reduced to three days per week.
- 147. Over time, some of these community based activities may have to be reduced in order to concentrate limited staffing resources on the needs of those with the most complex needs. Some reduction in the number of attendances at day centres may also be necessary to allow for an improvement in staffing to service user ratios for the most dependent people. As a first step a Reviewing Officer has been appointed to undertake a programme of reviews of individual care plans to ensure that all clients are receiving the appropriate level and type of day opportunities.
- 148. The long-term plan, approved by Cabinet in June 2007, is to provide a smaller buildings-based service, located in two centres run directly by the Council, which focuses more resources on delivering services for people with high dependency, who are living at home with family carers or in supported housing. The remaining clients would increasingly access day opportunities outside DACHS through a mix of individual budgets, services delivered by the independent sector and by colleges, as well as paid work.
- 149.A further report will be presented to Cabinet in June 2009 on a renewed change programme for day services. Some of the key issues are as follows:
 - To reduce the number of large day centres.
 - To improve facilities in the remaining centre (s) for people with very complex needs.

- To increase the use of ordinary facilities in the community e.g. by transferring some activities from day centres to community centres; and make better use of local organisations.
- To enable more people with complex needs to access the community.
- To reduce the overall number of people in the service
- To reduce the use of transport and support more people to travel independently to centres.
- To enable more people to make use of personal budgets.
- To change more quickly than we have over the past two-three years. We have to build on the five year plan; we can suggest changes to the plan but we cannot disregard it.

Support for carers

- 150. One of the key support services for family carers is the provision of respite care for the relative they support. Currently this is provided through residential care, family respite care and a limited NHS service at Ridge Hill. As with other services people may choose other options for example a holiday for their relative when they have their own budget. Carers are also eligible for Carers Direct payments and have demonstrated that they have found a variety of ways to use these to enable them to carry on the long term task of providing care. (Dudley Carers Strategy)
- 151. The current use of the residential facility has averaged at approximately 76% of its capacity over the past year, although there is some seasonal fluctuation within this overall figure.

Direct Payments/personal budgets

- 152.34 people with a learning disability receive a Direct Payment. People who receive Direct Payments are free to purchase their support from external organisations or individuals of their choice. They may combine the direct payment with other resources, for example the Independent Living Fund, if they meet the eligibility criteria.
- 153. More recently the Council has begun to pilot personal budgets which give the user greater flexibility in the way that these can be used including the option to purchase Council services. A group of ten clients has been identified who are now in receipt of personal budgets
- 154. It is important that all providers are considering how they will be adapting to this new environment where the service user is their direct customer. Personal budgets will also challenge traditional categories of service and by implication the current regulatory classifications. For example someone might want to be supported by the same staff member, at home, in the community or for short breaks in a residential home. Currently this cuts across domiciliary and residential categories of regulation.

- 155. Providers will need to listen carefully to service users and their families about the flexibility they are likely to want in terms of support and what is most important to them in terms of how the service is delivered.
- 156. The Council has established a transformation team that will be looking at how we develop the infrastructure to support people with personal budgets. Key priorities for the team include improvements in published information about services in accessible formats. And the commissioning of brokerage services to support people to plan their care and support.

Specialist Health Services

- 157.Recent reports, "Death by Indifference" and the more recent "Healthcare for All" have highlighted key issues for the NHS and people with a learning disability. In brief some of these are:-
 - The failure nationally of mainstream primary and secondary health care to provide the same level of service as for other citizens, and make reasonable adjustments for the needs of people with a learning disability. This applies particularly in the area of communication between health staff and the person with the learning disability.
 - The increasing life expectancy of people with a learning disability means that they are likely to suffer from degenerative diseases such as dementia. This is likely to apply particularly to people with conditions such as Downs Syndrome.
 - The improvements in medical science which means that people with very profound physical and sensory disabilities are surviving into adulthood.
 - a significant number of younger people in transition to adult services who have behaviour that challenges services.
- 158.Locally the following areas for development and improvement have been identified, following from national reports, internal reports and surveys, and focus groups with patients and carers.:-
 - Making sure that everyone has an annual health Screen and a Health Action Plan
 - Continued development of screening i.e. bowel; cervical; breast and testicular; diabetic retinopathy and all areas covered by the NSFs.
 - More sensitive appointment processes in both primary and secondary care for people with complex needs and long term conditions
 - More work with mainstream hospital staff for training and adapting procedures to better meet the needs of people with a learning disability.
 - Making sure that end of life treatment is in accordance with the wishes of the person.
 - Better accessible information for clients and carers on health conditions, healthy living, relationships and sexual health.
- 159. Further investment in the development of the Special Need Register would enable

the baseline information to be validated and its accuracy expanded. In addition concentration on the development of the NCRS system would be the key to gathering and tracking health care pathways for patients with learning disabilities within the Health Care system. Without a whole system approach between, surgeries, Primary and Secondary care the pathways taken by these clients would be impossible to track. Data collection by the Trust in respect of GP activity via Reed Codes and the Chronic Disease registers would also support the gathering of data.

- 160. Service specifications for the new clinical Directed Enhanced Services (DES) for 2008/9 have been released by the Department of Health. Building on the QOF register for patients with learning disabilities practices are required to liaise with the Local Authority and identify those patients with moderate to severe learning disabilities. Practices are also expected to attend a multi-professional education session. Once this register is in place practices are required to provide an annual health check on these patients.
- 161. The DES will be reflected in the new Primary Care Strategy for Dudley, which will be published shortly. The Strategy will also address the commissioning of an enhanced medicines use review service from community pharmacy that recognises the additional level of support required for learning disability clients.
- 162. The Learning Disability Specialist Health Service has already put in place a number of initiatives to address these recommendations and can therefore demonstrate that it is working towards providing services to people with a learning disability that are accessible, and treat these individuals as equal citizens, with equal rights of access, to equally effective treatments.

Work force development

- 163.A key element in delivering good quality, flexible, person centred services in all settings is the skills and attitudes of the people employed to deliver that care and support. It is therefore essential that both the Council and the PCT continue to invest in training for staff across all sectors of the learning disability health and social care market.
- 164. Within the Specialist Service in the PCT, roles and responsibilities continue to change as new support requirements are identified and completed projects sometimes allow change or programmes of work are adapted to allow support to be changed to meet these needs. The service has carried out skill mix reviews of each post to ensure the new vacancy meets identified needs. To continue to develop to meet the complexity of support needs clients are presenting with will require new areas of specialism.

165.LEARNING DISABILITY JOINT REVIEW

166. During autumn 2008, the Commission for Social Care Inspection, the Health Care Commission and the Mental Health Act Commission jointly carried out a series of reviews in nine Councils, to assess how the Councils with their local Primary Care Trusts commission services for people with learning disabilities and complex needs.

Dudley was one of the Councils selected to take part in a Review

- 167. The inspection programme included: an in-depth examination of five cases; a public meeting; focus groups with carers, providers, advocacy groups and Council and PCT staff and interviews with managers from the Council and PCT.
- 168. The expert by experience carried out mystery shopping of local services to find out whether these services were accessible to people with complex needs.
- 169. The Review is not scored but will be used by CSCI as a source of evidence for the Social Care performance review of the Council for 2008-2009.
- 170. The Joint Review identified some areas for development and many strengths with Dudley services for people with a learning disability and complex needs.
- 171. The recommendations of the Joint Review are being addressed through the Action Plan attached to the Strategy.
- 172. The major area for improvement relates to Day Services; a report on the modernisation of Day Services will be brought to Cabinet in June 2009.

SAFEGUARDING

- 173. Safeguarding vulnerable adults is everyone's business. Safeguarding responsibilities should be clearly defined for all professional groups.
- 174. Safeguarding is more than just protection from abuse and neglect, although this is the most important area. It would include other issues such as hate crime against disabled people; poor care practices in hospitals and forced marriage.
- 175. Councils have a leadership and co-ordinating role, which could involve wideranging new tasks in future. There should be a duty on other agencies to work in partnership with Councils.
- 176. More preventive work is needed with vulnerable people with a learning disability to educate, inform and alert them about abuse and to help them to know how to report any concerns.
- 177. Councils and NHS bodies will be performance managed on safeguarding activity. This will take account of the experiences of people with learning disability who have used safeguarding services.
- 178. The Joint Review of Learning Disability Services highlighted two specific areas for improvement:

- Better public information for all service user groups about how to recognise and report abuse. We are working with Marcomms and with service users to develop this material.
- Outcomes how do we know that safeguarding arrangements are effective? We are now monitoring outcomes for individual service users to see whether intervention had a positive effect for them and was successful in protecting them from further abuse or neglect.

ACTION PLAN

- 179. The table attached in appendix 1 sets out the actions that the Council and PCT plan to take in the next 12 months to address the issues highlighted by the needs analysis and gap analysis in this Joint Service and Commissioning Strategy.
- 180. This action plan will be regularly reviewed by the Joint Commissioning Group and progress on the action points reported to the Learning Disability Partnership Board.
- 181. Many of the areas for development already have working sub groups of the Partnership Board. Each group will have its own detailed implementation plan. The Action Plan attached to this Strategy gives an overview of all the commissioning activity planned for the next 12 months.