

# Planning4care: Learning Disability strategic needs assessment for Bolton

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Planning4care strategic needs assessment tool developed by  
Care Equation and Oxford Consultants for Social Inclusion (OCSI)



# 1. Acknowledgements

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**Planning4care** Strategic Needs Assessment developed by Care Equation and Oxford Consultants for Social Inclusion (OCSI). For further information on Planning4care see [www.planning4care.org.uk](http://www.planning4care.org.uk).



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## 3. Executive summary

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### 3.1 Background

This report highlights the current and projected learning disability needs in Bolton, potential service implications and current use of learning disability services. The data and analysis is based on the Planning4care Learning Disability methodology and tool which:

- Produces locally sensitive baselines and projections of demand for services by LD groups;
- Models cost and service implications based on locally adjustable scenarios of demand and service patterns;
- Is designed for easy access by users;
- Is practically robust and requires a manageable amount of data input;
- Has outputs that can translate into quantifiable service requirements;
- Achieves a balance between over-simplification and over-complexity;
- Produces a credible evidence base for planning and commissioning.

### 3.2 Needs categorisations by severity and category

The Planning4care methodology is built on a clearly defined *needs classification* which provides a framework for describing people with learning disabilities, based on both severity and condition:

- *Severity*: While the actual issues presented for somebody with a learning disability cover a broad range of daily living functions, levels of severity are technically defined in terms of IQ level. While this is not completely standardised at the lower levels, the definitions adopted by the British Institute of Learning Disabilities are: Profound Learning Disability (IQ < 20); Severe Learning Disability (IQ 20 – 50); and Moderate (or Mild) Learning Disability (IQ 50 – 70).
- *Category*: While *severity* is likely to influence the *level* of support needed, the *nature* of the learning disability will influence the *type* of

support required. The breakdown by nature of learning disability is based on those categories identified as most important in the consultations with the pilot councils, and include: general autistic spectrum conditions, Asperger's syndrome, and Down's syndrome.]

- The list of important categories also included challenging behaviour. As a result of the pilot work we identified the presence of serious challenging behaviour as a key characteristic, in addition to severity, in determining the likely level of resource requirements – raising these for people with SLD, MLD levels of severity to the equivalent of the PMLD level. We have therefore added 'SLD/MLD with serious challenging behaviour' as a sub-category of the main (severity-based) needs classification

Our methodology to develop estimates of need at local level is based on a range of sources, see Section 6 for more details.

### 3.3 Estimates of need (Section 7)

#### *Prevalence by severity*

- The proportions of those with Profound and Multiple Learning Disabilities (PMLD) vary only slightly between Bolton, and the region and England. Overall estimates for this group are relatively small, with 81 across the District aged 18-64, 14 aged 14-17 and 10 aged 65+.
- For those with Severe Learning Disabilities (SLD), Bolton has similar proportions to the corresponding regional and national figures - 0.5% of those aged 18-64 (670 people), 0.3% of people aged 65+ (83 people) and 0.5% of those aged 14-17 (68 people).
- In addition, around 3,430 people aged 18-64 across Bolton are expected to have moderate learning disability (MLD), with an additional 320 aged 14-17 and 780 aged 65+.

- Around 60 people aged 18-64 with a severe or moderate level of learning disability are estimated to also exhibit serious challenging behaviour; the numbers in the 14-17 and 65 + age groups are estimated to be <10 in each case

### *Projected growth*

- The overall number of people aged 18-64 with learning disabilities is projected to increase by around 0.25% across Bolton to 2029, well below projected increases across England (8.7% increase) and the region (4% increase). The largest increases are seen in the PMLD group, with a projected growth of 36% to 2029
- The large projected growth in the PMLD group is due to expected future improvements in infant mortality and life expectancy for those with PMLD<sup>1</sup>, resulting in increased prevalence rates for PMLD.
- The population aged 65+ is projected to increase significantly across Bolton between 2009 and 2029, with numbers with learning disabilities projected to increase by 36% to 2029. However, this is slower than the rate of increase across the region and England as whole.

### *Prevalence by condition*

- 1,840 adults aged 18-64 (1.2%) across Bolton are estimated to have Autistic Spectrum conditions, similar to the national average (1.2%) with an additional 160 people aged 14-17 (1.2%) and 440 people aged 65+ (1.1%).
- Of these, 830 adults (aged 18-64) are expected to have Asperger's syndrome/ high functioning autism, with another 74 aged 14-17 and 200 aged 65+. Proportions of the population affected are similar to regional and national averages.
- 120 people aged 18-64 are estimated to have Down's syndrome, with around a further 12 aged 14-17. Due to early mortality of people with

Down's syndrome, the number aged over 65 is expected to be very small.

- Of the people with Down's syndrome aged 18-64, a small number (around 12 in total) are estimated to also have early onset dementia.

## 3.4 Service implications – need and take-up in Bolton (Section 8)

- Planning4care estimates indicate that the number of adults aged 18-64 with Profound and Severe levels of learning disability across Bolton is around 750. Based on the number known to Bolton services, most of this group are likely to be receiving services.
- There are an estimated 5,050 adults (18+) across the LA area with a learning disability at moderate level and above, with around 13% of these known to services. Assuming that most adults with PMLD and SLD levels of learning disability are known to services, this indicates that very few people with a moderate level of learning disability receive some form of social care support.
- Around 92% (565 people) of people with learning disabilities aged 18-64 known to social care services are supported in the community (this compares with an average of 80% for England). 36.1% (around 220) are living permanently with family or friends; around a further 65 live independently in owner-occupied or rented accommodation. For 53.0% of those supported in the community, there is also a carer service provided, with carer advice or information being given in a further 4.9% of cases.
- It is interesting to compare these current data with the results of the Valuing People survey undertaken in 2003-04. The survey found that 30% of those with profound and multiple levels of learning disability, 17% of those with severe learning disabilities and 13% with moderate learning disabilities were in residential or NHS accommodation. Based on the Bolton estimates, this would be the equivalent of around 580 people. Of those living in the community, just 4% (2% of those with

<sup>1</sup> Emerson, E. (2009). Estimating future numbers of adults with profound multiple learning disabilities in England.

severe levels of learning disability and 7% with moderate learning disability) were living alone.

### 3.5 Cost implications (Sections 9 and 10)

- Based on case studies provided by the pilot areas, we have identified indicative costs for social care, community and professional support for the different LD needs groups (PMLD, SLD, MLD and SLD/ MLD with serious challenging behaviour) - see Section 9.
- The number of case studies for each needs group is small, and cannot therefore fully represent the range of support needs that may be

relevant for different groups. This material should therefore be regarded as illustrative only. Comparison of the average weekly spend per client against the cost identified from the pen portraits suggests that the average pen portrait costs are above the average social care budget spend per client.

- Analysis of LD budgets for the pilot areas (Section 10.2) shows significant variation in both annual spend per capita (working-age population), and average spend per client receiving services. This variation is not explained by differences in the average number of clients per working age-population.

## 4. Introduction and context

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### *Planning4care Older People*

Planning4care Older People is a strategic planning tool for commissioners and providers of older people's social care. The tool:

- profiles the older population by levels of care needs (both the whole 65+ population, and those that are receiving publicly-funded services);
- takes account of local risk factors and maps areas of greatest needs;
- links levels of social care need to service requirements and costs;
- projects future costs and service requirements;
- enables users to explore the impact of different planning scenarios.

### *The need for better information on Mental Health and Learning Disability groups*

Planning4care users have emphasised the importance of gaining a better understanding and analysis for other service users, alongside the older people social care needs estimates currently provided by Planning4care. In particular, local partners have highlighted the need for a similar tool and methodology that provides information for two additional user groups – Mental Health (MH) and Learning Disability (LD) groups.

Nationally, this need for better information is well recognised, for example “[in mental health] there is a huge need for information to support commissioning and service planning, including information and tools to understand how the demographic profile translates into needs for services and service models, and tools that help people understand and benchmark their services.”<sup>2</sup>

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<sup>2</sup> NHS Information Centre (2006). *Making sense of mental health information*.

### *Extending Planning4care to Mental Health and Learning Disability*

We have extended the Planning4care tool and methodology to cover the Mental Health (MH) and Learning Disability (LD) groups, by developing a methodology and tool which:

- produces locally sensitive baselines and projections of demand for services by MH and LD groups;
- models cost and service implications based on locally adjustable scenarios of demand and service patterns;
- is designed for easy access by users;
- is practically robust and requires a manageable amount of data input;
- has outputs that can translate into quantifiable service requirements;
- achieves an optimum balance between over-simplification and over-complexity;
- produces a credible evidence base for planning and commissioning.

### *What does this report contain?*

This report highlights the current estimates and projections of numbers of adults (including older people), and young people in transition, with a learning disability in Bolton, and sets these within the context of current usage of adult social care services. The analysis includes:

- Numbers and rates of people aged 18-64, 65+, and 14-17, with learning disabilities by level of severity;
- Numbers and rates of people aged 18-64, 65+, and 14-17, by selected diagnostic<sup>3</sup> categories;
- Current local use of adult social care services for people with a learning disability;

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<sup>3</sup> Also includes numbers of adults on the autistic spectrum who do not have a learning disability – i.e. those with Asperger's syndrome and high-functioning autism.

- Current living circumstances of those with a learning disability known to social care services.

- Illustrative costings of services for different needs groups and comparisons of overall spend (pilot councils).

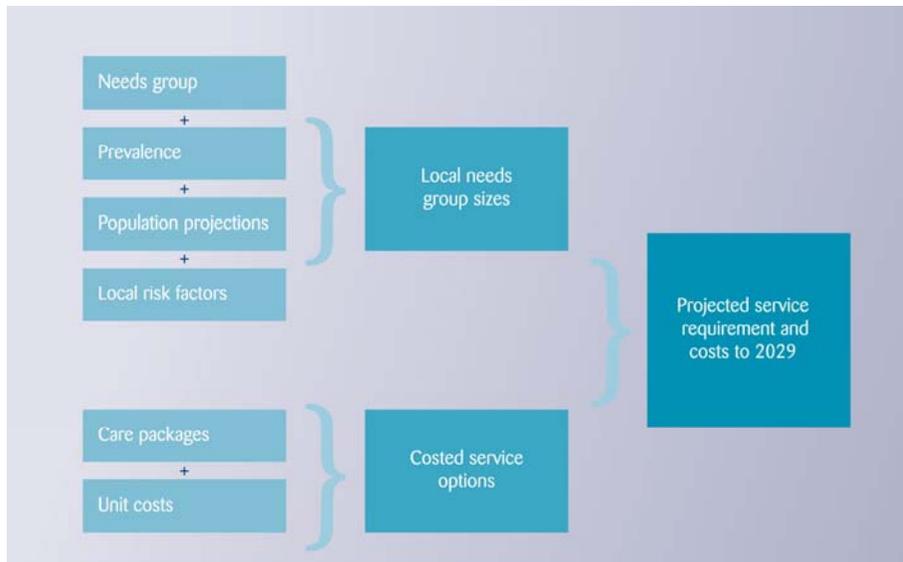
## 5. Project objectives, pilot areas and workshop

### *Key objectives for the project*

In extending the Planning4care commissioning tool to the Mental Health and Learning Disability groups, we have been guided by the same overall approach as used with Planning4care for older people (see diagram below).

The project key objectives are:

- *Build the model around a clearly defined needs/ dependency classification*, providing a shared framework and language for describing the MH and LD groups across the whole spectrum of need. In this way information and analysis on need, user preferences and service uptake across agencies can be linked to a clear set of needs and outcomes.
- Design a *classification framework that is meaningful for commissioning purposes* and capable of linking in with both 'bottom up' data such as case recording and user consultation, and 'top down' information sources such as prevalence rates.
- Use and develop national prevalence data from well established sources as a starting point for providing basic local estimates and projections for demand.



- Develop indices that enable calculation of refined local estimates, i.e. adjusted for relevant local circumstances that affect demand and take up of services (may for example include indices to adjust age, gender, marital status, household income, deprivation level, ethnicity).
- Link estimates for needs groups to typical service configurations/ costs.
- Link current patterns to projected demographic trends to provide estimates for future levels of need, service requirements and costs
- Develop *local tools to disseminate the information*, providing all data in easy-to-use output format, eg Word report and Excel data.
- Develop a training package to support initial implementation.

### *Pilot partners and workshop*

Alongside the development of the technical methodology, we have tested our approach with a group of pilot areas: Derbyshire, Essex, North East Lincolnshire, North Tyneside and Rochdale<sup>4</sup>. The project pilot areas provided detailed local datasets, enabling validation and testing of the Planning4care methodology. In addition, the pilots provided input in deciding the most useful content and format of the project outputs, at a series of inception meetings held with each area. An interactive workshop was held with the pilot partners and the Planning4care team in March 2009, which:

- explored the project methodology;
- identified the key commissioning questions that the project can help support locally;
- identified how the project outputs could best support local work;
- summarised the local data that could be provided and used for validation of the model;
- decided the key project outputs.

<sup>4</sup> Bolton was also involved at a later stage of the pilot period, providing case studies for the costs analysis.

## 6. How do we categorise learning disability needs, and what sources have we used?

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### 6.1 How do we categorise learning disability needs?

As outlined above, the Planning4care methodology is based on identifying a clearly defined classification of types and levels of need for a particular client group. This framework should be meaningful for commissioning purposes and capable of linking in with 'top down' information sources such as prevalence studies and 'bottom up' data from case recording. A balance has to be struck in each case between making the categories sufficiently well-defined to enable them to be associated with meaningful, if broad-brush, resource implications - and avoiding too much detail.

In our discussions with the pilot authorities it was agreed that, for adults with Learning Disabilities:

- level of severity is the appropriate primary basis for identifying Learning Disability needs groups. It is particularly important to separately identify those with the most profound levels of disability. For planning and resourcing purposes there needs to be a distinction between people with a combination of learning disability and physical/sensory disability, and those with a combination of learning disability and behavioural difficulties or other mental health issues.
- it would be helpful, separately, to also have prevalences and projections of those with particular diagnostic conditions – especially autistic spectrum conditions, including (separately) those with Asperger's syndrome/ high-functioning autism. Prevalence of Down's syndrome was of interest primarily in connection with the link to early onset dementia. Prevalences and estimates of numbers with early onset dementia have therefore also been included within the Learning Disability part of the Planning4care tool.
- living circumstance is the other key dimension strongly affecting the level of care package required.

### 6.2 What needs categorisations have we adopted?

#### *Prevalence by levels of severity*

While the actual issues presented for somebody with a learning disability cover a broad range of daily living functions, levels of severity are technically defined in terms of IQ level<sup>5</sup>.

In order to link with established usage, and the available knowledge base around prevalence and risk factors, we have adopted the 'standard' severity classifications (as used, for instance, in the classification of Special Educational Needs) of Profound and Multiple Learning Disability (PMLD), Severe Learning Disability (SLD) and Moderate Learning Disability (MLD). While this is not completely standardised at the lower levels, the definitions adopted by the British Institute of Learning Disabilities are:

- Profound Learning Disability IQ < 20
- Severe Learning Disability IQ 20 – 50
- Moderate (or Mild) Learning Disability IQ 50 – 70.

Similarly, there is no standard definition of 'profound and multiple' learning disabilities. For the purposes of their scoping study, CSCI (Tempest & Fruin, 2006) adopted the following:

- Profound intellectual impairment; and
- Additional disabilities, which may include sensory disabilities (eg visual impairment or hearing loss), physical disabilities and/ or autism or

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<sup>5</sup> Recent work based on the Sheffield and Leicestershire Learning Disability registers (Institute of Public Care, 2009, Working Paper 1: *Estimating the Prevalence of Severe Learning Disability in Adults*) uses a definition of Severe Learning Disability based on the Social and Physical Incapacity (SPI) diagnostic ratings. In terms of prevalence, this lies between the IQ-based SLD and MLD levels.

mental illness. Challenging or self-injurious behaviour may also be present.’

As a result of the ‘pen portrait’ exercise undertaken as a part of the pilot study, we established that, in order to provide a comprehensive primary needs classification framework, we needed also to include a separate category of people with severe or moderate level learning disabilities who also had serious challenging behaviour. Such behaviours, which may encompass aggression, self-injury, destructiveness, hyperactivity, inappropriate sexual or social conduct or bizarre mannerisms, can affect the health and safety both of the person themselves and those around them. As a result, people with serious challenging behaviour are likely to require a more intensive level of supervision (typically 1:1 or 2:1 at all times) than would be indicated by the LD level alone.

The final set of primary (severity) categories adopted, then, was:

- Profound and Multiple Learning Disability (PMLD)
- Severe Learning Disability (SLD)
- Moderate Learning Disability (MLD)
- Severe or Moderate Learning Disability with Serious Challenging Behaviour.

### *Sources for prevalence by severity*

The main source of national prevalence rates of different levels of severity for people with Learning Disabilities is the work of Emerson and Hatton (2004) at the University of Lancaster. These give estimates and projections of the numbers of people with learning disabilities by age and gender in England who are known to services (the ‘administrative prevalence’) and then develop on these to estimate whole-population prevalences of people with learning disabilities at moderate level and above (the ‘true’ prevalence). The ‘true’ and ‘administrative’ prevalence rates are adjusted into the future by Emerson and Hatton (2004b) to take into account demographic shifts and change (ie, improvements) in life expectancy for those with learning disabilities.

Recent work by Emerson (2009) provides numbers at national level with profound and multiple learning disabilities projected to 2026, based on changes in birth rates, incidence of PMLD, survival rates of infants with PMLD

and changes in mortality rates for people with PMLD. Based on these factors, the prevalence rate over time for PMLD is expected to increase, resulting in a faster increase in the numbers of people with PMLD than would be expected simply given projected population increases. Based on this, we have calculated the proportion of the ‘administrative population’ with PMLD, which increases from 9% in 2009 to 12% of the administrative population by 2029<sup>6</sup>. This proportion is applied to each of the age-gender administrative prevalence rates<sup>7</sup>.

Work by Emerson & Hatton (2008) also estimates that 82% of adults known to services (the ‘administrative population’) had learning disabilities at either profound and multiple (PMLD) or severe (SLD) levels. This is used in combination with the current estimates of PMLD numbers (see above) to estimate the proportion of the ‘administrative population’ with SLD in 2009. This proportion is then applied to future years, meaning that the size of the SLD group grows with the size of the administrative population.

The prevalence of people with moderate learning disabilities (MLD) is estimated based on the MLD group making up the remainder of the ‘true’ learning disability population, after the PMLD and SLD groups are taken out.

### *Prevalence by condition*

While *severity* is likely to influence the *level* of support needed, the *nature* of the learning disability will influence the *type* of support required. The breakdown by nature of learning disability is based on those categories identified as most important in the consultations with the pilot councils

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<sup>6</sup> This proportion is consistent with secondary analysis of the Valuing People survey undertaken for the CSCI scoping study on people with profound and multiple learning disabilities (Tempest & Fruin 2006), which indicates that people with profound and multiple learning disabilities constitute between 10% and 12% of the ‘administrative population’.

<sup>7</sup> We have made the assumption that the proportionate of people known to services with PMLD is the same for all adult age groups. In practice this proportion is expected to be lower in the older age groups due to the early morbidity of this group; however, at present there is not data available to model this more precisely.

People with an *autistic spectrum condition* have problems in particular with social interaction and social communication; they have practical cognitive disabilities and patterns of behaviour which make it very difficult for them to function within the normal framework of society. Around half of people with an autistic spectrum condition fall into the category of “high functioning autism” – i.e. they actually have an IQ>70; indeed many have well above average IQ. This group, which includes people with *Asperger’s syndrome*, have historically had particular difficulty in accessing any form of support services since they fall outside the definitions and boundaries of eligibility for both learning disability and mental health services; where services *have* been available they have frequently been inappropriate. This situation is now being taken up as a national concern, with the national adult autism strategy due to be published early in 2010.

The more severe levels of learning disability are sometimes associated with a range of *challenging behaviours*. Such behaviours, which may encompass aggression, self-injury, destructiveness, hyperactivity, inappropriate sexual or social conduct or bizarre mannerisms, can affect the health and safety both of the person themselves and those around them.

*Down’s syndrome* is a chromosomal disorder which causes learning disabilities and multiple malformations; it is associated with a major risk of heart malformations, a lesser risk of under-development of the small intestines, and a minor but still significant risk of acute leukaemia. It also carries an increased incidence of *early onset dementia*. Down’s syndrome occurs at a rate of around 1 per 1,000 live births; 10% of live-born babies with Down’s syndrome die before the age of 5.

### 6.3 What sources have we used?

*Sources for prevalence by condition: autistic spectrum conditions, including Asperger’s syndrome and high-functioning autism*

The national prevalence of autistic spectrum conditions has been based on the study of Baird et al (2006) which indicated an overall prevalence of a full range of autistic spectrum conditions among children aged 9-10 as 116 per 10,000,

with a male:female ratio of 3.3:1. We have adopted these same differential male and female prevalence rates across all age groups.

The same study identified that 45% of those with an autistic spectrum condition had an IQ greater than 70 (i.e. above the range for a learning disability). We have therefore taken the prevalence rates for Asperger’s syndrome and high-functioning autism as 45%<sup>8</sup> of the overall autistic spectrum rates.

*Sources for prevalence by condition: Serious challenging behaviour*

The rates of people with a learning disability who have serious challenging behaviour have been calculated as 7.3% of the administrative rates (Emerson, 2001).

*Sources for prevalence by condition: Down’s syndrome*

National prevalence estimates for Down’s syndrome have been based on a combination of the following sources:

- UK rate of Down’s syndrome per 10,000 live births, combined with rate of live-born babies with Down’s syndrome who die before the age of 5 (*NHS National Library for Health*) – to give a prevalence rate from age 5+ of 8.2 per 10,000 population
- Estimated rate of 0.36 per 10,000 people aged 65+ with Down’s syndrome, based on Sheffield Learning Disability case register (POPPI, 2008)
- Estimate from Mantry et al (2008) of an average prevalence of 5.9 per 10,000 for the whole population aged over 16.

We have combined these to produce a set of model prevalences based on 8.2 per 10,000 for the younger adult population, and reducing from age 45 to an

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<sup>8</sup> We have based both of these groups on the Baird et al study, for consistency. This gives an overall rate of 52 per 10,000 for high-functioning autism. A study by Ehlers & Gillberg (1993) of children with autistic spectrum disorders and an IQ of 70 and above indicated that the overall prevalence could be as high as 71 per 10,000. The Planning4care values should therefore be seen as a lower estimate.

average value of 0.36 per 10,000 at 65+, so as to give an overall population average of 5.9 per 10,000 for the population over 16.

#### *Sources for prevalence by condition: early onset dementia*

Prevalence rates by age and gender for early onset dementia have been taken from the Dementia UK report (Alzheimer's Society, 2007). This has been included within the learning disability, rather than the mental health, part of the tool because of the interest in the connection with Down's syndrome. It should be noted that the predominant prevalence of early onset dementia is in the 55-64 age band, when the prevalence of Down's syndrome is reducing (due to early mortality).

#### *Sources for prevalence by condition: Down's syndrome with dementia*

Numerous studies have indicated that people with Down's syndrome are at increased risk of developing Alzheimer's disease at a relatively young age. The numbers of people with a combination of Down's syndrome and dementia have been calculated on the basis of the age-related prevalences of dementia among people with Down's syndrome from the Netherlands-based study of Coppus et al (2006).

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## 6.4 How have local adjustment factors been determined?

### *Local adjustment factors*

The other key aspect of the Planning4care methodology is the generation of *locally sensitive* prevalence estimates through linkage to local-level socio-economic risk factors, where appropriate.

Past studies have indicated that the key local risk factors associated with the prevalence of different severity levels of learning disability are ethnicity (especially for PMLD) and neighbourhood deprivation (especially for MLD). For the local level Planning4care estimations we have used unpublished odds-ratio data - derived from an analysis of the 2008 PLASC data and supplied to us by Professor Emerson and team at the Centre for Disability Research, University of Lancaster – to calculate local-level adjustments to the national prevalence rates.

For autistic spectrum conditions, we have similarly used odds-ratio values supplied by Professor Emerson and team.

There is no systematic evidence for a connection between socio-economic factors and the prevalence of Down's syndrome or early onset dementia, so local estimates in these cases have been based simply on the national age and gender related prevalence rates.

### *Population estimates and projections*

We have developed projections for our estimates of future need levels. These are based on applying the sub-national population projections, by sex and five-year age band, to the current local estimates of prevalence. Our analysis uses the most recent sub-national population projections for 2006-2031, based on the 2006 Mid Year Estimates and published in June 2008.

In order to minimise the impact of transitory student populations on overall prevalence rates, we have adjusted the population projections to remove students from the address where they are studying (based on Census data), and reallocating them to LAs based on the 15-24 population<sup>9</sup>.

Estimates of future numbers of people with Moderate, Severe, and Profound and Multiple Learning Disabilities, and serious challenging behaviour, have been based on the national level prevalence rates developed by the Lancaster University Centre for Disability Research. These include additional adjustment factors over and above straight age/gender based projections:

- “ageing” of the Pakistani and Bangladeshi ethnicity profile (relative to the 2001 Census; no allowance was included for effects of future migration patterns);
- reduced mortality rates in future among older adults with learning disabilities;
- reduced mortality rates in future among children with profound and multiple learning disabilities.

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<sup>9</sup> Re-allocation was done separately for the 15-19 and 20-24 age-bands, with local populations for these age groups (after removing student numbers) 'upweighted' by the national average proportions of students in these age-groups.

## 7. Estimates of Learning Disability need in Bolton

### 7.1 How many people aged 18-64 with a learning disability are there in Bolton?

#### Overview

This section presents estimates of the numbers of adults of working age with particular levels of *severity*<sup>10</sup>, and particular *categories*, of learning disability. Each of the categories encompasses a full range of levels of severity. We have not attempted in general to combine these two frameworks to provide diagnostic categories by severity as this would give too detailed a typology to be practical. The exception is the combination of SLD, MLD levels of learning disability with serious challenging behaviour, as it was clearly apparent from the case study examples that this places people into a different needs category in terms of resource requirements. Serious challenging behaviour will also occur in people with PMLD, but we have not identified these as a separate sub-category since they will already be counted as receiving intensive care packages on account of their level of disability.

We note that the prevalences of particular diagnostic categories do not account for all those with learning disabilities; we have estimated local prevalences just for those categories for which prevalence information is available, and which were identified by the pilot councils as being particularly useful. Neither are the diagnostic categories distinct. In particular, Asperger’s Syndrome/ HFA is a subset of the full autistic spectrum. Also, challenging behaviour frequently occurs in combination with autistic spectrum conditions or Down’s syndrome. At LA level, for the 18-64 age group, we address the overlap between the incidence of early onset dementia and people with Down’s syndrome.

<sup>10</sup> As a result of the pilot study work, SLD/MLD with serious challenging behaviour is henceforth included as a sub-category of the primary (severity-based) needs classification.

#### Level of need in Bolton

Table 7.1 shows the Planning4care estimates of the current and projected numbers of adults aged 18-64 in Bolton expected to have a learning disability at the different *levels* of severity. Table 7.2 shows the numbers expected to have different *types* of learning disability. Table 7.3 shows the numbers of adults in the age groups 18-24, 25-49 and 50-64 with Down’s syndrome and with early onset dementia. We note that the incidence of early onset dementia in people with Down’s syndrome occurs predominantly in the 50-64 age band.

Table 7.1: Estimated numbers of adults in Bolton aged 18-64 with Learning Disabilities, by severity

	2009	2019	2029	% change 2009 - 2029		
				Bolton	North West	England
PMLD	81	88	110	36%	37%	44%
SLD (total)	670	660	670	0.0%	3.8%	8.7%
MLD (total)	3,430	3,410	3,410	-0.6%	3.2%	7.8%
SLD/ MLD with serious challenging behaviour	62	60	60	-3.2%	0.6%	5.2%
<b>Total</b>	<b>4,180</b>	<b>4,160</b>	<b>4,190</b>	<b>0.2%</b>	<b>4.0%</b>	<b>8.7%</b>

Source: Planning4care Estimates, 2009<sup>11</sup>

<sup>11</sup> Baseline figures are derived from Emerson and Hatton (2004b) age-gender prevalence rates of ‘administrative’ and ‘true’ rates of Learning Disability. These prevalences are locally adjusted using Odds Ratios for deprivation and ethnicity (Emerson, unpublished). Projected estimates are based on 2006 ONS sub-national population projections, and projected learning disability prevalence rates (Emerson, 2004b; Emerson, 2009). See Section 6 for more details.

*Table 7.2: Estimated numbers of adults in Bolton aged 18-64 with Learning Disabilities, by category*

	2009	2019	2029	% change 2009 - 2029		
				Bolton	North West	England
Autistic Spectrum (total)	1,840	1,820	1,840	0.2%	3.6%	7.8%
Aspergers Syndrome	830	820	830	0.2%	3.6%	7.8%
Downs Syndrome	120	110	110	2.1%	1.3%	6.3%

Source: Planning4care Estimates, 2009<sup>12</sup>

*Table 7.3: Estimated numbers of adults in Bolton with (a) Down’s syndrome; (b) early onset dementia; (c) Down’s syndrome and dementia*

	Estimated numbers with Down’s syndrome (2009)		Estimated numbers with early onset dementia (2009)		Estimated numbers with Down’s syndrome and dementia (2009)	
	N	%	N	%	N	%
18-24	20	0.08%	0	0.0%	<10	0.0%
25-49	73	0.08%	11	0.1%	<10	0.0%
50-64	22	0.05%	56	0.1%	<10	0.0%
<b>All</b>	<b>120</b>	<b>0.07%</b>	<b>68</b>	<b>0.1%</b>	<b>12</b>	<b>0.2%</b>

Source: Planning4care Estimates, 2009<sup>13</sup>

<sup>12</sup> National prevalence of autistic spectrum conditions has been based on Baird et al (2006). These prevalences are locally adjusted using Odds Ratios for deprivation and ethnicity (Emerson, unpublished). Prevalences for serious challenging behaviour are calculated as 7.3% of the ‘administrative’ (Emerson, 2001). National prevalence estimates for Down’s syndrome are based on NHS National Library for Health, POPPI (2008) and Mantry et al (2008). Projected estimates are based on 2006 ONS sub-national population projections. See Section 6 for more details.

<sup>13</sup> National prevalence estimates for Down’s syndrome are based on NHS National Library for Health, POPPI (2008) and Mantry et al (2008). Age-gender prevalence rates for early onset dementia are taken from the Dementia UK report (Alzheimer’s Society, 2007). The numbers of people with a combination of Down’s syndrome and dementia

Tables 7.1 to 7.3 show:

- Across Bolton, there are an estimated 81 people aged 18-64 with profound and multiple learning disabilities (PMLD), 670 with severe learning disabilities (SLD), and around 3,430 people aged 18-64 are expected to have moderate learning disability (MLD).
- The overall number of people aged 18-64 with learning disabilities is projected to increase by around 0.2% across Bolton to 2029, slower than the increase across the region (4%) and England as a whole (8.7%). The largest increases are seen in the PMLD group, with a projected growth of 36% to 2029.
- The large projected growth in the PMLD group is due to expected future improvements in infant mortality and life expectancy for those with PMLD<sup>14</sup>, resulting in increased prevalence rates for PMLD.
- 1,840 adults (18-64) across Bolton are estimated to have Autistic Spectrum conditions; of these, an estimated 830 have Asperger’s syndrome/ high functioning autism.

have been calculated on the basis of the age-related prevalences of dementia among people with Down’s syndrome (Coppus et al, 2006). See Section 6 for more details.

<sup>14</sup> Emerson, E. (2009). Estimating future numbers of adults with profound multiple learning disabilities in England.

## 7.2 How many people of transition age with a learning disability are in Bolton?

### Overview

Estimates are also presented in each case of the numbers of young people aged 14-17 who may be expected to be in transition between children’s and adult services.

### Level of need in Bolton

Table 7.4 shows the Planning4care estimates of the current and projected numbers of young people aged 14-17 in Bolton expected to have a learning disability at the different levels of severity, while Table 7.5 shows the numbers expected to have different *types* of learning disability.

The tables show:

- Across Bolton, there are estimated to be just under 15 people aged 14-17 with profound and multiple learning disabilities (PMLD), 68 with severe learning disabilities (SLD), and around 320 people expected to have moderate learning disability (MLD).
- The population aged 14-17 is projected to fall across Bolton between 2009 and 2029, leading to projected falls in the total numbers of people of transition age with a learning disability.
- However, PMLD groups are projected to increase (albeit from a low base), with the projected growth in the PMLD group due to expected future improvements in infant mortality and life expectancy for those with PMLD.

Table 7.4: Estimated numbers of people in Bolton aged 14-17 with Learning Disabilities, by severity

	2009	2019	2029	% change 2009-2029		
				Bolton	North West	England
PMLD	14	14	19	36%	24%	29%
SLD (total)	68	62	70	2.9%	-0.5%	6.9%
MLD (total)	320	290	310	-3.1%	-6.3%	0.5%
SLD/ MLD with serious challenging behaviour	<10	<10	<10	-3.0%	-6.1%	0.6%
<b>Total</b>	<b>410</b>	<b>370</b>	<b>400</b>	<b>-1.1%</b>	<b>-4.0%</b>	<b>3.1%</b>

Source: Planning4care Estimates, 2009 (see footnote under Table 7.1)

Table 7.5: Estimated numbers of people in Bolton aged 14-17 with Learning Disabilities, by category

	2009	2019	2029	% change 2009-2029		
				Bolton	North West	England
Autistic Spectrum (total)	160	150	170	3.6%	0.1%	7.1%
Aspergers Syndrome	74	69	77	3.6%	0.1%	7.1%
Downs Syndrome	12	11	12	2.6%	0.1%	7.3%

Source: Planning4care Estimates, 2009 (see footnote under Table 7.2 for details)

### 7.3 How many people aged 65+ with a learning disability are in Bolton?

#### Overview

Estimates are also presented in each case of the numbers of older people - aged 65+ with learning disabilities.

#### Level of need in Bolton

Table 7.6 shows the Planning4care estimates of the current and projected numbers of young people aged 65+ in Bolton expected to have a learning disability at the different levels of severity, while Table 7.7 shows the numbers expected to have different *types* of learning disability.

The tables show:

- Across Bolton, there are estimated to be around 10 people 65+ with profound and multiple learning disabilities (PMLD), 83 with severe learning disabilities (SLD), and around 780 people expected to have moderate learning disability (MLD).
- The population aged 65+ is projected to increase across Bolton to 2029, with numbers in this group having learning disabilities projected to increase 48.6% to 2029 (compared to 55.4% nationally), and by a 92.2% in the PMLD group aged 65+<sup>15</sup>.

*Table 7.6: Estimated numbers of adults in Bolton aged 65+ with Learning Disabilities, by severity*

	2009	2019	2029	% change 2009-2029		
				Bolton	North West	England
PMLD	10	14	19	92.2%	98.0%	104.8%
SLD (total)	83	110	120	45.2%	49.2%	54.3%
MLD (total)	780	1,010	1,160	48.4%	50.1%	54.8%
SLD/ MLD with serious challenging behaviour	<10	<10	11	40.7%	44.3%	49.1%
<b>Total</b>	<b>880</b>	<b>1,130</b>	<b>1,300</b>	<b>48.6%</b>	<b>50.6%</b>	<b>55.4%</b>

Source: Planning4care Estimates, 2009 (see footnote under Table 7.1 for details)

*Table 7.7: Estimated numbers of adults in Bolton 65+ with Learning Disabilities, by category*

	2009	2019	2029	% change 2009-2029		
				Bolton	East	England
Autistic Spectrum (total)	440	550	640	45.7%	48.9%	53.6%
Aspergers Syndrome	200	250	290	45.7%	48.9%	53.6%
Downs Syndrome	<10	<10	<10	41.1%	44.7%	49.6%

Source: Planning4care Estimates, 2009 (see footnote under Table 7.2 for details)

<sup>15</sup> Again, the large projected growth in the PMLD group is due to expected future improvements in infant mortality and life expectancy for those with PMLD. However, these should be regarded as upper estimates, since the proportion of people known to services with PMLD level of disability is likely in practice to be lower in the older age groups (see footnote 7).

## 7.4 People with learning disability in Bolton and comparator areas, by severity

### Level of need in Bolton

Table 7.8 shows the Planning4care estimates of the current and projected numbers of adults aged 18-64 in Bolton and comparator areas expected to have a learning disability at the different levels of severity, while Tables 7.9 and 7.10 show the same data for the transition 14-17 and 65+ age groups.

The tables show:

- The proportions of those with profound and multiple learning disabilities (PMLD) vary only slightly between Bolton, and the region and England. Overall estimates for this group are relatively small, with 81 across the District aged 18-64, 14 aged 14-17 and 10 aged 65+.
- For those with Severe Learning Disabilities (SLD), Bolton has similar proportions to the corresponding regional and national figures – 0.5% of those aged 18-64 (670 people), 0.3% of people aged 65+ (83 people) and 0.5% of those aged 14-17 (68 people).
- Bolton has a slightly higher proportion of people with a Moderate Learning Disability (MLD) than the national and regional averages, with 2.4% of people aged 18-64 (3,430 people), 1.8% of people aged 65+ (780 people) and 2.3% of those 14-17 (320 people) in this group.
- Around 60 people aged 18-64 with a severe or moderate level of learning disability are estimated to also exhibit serious challenging behaviour; the numbers in the 14-17 and 65+ age groups are estimated to be less than 10 in each case

Table 7.8: Estimated numbers of adults aged 18-64 with Learning Disabilities by severity, Bolton and comparators

	PMLD		SLD (total)		MLD (total)		(SLD/ MLD with serious challenging behaviour)	
	N	%	N	%	N	%	N	%
<b>Bolton</b>	<b>81</b>	<b>0.06%</b>	<b>670</b>	<b>0.51%</b>	<b>3,430</b>	<b>2.4%</b>	<b>62</b>	<b>0.05%</b>
North West	2,160	0.06%	17,730	0.50%	89,470	2.3%	1,620	0.05%
England	16,240	0.06%	131,790	0.50%	643,430	2.2%	12,000	0.05%

Source: Planning4care Estimates, 2009 (see footnote under Table 7.1 for details)

Table 7.9: Estimated numbers of young people aged 14-17 with Learning Disabilities by severity, Bolton and comparators

	PMLD		SLD (total)		MLD (total)		(SLD/ MLD with serious challenging behaviour)	
	N	%	N	%	N	%	N	%
<b>Bolton</b>	<b>14</b>	<b>0.1%</b>	<b>68</b>	<b>0.48%</b>	<b>320</b>	<b>2.3%</b>	<b>&lt;10</b>	<b>0.04%</b>
North West	350	0.1%	1,710	0.47%	8,070	2.2%	150	0.04%
England	2,520	0.1%	12,070	0.47%	54,720	2.1%	1,020	0.04%

Source: Planning4care Estimates, 2009 (see footnote under Table 7.1 for details)

Table 7.10: Estimated numbers adults aged 65+ with Learning Disabilities by severity, Bolton and comparators

	PMLD		SLD (total)		MLD (total)		(SLD/ MLD with serious challenging behaviour)	
	N	%	N	%	N	%	N	%
<b>Bolton</b>	<b>10</b>	<b>0.03%</b>	<b>83</b>	<b>0.3%</b>	<b>780</b>	<b>1.8%</b>	<b>&lt;10</b>	<b>0.02%</b>
North West	270	0.03%	2,240	0.3%	20,610	1.7%	200	0.02%
England	2,000	0.03%	16,130	0.3%	144,340	1.6%	1,460	0.02%

Source: Planning4care Estimates, 2009 (see footnote under Table 7.1 for details).

## 7.5 People with learning disability in Bolton and comparator areas, by category

### Overview

The breakdown by category of learning disability is based on the categories identified as most important in the consultations with the pilot councils. While *severity* is likely to influence the *level* of support needed, the *nature* of the learning disability will influence the *type* of support required.

### Level of need in Bolton

Table 7.11 shows the Planning4care estimates of the current and projected numbers of adults aged 18-64 in Bolton and comparator areas expected to have a learning disability by category, while Tables 7.12 and 7.13 show the same data for the transition 14-17 age group and 65+ age group.

The tables show:

- 1,840 adults (1.2% of the population) across Bolton are estimated to have Autistic Spectrum conditions, similar to the regional and national averages (1.2%), with an additional 160 people aged 14-17 (1.2%) and 440 people aged 65+ (1.1%).
- Of those with an autistic spectrum condition, 830 adults (aged 18-64) are expected to have Asperger’s syndrome/ high functioning autism, with another 74 aged 14-17 and 200 aged 65+.
- There are estimated to be relatively few people with Down’s syndrome across Bolton with around 115 people aged 18-64, around 12 aged 14-17 and less than 10 aged 65+.

Table 7.11: Estimated numbers of adults aged 18-64 with Learning Disabilities by category, Bolton and comparators

	Autistic spectrum		Asperger’s / HFA		Challenging behaviour	Down’s syndrome
Bolton	1,840	1.2%	830	0.5%	68	115
North West	50,200	1.2%	22,590	0.5%	1,780	3,097
England	375,780	1.2%	169,100	0.5%	13,180	23,378

Source: Planning4care Estimates, 2009 (see footnote under Table 7.2 for details)

Table 7.12 Estimated numbers of young people aged 14-17 with Learning Disabilities by category, Bolton and comparators

	Autistic spectrum		Asperger’s / HFA		Challenging behaviour	Down’s syndrome
<b>Bolton</b>	<b>160</b>	<b>1.2%</b>	<b>74</b>	<b>0.5%</b>	<b>&lt;10</b>	<b>12</b>
North West	4,280	1.2%	1,930	0.5%	170	297
England	30,560	1.2%	13,750	0.5%	1,210	2,123

Source: Planning4care Estimates, 2009 (see footnote under Table 7.2 for details)

Table 7.13 Estimated numbers of adults aged 65+ with Learning Disabilities by category, Bolton and comparators

	Autistic spectrum		Asperger’s / HFA		Challenging behaviour	Down’s syndrome
<b>Bolton</b>	<b>440</b>	<b>1.1%</b>	<b>200</b>	<b>0.5%</b>	<b>&lt;10</b>	<b>&lt;10</b>
North West	12,440	1.1%	5,600	0.5%	220	41
England	91,830	1.1%	41,320	0.5%	1,610	300

Source: Planning4care Estimates, 2009 (see footnote under Table 7.2 for details)

## 8. Service implications

### 8.1 Current patterns of support for people with learning disabilities in Bolton

Table 8.1 gives the proportions of working age adults with learning disabilities in Bolton in different forms of ‘settled’ and ‘non-settled’ accommodation. These are taken from the NASCIS return L2<sup>16</sup>. These proportions have then been applied to the total number of people (aged 18-64) with learning disabilities known to services<sup>17</sup>, to give an estimate of the total full-year numbers in different forms of accommodation during 2008-09.

Table 8.2 gives the numbers of adults with learning disabilities in Bolton who were supported in the community during 2008-09, and the numbers (and proportions) receiving different types of service. This data is taken from NASCIS return P2f and C2.

The tables show:

- Bolton has a very much lower proportion of working age adults in long-stay accommodation (registered care home etc)<sup>18</sup> and a lower proportion living independently in the community than the average for the region or nationally, and a higher proportion of people living in the community with family or friends .
- Of those supported in the community, a high proportion receive a carer service (53% compared to 18% in the North West and 20% nationally); a lower than average proportion attend a day care service.
- People over 65 receive a very much more restricted range of services than younger adults – primarily home care.

<sup>16</sup> This information began to be gathered for the first time in October 2008; it therefore covers only those receiving assessments or reviews in the second six months of the year 2008-09.

<sup>17</sup> Taken from the P1 return.

<sup>18</sup> Note, this is an estimate based on part-year L2 data; the P1 return indicates a total of 65 people aged 18-64 with learning disabilities who are in residential care

*Table 8.1: Proportions and number estimates of people of working age with learning disabilities in different forms of accommodation*

	Registered care home, nursing home, long-stay hospital	Other non-settled accom'n	Supported accom'n/ sheltered housing/ APS	Settled in community with family or friends	Living independently
% of those receiving services in Bolton	4.8%	2.4%	24.1%	53.0%	15.7%
Estimated Number	30	15	150	330	100
% in North West	11.6%	2.1%	23.1%	37.0%	26.2%
% England	28.4%	2.0%	17.4%	35.8%	16.5%

Source: National Adult Social Care Intelligence Service (NASCIS), 2009

Table 8.2 Adults supported in the community, by service type

	Total supported in the community	home care	day care	direct payments	short-term residential	professional support	carer service	carer advice
numbers in Bolton	565	195	175	110	40	210	320	30
	50	35	--	--	--	5	--	--
% of those supported in community (total)		37.7%	28.7%	18.0%	6.6%	35.2%	52.5%	4.9%
% in North West		40.1%	46.3%	11.4%	4.9%	36.2%	17.7%	4.6%
% in England		33.3%	48.1%	12.4%	5.5%	37.7%	20.0%	6.8%

Source: National Adult Social Care Intelligence Service (NASCIS), 2009

## 8.2 Comparison of need against current service data in Bolton

Table 8.3 compares the estimated numbers in Bolton with different levels of severity of learning disability with the total numbers recorded as known to the council<sup>19</sup>.

- The estimated number of adults aged 18-64 across Bolton with profound or severe learning disabilities is around 750. Based on the number known to Bolton services, most of this group are likely to be receiving services
- However, there are is an estimated total of 5,050 adults across the LA area with a learning disability at moderate level and above, with around 13% of these known to services.

Table 8.3: Estimated numbers with different levels of severity of learning disability compared to total number known to social care services

Age	Estimated numbers of adults with LD in Bolton			Number known to Bolton council services (2008-09)
	PMLD	SLD	MLD	
18-64	81	670	3,430	615
65+	10	83	780	60

Source: National Adult Social Care Intelligence Service (NASCIS), 2009; *Planning4care Estimates*, 2009

### Current patterns of support against levels of need

Estimates indicate that around 13.4% of adults (age 18+) with a learning disability at moderate level and above are currently known to social care services. Assuming that most adults with PMLD and SLD levels of learning disability are known to services, this indicates that very few people with a moderate level of learning disability receive some form of social care support.

Around 92% (565 people) of people with learning disabilities aged 18-64 known to social care services are supported in the community (this compares with an average of 80% for England). Of these, about 53% (around 330) are living permanently with family or friends; around a further 100 live independently in owner-occupied or rented accommodation. For 52.5% of those supported in the community, there is also a carer service provided, with carer advice or information being given in a further 4.9% of cases.

It is interesting to compare these current data with the results of the Valuing People survey undertaken in 2003-04. The survey found that 30% of those with profound and multiple levels of learning disability, 17% of those with severe learning disabilities and 13% with moderate learning disabilities were in residential or NHS accommodation. Based on the Bolton estimates, this would be the equivalent of around 580 people. Of those living in the community, just 4% (2% of those with severe levels of learning disability and 7% with moderate learning disability) were living alone.

<sup>19</sup> Taken from NASCIS return L2 (2008-09)

## 9. Methods for estimating cost of care for adults with Learning Disabilities

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### 9.1 Overview

In this section we link the needs categorisations (used above for estimating prevalence) to indicative support needs and costs, in order to model overall costs for supporting people with learning disabilities now and in the future.

### 9.2 Methodology

Bolton and the five pilot areas provided a series of case studies, as a basis to determine representative costs for the different levels of LD severity (PMLD, SLD, MLD) as used in the initial prevalence estimates. The case studies requested were based on a combination of levels of LD severity and diagnostic characteristics, in order to determine whether there were particular characteristics that would tend to incur significantly different costs within a given level of severity, indicating a modification to the needs groupings.

#### *Costing social care and support*

- Social care and support input, including support workers, home care, day activities, respite care and night support, were costed through collaboration with the Care Funding Calculator (CFC)<sup>20</sup> project. The CFC calculates a normative social care cost based on the precise support requirements of an individual client. We applied the CFC tool to the 'case study' examples provided by the pilots in order to generate a set of indicative resource levels and costings for community based support for people falling within the different Learning Disability needs groups adopted by Planning4care<sup>21</sup> (see Table 9.3).

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<sup>20</sup> CFC has been developed by the South East RIEP, and is now being rolled out on a national basis, see <http://www.southeastiep.gov.uk/page.asp?PageRef=152>. Thanks to Suzanne Gale at the South East RIEP, and Jessica Bar at London Borough of Barnet, for their support in using CFC with Planning4care.

<sup>21</sup> See Section 6 above for further information on our methodology.

- In each case, where appropriate, separate CFC costings were produced for (a) supporting the client in their own home, and (b) supporting them in their own accommodation within an Independent Living scheme. In the latter case, the CFC allows for an additional background support element (i.e. in addition to the specific support needs of the individual) – the cost of this being shared across the service users in the scheme. For the case studies we have assumed that version (a) is based on a single service user in each case, and version (b) on an Independent Living scheme comprising a 5-flat complex with one service user in each. This avoids introducing variation between the costings due to variations in living arrangements, rather than variations in support needs. The case studies do, however, allow for variation in the degree of informal support available. Further variations and assumptions are outlined in the individual costings (Table 9.2).
- Different unit costs may apply in different localities. These can be changed in the CFC tool, in which all councils are placed in one of four cost bands. Three of the pilot councils<sup>22</sup> fall into the lowest cost group (cost group 1), while the others<sup>23</sup> fall into cost group 2. Table 9.2 gives both sets of costings (with the Group 2 costs in brackets).

#### *Costing community and professional support*

- Community health and other health/ social work professional input was costed using national unit costs of health and social care (PSSRU 2008)<sup>24</sup>; see Table 9.1 below.

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<sup>22</sup> Derbyshire, North Tyneside, and North East Lincolnshire are in cost group 1.

<sup>23</sup> Rochdale and Essex are in cost group 2, as are Bolton who also provided case studies.

<sup>24</sup> PSSRU, 2008, Unit Costs of Health and Social Care.

### *An additional ‘serious challenging behaviour’ needs group*

Based on the CFC tool indicative costings, we identified a key factor underpinning the level of costs as the presence of ‘serious challenging behaviour’ – requiring a more intensive level of supervision (typically 1:1 or 2:1 at all times) than would be implied by the LD level alone. We have therefore identified a separate needs category comprising SLD/MLD in combination with serious challenging behaviour<sup>25</sup>. The case studies were used as a basis for developing indicative costings for these groups.

### 9.3 Application of cost estimates to case studies

Table 9.2 below gives the example support needs and costings developed through the case study material. General assumptions adopted in the costing of the case studies are given below. All of these parameters can optionally be varied within the CFC tool.

#### *At home*

- Household includes a single service user
- A daytime shift is 15 hours
- A waking/sleeping night is 9 hours
- No available shared background support or on-call night support
- All support is at ‘basic grade’ (as opposed to ‘more skilled worker’) unless otherwise noted.

#### *Independent Living*

- Service user lives alone but facility has 4 other flats, giving total service capacity of 5
- A daytime shift is 15 hours
- A waking/sleeping night is 9 hours
- Shared background support is 8 hours Mon-Fri; 4 hours Sat/Sun
- Includes shared on-call and sleep-in night cover

- All support is at ‘basic grade’ (as opposed to ‘more skilled worker’) unless otherwise noted.

The CFC tool gives a range of costings in each case, based on a range of hourly rates. The social care costings given in Table 9.3 represent the mean of the maximum and minimum values. In some instances variations have been made to the CFC costings (e.g. the inclusion of allowance for respite care); these are as indicated in the ‘pen picture examples’ column.

The final columns of Table 9.2 and 9.3 give indicative costings (where information was included in the case studies) for community health support, and other regular health/social care professional support. We have assumed that case management/ care coordination support is required in all cases; this has been added where no care coordinator/ social worker cost has been explicitly indicated in the case study. The unit costings adopted here are based on *PSSRU, 2008, Unit Costs of Health and Social Care*, see Table 9.1:

*Table 9.1: Unit costings for community health and other regular health/social care professional support*

	Cost per hour face-to-face contact	Cost per week for monthly contact
Care Coordinator/ Social Worker	£138	£32
Consultant Psychiatrist	£274	£63
Clinical Psychologist	£72	£17
Occupational Therapist/ Speech & Language Therapist (SALT)	£40	£9
Community Nurse	£64	£15
Clinical Support Worker	£23	£5
Community Health Clinic (e.g. chiropody, audiology)	£23	£5

Source: PSSRU, 2008

<sup>25</sup> There will also be people with serious challenging behaviour in the PMLD group, but these will already be counted as receiving intensive packages of care.

Table 9.2: Illustrative examples of support needs and costs

Pen picture examples		Informal support (if any)	FACS level	Indicative ongoing social care costs (daily living) £ per week		Indicative community health and other health/ social care professional support £ per week
				Supported in own home	Independent living	
<b>1. PMLD</b>						
	No community-based pen pictures currently available (see note 2 following this table)					
<b>2. SLD/MLD with serious challenging behaviour</b>						
Example 2.1	Female aged 22, moderate to severe LD with significant behavioural impairment. For safety, requires 2 staff to support at all times in the day and 2 sleeping in at night; requires support with self-care skills and considerable assistance with domestic activities. Multi-disciplinary team have stipulated that client requires a single person service.		Critical	£2,868 [£3,255]	N/A <sup>26</sup>	Psychiatrist (weekly) CPN (1/2-hr weekly) Social worker (weekly) Psychologist (weekly) Challenging behaviour specialist <sup>27</sup> (weekly) £588
Example 2.2	Male aged 31; mild LD with serious self-injurious and sexually inappropriate behaviour; serious risk of (re)-offending. Requires 1:1 support during waking hours, and waking night cover.		Critical	£1,434 [£1,628]	£1,612 [£1,827]	Psychiatrist (monthly) Community LD Nurse (weekly) Social Worker ( 2 hrs weekly) £403
<b>3. SLD</b>						
Example 3.1	Male aged 60, severe LD (Down’s syndrome); also severe hearing impairment, sight impairment and early stage dementia; non verbal but communicates with gestures; can be incontinent at night. Needs 1:1 support for all aspects of daily living; supervision needed at all times on a 1:3 ratio; sleep-in support needed at night. Social care costing includes addition to CFC costing of 5		Critical	£1,221 [£1,341]	£1,098 [£1,215]	Psychiatrist (monthly); Speech & Language Therapist (6-weekly) Care coordinator (monthly) £102

<sup>26</sup> As client requires 2:1 support at all times, independent living based on a degree of shared support unlikely to be appropriate

<sup>27</sup> Assumed clinical psychologist rate

Pen picture examples	Informal support (if any)	FACS level	Indicative ongoing social care costs (daily living) £ per week		Indicative community health and other health/ social care professional support £ per week
			Supported in own home	Independent living	
days per week Day Centre cost @ £47 per session (from PSSRU 2008 Unit Costs)					
<p>Example 3.2</p> <p>Male aged 24, autism (LD level not specified). Spends most of his time in his own room which has been specially adapted for his needs. Requires 24-hr support to keep him safe; needs help with personal care on a daily basis. Social care costing includes adjustment to average weekly CFC costing (home care version) to allow for respite care by costing 4 weeks of the year at IL rate.</p>	Lives in family home; father transports to/ from services	Critical	£901 [£1,027]	£1,187 [£1,354]	Care coordinator (assume monthly) Social worker (assume monthly) Occupational Therapist (periodic - assume average monthly) Psychologist (periodic - assume average monthly) £90
<p>Example 3.3</p> <p>Female aged 25, moderate LD with severe hearing impairment and physical disability. Can manage basic personal care, but requires 1-1 support with all other activities of daily living.</p>		Substantial	£989 [£1,130]	£1,167 [£1,329]	Psychologist (weekly) Chiropody, audiology clinics (bi-monthly) Care coordinator (monthly) £109
<p>Example 3.4</p> <p>Male aged 21; moderate LD with Asperger's syndrome and some challenging behaviours. Requires daily support with all personal care and support for social activities; attends specialist education centre 5 days per week; requires sleep-in night cover.</p>		Substantial	£1,161 [£1,328]	£1,339 [£1,527]	Psychiatrist (assume monthly) Psychologist (assume 2-weekly on average) Care coordinator (monthly) £131
<b>4. MLD</b>					
<p>Example 4.1</p> <p>Male aged 31, autism (LD level not specified); experiences regular episodes of anxiety– liable to be related to breaks with routine. Independent re personal care, but requires some support with household tasks (including cooking); requires support</p>		Not specified	£627 [£717]	£805 [£916]	No details supplied

	Pen picture examples	Informal support (if any)	FACS level	Indicative ongoing social care costs (daily living) £ per week		Indicative community health and other health/ social care professional support £ per week
				Supported in own home	Independent living	
	with shopping and all aspects of financial management; package assumes shared night cover.					
Example 4.2	Male aged 39 with Down's syndrome (mild LD); obese and suffers from minor heart problem; little understanding of finance and budgeting. Relatively independent but needs prompting and support to get up in the morning and go to bed at night (with attendant tasks). Case study specifies on-call night support; 'home' version of CFC attributes this cost on a non-shared basis.		Moderate	£494 [£557]	£536 [£608]	Community LD Nurse (monthly); Psychologist (assumed weekly) Care coordinator (monthly) £119
Example 4.3	Male aged 21 with autism (moderate LD); manages own personal care with minimal support; can make basic meals with verbal prompts; requires support with all financial activities; attends college 3 days a week. Currently receiving day-to-day support from parents. Social care costing includes adjustment to average weekly CFC costing (home care version) to allow for respite care by costing 4 weeks of the year at IL rate.	Lives in family home; transported to and from college by parents	Substantial	£409 [£452]	£573 [£637]	No details supplied
Example 4.4	Male aged 46, moderate LD plus some physical disability and anger management problems. Independent re basic personal care; requires assistance with preparing cooked meals, heavy domestic chores and finances. Social care costing includes addition to CFC costing of 2 days per week Day Centre cost @ £47 per session (from PSSRU 2008 Unit Costs)		Moderate	£257 [£281]	£435 [£479]	Psychologist (weekly) Care coordinator (monthly) £104
Example 4.5	Female aged 26; mild to moderate LD with Aspergers. Currently living in family home; receives 10 hours per week (NAS) outreach support	Lives at home with mother	Moderate	£126 [£144]	£303 [£343]	Care coordinator (monthly) £32

### 9.4 Interpretation and use of indicative costings

Table 9.3 below uses the case study materials developed in Table 9.2 to give lowest, mean and highest indicative costs for each of the needs groups identified.

Table 9.3: Mean indicative costs per group<sup>28</sup>

Needs group	Ongoing social care costs (daily living)(£ pw)			Community health/ professional support (Mean cost, £ pw)	Mean total community cost (social care, comm health) (£ pw)
	Lowest case (home care or IL)	Highest case (home care or IL)	Mean (all cases)		
PMLD			see note 2 below		see note 2 below
SLD/MLD with serious challenging behaviour	£1,430 [1,630]	£2,870 [£3,260]	£1,970 [£2,240]	£500	£2,470
SLD (other)	£900 [£1,030]	£1,340 [£1,530]	£1,130 [1,280]	£110	£1,240
MLD (other)	£130 [£140]	£800 [£920]	£460 [£510]	£90	£550

Costs given are for cost group 1 (Derbyshire, North East Lincolnshire and North Tyneside), while costs in square brackets are for cost group 2 (Bolton, Essex and Rochdale)

#### Notes and observations

- 1 It is important to recognise that the number of case studies for each needs group is small, and cannot therefore fully represent the range of support needs that may be relevant for different groups. This material should therefore be regarded as illustrative only.
- 2 No case studies/ costings have to date been obtained for care in the community of people with profound and multiple learning disabilities. However, we suggest that this would be likely to be at a similar level to serious challenging behaviour, where the two case studies are based on requiring 2:1 and 1:1 support at all times respectively. The community health care component is likely to be greater for people with profound and multiple disabilities.
- 3 These high intensity community care costs may be compared with residential care costs for people with learning disabilities. The PSSRU 2008 unit costs cite £1,335 establishment costs per resident week for NHS residential campus provision. The 2008-09 average social services unit cost for LD residential care was £1,140 (NASCIS, 2008-09)<sup>29</sup>, with average upper tier local authority values ranging from £640 to £2,380.
- 4 Indicative costs for people supported in their own homes may be significantly reduced where they are living with family members; however, where they are living alone there can be economies of scale introduced through the shared support services possible under Independent Living schemes.
- 5 Where information has been available to enable indicative estimates of the costs of community health and other professional support for people with learning disabilities supported in the community, these costs appear in general to constitute between about 10% and 20% of the overall (health and social care) support costs. It is likely that this proportion would become higher in the case of people with profound and multiple disabilities.
- 6 No case study information was available for people with Asperger's syndrome/ high functioning autism, but without a Learning Disability,

<sup>28</sup> Rounded to nearest £10

<sup>29</sup> See <http://nascis.ic.nhs.uk/>

because this group tends by definition to fall outside of the remit of learning disability services. They are also likely to fall outside the remit

of mental health services.

## 10. Estimating cost of care for adults with Learning Disabilities in Bolton

### 10.1 Overview

The indicative costings drawn from the case study examples in the previous section provide an illustration of the ongoing social care and community health/ professional support costs for the different needs groups. In addition, the case studies identified a key addition to the needs typology: the presence of *serious challenging behaviour* in people with severe and moderate levels of learning disability is a key critical factor affecting the level of care package required for people in these groups<sup>30</sup>.

It would be possible to apply the indicative costs in Table 9.3 to the total Planning4care estimates of numbers and projected numbers in the different needs categories to give a broad indication of the total societal costs (compared with LA expenditure) of caring for people with different levels of learning disabilities. However, we have not done so, for four key reasons:

- The number of case studies for each needs group is small, and not randomly sampled, so may not therefore fully represent the range of support needs that may be relevant for different groups
- The main sub-factor likely to affect the size and cost of care packages is whether the client lives alone, or with informal support. A recent study based on the Sheffield and Leicestershire Learning Disability registers<sup>31</sup>

<sup>30</sup> The prevalence of the subgroups of people with severe and moderate levels of learning disability and with serious challenging behaviour is determined as 7.3% of those with severe and moderate learning disability known to services (the 'administrative' prevalence). We have considered only those in the 'administrative' group with severe and moderate levels of learning disability; there will also be people at PMLD level with serious challenging behaviour, but these will already be counted as receiving intensive packages of care. Also see Emerson E, *Challenging behaviour: Analysis and intervention in people with severe intellectual disabilities* (second edition, 2001), p.19

<sup>31</sup> Institute of Public Care, 2009, Working paper 1: *Estimating the Prevalence of Severe Learning Disability in Adults*.

indicated that a high proportion of adults with learning disabilities continue to live supported by parents, ranging from 66% of 20-24 year-olds to 5% of 60-64 year-olds with a 'severe' level of learning disability as defined by the SPI (Social and Physical Incapacity) diagnostic ratings. Local NASCIS returns (2008-09) indicate that 53.0% of people with learning disabilities receiving services in Bolton are settled in the community with family or friends (Table 8.1). Whilst the case studies in this section include some instances of clients living in the family home with parental support, the small number of case studies at present does not allow separate sets of indicative costings to be developed for those living alone and those living with family.

- The indicative costings given by the case studies are for the provision of community-based care, in line with the current movement towards younger adults with disabilities being supported at home or in independent living schemes in the community, rather than in residential homes. However, the likelihood in most locations is that significant numbers, especially among the more severely disabled, are currently still living in residential care.
- For some types of learning disability in particular it is likely that people will move in and out of services rather than accessing them continuously. At England level, the estimated total number for 2009 of people aged 18-64 with a learning disability and known to services (the 'administrative' total) is 182,600. From the RAP returns for 2008-09<sup>32</sup>, the total number of people aged 18-64 with learning disabilities receiving social care services during the year was 128,000.

However, the indicative costings do provide a broad comparison for ongoing social care and community health/ professional support costs for the different needs groups.

<sup>32</sup>From NASCIS 2009 at <http://nascis.ic.nhs.uk>

## 10.2 Actual spend on Learning Disability services across Bolton and the pilot areas

Tables 10.1 and 10.2 show the LD budget and average spend per capita, and per client, across Bolton and the pilot areas.

The tables show significant variation in both annual spend per capita (working-age population), and average spend per client receiving services. At the upper end, Essex spends £146 annually for every 1,000 people of working-age (35% above the national average of £106), and an average of £36,600 per client (37% above the national average). At the lower end, North East Lincolnshire spends £64 annually for every 1,000 people of working-age (40% below the national average), or an average of 14,700 per client annually (45% below the national average).

This variation is not explained by differences in the average number of clients per working age-population, which varies to a much lesser degree (from 386 clients per 100,000 population in Bolton, to 458 in Derbyshire). It is likely that expenditure differences are in part due to differences between the caseload severity. Further analysis of local cases would be needed to explore this further.

Comparison of the average weekly spend per client against the cost identified from the pen portraits (Table 9.3) suggests that the average pen portrait costs (weighted by the estimated numbers within each needs group known to services) are above the average social care budget spend per client. As identified in Section 9.4, the number of case studies for each needs group is small, and the sample of pen portraits was not taken randomly from actual clients.

Table 10.1: LD budget and average spend per capita across Bolton and the pilot areas

	Total working-age population 2008 (000)	Total adult LD budget 2008-09 (£ 000)	Assessment & care mgmnt (£ 000)	LD budget excl care mgmnt (£ 000)	Annual spend per 1000 working-age population (£)
Essex	843	126,867	3,327	123,540	146
North East Lincolnshire	95	6,544	424	6,120	64
Derbyshire	463	54,295	1,545	52,750	114
Rochdale	127	14,547	1,080	13,467	106
North Tyneside	122	15,958	1,034	14,924	122
Bolton	159	14,752	2,004	12,748	80
England	31,938	3,639,973	252,921	3,387,052	106

Table 10.2: LD budget and average spend per client across Bolton and the pilot areas

	Total adult LD budget 2008-09 (£ 000)	Number of clients receiving services 2008-09	Average number of clients per 100,000 working-age pop'n	Average annual spend per client (£)	Average weekly spend per client (£)
Essex	126,867	3,375	400	36,600	700
North East Lincolnshire	6,544	415	436	14,700	280
Derbyshire	54,295	2,120	458	24,900	480
Rochdale	14,547	535	421	25,200	480
North Tyneside	15,958	505	413	29,600	570
Bolton	14,752	615	386	20,700	400
England	3,639,973	127,975	401	26,500	510

## Appendix A Learning Disability References

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