

## SERVICES COMMISSIONED FOR PEOPLE WITH LEARNING DISABILITIES IN BIRMINGHAM

### 1. INTRODUCTION:

BENPCT commissions learning disability services on behalf of the 3 Birmingham PCTs.

### 2. DEMOGRAPHICS AND TRENDS IN NEEDS:

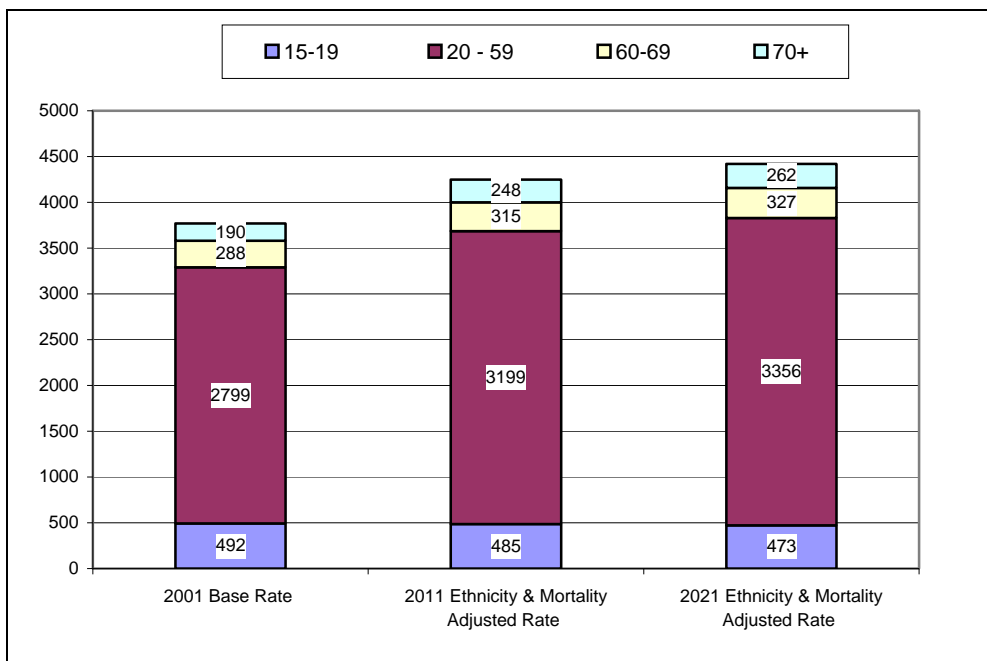
2.1 Based on projections of the 2001 Census, it is estimated that Birmingham has:

25,115 people with a mild or moderate learning disability – most of whom can live independently without support

4,020 people with a severe or profound learning disability – most of whom will require significant help with daily living.

2.2 Chart 1 shows the predicted change in the age profile of the population likely to require health and / or social care services, increasing in numbers to 4,247 by 2011 and 4,418 by 2021. Although the birth rate of people with learning disabilities in Birmingham is stable, those who have survived have considerably more complex health and disability needs.

**Chart 1 Number of Adults with a learning disability needing individualised health or social care services in Birmingham by age group from 2001 – 2021**



Ref: Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Emerson & Hatton, 2004 applied to population from the 2001 Census

2.3 The numbers are rising of people with a learning disability aged 50 and over as health care and standards of living improve. Although their life expectancy is moving towards that of the general population many will experience the problems of ageing earlier than their counterparts in the general population and there is still an increased risk of early death. This is particularly a problem for people

with Downs Syndrome, 50% of whom are expected to develop a very aggressive form of dementia by their 50<sup>th</sup> birthday with a life expectancy of between 5 – 15 years from diagnosis.

2.4 About a third of people with a severe or profound learning disability using services also have an autistic spectrum disorder. Recent evidence shows a 4 fold increase in the incidence of autistic spectrum disorders in the current 5 year olds compared to 15 years olds in Birmingham special schools that cannot be solely explained by better diagnosis and widening of the diagnostic criteria.

2.5 By 2021, the proportion of South Asian people with learning disabilities aged 20 or over is expected to increase from 19% to 28% of the overall population of people with a learning disability and by 2011 they will make up 42% of those aged 20 to 39.

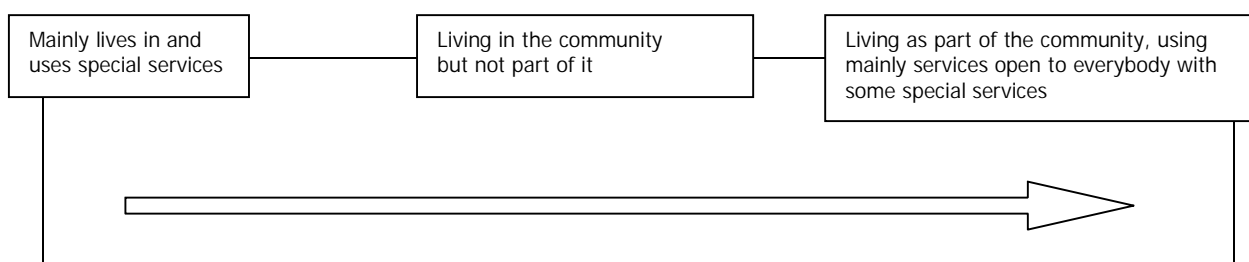
2.6 People with learning disabilities have an increased risk of morbidity and early mortality compared to the general population and health screening shows high levels of unmet physical, sensory and mental health needs. A pilot in Birmingham indicated that 9,000 individuals with learning disabilities have significant health risks but the 4,500 most at risk are those with the highest dependency needs and already known to services.

**2.7 Summary of additional care / health needs of people with learning disabilities and their carers:**

	<b>Predicted Number</b>
Estimated total population of people with LD in Birmingham	29,135
PLD expected to be known to existing services	4,495
PLD with significant physical dependencies	1,933
Behaviour problems - frequent	1,888
Behaviour problems that pose major challenges to ordinary life	1,341
Dementia	6,120
Poor dental care	10,342
Epilepsy	6,234
Major mental health needs	1,259
Psychosis	850
<b>Carers of PLD in Birmingham</b>	<b>1,473</b>
Female carers of PLD	1,311
Female carers of PLD with life limiting disorders	589
Carers aged over 70	518

Based on prevalence rates produced by Emerson et al

**3. Strategic direction of travel for meeting needs:**



3.1 The Joint Commissioning Strategy for people with learning disabilities proposes that the amount of specialist services that only people with learning disabilities and their carers will use, will

be kept to a minimum. People's needs will be met in the least restrictive settings possible, based on risk assessment. Services that are open to everyone may have to change to make it easier for people with learning disabilities and their carers to use them.

#### **4. COMMISSIONED SPECIALIST HEALTH SERVICES:**

4.1 BEN PCT, as the lead commissioner, commissions about £31m of specialist health care services

4.2 Health services are commissioned on a citywide basis largely from the specialist Learning Disability Directorate of South Birmingham PCT and include:

- LD community nurses with specialists in ageing, epilepsy and Health Facilitation
- Psychiatry
- Clinical Psychology
- Speech & Language Therapy
- Physiotherapy, Dietetics and Occupational Therapy
- Supported Living Outreach Team (SLOT) nurse consultancy team to oversee the management of people with extreme challenging behaviours in their own homes
- Community Forensic Team including a Forensic step down unit with 9 beds in 4 houses in the community that are registered as a hospital under the Mental Health Act
- Birmingham Community Assessment Team – providing assertive outreach assessment and treatment, in the community, a day hospital and 6 in-patient beds
- Health related day and respite care services
- Health related end of life and step down rehab care services

4.3 Specialist health services are also commissioned from other providers:

- 9 in patient beds from Coventry & Warwickshire Partnership Trust
- Spot purchased in patient beds from independent sector hospitals
- Independent sector day services

#### **5. COMMISSIONED SPECIALIST SOCIAL CARE SERVICES:**

5.1 BEN PCT, as the lead commissioner, funds about £26.5m of social care services for adults with learning disabilities as a legacy from the closure of the Monyhull and St Margaret's long stay hospitals in 1996. £5.3m is routinely transferred each year to Birmingham City Council for them to commission social care services for these individuals and their successors. The remaining services are commissioned by BENPCT on behalf of the local authority from a range of providers as follows:

5.1.1 Social care services commissioned by BENPCT from SBPCT:

- Care services in independent sector care homes and care homes with nursing
- Care services in 3 homes owned by the NHS
- Specialist day and respite care services

5.1.2 Social care services commissioned by BENPCT from independent sector agencies:

- Care services in independent sector care homes and care homes with nursing

#### **6. KEY ISSUES FOR CHANGE:**

- Poor access to mainstream health services especially primary care, acute hospital services and mental health services
- Recent significant growth in the numbers of people requiring support with dysphagia and Home Enteral Tube Feeding in particular
- Escalation of obesity related health problems

- DoH policy that all people must be discharged from NHS owned and run care provision by March 2010 (aka Campus Closure Programme). The definition was broadened recently and there are 25 people in Birmingham affected by this Programme.
- SBPCT respite care homes are not CSCI registered and most will not meet the registration standards without significant investment
- The S31 (now S75) Pooled Budget to be expanded to transfer the PCT social care funding for learning disability services to the local authority
- High risk of escalation in the costs of care services as service that used to be provided by SBPCT in care homes are re-tendered. Managing the risks arising from TUPE entitlements is the main factor.
- Growth in the numbers with dementia who have poor life expectancy that could be tripled with better informed services
- Poor access to services and management of high levels of challenging behaviour for some carers.
- Increased complexity of teenagers in transition

## **7. DEVELOPMENTS PLANNED for 2008-11:**

- Increase in capacity and modernisation of specialist dietetics to:
  - Develop services to support Home Enteral Tube Feeding
  - Develop outreached healthy lifestyles activities in community leisure settings as a fun activity.
- Hold a Health Event at Villa Park, 17<sup>th</sup> October 2008, to increase take up of annual health checks and Health Action Plans in particular and showcase health promoting services. Continue to engage GPs in doing the checks and facilitating access to acute hospitals
- Increase the capacity of the Supported Living Outreach Team to grow from 35 to 80 cases of people with high levels of challenging behaviours.
- Increase the capacity of the BCATs assertive outreach team to reduce hospital admissions by stabilising people's community living arrangements and to facilitate the discharge from hospital to the community of forensic cases requiring intensive support.
- Review and extend the Pooled Budget with the local authority
- Re-provide for all people affected by the Campus Closure Programme
- Procure alternative independent sector care provision in all care homes served by SBPCT and novate all the social care contracts to the local authority to manage.
- Facilitate the integration of community health and community care services
- Agree the future of SBPCT day and respite care services.
- Development and dissemination of information on learning disability and related services to community organisations including Asian media to create understanding and improve access to services
- Further development of training for South Asian households on the management of challenging behaviour
- Develop dementia screening tool and implement for all over 30 years of age
- Develop dementia and end of life outreach services for people with learning disabilities
- Develop information in accessible formats on aspects of the ageing process
- Implement the Transitions Pathway for all teenagers with complex needs to ensure smooth transfer to adult services.

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**13<sup>th</sup> June 2008**

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