

KINGSTON PRIMARY CARE TRUST
SERVICES FOR PEOPLE WITH LEARNING DISABILITIES
REPORT FOR JOINT COMMISSIONING GROUP
JANUARY 2007

INTRODUCTION

This report outlines the profile of service users accessing specialist health care support from the community learning disability teams in Kingston and Richmond. An analysis of support needs is included.

Classification of learning Disability

The criteria used to determine if a person has a learning disability and therefore eligible for support from the community teams is detailed below. This classification is used by Kingston and Richmond teams.

There are three core criteria that need to be met for a person to be considered to have learning disability:

- significant impairment of intellectual functioning
- significant impairment of adaptive / social functioning
- age of onset of the these impairments before adulthood.

Classification of learning disability should only be made on the basis of assessed impairments of both intellectual and adaptive/social functioning which have been acquired before adulthood.

Following recent *BPS recommendations, the health professionals use two categories of sub-division of learning disability: significant and severe, in reference to both intellectual and adaptive/social functioning.

When making a judgement as to the degree of impairment of adaptive/social functioning, the following levels of support are considered.

Intermittent	Supports on an 'as needed basis' characterised by episodic nature. Person does not always need the support(s), or only short-term support(s) are needed during life-span transition (e.g. job loss or an acute medical crisis). Intermittent supports may be of high or low intensity when provided.
Limited	Supports characterised by consistency over time, time-limited but not of an intermittent nature. Person may require fewer resources than more intense

	levels of support.
Extensive	Supports characterised by regular involvement (e.g. daily) in at least some environments (such as work or home) and not time-limited.
Pervasive	Supports characterised by their high intensity are provided consistently across environments.

People with suspected learning disability or suspected autistic spectrum disorders are assessed by the health professionals who will then make recommendations on the level of health care support they may require.

***Reference: “Learning Disability: Definitions and Contexts”
Professional Affairs Board of The British Psychological Society
2001**

Prevalence of learning disability

It is estimated that 20 people per 1000 (2% of general population) in the UK have learning disability with 3-4 per 1000 having severe or profound learning disability. Valuing People estimates there are around 210,000 people with severe learning disabilities and more than 1.2 million people with mild/moderate learning disabilities in England. This equates to 8 people with severe LD and 50 with moderate/mild on a GP practice list of 2000 (reference: “Valuing Health for All” Institute of Applied Health and Social Policy, June 2003)

Service User Profile.

This report focuses on the activity of the health elements of the community teams and therefore does not include service users who have been placed out of borough. Out of borough clients continue to be care managed by the learning disability teams but their health needs are met by the local health services in the receiving borough.

Richmond

Total number of people known to services with a LD = 485
Number of people placed out of borough = 120
Number of people accessing community team services (in borough) = 328

Kingston

Total number of people known to services = 450
Number placed out of borough = 36
Number of people accessing community team services (in borough) = 280

Active clients by borough



Figure 1: LBRUT active clients

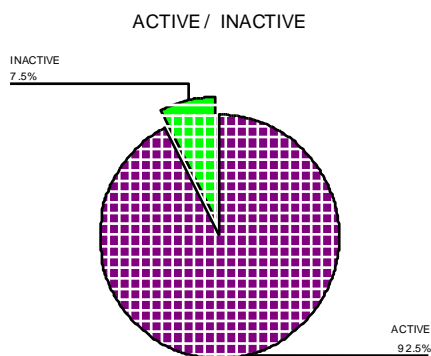


Figure 2: RBK active clients

Active clients are defined as those clients currently receiving input from the teams. Inactive are those people who have had previous involvement with the team but are not currently in need of input. Service users may need support intermittently throughout their lives, often during periods of life transition. This pattern of intermittent input as required, throughout the service users life span enables community teams to build up extensive knowledge of the current and predicted needs of the service users, resources available and allows rapid response should change in need occur.

Gender

There is a higher incidence of learning disability in the male population. The figures for Richmond and Kingston are in line with national trends. The profile is very similar in Richmond and Kingston.

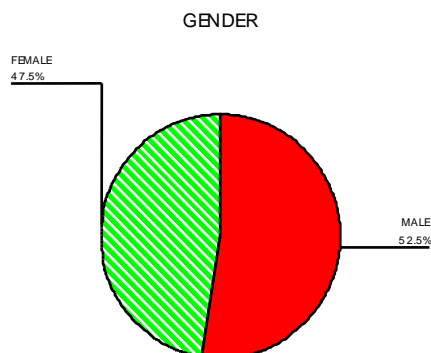


Figure 3: LBRUT Client gender

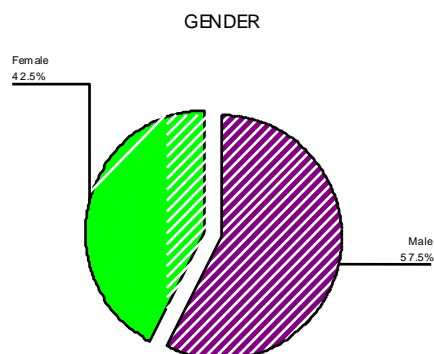


Figure 4: RBK Client gender

Age

	N	Range	Minimum	Maximum	Mean
AGE	328	72	18	90	43.60

Table 1: LBRUT Age statistics

	N	Range	Minimum	Maximum	Mean
AGE	280	86	18	104	42.65

Table 2: RBK Age statistics

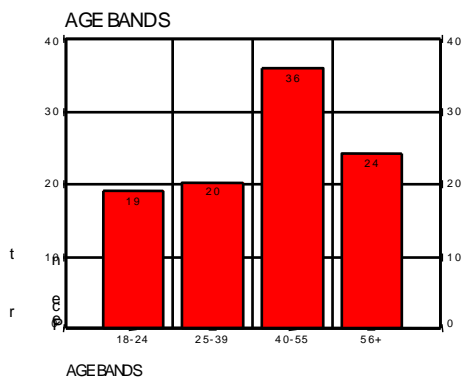


Figure 5: LBRUT Age Bands

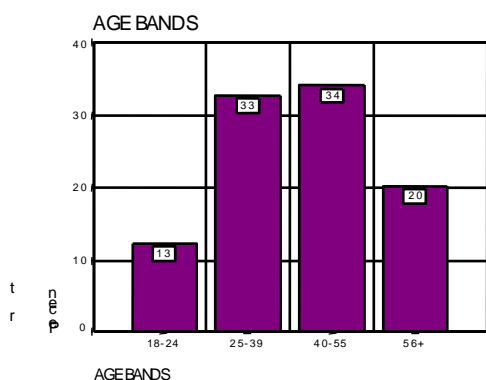


Figure 6: RBK Age Bands

The age distribution in the older age brackets is very similar in each borough. There appears to be a greater number of service users in the 25 -39 age bracket in Kingston.

Support Needs

Service users are accepted into the service at age of 18 if they fulfil the criteria for access to service. They may need supports of varying types and intensities throughout their lives.

The following classifications are used to describe the level of support needs of the current population of service users accessing specialist health supports from the community teams.

Intermittent

Requires episodic input of a time limited nature usually during periods of life transition eg, moving home, acute health crisis etc. Supports may be of high intensity but for short duration.

Limited

Support needs are of a more regular, consistent nature, time limited. Less resources are required than higher levels of need.

Extensive

Support is characterised by regular inputs on an ongoing basis in several environments.

Pervasive

Support is of high intensity, provided across all environments and on an ongoing basis.

The support needs may change over time with factors such as family circumstances, age, environment, medical conditions, impacting on the services users ability to manage. Service users may move between bands as circumstances change. This is particularly so for service users supported by family carers whose needs may change suddenly from lower to higher bands should the carers no longer be able to provide the support.

Service users living independently may also present with extensive needs in order to maintain them in their environment.

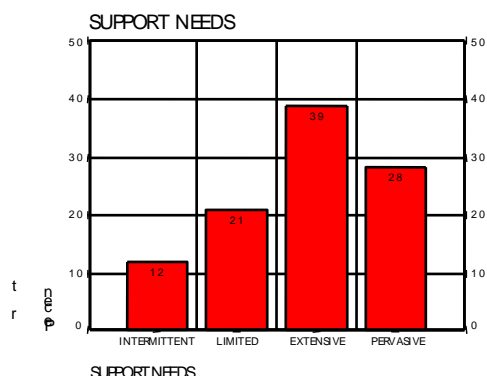


Figure 7: LBRUT Support Needs

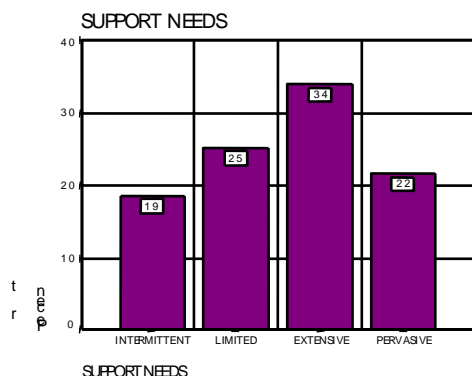


Figure 8: RBK Support Needs

Accommodation Needs

The following classifications have been used

Family home – living with family carers.

Independent – living independently with or without community support.

Supported living – living in a supported living environment, with regular staff support available.

Residential care – living in registered care home, full staff support available.

NHS – resident in NHS accommodation eg Elmbridge Lodge, Wesley Lodge

Other – registered nursing home, any other accommodation not listed.

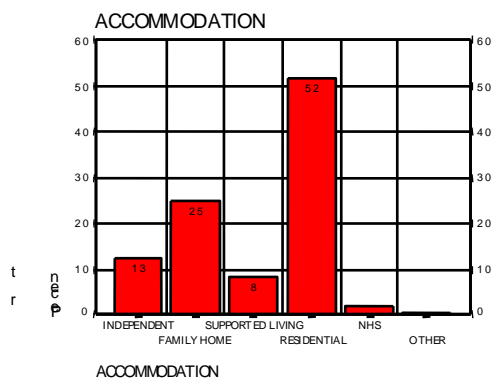


Figure 9: LBRUT Living circumstances

This chart illustrates that the greater number of service users in Richmond live in residential care.

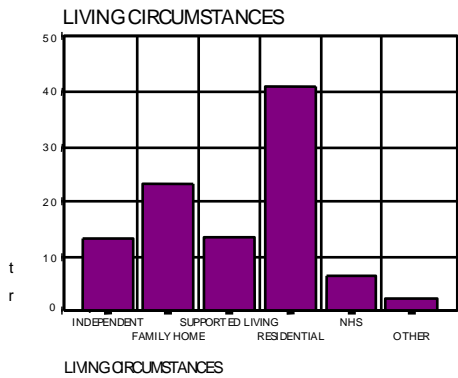


Figure 10: RBK Living circumstances

The distribution is similar in Kingston. There are similar numbers of people living with family carers in each borough. It is likely that a significant proportion of these carers will be older.

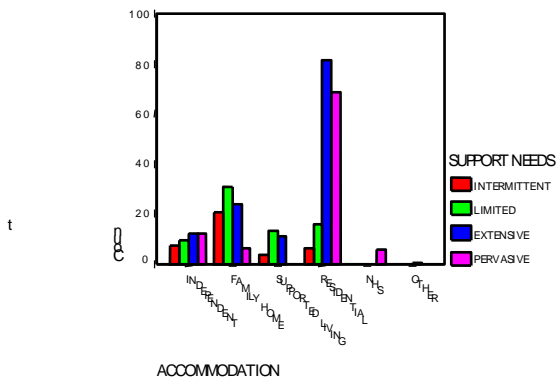


Figure 11: LBRUT support needs by accommodation

This chart demonstrates that as expected people living in residential care have extensive or pervasive needs.

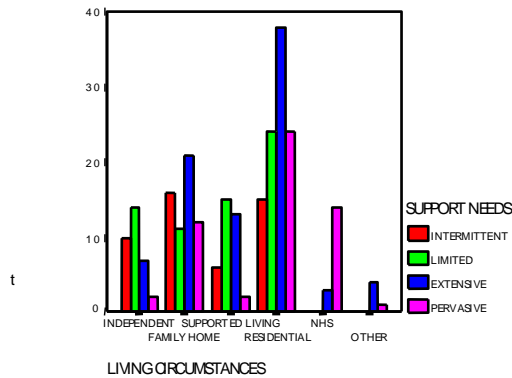


Figure 12: RBK support needs by accommodation

The distribution in RBK shows a similar level of extensive needs for people in residential care but there is a much higher proportion of people living at home with family carers who also have extensive needs. As many of these needs will be met by the family should the family support systems fail there is likely to be additional pressure on services.

The high proportion of pervasive needs in NHS accommodation can be explained by Kingston commissioning a higher number of places in Elmbridge Lodge.

Clinical Needs

People with learning disabilities present with a range of complex health and social care needs that determine the level and intensity of the support needed from community team services.

Co-ordinated multi-disciplinary packages of input are essential to meet these complex needs.

Packages of support

Community team health professional input activity is currently described in direct client contacts. It is important to note that a referral to the team enables access to some or all of the following elements:

- Assessment
- Intervention (direct treatment)
- Liaison
- Staff /carer support/ training
- Consultancy
- Systemic work
- Organisational support
- Multi professional expertise
- consultancy

The types of complex needs that service users may present include: eating and drinking problems (dysphagia), mental health issues, challenging behaviour, complex physical disability, sensory impairments, and autistic spectrum disorders.

People with learning disabilities have a higher incidence of conditions such as gastro-intestinal cancer than the general population (48 -58.5% vs 25% of cancer deaths). (Cooke, 1997; Duff et al 2001; Janker 1990)

Community teams in both boroughs have managed a number of terminal and palliative care cases. There is an extremely good working relationship between the community teams and the palliative care team to ensure appropriate and sensitive end of life management in line with best practice in this area.

The prevalence of dementia is much higher amongst older adults with learning disabilities compared to the general population (21.6% vs 5.7% aged 65+; Cooper, et al 1998). Figures for dementia have not been included in this report as the community teams in both boroughs are in the process of developing a clinical database of people diagnosed or suspected of having dementia, and accurate figures were not available for this report.

An analysis was though carried out of some of the other complex needs managed by the community teams.

Eating and Drinking problems (dysphagia)

Swallowing problems are more common in people with learning disabilities and if not managed appropriately can lead to respiratory tract infections, a leading cause of death for this client group.

One study has suggested that respiratory disease was a leading cause of death in 52% of adults with a learning disability compared with 15% of males and 17% females in the general population.

(Understanding the patient safety issues for people with learning disabilities, NPSA February 2004)

Epilepsy

The prevalence rate of epilepsy has been reported as 22% compared with prevalence rates for the general population of 0.4 -1%. People with learning disabilities often have more severe and complex forms of epilepsy and present greater diagnostic problems due to difficulties in communication and cooperation with investigations. Epilepsy is also a significant cause of death in this population.

Mental health problems

People with learning disabilities require support with emotional and psychological needs. Estimates of the numbers of people with learning disabilities who have mental health problems vary between 5 – 50 %. This variation is due to variations in the definitions of the problems and the procedures used for identification. Recognition of mental health problems and diagnosis of mental illness is more difficult than in the general population.

For this report the active psychiatric caseload was considered.

Complex physical disability.

Up to 30% of people with learning disabilities have associated physical disabilities most often cerebral palsy. Multiple disabilities are associated with complex health needs. For this report complex physical disability has been defined as severe physical disabilities, wheelchair dependent and totally dependent in all aspects of physical care.

Clinical Need

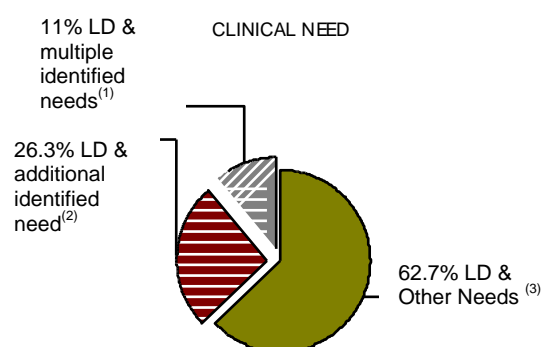


Figure 13: LBRUT Client Clinical need

Service users may present with combinations of need eg complex disability and dysphagia, psychiatric conditions and epilepsy.

The figure for LD only does not take into account other needs not analysed eg sensory impairments, challenging behaviour, autism etc.

(1) More than one clinical need identified for the purpose of this report (Epilepsy, dysphagia, complex disability, psychiatric conditions)

(2) One additional clinical need identified for the purpose of this report (Epilepsy, dysphagia, complex disability, psychiatric conditions)

(3) Other needs include behavioural problems, autistic spectrum disorders, emotional problems etc.

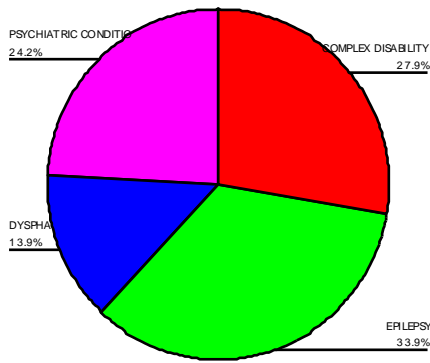


Figure 14: LBRUT Clinical need breakdown

This chart represents the relative proportions of each condition within the group identified as having complex needs. The overlaps between each category have not been illustrated.

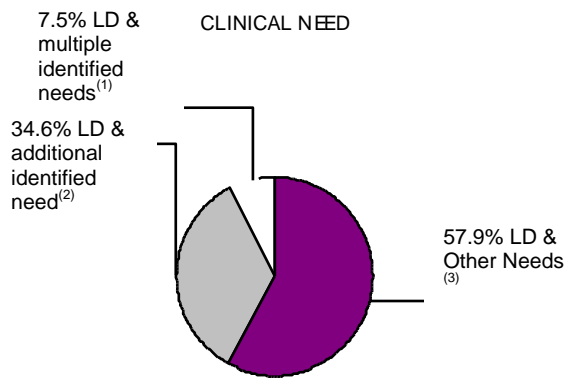


Figure 15: RBK Client Clinical need

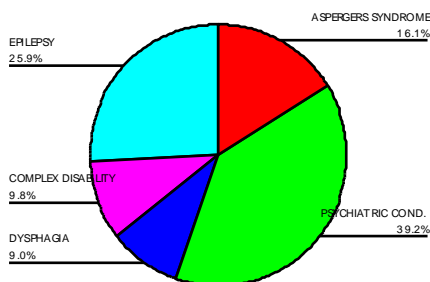


Figure 16: RBK Clinical need breakdown

Normansfield

An analysis has been done of the survival rates of people who were resettled from Normansfield Hospital to in borough provision in 1996/7. Normansfield closed in 1997 and its last residents (excluding Kingston Road) moved out 10 years ago.

Using information from the nominal roll of Normansfield (1995) 75 people have been identified who moved to residential provision within LBR. This figure excludes people who were resettled prior to this date to homes such as Glamorgan Road and Seymour Road. It also excludes residents of the Kingston Road houses as they were resettled much later to Langdon Park. Of the 75 people resettled 25 have died and 2 people have subsequently moved to residential provision out of borough.

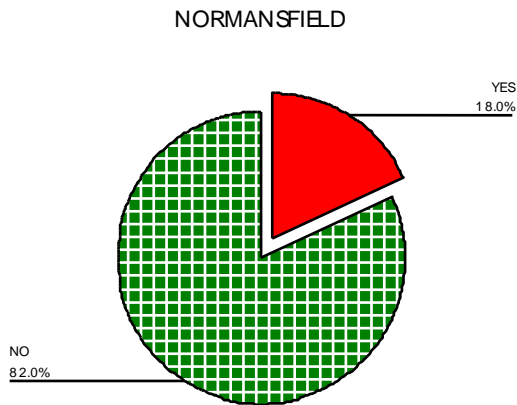


Figure 17: Normansfield Clients

This chart shows the percentage of ex Normansfield clients of the active caseload of the Richmond teams.

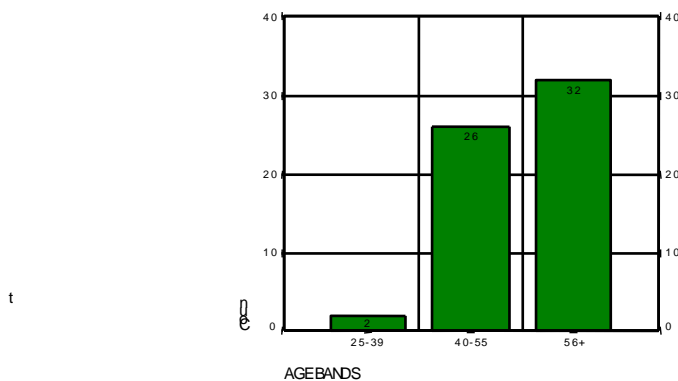


Figure 18: Normansfield client age breakdown

The majority of the ex Normansfield clients resettled in borough are in older age brackets.

Issues for future service provision.

Ageing population

People with learning disabilities are living longer and life expectancy for people with mild LD is similar to that of the general population.

As life span increases learning disability services must be flexible to meet the needs of an ageing population. People with learning disabilities experience the same age related problems as the general population including heart disease, diabetes, arthritis, stroke and osteoporosis. As people live longer they require support from services over an increasing period. Older people with learning disabilities tend to continue to receive support from learning disabilities services as older people's services have great difficulty in managing the specific issues related to a persons learning disability.

Accommodation needs

There is a move in both boroughs towards supporting people to live more independently by increasing the range of accommodation options available to people and providing more individualised packages of support.

The community teams are committed to supporting this approach but it will present challenges for the provision of specialist health inputs.

Community team health staff provide direct input into residential homes, supporting and facilitating staff to meet the needs of the service users. Health professionals are able to work with staff teams and care providers to address the specific needs of the service users, enabling early identification of issues or concerns and enabling management strategies to be implemented speedily averting crises and potential placement breakdown.

Residential care settings are skilled in implementing recommendations and guidance from the teams to put in place structures and support systems to manage complex issues such as autistic spectrum disorders, behavioural problems and eating disorders such as Prader- Willi. These support structures will be more difficult to replicate in more independent settings with more dispersed staffing structures.

Risk and Vulnerability

People with learning disabilities frequently experience disadvantage in many areas such as housing, employment and relationships.

As service users are supported to live more independently, exercise choice and take more control over their lives they will inevitably be exposed to the risks experienced by the general population. People with learning disabilities have increased vulnerability and are at greater risk of abuse.

Further consideration will need to be given as to how service users will be supported to make informed, safe and healthy choices while living more independent lives. Physical and mental health surveillance and monitoring will be key.

Community teams have considerable knowledge of the range and types of inputs that are effective in supporting people in the community. Robust joint working relationships with other services will be essential, including mental health, older peoples, housing and primary healthcare.

There have been an increasing number of referrals to the teams for people with mild learning disability who have into contact with the criminal justice system. Management of forensic and offending behaviour is likely to become a bigger issue for the community teams.

It can be predicted there will also be an increasing numbers of referrals to the community teams for support with issues such as drug and alcohol dependency, sexual health issues and parenting.

Health monitoring

Health facilitation is one of the key roles for community teams described in Valuing People. Robust health action planning systems need to be developed in partnership with primary care services. People with learning disabilities will experience the same difficulties in living healthy lifestyles as the general population, but the ability to understand the consequences of their choices and decisions will be impaired in many cases.

Studies have shown that people with learning disabilities have much higher unmet health needs than the general population and it will be an increasing challenge to ensure that appropriate access and support is available for those living more independently in the community where 24 hour staff support is not available.

Aspergers Syndrome

Kingston L.D. Team provides specialist health inputs to this group of people. This is not the case in Richmond although specific time limited pieces of work by the LD team have been undertaken to support joint working with mental health services if appropriate.

Summary

This report analyses some of the current support needs of service users referred to the learning disability teams. It outlines some of the predicted needs for the future and considers the impact of changing service user profiles on service delivery.