

CARERS ADVOCACY: Service Specifications

1. Population Needs

1.1 National context

By combining information collected by government departments on the presence of learning disabilities among people using services, overall population predictions for England and the results of epidemiological research, we estimate that in England in 2015 there were 1,087,100 people with learning disabilities, which is around 2% of the population, including 930,400 adults.¹ On average, adults with a learning disability die 16 years earlier than the general population – 13 years for men, 20 years for women.²

The NHS Long Term Plan highlights the ambition to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives. In the Plan, it also sets the aim to provide timely support to children and young people with learning disabilities as well as their families.

1.2 Local context

¹ Learning Disabilities Observatory People with learning disabilities in England 2015: Main report. Public Health England; 2016. Available: <https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015>

² CIPLOID (Confidential Inquiry into Premature Deaths of People with Learning Disabilities) Full final report; University of Bristol; 2013. Available from: <http://www.bristol.ac.uk/cipold/reports/>

The target population for this contract covers the Royal Borough of Kensington and Chelsea which has a diverse population including areas of high deprivation and significant affluence. For example part of the Golborne area of North Kensington falls within the top 5% of one of the most deprived areas nationally, and large parts of the north are within the top 10% of the most deprived and also Queen's Park & Paddington in north Westminster, at approx. 230,000 residents across 42 GP Practices. This diverse population covers area of high deprivation and significant affluence.

According to the national study, the number of people with learning disabilities recorded in health and welfare systems is much lower than the actual prevalence.¹ Local QOF data 2017-18 shows just 0.26% (658 people) of this population are registered with their GPs as having learning disabilities. However, based on the national estimated prevalence, approximately 2% of population have learning disabilities. Therefore, the actual numbers of people with learning disabilities in the geography is

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	✓
Domain 2	Enhancing quality of life for people with long-term conditions	✓
Domain 3	Helping people to recover from episodes of ill-health or following injury	
Domain 4	Ensuring people have a positive experience of care	✓
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	✓

Local defined outcomes

- Expected outcomes include:
- Improvement in numbers of parent carers receiving support for Carers Assessment and Needs Assessments.
- Improvement in the transition from Children to Adult Services
- Increase in proportion of parent carers accessing advice relating to benefits, housing and education.
- Increase in liaison with services and professionals to access the best support for families.

- Increase in proportion of parent carers receiving regular information updates via email/text messages.
- support information via quarterly newsletter
- Ensuring parents participate in the ongoing monitoring and development of local services for people with learning disabilities.
- Ensure parents voice is heard in the outcomes from the Local Learning Disability Strategy '*Changing Lives*'

3. Scope

3.1 Aims and objectives of service

- To offer a Support and Advocacy Service, for Parents and Carers of Adults with Learning Disabilities.
- To employ a Carers Advocate who supports parents in a variety of ways such as form filling, issues relating to health, attending meetings.
- To provide Transitions/Education guidance and support for parent carers as part of the Statutory IASS Service. This is part of the implementation of the Children and Families Act and which there is an MOU with RBKC and Health.
- To provide opportunities for parents to meet to exchange ideas and reduce isolation.
- Signpost Parents to a Specialist Counselling Service in partnership with the Tavistock Institute.
- To provide an After school and Holiday Provision for young people with complex needs
- To provide training courses covering a wide range of skills and knowledge.
- To provide information and practical help on health, education, benefits, and transport issues and a range of other local and national services.

3.2 Service description / Care Pathway

Service should have knowledge of local services for local people, all have been identified as a gap in support of local health services, including:

- Family support service for newly diagnosed children up to 14 this service helps with form filling, housing, short breaks and other issues families may have.
- Independent Advice and Support Service (formerly Parent Partnership Service) which supports families to understand the Special Educational Needs system
- Should support parents and carers of adults with learning disabilities practical support through professional advocacy or

Offer parents and carers of adults with learning disabilities independent, practical support, advice and information. To also support parents/carers of young people from the transition age through to adulthood and continue to raise awareness of support and services available for learning disabilities ensuring the expertise of local parent carers is used for the ongoing monitoring and development of services for people with learning disabilities.

Access

Access can be made by a number of sources including statutory, charitable and voluntary organisations as well as by organisations in the private sector and individuals referring themselves.

Referrals

The following referral eligibility will apply:

- Parent carers of people aged over 14 years who have a learning disability living in RBKC only.

3.3 Population covered

The Advocacy Service is available to people registered with a GP Practice in the Kensington and Chelsea (K&C) area. Venues outside the K&C boundary will not be used without written agreement from the Lead Commissioner.

3.4 Hours of operation

The Carers Advocacy Service will operate Mondays to Fridays 09:00 – 17:00. The hours of operation may extend to cover outside of these hours.

3.5 Staffing

There will be **1 WTE advocacy worker**. One WTE post will work with a minimum of 20 professional advocacy cases over the 6-month period.

Advocacy worker will provide professional advocacy that that delivers the 10 key principles of the advocacy charter:

- Clarity of Purpose
- Independence
- Putting People First
- Empowerment
- Equal Opportunity
- Accessibility

- Accountability
- Supporting Advocates
- Confidentiality
- Complaint

The provider will ensure that the Carers Advocacy Service is provided by suitably qualified, competent and experienced staff. All staff must be provided with regular, high-quality support, training and supervision which enable them to deliver against their roles to the best of their abilities.

3.4 Any acceptance and exclusion criteria and thresholds

The service will focus on parents and carers of adults with learning disabilities.

No service user would be unreasonably excluded from accessing the service. The provider is expected to use all reasonable means to ensure that the service is accessible to all minority and hard to reach groups within the geographical boundary covered by West London 'Borough Team' only for Kensington and Chelsea area.

3.5 Interdependence with other services/providers

The Family Carers advocate will be involved in ongoing and one-off advocacy and carer activity at a local level. This will also include working with other local voluntary sector organizations and Black and Minority Ethnic organizations, particularly those located in the borough within Kensington and Chelsea only.

Relevant links will be made by the provider with other services including but not limited to:

- GPs practices in the Royal Borough of Kensington and Chelsea
- CNWL Learning Disability Services
- RBKC Learning Disability Services
- RBKC SEND Services
- Colleges

4. Location of Provider Premises

The provider will provide the service from its registered office as well as a range of community locations across Royal Borough of Kensington and Chelsea.

5. Applicable Service Standards

5.1 Compliance

The Provider will comply with relevant:

- Guidance and other applicable NICE standards
- Applicable local standards set out in this Contract

5.2 Monitoring

The monitoring report will provide information but not limited to:

- Total numbers of referrals
- Outcome of referrals: accepted or signposted to other organisations
- Organisations referrals were signposted to
- Type of support referrals needed
- Service demographic report analyses the data of age, gender, ethnicity and postcode
- Case study

5.3 Evaluation

The service will produce an annual evaluation information.

6. Applicable quality requirements and CQUIN goals

6.1 Applicable Quality Requirements

7. Information Requirements

The service will be required to provide comprehensive data to support the ongoing evaluation of the service.

