

Learning and Complex Disabilities Service (LCDS)

Information for
professionals

March 2011



We are a unique national service offered to children, adolescents and adults, specialising in psychological treatments for patients with learning disabilities and developmental disorders.

The importance of specialist services for this patient group:

Numerous national investigations have found that there is an inequity of access to services for people with learning disabilities, autism, Asperger's, and similar disabilities. There are often gaps in provision and the quality of services is variable. It is important that local services for people with learning disabilities, adult mental health, and CAMHS address the specialist mental health needs of this group, and that access to appropriate interventions such as psychotherapy are equitable.

There is a need across London and the surrounding areas for a service such as LCDS that is equipped to provide the specialist skills required for a psychotherapy service for people with learning disabilities and other complex disabilities, and that can:

- See patients with particularly complex needs.
- Meet gaps in local provision.
- Provide consultation and support to local services to increase their confidence and ability to support

these patients in local settings.

- Develop and evaluate models of best practice.

What type of patients do we see?

We see children, young people and adults who have at least one of the following conditions:

- A diagnosed learning disability
- Borderline or unclearly defined learning disabilities
- Autism, Asperger's Syndrome and related neuro-developmental disorders
- Brain Injury, sensory difficulties or other neurological difficulties

Our patients have complex problems in multiple areas which may include educational, social, occupational, family, mental and physical health. These complex cases have usually already received a great deal of input from local services but continue to have significant problems, indicating the need for specialist work.

Commissioners can be reassured that only patients who are appropriate for this specialist service are accepted. There were 50 referrals made to LCDS between the 1st September 2009 and 31st August 2010; 37 were accepted and 13 were rejected, therefore 26% were rejected.

How do we differ from general learning disability, adult mental health and CAMHS?

Learning disability services are restricted in their ability to meet the mental health needs of patients, and generic adult and CAMHS services will at times need to turn to more specialist mental health services for people with learning difficulties such as if a psychodynamic assessment is indicated. In most areas, there are also patients who do not fit eligibility criteria for local services.

LCDS is able to compliment and support local provision by:

- Seeing complex cases when local services are unable to meet their needs.
- Offering psychodynamic assessments for people with learning difficulties and developmental disorders when they are not available locally.
- Offering a service to patients in the transition stage, i.e. 16+, for whom continuity of service is particularly important and not always available locally.
- Seeing patients who do not fit local eligibility criteria. E.g. we do not use strict IQ eligibility criteria, and accept referrals for patients who have an IQ above 70 but still have serious difficulties relevant to our service provision.

What do we offer?

There are two types of services offered under the London contract:

1. Patient Services

Patients can be referred for assessment only, or can continue into treatment. A key feature of our service is liaison and consultation with local services and the patient's support network, thereby significantly enhancing the quality and effectiveness of the service.

Our team offers a range of treatments tailored to the patient's needs. These may include the following:

- Specialist assessment including: Autism Diagnostic Observation
- Schedule (ADOS), Autism Diagnostic Interview-Revised (ADI-R), and psychological testing if indicated
- Individual psychotherapy
- Family therapy
- Group therapy
- Consultation and liaison with the professional network

We are committed to liaison and consultation with local services and the patient's support network.

2. Consultation

Learning Disability and mental health services can also seek a consultation about a particular patient. Often there is a desire to see the service for help about thinking through a complex case. Common issues are often around difficulties about formulation and differential diagnosis. In such cases we are able to assist in exploring various treatment options, and discussing staff group dynamics around a particular patient. We usually begin by meeting with the referrer and involved professionals. We might see the patient as part of the consultation if we think this would be helpful and in the patient's best interest.

Examples of requests from local services that we have met include:

- A team find themselves split on their views about a patient and are unable to agree on a plan. They would like help with understanding what is happening so that they can move forward.
- A local service is working with a child who is not responding to treatment and has co-morbid learning disability as well as mental health issues. There are also parenting difficulties, cross-cultural issues, and concerns about child protection issues. They would like help with how to approach the multiple concerns.

- A patient exhibits worrying behaviors that are utilizing a great deal of local resources, and they would like help with a formulation of the patient and weighing the risks/benefits of various options.

Outcomes:

The service is implementing the following outcome measures and aims to be able to report initial results in 2011.

- **Adults:** we are a piloting partner for the Clinical Outcomes in Routine Evaluation- Learning Disability (CORE-LD).
- **Children:** we are participating in CAMHS Outcomes Research Consortium (CORC) measures.
- We had a consultation from *Hackney People First*, service users' group, run by people with learning disabilities who provided various recommendations to improve accessibility to our service.

Patient Experience

The service has succeeded in eliciting patient views, a challenging task with this patient group, which reveal high levels of patient satisfaction. Our pilot patient survey in June 2010 used questions adapted from the Experience of Service Questionnaire. We added photo symbols, as well as larger font type to improve accessibility for our patient group. We used

a three rather than five point scale measure (i.e. Yes, OK, Not really) to make the survey simpler for service users to score.

14% of adult patients responded, aged 20-24 years.

100% of respondents rated the following statements very positively (i.e. "Yes"):

- *I feel the people listened to me*
- *It was easy to talk to the people who saw me*
- *I feel people here know how to help me*
- *It is easy to get to the place I have my appointment*
- *I think other people who need help might like to come here*

No statements were answered very negatively (i.e. "Not really")

25% of parents/carers responded, with patient ages ranging from 8 to 17 years.

Statements rated very positively by over 80% of parents / carers:

- *I feel the people who saw me listened to me*
- *It was easy to talk to the people who saw me*
- *I was treated well by the people who saw me*
- *My views and worries were taken very seriously*
- *My appointments are at a convenient time*

One parent rated most items very negatively but made no free comments to elaborate.

Future developments

We are currently responding to the patient feedback from this survey, recommendations from People First (a voluntary organisation run by people with difficulties), and input from clinicians, by taking the following measures:

- Working on providing patients with more information about our service so that they have an understanding of the process.
- Developing our website and making a video for patients to improve accessibility.
- Continuing to develop services for children and adults with emotional difficulties associated with autistic spectrum disorder/ Asperger's Syndrome in coordination with other Tavistock services.
- Conducting a survey of referrers' views
- Providing training to other professionals through courses and conferences.



Contact details:

Learning and Complex Disabilities Service (LCDS)
The Tavistock and Portman NHS Foundation Trust
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: +44 (0) 20 8938 2537

Email: lcds@tavi-port.nhs.uk

