Mental Health and Challenging Behaviour in people with Learning Disabilities

Background

Professor Sally-Ann Cooper and the Scottish Learning Disabilities Observatory analysed primary health-care data on 1,424,378 adults registered with 314 representative Scottish practices. Adults with intellectual disabilities had significantly higher prevalence for:

- Depression (15.8% compared to 10.1% for no LD).
- Anxiety (8.1% compared to 3.9% for no LD).
- Schizophrenia (and related non-organic psychosis) or bipolar (5.6% compared to 0.9% for no LD).

For dementia the proportion of people with LD who have dementia is small, as people with LD die younger so the age distribution is different. However people with intellectual disabilities, particularly Down’s syndrome, develop dementia at a much earlier age.

In addition to mental illness, people with LD often have coexisting autistic spectrum disorders, behaviours that challenge services, offending behaviour, or physical health conditions. It is often hard to distinguish between these conditions especially when people have more severe intellectual impairments.

In 2014 the Foundation for People with Learning Disabilities reported on a national survey conducted to gather qualitative and quantitative information on the current experiences of people with learning disabilities, their families, friends and staff when accessing support for their mental wellbeing. People with learning disabilities and their families have made it clear in the interviews and survey that it is hard to access mental health support and services.


Key findings included:

- They are unfamiliar with how mental health services are delivered and found it difficult to navigate them.
- People with learning disabilities were unlikely to seek help for mental health problems.
- Their symptoms are often attributed to their learning disability (diagnostic overshadowing) or classed as challenging behaviour.
- The mental health needs of people with mild to moderate learning disability frequently go unmet, due to the fact that their symptoms are not recognised, understood or supported by frontline staff.
- Making access and information easier to read, in plain English, would make it easier for everyone in the wider public to access services too.

Foundation for people with learning disabilities report Feeling Down: Improving the mental health of people with learning disabilities.

People with learning disabilities said that:

- People did not see them—they just saw their learning disability.
- The information that was provided was not accessible and in a format that they could understand.
- They were not believed, listened to or supported when they felt down
- They wanted to have more control around their mental health.
- A diary and information to explain what was happening to them would make it easier to talk to staff and tell the GP how they were feeling.

Family members and friends said that:

- Access to support, getting the GP to believe them or refer them to a specialist, was the biggest barrier to their son/daughter’s mental health and was extremely hard.
- That the long wait was detrimental to their son/daughter’s wellbeing.
- Psychological support was valuable once received.

Professionals said that:

- Not enough was being done to support the mental health needs of people with learning disabilities.
- Support from GPs was crucial in accessing mental health support but difficult to obtain.
- Mental health services needed to improve and make reasonable adjustments to ensure access.
- Support during treatment and aftercare was crucial in supporting the mental health needs of people with learning disabilities.
- There was a need for better and more joint work between mental health services.
Assessment of mental health or challenging behaviour problems

As a GP you may be asked to assess a person with LD who is has an apparent decline in function or presents with behaviours that challenge. You will need to adjust your assessment depending on the level of a person’s intellectual ability, especially their memory and communication. Patients with mild LD may be capable of reporting emotions such as anxiety and depression as well as psychotic symptoms, such as hallucinations or delusions. Patients with severe LD rarely have this ability and you will need to rely on direct observation or staff reporting than self-reporting.

Consider a mental health problem if a person with learning disabilities shows any changes in behaviour, for example:

- Loss of skills or needing more prompting to use skills.
- Social withdrawal.
- Irritability.
- Avoidance.
- Agitation.
- Loss of interest in activities they usually enjoy.

If you identify an issue try to cover:

- An understanding of the nature of the problem and its development.
- Precipitating and maintaining factors.
- Any protective factors.
- The potential benefits, side effects and harms of any interventions.
- The potential difficulties with delivering interventions.
- The reasonable adjustments needed to deliver interventions.
- The impact of the mental health problem and associated risk factors on providing care and treatment.

It is important to assess carefully all possible causes. A person with LD who has toothache, an ingrowing toenail or gastro oesophageal reflux disorder may behave in an aggressive manner out of frustration and persistent pain, especially if they cannot communicate this.

Possible reasons for a decline in function or challenging behaviour:

- **Physical health problems** - a thorough history, examination and relevant clinical tests are needed. If the person is non-verbal it is essential to do a head to toe examination and include the mouth, skin and feet. The Royal College of Physicians (RCP) has led the development of a standard National Early Warning Score (NEWS) in the assessment and response to acute illness. ³ This has been

³ https://www.rcplondon.ac.uk/projects/outputs/national-early-warning-score-news
Six simple physiological parameters form the basis of the scoring system:

1. respiratory rate
2. oxygen saturations
3. temperature
4. systolic blood pressure
5. pulse rate
6. level of consciousness.

Most GP IT systems have templates for the recording of physiology useful in the documentation of patients who are unwell with infection and for calculating risk. Other templates are available here.

If the person is taking an antipsychotic consider the rare, but life threatening, neuroleptic malignant syndrome (NMS) that is characterized by fever (above 38°C), muscular rigidity, altered mental status, and autonomic dysfunction. NMS is most common after initiation or increase in dosage of therapy.

- **Sensory impairment** - particularly the development of visual and/or hearing impairments. Look for common problems such as cataracts and for earwax.
- **Dementia** - this is usually a diagnosis of exclusion.
- **Sleep problems** - obstructive sleep apnoea is particularly common in people with Down’s syndrome
- **Impact of life events** - such as moving home or death of a relative or fellow resident in a residential home
- **Abuse** - consider physical, emotional, financial or sexual abuse. Ask ‘Is anyone is hurting you?’ Or ‘has anything horrible has happen to you?’
- **Medication** - consider the side effects of drugs particularly those with anticholinergic or sedating side-effects.
- **Environment** - an environment that provides under or over stimulation or isolates can lead to a decline in function or behaviours that challenge.
- **Mental Health Problems** - the most common of these is depression.

**Treatment of mental health or challenging behaviour problems**

NICE has developed a pathway for the treatment of mental health problems in people with LD.

Consider referral to the Community Learning Disability team or the Community mental health team and the following treatments

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A. Psychological Interventions

- Consider cognitive behavioural therapy, adapted for people with learning disabilities, to treat depression or sub threshold depressive symptoms in people with milder learning disabilities.
- Consider relaxation therapy to treat anxiety symptoms in people with learning disabilities.
- Consider using graded exposure techniques to treat anxiety symptoms or phobias in people with learning disabilities.

B. Occupational interventions

Try to support people with LD to:

- Engage in community activities, such as going to a library or sports centre.
- Access local community resources, such as libraries, cinemas, cafes and leisure centres.
- Take part in leisure activities, such as hobbies, which are meaningful to the person.

Reasonable adjustments may be needed to do this, such as a buddy system, transport, or advising local facilities on accessibility.

Actively encourage adults with learning disabilities find and participate in paid or voluntary work that is meaningful to them, if they are able.

C. Medication interventions

Only specialists with expertise in treating mental health problems in people with learning disabilities should start medication to treat a mental health problem in:

- Adults with more severe learning disabilities.
- Children and Young people with any learning disabilities.

Prescribers should record a summary of what information was provided about the medication prescribed, including side effects, to the person and their family members, carers and any discussions about this:

- When the medication will be reviewed.
- Plans for reducing or discontinuing the medication, if appropriate.
- Full details of all medication the person is taking, including the doses, frequency and purpose.
For people with learning disabilities who are taking antipsychotic drugs and not experiencing psychotic symptoms:

- Consider reducing or discontinuing long-term prescriptions of antipsychotic drugs.
- Review the person's condition after reducing or discontinuing a prescription.
- Consider referral to a psychiatrist experienced in working with people with learning disabilities and mental health problems.
- Annually document the reasons for continuing the prescription if it is not reduced or discontinued.

D. Other interventions

Consider changes to the environment, parent or staff training programmes.