Mental illness in people with intellectual disability

Chris Perkins

Correspondence to: cjperkins@xtra.co.nz

***Chris Perkins** worked in general practice for eight years before training in psychiatry. She now works as a psychiatrist, mainly in the areas of old age and dual disability (ID and mental illness) with the Bay of Plenty District Health Board.*

Introduction

Diagnosing mental illness in a person with intellectual disability (ID) can be difficult. It is often unclear whether dysfunctional behaviour or extreme emotional expression represents mental illness, whether it is the communication of distress related to physical, social or environmental factors, part of a syndrome that includes ID or some combination of the above. Many people with ID have sensory deficits or medical conditions that complicate the picture.

People with ID are very prone to mental illness. They have limited coping abilities and the additional effect of mental illness on functioning can have serious consequences. Thus it is important to assess and treat mental illness promptly and adequately.

In this article I discuss the diagnosis and management of mental illness in adults with ID. I will not discuss the Autistic Spectrum Disorders – a topic justifying its own paper.

Epidemiology

One per cent of the adult population in New Zealand have ID: 28 900 individuals.[1]

Intellectual disability is defined by an IQ of less than 70, plus extremely low measured adaptive functioning (ability to perform various day-to-day tasks), present prior to the age of 18.[2,3] Educational psychologists in New Zealand do not routinely perform IQ tests; formal testing often first takes place when the person needs to access support services as an adult. The GP is unlikely to receive the result of testing and may know of the patient's ID from long-term acquaintance or via family or caregivers. Most ID is mild, i.e. IQ in the 55–70% range and the person is able to function fairly independently.

Mental illness in people with ID has traditionally been underreported because it is unrecognised, undiagnosed and untreated. There is a tendency to believe that the problem is 'behavioural', caused solely by the ID rather than due to mental illness ('diagnostic overshadowing'). The quoted prevalence of psychiatric illness among adults with intellectual disability varies widely – between 10% and 39%.[4]

Aetiology

Biological, social and psychological factors contribute to the development of mental illness in people with ID.

As well as causing ID, some conditions also increase the risk of developing psychiatric illnesses, e.g. dementia in Down Syndrome. Physical conditions (such as epilepsy) associated with ID and the treatment of such conditions may cause psychiatric symptoms. People with ID often have difficult developmental pathways, with multiple losses (such as separation from family) and a high vulnerability to abuse. Opportunities for achievement in the educational, occupational and recreational spheres are reduced. Many people with ID are aware of their disability and the difficulties they cause others; the mere presence in the family of someone with ID increases family stress. If they look or act in an unusual way they may be stigmatised or bullied. All this affects self-esteem.

Communication deficits can result in emotional and behavioural disturbance and limited coping skills make it difficult to deal with adverse situations in day-to-day life.

Making the diagnosis of mental illness

Obtaining the history

Communication difficulties

Most psychiatric diagnoses are made on the basis of self-report, but some people with ID have limited ability to describe symptoms. Even if the person is able to articulate well, be sure that he/she understands the questions and is comfortable and not feel-

ing rushed. Sometimes anxiety can be reduced by an indirect approach, e.g. talking about symptoms to a soft toy or saying *'some people feel like this...'* Some people with ID have a tendency to 'yea-say', i.e. agree with the questioner or give the answers that they think the doctor wants.

It is vital that, as well as talking to the person with ID in private, you also (with the person's agreement) get a history from the carer.

Differences in presentation

Illnesses can present differently in people with ID from those with normal intelligence: the more severe the ID, the greater the difference in presentation from the usual. For example, it is unlikely that someone with severe or profound ID will present with complex or abstract symptoms such as worthlessness or hopelessness.

More commonly they will demonstrate loss of skills, new behavioural problems or an exacerbation of old ones. Irritability (expressed behaviourally) is a common symptom in depressive disorders and delusions are usually simple, e.g. the false belief that 'someone is going to hurt me' or relevant only to that person, e.g. a person with moderate ID and hypomania has the grandiose belief that he can read a book.

Idiosyncratic expressions may be mistakenly interpreted, e.g. a man complaining about having bats flying round inside him was deemed psychotic. Careful questioning revealed that he meant he had 'butterflies in his stomach', a phrase he had heard at an anxiety management group. A woman with a crocodile under her bed was explaining her experience of sexual abuse. A person who reported 'hearing voices', was asked when he last heard them. He stated this had been at McDonalds, from the neighbouring table.

Box 1. Factors predisposing people with ID to mental illness

- Neuropathology causing both ID and mental illness
- Multiple losses
- Communication deficits
- Inadequate coping skills
- Family stress
- Limited social relationships and skills
- Reduced opportunities for occupation and recreation
- Adverse effects on self-esteem of disability
- Vulnerability to abuse
- Co-morbidity with medical illness and side effects from treatment

Looking at the context

Getting a full history can be challenging, but will help avoid an incorrect diagnosis. For example, a person who appears depressed, irritable and withdrawn in a work situation but cheerful and chatty at home is unlikely to have a major depressive episode; more likely, this is a situational difficulty at work, such as bullying or being asked to do something beyond her skills. Someone who has always talked to himself, or his relatives when alone at night is probably just processing the day's events, but if this is a new phenomenon associated with distress he could be responding to hallucinations.

Mental illness in people with ID has traditionally been underreported because it is unrecognised, undiagnosed and untreated

Because many people with ID live in group homes with changing staff, it can be difficult to get a longitudinal picture. Communication between workplace and the residential home is not always adequate. Staff, unaware of the importance of the history for diagnosis, may not be able to provide useful information or be biased because they are angry about the person's behaviour. Changes in the environment; even those that appear relatively minor, such as a staff member leaving a supported home, might be very important to the individual with ID. The GP can request an NGO manager or practice nurse to do the time-consuming detective work needed to get the full picture.

It is important to assess the caregiver as well. Family and formal caregivers may have been stressed for a long time and now be at crisis point. Without some form of relief they will be unable to assist in managing the situation.

Box 2. Hints for interviewing a person with ID[5,6]

- Allow plenty of time
- Relaxed, familiar environment (at home if possible)
- Spend time interacting generally first to reduce anxiety
- Allow for visual/hearing impairments
- Use any special form that the person uses to communicate, e.g. signing
- Use visual strategies, e.g. pointing to pictures, drawing
- Make sure you have the person's attention before speaking
- Good eye contact
- Use open questions
- Articulate clearly
- Active listening, check you understand
- Straightforward language: short sentences, concrete, repeat and rephrase
- Take into account tendency to please and acquiesce
- Use family or caregivers to help understanding

Differential diagnosis

Mental or physical illness?

Perhaps the most important role for the GP is to rule out physical problems. Many people with ID presenting with psychiatric symptoms such as fatigue, sleep and appetite disturbance, mood change and withdrawal

from activities have unrecognised physical illness. The person may not be able to report symptoms that would allow the GP to decide even which organ system is involved. A longitudinal history and a thorough search for physical abnormalities are mandatory.

The common physical illnesses associated with various forms of intellectual disability are beyond the scope of this article, but information can accessed via www.intellectualdisability.info (St. George's University of London) and other websites. Some examples are given in Box 3.

Box 3. Useful websites

www.learningdisabilities.org.uk/publications
www.chromosomehelpstation/chromosgroups.htm
www.thenadd.org/index.shtml
www.library.nhs.uk/learningdisabilities
www.moh.gvt.nz/disability
www.donaldbeasley.org.nz
www.rcpsych.ac.uk

Sleep patterns change with depression, but could be secondary to obstructive sleep apnoea. People with Down Syndrome have a craniofacial structure and differences in lymphoid tissue that make them more susceptible to this condition. Chronic obstructive pulmonary disease, gastro-oesophageal reflux, menopausal changes, seizures, congestive heart failure and visual impairment affect sleep. Nutritional disorders, skin, dental, eye and ear problems can be associated with depression-like symptoms.[7] People with Down Syndrome are prone to hypothyroidism which may present as depression.

Aggression and irritability, while common in depression, also result from pain, physical illness or as a side-effect of medication. Constipation is common and may be associated with depression, anxiety and the use of psychotropic medication. Annual medical examinations of people with ID are recommended[8] and sometimes standardised, e.g. the Cardiff Health Check (obtain via www.rcgp.org.uk).

Sometimes performing a physical examination and diagnostic testing is a challenge requiring several visits to increase trust, repeated careful explanation and the assistance of a trusted caregiver.

ID or mental illness?

It is often very difficult to decide whether a person's behaviour relates to mental illness or ID. For example, explosive outbursts of anger could be an expression of frustration by someone who has little verbal expression and lacks control over her environment or a response to threatening auditory hallucinations associated with paranoid schizophrenia. Self-injury such as wrist-chewing or eye-poking is associated with some genetic conditions, e.g. Lesch-Nyhan Syndrome, but is also seen in depression.

It is very important not to automatically attribute someone's behavioural problem to their ID without carefully looking for other causes, especially if there is a change in the pattern or intensity of such behaviours. A careful longitudinal history, observation for other psychiatric signs or symptoms or, if necessary, a therapeutic trial of medication or other treatment may clarify the diagnosis.

Some types of behaviour are associated with certain syndromes also causing ID. This association is called a behavioural phenotype, defined as *'a characteristic pattern of motor, cognitive, linguistic, and social abnormalities that is consistently associated with a biological disorder.'*[9] The behaviour is not always present, but the probability of its occurrence is increased. Some examples are listed in Box 4.

There are some behaviours that, while not specifically linked to one genotype (thus not by definition a behavioural phenotype), are found in several different neurogenetic syndromes. These include attention problems, hyperactivity, impulsivity, self-injury, aggression, autistic-like and perseverative behaviours.

Current research seeks to link an abnormal gene to its behavioural expression via the downstream effect on brain chemistry, brain structure or brain circuits.

Box 4. Examples of behavioural phenotypes

- **Down Syndrome**
  Placid, good tempered, though may be aggressive, impulsive, hyperactive.
- **Velocardiofacial Syndrome**
  Withdrawn, poor social interaction skills.
- **Prader–Willi Syndrome**
  Compulsive eating, skin-picking, irritability, low frustration tolerance.
- **Angelman Syndrome**
  Hyperexcitable, laugh inappropriately, sleep disturbance.
- **Fragile X Syndrome**
  Gaze aversion, attention and concentration problems, hyperactivity disorder, shyness, social anxiety.
- **Foetal Alcohol Syndrome**
  Inattention, impaired executive function, impulsivity, hyperactivity.
- **Lesch–Nyan Disease**
  Self-injury…usually self-biting, sometimes compulsive aggression.

Box 5. Examples of mental illness associated with certain causes of ID

- **Down Syndrome**
  Alzheimer's type dementia in >50% aged over 50.
- **Velocardiofacial Syndrome**
  25% develop psychosis in adolescence, schizoaffective and bipolar spectrum disorders common.
- **Prader–Willi Syndrome**
  Increased rates of depression, anxiety and compulsive behaviour, psychosis (up to 100% in some types).
- **Fragile X Syndrome**
  Anxiety, avoidance and mood disorders common.
- **Foetal Alcohol Syndrome**
  Conduct disorder and antisocial behaviour.

'Because these downstream systems may be affected by environmental and interpersonal interventions, the expression of a genetic disorder may be modified by targeted interventions.'[10]

Thus no need for therapeutic nihilism!

Some particular syndromes increase the vulnerability of the person to mental illness. Examples of such associations are listed in Box 5.

Diagnostic tools

Diagnostic systems have been developed to improve diagnosis of mental illness in people with ID.[11,12,13] GPs are not likely to own these manuals, but Dual Disability teams may refer to them.

Management

Physical conditions are treated as necessary.

Once a psychiatric diagnosis is made or suspected, management runs along the same bio-psycho-social lines as with people with normal IQ. The person and caregiver should be given an explanation of the diagnosis and treatment options, including self help. It may be useful for the person or caregiver to keep a diary of symptoms and side effects.

People with ID do not always cooperate with treatment: caregivers and family, who know the person well, can advise on the best approach. On the other hand, the person with ID may be more compliant with medication than most, increasing the risk of side effects, which they will not necessarily communicate to others. Family and caregivers need education about common side effects so that they can recognise these and be given a contact number to use if they are concerned.

Medication

Caution is needed using psychotropic drugs. People with ID may have idiosyncratic reactions (e.g. disinhibition with benzodiazepines) or acute sensitivity to side effects such as lowering of seizure threshold with some neuroleptics. It therefore pays to start at a low dose and gradually increase to evaluate the effect. Overmedication is common – caregivers tend to present when the person is in crisis and later be reluctant to discuss reduction even after the appropriate period of treatment.

GPs can be pressured to prescribe psychotropic medication for environmental/social problems. Careful explanation as to why this is not an appropriate response or referral for a second opinion may help.

Psychological approaches

Generally, behavioural therapies are better for people with severe or profound ID, while adaptations of usual psychotherapies can help people with mild-moderate ID. It is often difficult to find a therapist with the necessary expertise to work with people with ID; it may be best to consult the local Mental Health Service.

ACC provides funding for those who have been sexually abused, but again, finding a suitable counsellor can be difficult. It is not always recommended to use disclosure of the trauma as a treatment modality, as people with ID do not always have the cognitive ability to rationalise, process and close, or have the behaviour and emotion regulation skills to cope with their emotions.

'Behaviour Support Teams', working in most areas, provide behaviour management to people with ID who require such assistance. However, it is not their brief to manage people with mental illness. They are more likely to be a source of referrals!

Social

Sometimes a more practical approach is just as helpful as psychotherapy,

Box 6. Summary of difficulties in diagnosis

Patient factors

- Limited verbal skills
- Sensory deficits
- Suggestibility to person in authority
- Effect of ID on presentation
- Physical illness mimicking mental illness.

Doctor factors

- Time
- Communication skills
- Attribution of mental illness symptoms to ID 'It's all behavioural'
- Professional beliefs: 'they aren't really affected by mental illness…'

System factors

- Lack of communication between different parties
- Obtaining longitudinal history
- Reluctance of MH services to be involved.

e.g. for the person with ID to have a change of occupation, or respite for the carer. Limited resources in the disability sector, especially in smaller centres, can make it difficult to change a person's social setting, e.g. moving them from one residential home or work situation to another. However, providers of such services can often work out a satisfactory solution to improve the person's quality of life.

Informed consent

People with mild-moderate ID can usually give consent (or assent) to treatment if the matter is simply and clearly explained. However, those with more severe ID need an agent to do so for them. Sometimes the person is estranged from the family and has no Welfare Guardian, making it difficult to obtain consent, particularly for major procedures. In such cases it may be necessary to apply for an order for treatment under the Protection of Personal and Property Rights Act (1988). In situations of more urgency, the duty of care of the clinician prevails.

'If a person is clearly unable to consent (to a behavioural intervention), it is good practice to consult with the stakeholders in a person's life, including support workers and family/whanau, prior to commencing the treatment. In these circumstances, the "duty of care" of the health professional prevails. It is a clinician's duty of care to ensure evidence based practice is followed in the best interest of the client, using the least restrictive option, with the best quality of life outcome.'[14]

DHB services

Recently many DHBs have set up 'Dual Disability' (ID/Mental Health) services. These multidisciplinary teams aim to plug the gap between Disability and Mental Health Services. Referral processes differ between regions. Teams may accept direct referrals from GPs or require GPs to refer first to generic mental health teams. The team may be willing to offer telephone advice on management and referral.

If necessary a person with both ID and suspected mental illness can be admitted under the Mental Health Act to an inpatient unit. Often the chaotic inpatient environment is disturbing and frightening for someone with ID and is better avoided if possible.

Often the chaotic inpatient environment is disturbing and frightening for someone with ID and is better avoided if possible

If the person has committed a crime, special legislation – the IDDCR Act[3] – allows for admission and containment in treatment units. There are wards in some forensic units specifically for treatment of people with ID. Obviously (if possible) it is better to treat any mental illness before it gets to this point.

In summary, this is a challenging area of work, but can be rewarding. Dual Disability Services recently set up around New Zealand can offer support and assistance.

Acknowledgement

The author would like to thank Lynne Johnson and Drs Anne Templeton, Marleen Verhoeven and Bonnie Miller for their contributions to this paper.

Competing interests

None declared.

References

1. Ministry of Health. Living with disability; The 2001 household survey and residential facilities survey. Wellington: MOH; 2005.
2. American Psychiatric Association. Diagnostic and Statistical Manual IV TR. 2000.
3. Intellectual Disability (Compulsory Care and Rehabilitation) Act No.116 (IDDC&R Act) Sec.7. New Zealand Statutes 2003.
4. Deb S, Matthews T, Holt G, Bouras N. Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability. Brighton: Pavilion; 2001.
5. Bray A. Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with intellectual disability; June 2003.
6. Royal College of Psychiatry website www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthproblems/learningdisabilities.aspx
7. Sulkes S, Emmick LS. Behavioral manifestations of physical conditions in mental health. In: Davidson PW, Prasher VP and Janicki MP (editors). Intellectual disabilities and the aging process. Oxford: Blackwell Publishing Ltd; 2003. p.67–75.
8. DRC Formal Investigation Report. Equal treatment: Closing the gap. A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems. UK: Disability Rights Commission; 2007. www.drc.gb.org
9. Flint J, Yule W. Behavioural phenotypes. In: Rutter M, Taylor E, Hersov L (Eds). Child and adolescent psychiatry. 3rd ed. Oxford: Blackwell Scientific; 1994. p.666–687.
10. Harris JC. Genetics, behaviour and behavioural phenotypes. Intellectual disability. Understanding its development, causes, classification, evaluation and treatment. New York: Oxford University Press; 2006. p.193.
11. Royal College of Psychiatrists. Diagnostic criteria for psychiatric disorders for use with people with learning disabilities/mental retardation (DC-LD). London: Gaskell; 2001.
12. National Association for the Dually Diagnosed. Diagnostic Manual-Intellectual Disabilities DM-ID. 2007.
13. Prosser H, Moss S, Costello H, Simpson IN, Patel P. The Mini PAS ADD c An assessment schedule for the detection of mental health problems in adults with developmental disabilities. Manchester: Hester Adrian Research Centre; 1996.
14. Webb OJ, Reid M, Verhoeven M, Eggleston E. Principles of psychological work with people with intellectual disabilities. In: Evans IM, O'Driscoll M, Rucklidge JJ (Eds). Professional practice of psychology in Aotearoa New Zealand. New Zealand Psychological Society. (In press).