

Key Points for Psychiatrists managing People with Mild Intellectual Disability in Emergencies

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Introduction

- Many professionals can feel under skilled when working with patients with ID. The core skill set of any psychiatrist – **good communication and observation skills, familiarity with managing mental distress and liaising with carers and other professionals** – provides a firm foundation for working with people with ID.
- This document details the **common adjustments** that need to be made to the assessment and management process, to support all Psychiatrists dealing with people with Mild ID in emergency situations.
- Comorbid mental illness and challenging behaviour occurs more commonly in adults with ID than in the general population.
- Difficulty understanding and articulating emotional states is common; an observed change in behaviour should always lead to consideration of possible **physical or mental ill health**.
- Due to their cognitive status, people with ID may be less able to cope with changes than the general population; they may be unable to make sense of what is happening to them or their emotional response to it.
- People with ID often have **less control and choice** over their living circumstances than the general population. They are also at **higher risk of abuse**.

Common comorbid mental health and neurodevelopmental problems in ID

Anxiety	Manifestations can include angry outbursts, 'meltdowns', and self-injury. Check for physical signs of anxiety e.g. pulse and BP, even in the absence of overt distress.
Mood disorders	Often manifest through biological signs and/or behavioural change. Rapid cycling mood changes are more common in people with ID than in the general population.
Psychosis	Simple delusions and hallucinations may be reported or observed. Challenging behaviour may be in response to psychotic experiences – observing the behaviour is important.
Autism	Common co-morbidity – see separate 'Key Points' document for further information.
ADHD	Under-diagnosed in the ID population due to diagnostic overshadowing. Overactivity and difficulties with impulse control can present particular risk management issues in those with ID.
Challenging behaviour	A descriptor rather than a diagnosis, however a common cause of support breakdown and crisis presentation.

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Scenarios which raise suspicion of mental illness being the drivers for behavioural disturbance include the following:

- Behaviours occur across all settings
- Lack of response to to well-designed, consistent behavioural interventions
- Association with concurrent changes in sleep, appetite and/or daily functioning
- Evidence of hyper-arousal with increased autonomic activity e.g. tremor, fast pulse, sweating, accompanying the behaviours.

Personality Disorder

People with mild ID who have antisocial traits may pose a risk to others, while still being vulnerable themselves to exploitation and self-neglect. Risk assessment needs to take account of both elements and support from services arranged accordingly.

Those with borderline traits and mild ID are often highly vulnerable and need significant levels of support from services. Staff support is key and staff burnout can lead to crisis presentations. The person may have a crisis/contingency plan which can be actioned.

Crisis presentations in ID

People with ID present in crisis for a range of reasons; some of the common causes are:

Physical health problems	Always the first consideration. Myriad including constipation, infections (ear, respiratory, urinary), pain (dental, fractures, self-injury), GORD, sensory impairment, anaemia, thyroid disease.....
Deterioration in mental health	See above table.
Challenging behaviour	See above table. Has there been a change/increase in behaviour or a decrease in support/carer capacity?
Psychosocial stressors	Transitions e.g. finishing college, changes in routine e.g. holiday closure of services, loss, reduction in support package, change in support team, change in peer group, behavioural disturbance in peer group.
Medication side effects	Person may not be able to readily understand or report adverse effects. Common issues are: sedation, dizziness, cardiovascular compromise, hyponatraemia, seizures.

Making Reasonable Adjustments

Intellectual Disability is a **protected characteristic** under the Equality Act 2010. This means that health and social care services are required to make reasonable adjustments to ensure people with Intellectual Disability are **protected from discrimination** and able to access the care and treatment they need.

The **NHS England Website** has information on making Reasonable Adjustments to assessments for people with ID in **health settings** including hospitals:

<https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

Assessment

- Check if the person has a **communication or hospital passport** and read it before you see them.
- **Allow more time** for the appointment.
- Allow longer for the person to process and answer questions.
- **Don't assume understanding** if the person is just smiling and nodding – be aware of the risk of suggestibility and desire to please – probe further if not sure.
- Having a carer present may help with interpretation of the idiosyncrasies of the person's communication style; however this needs to be balanced with the opportunity for the person to speak confidentially.
- **Time is an abstract concept** - you may need to use fixed points of reference (e.g. before Christmas/after breakfast).
- A **third party history** is invaluable: check the carer that has been working with the person recently, rather than just back from a period of leave, for example.
- It is vital to find out **how the person functions normally** and **what has changed**. Are they different from baseline?
- Observational records e.g. ABC charts, weight charts, sleep charts, are also helpful.
- Stress and illness may significantly impact on the person's **communicative** and **decision-making ability** – consider if decisions can be delayed / revisited if it is safe to wait, to maximise participation.
- Be aware of **developmental level** of the person when assessing, for example 'self talk' or talking out loud to imaginary friends may be in keeping with their developmental stage and not indicative of mental illness.
- It can be difficult for people with ID to answer detailed questions about their symptoms. People with ID may not be able to explain why they hold certain beliefs or display certain behaviours.

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- In some cases it can be impossible to differentiate between complex psychopathologies; a therapeutic trial based on clinical judgement may be needed.
- Have a low threshold for investigating physical differential diagnoses of mental health symptoms eg. blood testing for potential depressive symptoms of fatigue and poor appetite.

Facilitating communication during the clinical assessment

Keep language clear and simple: e.g. “Do you eat well?” not “Has your appetite changed recently?”
Avoid tag questions: e.g. “You eat well, do you?”
Avoid negatives and pronouns
Avoid use of metaphor/simile/colloquialism
Some people with ID may struggle to answer open questions: try a binary choice e.g. “Do you prefer X or Y?” Reverse the options to check for a consistent response.
Closed questions with Y/N answers can be tried but may be leading for those who are suggestible.
Cognition and insight will vary along with the person’s level of ability: tailor your language accordingly: take advice from carers and their communication / hospital passport.

Management

Social support

Involving the person’s network of support is essential in order to facilitate discharge following a behavioural crisis.
Social Services may be able to increase / provide a package of support for a short period.
Placement breakdown should not be an indication for admission.
Emergency respite services may be an option when the support network can no longer cope. This is accessed through Social Services.
Where possible, the aim should be discharge from accident and emergency to home with a robust care plan .

Medication

- Unless there are clear symptoms of mental illness, it is often prudent to hold off prescribing; usually the clinical picture becomes clearer in time or social stressors/physical illnesses are resolved.
- When medication is essential, generally the same medications as used in mainstream psychiatry can be used.
- People with ID are more sensitive to side effects so **start low and go slow**.
- Liquid formulations and a syringe with small graduations may be required to allow titration.
- Remember that **many antipsychotics lower the seizure threshold** so advise patients/carers about this.
- PRN medication may occasionally be required in the short term for severe agitation where underlying physical causes have been excluded and the level of risk justifies it.
- Always consider **mental capacity** and clearly document your assessment and any best interest decision.

Hospital Admission

- Across the UK, Healthcare services now actively work to prevent people with ID and/or Autism being admitted inappropriately to hospital for challenging behaviour or due to social crises / placement breakdown secondary to this. Close working with Social Care Services and Funding Agencies is vital to the success of this process.
- Admission of people with ID can often end up with lengthy delayed discharge so a decision to admit should only be made after appropriate consultation.
- Admission should be primarily for assessment and treatment of an underlying mental health issue.
- If informal admission is being considered, remember to **check mental capacity** and follow appropriate legislation if the person lacks capacity to consent to admission and/or treatment.
- Some patients with mild ID may manage well on mainstream mental health wards. Indeed, some may be better placed there than in ID wards if they are more able as they may have more of a peer group.
- However, many people with mild ID are vulnerable in mainstream settings. Whilst they may have good verbal skills, this can mask their cognitive deficits. They may still be very **suggestible and vulnerable** to exploitation by more able patients. Be vigilant for this.
- Mainstream mental health wards should put in place **reasonable adjustments** to support the person in hospital.

Case Scenario: Jenny

Jenny is a 55 year old lady with Down's syndrome who has recently moved to a new residential care home. The home was given limited information about her past history, including of any mental health or behaviour problems.

Jenny is taken to A+E with increasing challenging behaviour over past 36 hours, including lashing out and screaming. They report that she hasn't eaten much in the last 72 hours and that she has been incontinent of urine, sleeping very little, restless and agitated.

Jenny is not co operating with any vital sign monitoring or examination. The A+E Medical Registrar reviews and speaks to you: "She's mentally unwell; I think you need to section her". You advise the Registrar to rule out a physical cause: he states: "She's not complying with anything; why can't you just see her? It's her mental health and learning disability".

Considerations:

- Risk of **diagnostic overshadowing**.
- Does she have a **hospital passport**?
- Have all **reasonable adjustments** been considered?
- Is the appropriate **Capacity** legislation being followed?

The Psychiatrist looks at Jenny's Hospital Passport and discusses with A&E Staff ways to help Jenny engage with investigations. She is moved to a corner cubicle and the carer who knows her best is allowed to sit with her. An A&E Nurse shows Jenny the oximeter and demonstrates how it is used on her carer: Jenny is curious and copies their action; she then accepts the probe on her finger. The Nurse then shows her the temperature probe and she accepts this.

Jenny is found to have a heart rate of 120 bpm, her temperature is 38.5°C and she has dry mucous membranes. She becomes drowsy and bloods are taken in her best interest. These indicate acute kidney injury, high white cell count and inflammatory markers.

IV antibiotics are commenced for a UTI and Jenny is moved to a side room near the Nurses' Station on a medical ward. Social Services are contacted to fund 1:1 support hours to allow her carers to stay with her on the ward. Jenny quickly improves and accepts oral antibiotics. She returns home with GP follow up.

Case Scenario: Tom

Tom is a 36 year old man with mild ID, autism and challenging behaviour. He takes Risperidone for aggressive behaviour. Tom is brought into A&E on a Sunday afternoon by his carers who are reporting that he has become 'unmanageable'.

There is a 1 week history of 'blowouts', causing extensive damage to his home, breaking furniture and throwing televisions. In between episodes he is described as his usual self, and his carers comment that he appears to be 'enjoying' his outbursts. There is no reported change to sleep, weight or appetite. Tom accepts a brief physical examination and seems to be in good health

Tom is seen by the Psychiatric Liaison Nurse who is worried he is thought disordered. The Nurse requests consideration for admission. The Psychiatric Registrar attends A&E to review Tom. When seen, Tom presents as calm, with repetitive speech and echolalia. He seems unable to discuss recent events but repeatedly says 'Sam gone'. The Psychiatrist enquires of Tom's carers about Tom's living circumstances and discovers that Sam was the Home Manager who recently left. The Psychiatrist concludes there is no obvious mental illness warranting admission. Social Services are contacted and agree to additional support hours on a short-term basis.

Follow up is arranged with the Community ID Service within 24hrs. The ID team identify that since the change in Manager, guidelines and protocols for managing Tom's behaviour were not being followed. Once this is addressed, Tom's behaviour quickly settles.

Curricula and Assessment Committee

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