

# The need for FASTER CARE in the diagnosis of illness in people with intellectual disabilities

### INTRODUCTION

The *Confidential Inquiry into premature deaths of people with learning disabilities*<sup>1</sup> reported the median age at death for the 247 people with intellectual disabilities (ID) in the study to be on average 16 years sooner than in the general population of England and Wales. Almost one-quarter (22%) were under the age of 50 years when they died, compared with just 9% in the general population. A comparator group of people without ID, who died at a similar age and from similar causes, experienced significantly fewer problems in all aspects of care provision, coordination, and documentation.

One of the contributory factors highlighted in the report was the delay in the care pathways of people with ID who had died, in particular delayed diagnosis. Of the 171 people with ID who had been identified as being unwell, by themselves or their carers, and who had responded promptly in reporting this to a doctor, almost one-quarter (23%) had one or more problems with their illness being diagnosed.

The problems of diagnosing illness in people with ID are well-rehearsed. Patient-related barriers include that people with ID may not identify symptoms promptly or communicate them articulately; they may be reliant on support to access services, present with illness in unusual ways, and have an atypical response to treatments. Clinician-related barriers relate to a lack of knowledge about the health issues of people with ID and a lack of skill in adopting appropriate approaches when assessing, diagnosing, treating, and monitoring illness in this patient group.<sup>2</sup>

The Confidential Inquiry additionally identified a number of issues contributing to delays in diagnosing illness:

- One in six (16%) people with ID whose deaths were reviewed were reported to have been particularly fearful of contact with medical professionals and interventions and, for most, no proactive work had been undertaken to try and address such fears.
- Reasonable adjustments to make services accessible for people with ID were sometimes not made, although this is a legal requirement.
- Family and paid carers trying to fulfil an

advocacy role for the individual commonly felt that they were not listened to and were sidelined by health professionals.

### POSITIVE PRACTICE IN DIAGNOSING ILLNESS

So what would positive practice look like in diagnosing illness in people with ID and how can we overcome some of these barriers?

#### Measures to reduce patient anxiety

Evidence from the Confidential Inquiry suggests that a positive, trusting, and respectful relationship between the doctor and patient is crucial. Where people are particularly fearful of contact, they may require a referral to the community learning disability team (CLDT) for desensitisation activities. In other cases, trust and respect can be garnered with contact that is not driven by a health emergency or painful intervention, but by social or casual contact. Examples include inviting people known to be reluctant to have contact with doctors or interventions to the surgery so that they can get to know the environment and the staff without having anything 'done' to them; inviting people with ID to help plan and host an 'open session' for their peers, in which patients can familiarise themselves with the environment and basic equipment; and producing practice information in easy-read formats to indicate a welcoming approach. One GP, for example, made a point of chatting with residents at a care home when visiting there, so that when ill, visits to or from the GP were less anxiety-provoking for the residents registered with that GP.

#### Managing appointments

In general, the timing and length of appointments for people with ID is likely to require a degree of flexibility. People with ID often require extra time to communicate their health concerns and assimilate information. They may also be sensitive to social situations, and sitting in a waiting room may raise levels of anxiety with a resulting

impact on behaviour and communication skills. One GP practice routinely made double appointments for people with ID; at another practice one GP would always see a particular person with ID, who lived unsupported in the community, whenever he turned up, often without an appointment, because she had prior knowledge of his personal circumstances.

#### Hone observation and listening skills

Prompt diagnosis of illness in people with ID involves the need for acute observation and listening skills, and having an open mind rather than making assumptions. Minimising distractions in the consulting room, talking to the person in short, simple sentences, and using a range of communication methods will help maximise the ability of the person to contribute to the consultation. A key resource is listening to the views of those who know the person well. They are likely to be 'tuned in' to picking up changes in behaviour, function, or abilities that may indicate where the problem is. 'Diagnostic overshadowing' — when a clinician attributes symptoms to a person's intellectual disability (or other long-term condition) rather than treatable causes<sup>3</sup> — can be avoided by GPs viewing a presenting problem in a multidimensional way ('cognitive complexity'), and being open to detecting comorbid conditions.<sup>4</sup>

#### Minimise watching and waiting

Clinicians 'watching and waiting' too long in the case of people with ID was raised as a concern in the Confidential Inquiry. Exactly how long is 'too long' can be a matter of conjecture, but given the high risk of multimorbidity and premature death in people with ID, a proactive strategy should be exercised. Referral to a CLDT or specialist intellectual disability service should be sought sooner rather than later if there are barriers to an individual accessing health care or in diagnosing or treating their illness.

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*"Diagnostic overshadowing can be avoided by GPs viewing a presenting problem in a multidimensional way."*

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*“Safety-net advice should include the specific clinical features (including ‘red flags’ or warning signs) that the patient (or parent/carer) should look out for.”*

### Safety netting

Safety netting is a consultation technique used to ensure the timely re-appraisal of a patient's condition.<sup>5</sup> Neighbour<sup>6</sup> described it as a core component of the GP consultation and defined safety netting from the GP perspective as encompassing three questions:

1. If I'm right, what do I expect to happen?
2. How will I know if I'm wrong?
3. What would I do then?

Almond *et al* reviewed this advice and developed a clinical consensus about safety netting in children with acute illness using a modified Delphi technique.<sup>7</sup> Their recommendations about safety netting are equally applicable to people with ID:

- If the diagnosis is uncertain, that uncertainty should be communicated to the patient (or parent/carer) so that they are empowered to re-consult if necessary.
- If there is a recognised risk of deterioration or complications developing, the safety-net advice should include the specific clinical features (including ‘red flags’ or warning signs) that the patient (or parent/carer) should look out for.
- Safety-net advice should give specific guidance on how and where to seek further help if needed.
- Where information about the likely time course of an illness is known, safety-net advice should include this information, but it should be made clear that if a patient (or parent/carer) has concerns they should not delay seeking further medical advice.

While no diagnostic rule is 100% sensitive, GPs are advised to consider referral to a specialist after repeated consultations for the same symptom where the diagnosis is uncertain (for example, three strikes and you are in).

### CONCLUSION

Diagnosis is a process which categorises

general features common to a group and can neglect the diversity and difference of individuals.<sup>8</sup> For some patients, including those with ID, a more individualised approach is likely to be required to reach a diagnosis, which would involve paying attention to the context of the consultation and our communication and relationship with the person concerned. As a way of memorising this, we propose using the acronym FASTER CARE:

- F Fear of contact with medical professionals or interventions are to be addressed proactively.
- A Address barriers to Access.
- S Keep your language Simple.
- T Take extra Time.
- E Engage with other informants (in particular, family and paid carers).
- R Develop a positive, trusting and Respectful Relationship.
- C Cognitive Complexity: view presenting problems in a multidimensional way.
- A Act: minimise ‘watching and waiting’ time and use a safety-net approach.
- R Identify and request the Reasonable adjustments a person might need if referring them for investigations.
- E Enlist the support of the CLDT.

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### REFERENCES

1. Heslop P, Blair P, Fleming P, *et al*. *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report*. 2013. <http://www.bristol.ac.uk/cipold/fullfinalreport.pdf> [accessed 30 Oct 2013].
2. Higgins S, O'Toole M. Meeting the health needs of people with intellectual impairment. In: LL Clark, P Griffiths, eds. *Learning Disability and other intellectual impairments: Meeting needs through health services*. Chichester: John Wiley & Sons, 2008.
3. Lindsay P, ed. *Care of the adult with intellectual disability in primary care*. London: Radcliffe Publishing, 2011.
4. Jones S, Howard L, Thornicroft G. Diagnostic overshadowing: worse physical health care for people with mental illness. *Acta Psychiatr Scand* 2008; **118(3)**: 169–171.
5. Bankhead C, Heneghan C, Hewitson P, Thompson M. *Safety netting to improve early cancer diagnosis in primary care: development of consensus guidelines. Final Report*. 2011. <http://webarchive.nationalarchives.gov.uk/20130513211237/http://ncat.nhs.uk/sites/default/files/Safety%20Netting%20Guidance%20for%20GPs.pdf%20.pdf> [accessed 6 Nov 2013].
6. Neighbour R. *The inner consultation*. Oxford: Radcliffe Publishing, 2004.
7. Almond S, Mant D, Thompson M. Diagnostic safety-netting. *Br J Gen Pract* 2009; **59(568)**: 872–874.
8. Boyle M. Minimum contents: why psychiatry can't cope with responding to the contents of hallucinations. *Open Mind* 1997; **87**: 12–13.