

Diagnostic Overshadowing: See Beyond the Diagnosis

This article considers ways of ensuring key health issues are not overlooked in people with intellectual disabilities.

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In this article, Jim Blair looks at ways of ensuring key health issues are not overlooked in people with learning disabilities

Healthcare settings are strange, unfamiliar places. We only tend to go to them when we are unwell either physically or mentally, so finding your way through what can seem like a maze is hard.

For people with learning disabilities it can seem a petrifying environment within which to make sense of what is happening. These same feelings are frequently experienced by health professionals when seeking to assess, treat and ensure safe reasonable care takes place for people with learning disabilities.

Too often, the training undertaken by clinical staff has not prepared them for working with people with learning disabilities in these constantly high-pressure environments.^[1] This is particularly pertinent to general healthcare where staff in those settings have “very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same, but rather may need to be adapted to meet special needs.”^[2]

This article sets out ways of reducing clinical risks such as diagnostic overshadowing, ensuring that health professionals see the person and not just their disability. Diagnostic overshadowing occurs when a health professional makes the assumption that a person with learning disabilities' behaviour is a part of their disability without exploring other factors such as biological determinants. Diagnostic overshadowing has been defined as “..once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed.”^[3]

In relation to people with a learning disability Emerson and Baines (2010) highlighted that it means “Symptoms of physical ill health are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities.”^[4] Gates and Barr (2009) noted that diagnostic overshadowing is particularly pertinent when new behaviours develop or existing ones increase.^[5] Given that people with learning disabilities have a much higher risk of experiencing a variety of diseases and conditions it is vital that physiological or pathological determinants in behaviour change are explored. If they are not, people with learning disabilities can suffer poor care and may even die when their death could be avoided. Gastrointestinal cancers are approximately twice as prevalent in people with a learning disability, coronary heart disease is the second highest cause of death for people with a learning disability and approximately 70% of people with a learning disability experience gastrointestinal disorders.^[6]

The Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD) [7] highlighted that people with a learning disability have far worse health outcomes than those in the general population. These include:

- Reduced access to, and less likely to receive, interventions for their obesity, including screening for thyroid disease and diabetes
- Greater risk of death from amenable causes (avoidable due to medical intervention)
- Variance (approximately 48%) in amenable death rates in the non-learning disabled population
- Low take-up for national cancer screening programmes, for example, breast, bowel and cervical
- Low uptake of immunisations such as 'flu vaccinations
- Increased risk of death due to respiratory infection – one of the highest causes of amenable death.

CIPOLD also found that women with a learning disability die on average 20 years younger than women who did not have a learning disability and men some 13 years younger than their non-learning disabled counterparts. Some of the most consistent reasons were:

- Delays or problems with diagnosis or treatment
- Problems with identifying needs
- Difficulty providing appropriate care in response to changing needs.

No health professional seeks to discriminate against his or her patient, but the evidence illustrates that people with learning disabilities have poorer health outcomes than the rest of the population. A central component in the health professional and patient relationship is creating trust and rapport. However, if the patient has difficulty communicating and being understood by others this development can take time and effort – not something every health professional feels able or willing to give. If this does not happen and human connection is not acquired then health professionals can easily slide into the trap of diagnostic overshadowing and thereby, often unwittingly, fail to apply the same diagnostic principles that they would afford others.[8]

Diagnostic overshadowing can occur during an assessment, such as when a health professional interprets a person with a learning disability rubbing their heads as a behaviour linked to their learning disability and fails to investigate any possible underlying health cause. Another example is when a person with a learning disability who has a pre-existing condition such as a gall bladder problem, develops a mental health problem and the initial health issue is no longer considered, as health professionals can get blinded by the mental health concerns and forget the other health need. This can lead to avoidable deaths, as if undetected or under monitored a gall bladder problem can result in it bursting and excess toxins entering the blood-stream with fatal effect. It is vital always to explore a physical or psychological reason behind a behaviour change or a new behaviour.

Key points to eliminate diagnostic overshadowing

- Be respectful. Don't make assumptions about a person's quality of life. Treat the patient in a way that is appropriate to their chronological age
- Respect confidentiality, as for any other patient

- Always communicate with the patient directly. If a person does not use verbal language to communicate, use pictures like the ones in the Books Beyond Words series, photos, symbols, signs, etc to engage with them
- Assess people's health and wellbeing so that any changes in behaviour that may signify changes in condition or an illness are not attributed to their learning disability
- Pay close attention to non-verbal communication, for example sounds, body positions, facial gestures and other non-verbal signs that may indicate pain, anxiety and discomfort
- Be aware of the physical setting and how you can adjust it to support the patient's access, comfort and safety
- Understand the issues around gaining consent clearly, and make every effort to gain consent
- Seek out help from people who know the patient best and engage with family or supporters to help you communicate effectively with them. This may help you get to know the person and understand what is in their best interests if they lack capacity to consent
- Ensure that the lines of communication with the patient, their family carers, advocates or supporters are clearly established throughout the healthcare journey
- Always liaise with Community Learning Disability Team colleagues such as community learning disability nurses and other community health professionals to support admission and discharge for hospital, or if someone with a learning disability does not turn up for an appointment. [9]

Conclusion

As health professionals we can all be guilty of making assumptions about people we see. But once we see the person and experience their abilities we can realise our assumptions were ill-founded. As noted earlier, many health professionals have had limited opportunities to experience during their formative training how to work and get to know people with a learning disability and how rich their lives are. We need to ensure that more is done to remedy this. There are pockets of good practice where people with a learning disability, family members, carers and supporters are involved in teaching, design and evaluation of health professionals and services within which they work, but much more needs to be done. Once this has become commonplace then there will be an end to diagnostic overshadowing and an increase in positive health experiences, outcomes and a significant reduction in avoidable deaths of people with a learning disability.

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