Worksheet 20: Working in a person-centred way with an individual with a learning disability and dementia

Around 1.5 million people in the UK have a learning disability (also known as an ‘intellectual disability’, partly to avoid confusion with specific learning *difficulties* such as dyslexia). One of the most commonly used definitions in the UK is that contained in the ‘Valuing People’ and ‘Valuing People Now‘ strategies. These state that a learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence).
- a reduced ability to cope independently (impaired social functioning).
- symptoms before adulthood, with a lasting effect on development.

It is understood that people with Down’s Syndrome are at risk of developing dementia of Alzheimer’s type about 30-40 years earlier than the rest of the population.

The prevalence of dementia in people with learning disabilities not associated with Down’s Syndrome is also raised to two or three times that expected in those aged over 65 years in the general population.

The availability of screening and treatment for people with a learning disability is inequitable across the UK and gaining an accurate diagnosis is often challenging.

Diagnostic overshadowing may impair the recognition of dementia if those supporting the individual with a learning disability attribute any changes in them to the learning disability rather than considering that there may be other causes.

It is important to establish an accurate baseline of cognitive and adaptive functioning for people with learning disabilities and particularly those with Down’s Syndrome because:

- There is no definitive ‘test’ for dementia.
- Its presence is a matter of eliciting a clinical history suggesting dementia and establishing evidence of change in function from a known baseline and then excluding other diagnoses that may mimic dementia.
- In the mainstream population it is much more straightforward to gauge pre-morbid functioning from self-report, employment history and so on than it is in the population of people with learning disabilities – where self-report is very limited and few paid carers are in possession of a full history.
- Unless a baseline is established when the person is healthy, it is very difficult to establish whether there has been a deterioration later in life. By the time an individual is referred with concerns, considerable deterioration may have occurred, and an accurate account of pre-morbid functioning may be difficult to construct.

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Belinda's story

Belinda is 42 and has a learning disability.

She has been living in supported housing a few miles from her parents' home.

Belinda had flourished in the supported housing environment and had started a loving relationship with Carl, who she enjoyed cooking for and going to the cinema with.

In recent months Belinda's family, friends and support worker noted that she seemed to be becoming more forgetful. Belinda seemed to be showing less interest in her appearance and daily living activities, and responded aggressively when prompted about these areas which is very out of character for her.

On one occasion Belinda went to visit her parents – a trip she has made many, many times – and became lost on her way back home. The police were called to help find her. This frightened Belinda at the time, though she is unable to recall this event now.

Belinda's parents took her to see her GP who referred Belinda to the local memory service for further assessments. These assessments supported a diagnosis of Alzheimer's disease. Belinda's parents feel that she needs to be moved into residential care.

What information would you need to be able to support Belinda in a person-centred way? Think about Kitwood's person-centred approach.

Where would you get this information?

How would you work with Belinda?

Forester-Morgan, T. & Mould, S. (2021) *The Dementia Care Training Library.*
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