

'A' for Adjustment Framework – A is for Attitude

Case Study – Marion's story

When Marion first moved into her new home, she arrived, using her wheelchair and wearing large oven mittens, which were taped around her wrists so she couldn't remove them. The support staff were told that these were to protect her hands when she bit them. Marion moved into a supported living setting, along with 6 other people with learning disabilities and complex support needs.

Marion often became distressed, crying, shouting and biting her hands. The little information that was available about her as a person suggested that this was challenging behaviour, linked to her learning disability.

Marion's keyworker didn't accept this as a reason. She could see a woman in distress, perhaps in pain, who was showing that something was wrong. Once registered, she took her to the GP. The GP couldn't find anything obviously wrong, but the support worker, with her team, kept observing and getting to know Marion, as they tried to work out what the matter was. They noticed that Marion's distress sometimes happened when she was out, or about to go out. Could it be that she was distressed or embarrassed about being incontinent when out? They duly supported her with the diet that was suggested, thickening her drinks and offering energy shakes when she hadn't eaten much.

Over the course of the next two years, Marion's Keyworker kept on trying to find out what was wrong. They looked into the incontinence, tried to help her with her emotions and supporting any embarrassment by helping her wear pads when going out. They spoke to health professionals and psychologists. Marion continued to regularly get distressed, crying and biting her hands. She continued to resist going out of the house.

A chance conversation that Marion's Keyworker had with a friend offered another option to look into. The friend happened to describe her recent experiences of finding out she was intolerant to lactose (milk-based products). She described the pain, the continence difficulties and the discomfort. Marion's Keyworker listened and responded quickly, contacting the GP, sharing the idea and gaining an appointment for Marion for tests and input from a dietitian. Finally, after removing lactose from her diet things changed dramatically. Marion's continence improved, she stopped biting her hands, and she was happier and more content and wanted to go out more often. It was clear in retrospect that for years, she had been suffering excruciating pain and discomfort. She had additionally hated the shame of going out in such circumstances, if this occurred when she could be seen by others.

This story has had a happy ending and a life changing experience for someone who was unable to verbally communicate what was wrong with them. It had a good outcome due to the tenacity and skill of a support worker in a supported living setting, who wasn't willing to accept that someone would act that way without cause and with the health professionals who were willing to listen, act and try things, based on what they were hearing from the person's supporters and their knowledge and observations of Marion's behaviour.


Health Education England



This learning resource was commissioned by Health Education England working together with the National Development Team for Inclusion and Skills for Care - August 2020.