

A person centred response: keeping Nan at the centre of her life.

Jane Sherwin

I'd like to tell you about two characters. The first had the following descriptions in her various files: arthritis, cataracts, congestive cardiac failure, periodic urinary tract infections, difficulty sleeping at times, needs a prompt to take medication, never owned a house, can't drive and never has, hardly goes out, uses a wheelchair to lean on and push around at home, can't get in and out of the shower over the bath, cannot shower herself, trips over her own feet, losing interest in cooking and eating, is not entirely safe with the gas stove, can't hang out the washing, can only do light cleaning, can only stand for short periods without leaning on something. If asked what the probable lifestyle of this person would be, many professionals would advise medical procedures for the various bodily complaints, a day service for her social isolation, a respite service to give her family a break, an in-home support service for her personal care and that eventually she would need to move to a nursing home.

The second character lived through World War 2 and the Depression, raised six children, is a grandmother, great grandmother, senior citizen, is a lover of crochet, gardening, TV game shows and Canasta, voted Labor all her life, is the Patron of a large hockey club, plum pudding maker, and her grandchildren describe the delightful smell of Johnson's baby powder around her and that she is wonderful to hug. Anyone asked to think about what would be a desirable lifestyle for this person is likely to say such things as that she would grow old in her own home, maintain her centrality in the family, maintain her roles, be surrounded by the comings and goings of family, be part of all important family rituals, be encouraged to do much for herself, be surrounded by the things that mean something to her, maintain her interests, keep healthy, maintain her connections to old friends even by phone and that she would have a reason to get out of bed each day.

Interestingly, these two identities are one person: my grandmother, known affectionately by her extended family and often by their friends as Nan.

This is the story of Nan having the lifestyle described in the second identity, despite having the problems in the first list. In everyday life, this is known as having an ordinary and typical life. It is what most of us hope for. It is living until we are no longer breathing.

For human service workers, this is the essence of person-centred responses: it begins with an appreciation of the fullness of an identity. It is worth being reminded that outside of human services, most people have never heard of 'person centred approaches', and surprisingly get by most days without even thinking about it. However, in service land, we need a way of describing a manner of working that is an antithesis of the traditional, historical approaches.

For most human services, the referral process and the service responses typically start with the list of deficits. The lifestyle that is crafted as a result is a service life, not an ordinary life. Had Nan's life been designed by most professionals, her lifestyle would have been a combination of human services with paid workers being the 'answer' to all of the things that she could no longer do.

An assessment by an ACAT team and the entry of an in-home support service opened the door to well meaning professionals doing their thing: they asked the questions, the file appeared on the dining table, they were the only ones that wrote in it; notes left by Nan's daughter about which potions and lotions to use were left unread; it was the service that determined who the workers were, what they would do and when they would come to assist. Strangers employed on a casual basis replaced absent core staff. In Nan's view, they were all 'nice girls' and they probably were in that they were caring and chatty. They knocked before they walked in and they (mostly) looked after Nan's dignity when they were involved in the intimacies of care. However personable the staff might be, a person-centred service might still not be delivered. We were aware that we had little influence over who these staff were, how they perceived an older person and what their responsibilities were. For a time went along with the arrangement because we couldn't see any alternative.

Eventually Nan's physical capacities declined. She could no longer stand; it was difficult for her to roll over in bed. Her physical involvement in the household chores was not possible. She was frequently in hospital and family members needed to be present to ensure that she was fed the meal that was left for her, that the family was kept informed about her treatment, and that we resisted pressures to send her where she didn't want to go, away from her family home.

By the time she celebrated her 97th birthday, the experience of the family was that it had been an enormous struggle to get decent service for her. Even services designed to keep older people in their own home were pressuring us to send her to a nursing home, and how did they do this? By threatening to withdraw the services that so far had helped keep her at home! How bizarre. At one stage a Coordinator said to me, in a voice that was like jabbing her finger into my shoulder, 'Your grandmother's most important need is to have a shower, don't you agree?', implying that hygiene through showering was the only way to get hygiene. 'No', said I, in my most Aha gotcha voice, 'the most important need for Nan is to be surrounded by loved ones, familiar possessions and familiar routines.'

It was clear that those in the service system held the power. This Coordinator could easily have withdrawn service; she could have talked about Nan in ways that made the workers resentful of assisting her. She was clearly unhappy at our disagreement with her assessment and advice. She argued Nan's 'rights to safety'. We agreed with the right; we disagreed with how these rights should be accorded. She argued workplace health and safety, with which we also agreed. Numerous unpleasant meetings were held.

Finally the Coordinator asked what it was that we wanted. 'To have what Nan wanted, to be at home', we said. 'To have the authority to choose staff and determine what they would do and when they would do it.' What this meant was that we wanted

Nan to be at the centre of her own life and the life of the family, not to be in 'a' centre or at the centre of a service-led set of solutions. We wanted Nan to be able to hold onto her roles, including matriarch of the family and homemaker even though she no longer did homemaking tasks. We wanted a relationship with a service that recognised that we too had 'expertise' about what was important. We wanted not to have to fit into a predetermined menu of service responses because that is an experience of service-centric work, not person centred. My sense is that she agreed to all this not because she recognised that Nan and her family have inherent authority that she was stomping on, but rather to get rid of a stressful and complaining 'case'.

Eventually we were fortunate to have a Coordinator who, while not using the language of person-centred service, clearly worked in that way. She saw her role as enabling Nan and the family to lead our lives. She did practical things like assist us with a more workable roster of staff and showed us how to physically assist Nan in bed. She told us what was likely to happen in a physical sense when Nan eventually died. We continued to have a major say over who the staff were and what they did. What she did *not* do was as important as what she did do. She did not intrude on family business, such as our vision for Nan, Nan's routines and our expectations of the quality of the care. We felt like she was on Nan's side. Her business was to enable Nan to stay in life, not to provide a substitute service life.

What this finally allowed would not have appeared in any set of service outcomes. Many wonderful moments happened because Nan stayed at the centre of her own life. The family had a reunion prompted by forecasts of Nan's imminent death; her son provided care in a way he never imagined he could; and the small moments became important such as being the recipient of a look of joyful love when she hadn't seen you for a few days.

I in turn learnt about person-centred responses. It is about ordinary lives, the vulnerable person holding onto their valued roles and freely given relationships, the levels of authority that we naturally have in our own homes not being usurped by the system, an equal and ethical partnership between the service and the person and family, and supports designed in a very individualised way.

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