

What's wrong with 'seeing the person first'?

'Person first thinking' makes it a virtue to 'see the person not the disability', considering it a kindness to overlook, or to make an effort to overlook, a person's impairment in order to see 'the person within' (Michalko, 2002). While at first sight this might seem a caring and compassionate approach within everyday nursing practice, on closer examination it can be seen as unhelpful and possibly even discriminatory. It rests upon outdated Cartesian ideas about the body and the self – as if the disabled person is trapped within a flawed body and there is a 'normal' healthy person struggling to get out (Cameron, 2014a). It is based on a number of misplaced assumptions about the experience of impairment, treating this as something invariably unpleasant and regrettable (Morris, 1991:19ff). It involves a persistent way of thinking about impairment that has long been contested by disabled people themselves (Cameron, 2015).

Person first thinking reflects an individual or medical model view (Oliver and Barnes: 2012) which identifies disability as embodied limitation. Medical model thinking has traditionally underpinned not only nurse education but institutional thinking about disability generally within wider society. It is reflected within cultural narratives and the ceaseless recycling of stereotyped representations portraying disabled people as *victims* or as *plucky strugglers* (Cameron: 2014b). The medical model is best summarised in the World Health Organisation's (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH) (1980: 47, 143). This involves the following definitions:

Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function

Disability: any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Disability is understood here as a characteristic of individual deficit or personal tragedy, as something arising directly from impairment, to be measured in terms of normality and abnormality. In the more recent International Classification of Functioning, Disability and Health (ICF) (WHO, 2012) disability retains its character as an unfortunate individual condition:

'an umbrella term covering impairments, activity limitations, and participation restrictions'

Language is important because it shapes the way we make sense of and experience the world. Reality is given structure within the narratives that circulate in everyday practice. When disability is considered as signifying personal loss and limitation, this impacts on encounters between disabled individuals and healthcare professionals with whom they interact. It excludes from consideration the possibilities that somebody might live with impairment as an ordinary part of their life, that they may consider impairment an important part of who they are in that it has shaped their life experience and who they have become as a person, and that they might like themselves and enjoy being who they are regardless of their impairment experience. Having someone 'kindly' overlooking their impairment involves an invalidation of their experience and a lack of awareness of the issues that can really make disabled people's lives difficult (Milton, 2017).

An alternative perspective has been developed by the Disabled People's Movement. The social model, developed initially by the Union of the Physically Impaired Against Segregation (1976) and later by Disabled People's International (DPI), re-defines disability as an unequal social relationship within a society which has failed to take account of the needs of people with impairments or to plan for their inclusion in everyday community life. The social model defines these terms as:

Impairment: the loss or limitation of physical, mental or sensory function on a long term, or permanent basis

Disability: the loss or limitation of opportunities to take part in the normal life of the community on an equal level of others due to physical and social barriers

(DPI, 1982, in Disability Equality in Education, 2002:35)

Within this view disability is not something that people *have* but it is something that is *done* to people with impairments. Disability does not signify something wrong with people's bodies but is rather about the way that society reacts to physical, sensory, cognitive and emotional difference. A historical analysis (Slorach, 2016) demonstrates how, as part of the industrialisation of society during the 19th Century, people with impairments were systematically removed from the social mainstream and incarcerated within a variety of institutions, asylums and hospitals. The production requirements of industrialised labour created a need for a 'normal individual' who could work within the factory system (Davis, 2017) while at the same time living arrangements within the developing towns and cities established a requirement for greater conformity and compliance with social norms of behaviour and self-presentation (Elias, 2001). People with impairments came under the

surveillance of increasingly powerful medical professionals and disability became regarded as a medical problem requiring treatment with the continued hope of cure (Cameron, 2014c). Having excluded people with impairments from ordinary community life, society has since seen little need to take their needs into account, resulting in the development of physical and social institutions, cultures and environments that are largely inaccessible to disabled people. While processes of addressing these have begun since the establishment of UK anti-discrimination legislation (the Disability Discrimination Act 1995, replaced by the Equalities Act 2010), attitudes and assumptions lag behind (Heaton, 2014).

While the social model has provided a tool for understanding disability as a structural issue, concern has been expressed by some disabled writers that it does not adequately address the lived experience of impairment or the challenges disabled people face as a result of impairment effects (Thomas, 1999). Impairment can be messy, tiring, and is not always easy to live with. This, however, does not mean it can only be experienced negatively, as a blight upon lives that might otherwise have been wonderful. Impairment can add depth to life, give a different perspective, and teach us much about the ambiguity of what it means to be human (Davies, 2012). This way of thinking is expressed in the affirmation model, a theoretical development emerging from expressions of disability pride within the disability arts movement (Swain and French, 2008). The affirmation model builds upon the social model, taking on board the restrictions and barriers faced by disabled people but also celebrating the fact that, whilst not always comfortable, life as a disabled person can be just as 'valuable, interesting and intrinsically satisfying' as the life of a non-disabled person (Cameron, 2014c: 25). The affirmation model offers new definitions:

Impairment: physical, sensory, emotional and cognitive difference, divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society.

Disability: a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal.

(Cameron, 2014d: 28)

The affirmation model establishes the rights of disabled people to be who they are *as they are* while also recognising the social relational nature of disability. The evaluation of disability as deficit takes place within countless everyday interactions, reminding people with impairments "I am abnormal and therefore need to know my place," while confirming to non-disabled people "I am normal and therefore entitled to my place." As Cal Montgomery has stated:

Every few hours I run up against people who feel free to remind me that I'm their inferior and that I should conform to whatever they've decided 'people like [me]' are supposed to be like (Montgomery, 2006: unpagged).

Disability involves an oppressive relationship that validates conformity of bodily comportment and invalidates aberration. The affirmation model provides disabled people with an insight with which to challenge the social pressures to conform. In the words of Amanda Baggs, an autistic woman:

In general I don't think the attitude of fixing someone helps anyone, least of all people who are so far from the norm that it's obvious that they'll never be made into the norm...It bothers me to hear autism described as a tragedy... We're part of the human condition and we're not a lesser part or a tragic part or sad or pitiful or pathetic (CBC News, 2009: unpagged).

The affirmation model is about the assertion by disabled people of the right to be different and to have that difference valued and included. This challenge to conventional ideas about disability has been expressed succinctly in Johnny Crescendo's lyric 'I love my body - It's the only one I've got', and widely in disability arts by people experiencing the spectrum of impairments (Cameron, 2007; Cameron, 2009; Cameron, 2011). Among these have been many autistic people, people with communication impairments and people with learning difficulties – from performers such as London-based reggae band Heart'n'Soul, the North East punk band The Fugertivs and theatre company The Lawnmowers in the 1980s and 1990s, to contemporary artists including Ian Lane, The Stealth Aspies, Heavy Load, Lost Voice Guy, Paul Wilshaw, Mind the Gap, Emma Robdale, Sarah Gordy, Nicky Priest, The Rockets. This thinking is summed up in Clare Sainsbury's claim to be recognised as an autistic person rather than as 'a person with autism':

We are not people who 'just happen to have autism'; it is not an an appendage that can be separated from who we are as people, nor is it something shameful that has to be reduced to a sub-clause (Sainsbury, 2009:12).

Joan Tollifson, another disabled writer, has made the point that imperfection is the essence of being organic and alive. Life's vulnerability, she argues, is part of its beauty. There is a need to cherish what actually is 'instead of being caught up and entranced by what we think would

be better' (Tollifson, 1997:106). The affirmation model involves a requirement to recognise this and to value difference for its own sake.

The medical model is experienced by disabled people as problematic in that it is materialised in everyday practice through the myriad of behaviours, decisions, and interactions taking place in the contexts in which they experience their lives. It is put into practice in the ways that services are planned and delivered, words are spoken, thoughts are left unspoken, and in gestures, assumptions, hopes and expectations. Because it is a dominant model of disability, reflecting the view of the world of the non-disabled, its character as a model, as a way of looking at things, is almost always overlooked. Medical model thinking does not appear as just 'one way of looking' but as established fact. It is considered common sense to regard impairment as misfortune. This impacts upon disabled people's lives not just in terms of professional judgements and assumptions about what are appropriate services, but also in terms of the restriction of life opportunities, experiences and roles (Cameron, 2014e). In this context, just like anybody else, many nurses have never considered the medical model as just one way of looking rather than as objective fact. They have not reflected on how different disability models impact on clinical decision making in practice or the outcomes of health care intervention (Brandon, 2014). This is also true for many disabled people who have never encountered the social or affirmation models. It is not surprising, given current thinking about disability, that many disabled people feel very negatively about their impairments and invest much effort and energy in trying to cover these up, hoping that they won't cause other people to treat them differently (Cameron, 2014f).

The affirmation model provides an opportunity for a renewed way of thinking that enables nurses to support disabled people in making sense of what it means to live with impairment in a disabling society. It is not that disabled people taking an affirmative view want to emphasise their impairments above other parts of who they are, but that they see no reason why their impairments should be downplayed. People have a right for their impairments to be recognised as significant parts of who they are – not necessarily the most important part, but important all the same. It is about establishing disabled people's rights to value themselves as they are, not only insofar as they can overcome or minimise the significance of their impairments. It involves a different way of looking to identify the real problems of disability.

Nurses could play a central role in supporting people to own impairment by cascading the values of the affirmation model in practice and by truly embracing what it means to deliver

holistic care. Nurses are directed to identify and address unwarranted discrimination and variation in practice, to improve outcomes, experience and use of resources, and to take opportunities to act as change agents to add value (NHS England: 2016). The updated Nursing and Midwifery (2018) code of professional conduct reminds nurses of their duty to tackle discrimination and provide leadership to ensure that people's wellbeing is protected, and their experiences of the health and care system are improved. If nurses are unaware of or ignore the value of the affirmation model, they are at risk of becoming stuck within the medical model thinking trap and the safety and quality of care cannot be continually enhanced. In this situation, disabled people will continue to experience modes of practice which perpetuate the separation of their being and dilute holism and partnership working. Nurses must challenge their thinking patterns to break the oppression endured by disabled people in healthcare settings. If nurses can open their minds and shift the cultures of practice this is likely to have a positive impact on future generations of disabled people in healthcare and more widely across society.

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