

Best Knowledge? Blending Knowledge in the Age of Person-Centred Support

Adrienne McGhee has been involved in the disability sector in Queensland for 16 years, and has held a variety of roles including those of disability support worker, service manager, systems advocate, freelance consultant, sessional academic, friend and advocate. She recently completed a PhD about the knowledge of support workers who work with people ageing with an intellectual disability. Adrienne promotes the blending of a full range of 'evidences' into a unique knowledge that is built with and around each person in order to produce desired outcomes in his or her life.

Every human action is informed by knowledge. Swimming, singing, communicating and working are all possible because, at some point in our lives, we learned how to swim, sing, communicate and work. Even breathing is informed by intrinsic knowledge that is coded in our DNA and stored in our brain and bodies: we are able to breathe because of *knowledge that exists apart from thought*.

Knowledge is also at the heart of how we engage with and support people with a disability. It shapes how we interact with every individual and informs our ability to generate real-world outcomes in his or her life. Knowledge is, as such, a crucial consideration in our discussions about how disability support workers assist with the expansion of people's worlds, and the achievement of their goals and dreams for ordinary and fulfilled lives.

This article reflects on knowledge as it is used by disability support workers and as it may contribute to the shape of people's lives. It begins with a brief discussion about the past, often oppressive, impact of able-bodied knowledge on people with a disability and their supporters. It then highlights the importance of bringing together – or blending – relevant, important and valued sources of knowledge as a way of promoting responsive, proactive and person-centred supports in people's lives, and concludes with some implications about the use of blended knowledge for the learning and development of support workers in the future.

The rise, fall and rise of 'non-local experts'

Throughout history, the lives of people with a disability have been directed and dominated by those without disability: the able-bodied. The knowledge used to subjugate people with a disability has typically been shaped by the prevailing paradigm – or way of thinking – of the times, which today is positivism (also known as science).

Science has given birth to an array of experts – people who claim to have information and expertise about a particular area of knowledge and practice, and who agree to work within a clearly defined set of ethics and regulations. Within the contemporary disability field, experts include such groups as doctors, physiotherapists, psychiatrists, educators, psychologists, researchers and social workers.

Used humbly and appropriately, expert knowledge can be of considerable benefit to people with a disability: doctors can diagnose and treat life-threatening pneumonia; social workers can locate community-based resources and services, and assist people to successfully navigate complex

bureaucracies; and speech therapists can teach people to communicate more effectively with a broader range of people. Scientific knowledge is a potentially powerful tool in the enhancement and expansion of people's lives.

Expert knowledge is not, however, always used to such positive ends. Historically, experts have often devalued the rich body of lived knowledge owned by the people themselves and the people who know them best, and instead reduced these individuals to objects on which they practice their profession. And while deinstitutionalisation brought a movement focused on restoring the ordinariness of life for people with a disability, in recent years managerialist approaches (such as quality and risk management) have resulted in a resurgence of expert knowledge in the form of 'evidence-based practice'. Evidence-based practice is supposed to be founded on the best available knowledge *as informed by experts and researchers*.

So despite growing rhetoric about person-centredness and self-direction, we increasingly find ourselves living in a world where the knowledge of 'distanced other' – the non-local experts – is valued more highly than that of *real people with real lives living in real places who experience real issues*.

Best knowledge in the real world

As a pracademic – someone who has one foot in the world of evidence-based knowledge and the other in real-world practice – I have struggled with the conundrum of what constitutes best knowledge in the lives of people with a disability for well over a decade. Having worked with and befriended many people with a disability during my time in this sector, I have often wondered what knowledge should inform our support to people with a disability, what best knowledge might look like, and how we should expect to see it reflected in people's lives.

During my PhD research in this area, I observed that the knowledge workers were using was considerably more complex in nature than had previously been discussed in the academic literature. As well as going to considerable lengths to incorporate the knowledge and perspectives of the people they supported (and, in many instances, their families and supporters), workers also drew on information learned during training; the regulations imposed upon them by their employers; their own personal, educational and professional backgrounds; the evidence-based knowledge held by professionals; and the internet to find opportunities, services and information that matched people's needs and circumstances. Workers' knowledge was, as such, made up of a vast and enmeshed blend of information, plans, values, strategies, approaches and actions that had been drawn from multiple places and people, and shaped into a form they used to respond to people's unique, real-life needs and priorities.

Blending knowledge

This drawing on, and blending of, multiple sources of knowledge was critical to the holistic support of the older people with an intellectual disability who were part of my study. Workers were supporting people with constantly changing needs, and were managing never-before-encountered issues as they journeyed deeper into the ageing process. For instance, workers increasingly found themselves supporting people with life-limiting illnesses such as dementia, Parkinson's disease, and cancer. They were also having to communicate concepts such as ageing, loss and death to

individuals whose ability to fully comprehend abstract principles was unknown and often remained unknowable. Workers also struggled with organisational systems, policies and procedures that prevented people from having choice about how to live out their old age.

There was no single source of knowledge that workers could use to navigate their way through these (and other) challenges. People with a disability didn't have answers that could address all of the issues they faced. Parents didn't have answers that could address all the issues. Managers didn't have the answers. GPs and specialists didn't have answers. Palliative care professionals didn't have answers. Educators didn't have answers. In order to carve out a path through complexity and dilemma, workers sourced knowledge and advice from these and other relevant stakeholders, blended them into a way forward (using processes such as reflection, discussion and analysis), and were then guided in its implementation by the people themselves (and sometimes family members) and more experienced supervisors.

In the context of my study, blending involved bringing together multiple sources of relevant and reputable knowledge into a highly targeted way of knowing about the person being supported. It was shaped to suit who the person was, and his/her personal circumstances and unique needs, goals and dreams. The blending process can contribute to the growth of a practical knowledge – such as a plan, strategy, attitude, behaviour or approach – that could be used in partnership with the person to bring about desired outcomes in his or her life.¹

Who supports the support workers? Implications for the growth of best knowledge

Our contemporary world is one where knowledge is produced at an exponential rate and is changing at a furious pace. No matter how dedicated we are to keeping up with advancements in health, developing strategies for improving social inclusion, or knowing our local communities, it is no longer possible to know and hold all the information we need for every activity we will undertake.

In the lives of people with a disability, we need workers who are focused on the goal of supporting people in ways that recognise, celebrate and respond to their uniqueness. We need workers who are committed to knowing better and more, and who are curious, courageous and creative in their pursuit of best knowledge. We also need workers who can use knowledge in ways that strengthen person-centred practice by finding it when it is needed, shaping it to suit circumstances, trialling it sensitively in people's lives, assessing its real-world value, and changing it to accommodate the ever-shifting landscape of life.

We also need to encourage workers to be this way. While our expectations for the highest standards of support should remain firm, we also need to recognise that workers' knowledge will – and should – always be in a state of flux, ready to adapt to the needs and preferences of the people they work with. As employers, we need to accept that it is challenging to work in a space where knowledge *is, and must always be, shifting if it is to remain best knowledge*. Well-intentioned mistakes will happen: it is how employers deal with them that will determine whether error becomes rich and deep learning that flows on into people's support.

Further, workers who diligently respond to the ever-changing needs, aspirations and lives of people with a disability will need opportunities to accumulate, to grow, and to shape their knowledge so they can offer relevant and effective supports that are aligned with who people are. We need to

acknowledge the time, guidance and strategic thinking required by workers to build robust bodies of knowledge. If we fail to create opportunities for workers to build strong individualised knowledge around people, we will inevitably compromise the quality of people's support and the outcomes we strive for.

Finally, we also need to move away from the assumption that flooding workers with knowledge they may never use is the best way to support learning and development. In our world of information overload and complexity of lived experience, giving workers more information may not be as important as showing them how to manage and shape the many knowledges available to them into a form that fits people's lives.

There is no replacement for knowledge that is grown out of real-world, lived experience. The fullest, most robust, support knowledge is, however, grown out of humble engagement with multiple sources of knowledge that are sensitively and sophisticatedly woven together into a tapestry that portrays the vibrant landscape of people's lives. Let's ensure disability workers are provided with well-thought-out foundations from which to grow a unique best knowledge around each person they support.

- 1. This process is one component of what I have called knowledge facilitation, a model of knowledge use for support workers that came out of my research. This model includes a number of concurrent processes that describe how workers can effectively use knowledge during support. These processes include: locating useful and appropriate sources of knowledge; evaluating their worth; synthesising – or blending – all of the high quality knowledge sources into a plan, strategy, attitude, behaviour or approach that can be actioned; using the knowledge alongside the person; reviewing whether the knowledge worked for the person and achieved his/ her goal; and revising and refining it so that can contribute to better outcomes.*