

## **Locale knowledge: Constructing place-based ways of knowing in complex disability service provision**

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### **Abstract**

The current study employed ethnographic methodology to explore the nature and use of knowledge by 26 disability support workers who supported older people with an intellectual disability living at three supported accommodation services in metropolitan south-east Queensland. This paper presents one vignette from the larger ethnography entitled “Katie’s story: The final voyage”. Katie’s story describes how, after a diagnosis of terminal cancer, Katie’s support team responded to her profound and intensifying need from within existing resources, developing an embedded, practitioner-constructed, place-based knowledge that enabled Katie to die-in-place with dignity. Findings from the ethnography identified that – in the face of multi-faceted dilemma, systems constraint, and continually shifting complexity – disability support workers accessed a range of knowledges which they synthesised and translated into a unique, dynamic, responsive, and actionable locale knowledge for the purpose of supporting the unique and changing needs of older people with an intellectual disability. Findings from the research challenge current understandings of disability support worker knowledge as deficient, instead identifying worker ways of knowing as highly targeted, person-centred, and constituting place-based responses to the everyday contingencies and dilemmas of support. Findings from the study have implications for the professional development of disability support workers in their efforts to optimise social inclusion with and for people with an intellectual disability.

**Key words:** intellectual disability, knowledge, support worker, ethnography, place-based, social inclusion.

### **Introduction**

Until the last few decades of the twentieth century, most people with an intellectual disability were dying at much younger ages than their non-intellectually-disabled peers. It is now widely acknowledged that many of these individuals will live well into middle-age and beyond (e.g. Bigby, 2004), this substantial increase in life expectancy representing a remarkable achievement for a group of people whose lived experience has often been one of widespread social exclusion (see for example, Friedlander, 1995; Hall & Kearns, 2001; Keith & Keith, 2013; Wolfensberger, 1972).

While the literature recognises that people with an intellectual disability are, on average, living longer, it also identifies that they are not necessarily ageing well (see Bigby, Webber, Bowers & McKenzie-Green, 2008; Haveman et al., 2009; McCarron et al., 2011; Torr, Strydom, Patti

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& Jokinen, 2010; Wiese, Stancliffe, Balandin, Howarth & Dew, 2012). Growing older with an intellectual disability in Australia has brought with it a number of challenges that must be met not only by the people themselves, but also by the full range of systems involved in their support. The lack of attention to the ageing of people with an intellectual disability at systems levels generally (Bigby, 2008, 2010) has resulted in the entrenchment of challenge at the coalface of support, with the onus for supporting continually changing and increasing need falling to disability support workers and the limited resources at their disposal.

The current study focused on exploring one of those resources – knowledge. Knowledge is not only fundamental to action (Burr, 1995; Dalitz, 2005; Gadner, Buber & Richards, 2004; Schön, 1987; Stehr & Grundmann, 2005), it is widely understood to be a – if not *the* – crucial organisational resource (Lundvall & Johnson, 1994; Nyhan, 2002; Pawson, 2006; Tomassini, 2002) and is a relatively low-cost mechanism for strengthening frontline practice. Thus, strengthening practitioner knowledge represents a foundational and inexpensive strategy for improving support to older people with an intellectual disability. Researchers have, however, published few targeted studies about the knowledge of disability support workers who work with people ageing with an intellectual disability, most of which have focused primarily on the explicit-factual dimension of workers' knowledge about a single aspect of people's lives, namely health (see Fahey-McCarthy, McCarron, Connaire & McCallion, 2009; Furniss, LoveSeed, Dodd & Lippold, 2011; Hanna, Taggart & Cousins, 2011; Herron & Priest, 2013; Whitehouse, Chamberlain & Tunna, 2000; Wilkinson, Kerr & Cunningham, 2005; Willis, Wishart & Muir, 2010; Wyatt & Talbot, 2013). Findings from these studies have resulted in predominantly deficit-oriented perspectives about support worker knowledge that have highlighted *what workers don't know* about supporting people ageing with an intellectual disability, and has left a gap in the literature regarding the full nature of knowledge used in the support to older people with an intellectual disability and the role of contextual influences on the development of knowledge.

This study was instead based on the premise that disability support workers have been supporting people with an intellectual disability to grow old within the context of formal service provision for a number of decades, and that knowledge of some form is being used by workers as they go about their everyday work with this group. At the time of this study, there were no peer-reviewed studies in the English language that had investigated knowledge as it is naturally operated at the coalface of support to older people with an intellectual disability. As such, very little is known about the knowledge workers draw on and use in their day-to-day work, and how they use knowledge to address the myriad of complexities faced by a newly emerging cohort of people ageing with an intellectual disability.

This study explored support worker knowledge as it is operated prior, during and after the moment of practice within its real-world, everyday context. It thus situates knowledge as a fundamentally complex, dynamic and nuanced entity that exists beyond the positivist-relativist epistemological divide (Pickering, 1995; Schön, 1983), a divide which has traditionally oversimplified the complexities intrinsic to social care practice (Craig & Bigby, 2015; Fook, Ryan & Hawkins, 2000; Peile, 1994; Trevithick, 2008, 2012) and overlooked the considerable human investment and emotional labour associated with frontline human service provision (Hochschild, 1983, cited in Kanasz & Zielińska, 2017). Knowledge in this study was therefore conceptualised within the emerging construct of an epistemology of practice (Argyris, Putnam & McLain Smith, 1985; Schön, 1983), and included the generalist orientation of empiricism and authoritative knowledge (such as scientific facts, evidence-based research, professional directive, information, policy and procedure, instruction, systems and structures); the personal and cultural systems of meaning that saturated workers' worlds (for instance, values, beliefs, attitudes, perceptions, intuition, opinions, emotions, schemas, assumptions); and the

construction of knowledge via the ordinary activities of support (such as actions, practices, skills, tacit knowledge and relationships). This view of knowledge was sufficiently broad to (1) acknowledge vastly different conceptualisations of knowledge as highlighted by Johnston (1998), Merton (1968), Siemens (2006) and Spender (2005); (2) facilitate the exploration of divergent ways of knowing in accordance with the uniqueness of each service context; (3) allow for the application of creative processes that support holistic and inventive ways of working with vulnerable and socially excluded consumers of human services (Peile, 1994); and (4) enable an understanding of support worker knowledge as derived from multiple and divergent sources of input that are synthesised into a unique, actionable and locale – or placed-based – knowledge.

## **Understanding knowing through doing: Methodology for the study**

### ***Study design***

The current study was undertaken by the author during a 16-month period at three disability supported accommodation services in metropolitan south-east Queensland. The qualitative research design was based in social constructionist epistemology (Berger & Luckmann, 1966) and ethnographic methodology. Ethnography is a highly naturalistic approach to research that requires researcher involvement in the cultures they are studying (Jones & Smith, 2017; Tedlock, 2000), and has previously been employed to explore subjects that underpin this study including organisational culture (see Babbie, 2010), the nature and use of knowledge (Beaulieu, 2010; Dalitz, 2005), and disability-based accommodation and support services (Croft, 1999; De Waele & Van Hove, 2005; Hamilton, 2018). The flexible and evolutionary nature of ethnography (Madden, 2010) enabled the researcher to explore a broad range of knowledges available to workers (including ‘hidden’ knowledges such as tacit knowledge – see Polanyi, 1958, 1966, 1969), as well as how knowledge was used and constructed by workers during the actual support of older people with an intellectual disability.

The primary ethnographic method used to collect data was participant observation. Participant observation enables researcher immersion into “the flow of people’s lives in as normal and everyday a manner as possible” (Madden, 2010, p. 82) by observing, talking with, and “joining in” the usual routines and activities of the participant group (p. 77). In this study participant observation was conducted in service consumers’ residences (which constituted an institution, group home, and two individual private homes); local communities (such as shopping centres, recreational venues, medical facilities, and special event locations); and in relation to organisational requirements (such as administrative functions, team meetings, and support worker training). In keeping with the largely evolutionary nature of field work, the second data collection method was naturalistic ethnographic conversation (Madden, 2010). Ethnographic conversation included private, in-depth semi-structured interviews with participants to explore their understanding of knowledge and how it was used during the support of older people with an intellectual disability; contextual conversations with service personnel in order to strengthen the researcher’s understanding of organisational contexts; and continuous on-site conversations and opportunistic focus groups with participants. Field notes were taken during and after all ethnographic activities, and resulted in more than 172,000 words of typewritten data for analysis.

### ***Participants***

Participants were disability support workers who were regular and permanent/casual paid employees of one of the three disability accommodation support services included in the study. During the data collection period, all 26 disability support workers who were regular employees of the services became participants in the study. Initially, however, only nine support workers

signed participant consent forms during the recruitment phase of the research, and these individuals became the researcher's 'coaches'. Coaches were those participants who demonstrated ongoing commitment to the research by regularly providing the researcher with invitations and opportunities to participate in support activities, coaching the researcher in service culture and organisational processes, participating in private ethnographic conversations, and engaging with the researcher during all phases of data collection and analysis. The remaining 17 participants began contributing to the research on their own initiative at various points during data collection. These participants engaged irregularly with the researcher, choosing when, where and how they would contribute to the data.

### **Sampling**

To be eligible for inclusion in the study, participants needed to be providing ongoing support to at least one person with an intellectual disability who was considered to be ageing. Sampling was, therefore, purposive in nature, and recruitment of participants was only undertaken in service locations where the ageing of service consumers was considered to be evident. Determinations regarding the existence of ageing at a service were made according to ten criteria (see Table 1).

**Table 1. Criteria for determining whether a service was supporting an older person with an intellectual disability**

<b>Criterion</b>	<b>Question</b>
Chronological age	Is at least one service consumer aged 50 or above (see Bigby, 2004)?
Support worker perceptions	Is at least one service consumer considered by some workers within the support team to be ageing?
Intensity of support needs	Is there a service consumer whose supports are considered by the support team to be changing in such a way as to have a substantial impact on the person, other consumers, and/or the capacity of the support team to meet the needs of other consumers?
Conditions contributing to early-onset ageing	Is there at least one service consumer with a condition that is thought to be contributing to premature ageing (for instance, a person with Down syndrome who is aged under 50 and has a diagnosis of dementia)?
Ageing well	Is at least one service consumer considered by the support team or general community to be ageing with minimal indications of decline?
Self-reports of ageing	Has at least one service consumer expressed that he/she is ageing, or that he/she wishes to undertake activities that are typically associated with ageing (such as retirement)?
Societal constructions of ageing	Is there at least one service consumer whom the general community may consider to be ageing (for example, is over the age of 65, accesses the aged pension or ageing services, or has retired)?
Community reports	Has at least one party external to the service (for example, a service consumer family member, community member, representative of another service provider) raised concerns about 'the ageing' of a service consumer?
Organisational response	Has the organisation responded to issues associated with ageing at the accommodation service (for example, made modifications to the home to facilitate mobility, increased support hours)?
Professional assessment	Has at least one service consumer at the accommodation service undergone an ageing-related assessment? On the basis of the assessment, is the service consumer considered to be 1) eligible for

	aged services and/or 2) experiencing conditions typically associated with ageing?
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A service only needed to meet one of the criteria to be included in the study. Two services met all 10 criteria; the third service met six of the criteria.

### ***Data analysis***

According to Madden (2010), analysis of ethnographic data is less about reducing data into patterns and themes than it is about distilling the findings into a coherent story that authentically reflects the researcher's immersion into participants' social worlds. In keeping with the constructionist epistemological orientation of the study, data was analysed using recursive analysis. Recursive analysis is often used to analyse ethnographic data (LeCompte & Preissle, 1994), and requires an iterative, multi-layered process of examination, comparison, condensing and revisiting of data which results in a sophisticated understanding of participants' social worlds (LeCompte & Schensul, 2013). Main processes incorporated into the data analysis approach for this study included thematic analysis (Braun & Clarke, 2006), visual displays (Braun & Clarke, 2006; DeVault & McCoy, 2006; Liamputtong, 2009; Patton, 2002; Strauss, 1987); conversation with participants, and writing and reflection (Richardson & St Pierre, 2005). These processes enabled the synthesis of factual information and evocative description into a rich ethnographic account (Madden, 2010) that illustrated how disability support workers constructed person-centred, place-based knowledge around the people they supported.

### ***Ethical considerations***

Ethics approval for the study was granted by the Queensland University of Technology (no. 1100001068).

Ethnography presents unique ethical challenges for researchers (Tomkinson, 2015), and one of the challenges emerging during this research was ensuring that service consumers' autonomy and rights were protected. While people with an intellectual disability were not participants in the study, the researcher spent several hours in each location prior to commencing data collection to ensure that all residents at the services were fully informed about the study, were comfortable with the researcher's presence, and were willing for the researcher to visit their homes and participate in their support during the 16-month-long data collection period. Where individuals were unable to provide explicit consent for the researcher's presence, permission was sought from parents or substitute decision-makers. All individuals with an intellectual disability, including decision-makers, provided their permission for the research to take place as requested.

Given the requirement for vivid description in the ethnographic narrative (Madden, 2010), ensuring the de-identification of participants and service consumers presented considerable ethical challenges for the author. All names and potentially identifying details (such as distinguishing features of research locations and the gender of male support workers) were changed or removed from the data to maximise confidentiality and substantially reduce the likelihood of participant re-identification.

### ***Limitations of the ethnographic approach***

Unlike studies conducted from the empiricist epistemological standpoint, ethnography is based in relativism (Crotty, 1998), and the resulting ethnographic narrative reflects the lived experiences of a limited number of contributors through 'storied reality'. While detailed and

evocative description of researcher immersion into participant culture strengthens qualitative research rigour through such constructs as credibility, transferability and authenticity (Whittemore, Chase, & Mandle, 2001), vignettes are unique to specific people and contexts, and, as such, the findings from this study cannot be generalised across the entire population of workers who support older people with an intellectual disability.

## **Constructing locale knowledge in complex and dilemma-rich contexts**

Research findings were presented as a collection of vignettes that depicted how support workers developed locale knowledge, that is, a real-world knowledge constructed out of workers' ongoing engagement in the everyday lives of older people with an intellectual disability. Vignettes described how support workers sourced multiple forms of knowledge during support activities and synthesised them into place-based ways of knowing aimed at responding to the preferences and unique needs of the people they supported. The resulting locale knowledges – which were specific to each team of workers, locations and service consumers – had varying levels of impact in the lives of older people with an intellectual disability.

Given the length of vignettes, and the ethnographic imperative to honour rich description and narrative, only one vignette can be presented in this paper. The following vignette<sup>1</sup> was selected for inclusion in this paper because it reflects the contributions of one of three teams in the study (this team was made up of eight participants, almost one-third of participants from the broader ethnography), and illustrates all three of the major themes of the overall findings: the *content of knowing* (what workers knew and didn't know during their support of older people with an intellectual disability); the *context of knowing* (how the support setting shapes the nature and use of worker knowledge); and the *construction of knowing* (how knowledge is shaped by workers to meet individual consumer needs). This vignette also depicts the potency of collectively and intentionally constructed placed-based locale knowledge: it tells the story of how one team of disability support workers built practice knowledge that engendered dignified support and responsive care for a socially-excluded person with an intellectual disability in highly challenging circumstances – in this instance, a woman with profound and complex support needs who had been diagnosed with terminal breast cancer.

### ***Katie's story: The final voyage***

I never met Katie. She had passed away from breast cancer three months before I commenced field work at the place she had last called home. Yet even with her death, it seemed that Katie had never really gone. Her illness and passing had profoundly affected many of her support workers, leaving an almost palpable sadness that lingered in the home like a sultry Queensland day long after the sun had gone down. As some workers talked about their current work, they would often default into discussions about Katie, tears creeping into eyes and spilling down faces as they shared the intense and confronting experience of supporting a service consumer – and a woman they cared deeply about – to experience “a good death”.

Described by her workers as a vibrant, courageous and spirited woman who engaged passionately with life, Katie lived with a severe intellectual disability and significant health, behavioural and communication issues. Most notable amongst her medical conditions was the seizure disorder that remained outside the full control of health professionals. It was not uncommon for Katie to endure 20 minutes of seizure activity at a time, the violence of which (prior to procuring the helmet which she wore almost everywhere) caused deep wounds to her

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<sup>1</sup> The vignette and accompanying analysis are adapted from the author's doctoral dissertation (McGhee, 2014).

head that often took months to heal. The lengthy healing period was exacerbated by Katie's fearless engagement with life, with Felicity telling me how, horrified, she had one day found Katie in the bathroom, bandages strewn on the floor and fingers knuckle-deep in a head wound as she explored the parameters of this newly discovered facet of self.

One day early in 2011 while supporting Katie to take a shower, a support worker noticed a lump in one of Katie's breasts. Tests and a biopsy revealed the lump was malignant and a mastectomy was quickly scheduled. The follow-up prognosis was, however, not favourable, and Katie's doctors conveyed little hope for her recovery. Katie's family, who had become integral part of her life in recent years, engaged in lengthy discussion with the clinic involved in her care. A growing understanding about the various treatment options and their likely impact on her quality of life and on Katie herself (who had, over the years, displayed a hatred for clinical settings), led the family to decide that putting Katie through additional treatment – which they were now sure offered no reasonable hope for survival – would compound the distress inherent in what already promised to be a difficult road ahead and was not what Katie would want. They decided the priority should be to support Katie to have the best end-of-life experience possible.

Investigations into possible community options for Katie revealed a dearth of services and professionals with the knowledge, expertise and confidence to support someone with a life-limiting illness who presented with Katie's needs. When her family and disability service were told by one mainstream provider that Katie would have to be kept under sedation during her treatment and longer-term care, the way forward seemed both limited and clear: Katie would be supported to continue living what everyone believed to be her preferred life, and would be provided with the opportunity to die at home.

At the time of the decision, Katie's service had almost no knowledge about how to provide Katie with the nursing and palliative care she needed. The service manager and workers, supported by the family and the service's executive officer, had simply decided they would do whatever it took to learn how to support her during this last stage of her life. Acutely aware of their lack of knowledge about how to provide the necessary care, the team sourced initial information through Katie's medical team and, during the subsequent months, worked on identifying and collating relevant knowledge and resources. They built up a network of informal and formal information support around Katie that included her family, professional staff within the auspicing organisation, the hospital surgical and oncology units, the breast clinic, wound management support, palliative care unit, community health practitioners, and Katie's GP, thereby establishing a collaborative hub of mutual learning and exchange of knowledge.

Workers also tapped into the knowledge base present in their own support team which included two nursing students (one of whom was already a registered nurse) and a worker with aged care experience who had previously cared for elderly people living in residential aged care during the last weeks and hours of their lives. Several workers who had worked with Katie for the duration of her life in community knew her well, and others brought a range of life experiences that enriched and lightened the home (such as a strong emphasis on creating a family environment) during this emotionally charged time. Support workers talked repeatedly about the leadership they received during Katie's illness, praising their manager as someone skilled in identifying workers' strengths and capitalising on resources, and who actively encouraged them to do the same.

Support workers had high expectations of each other regarding participation in, and contribution to, activities that strengthened their knowledge and expertise. Some workers put together files of information which they had sourced through the medical and allied health staff involved in Katie's care and via regular searches of the internet. The organisational nurse and the nurse on the support team provided training and practical advice to staff, and workers

sometimes practiced dressing chest wounds on each other to improve their practical skills. Workers continually shared their experiences with each other during shift overlaps and team meetings, by telephone, through file notes, messages to each other on the office whiteboard, and via email.

There were aspects of Katie's care, however, that were deeply confronting. The wound from Katie's mastectomy had never properly healed and, as sometimes occurs with breast tumours, the tissue became fungated. In addition to the visual distress it generated, the fungated tumour created a nauseating smell that permeated the home and became almost too sickening for some workers to bear. The wound itself was also difficult to manage. One support worker, who was also a registered nurse, described the wound as "very terrible" and a challenging one to dress, even for experienced professionals. Further, Katie would frequently tear the dressing off her chest and attempt to rip the dying flesh off her body as if she was pulling the scab from a healing sore, leaving her workers to clean and redress the wound multiple times during the day and night.

Additionally, Katie's workers worked largely alone. While workers who were rostered on shift during office hours could contact the service manager, other support workers, Katie's team of health care professionals, and the organisation's nurse for information and guidance when and if needed, workers who were rostered to work at night had little access to informational support and reassurance. Juliette explained how, when she called the emergency on-call support in the early hours one morning to assist her with a particularly upsetting situation, the employee who answered had so little knowledge of Katie's situation that the telephone call simply added to Juliette's distress. Members of the team had declared their willingness to provide support to each other on a 24-hour basis; however, Juliette was cognisant of their need to come to work fresh to face the inevitable challenges of the upcoming day and was unwilling to disturb their sleep. Not knowing what to do in a new and emotionally fraught situation, combined with working alone without access to knowledgeable support, was an angst-ridden, and sometimes highly distressing, experience.

Support workers also held the weight of responsibility for managing Katie's pain. The priority was for Katie to be pain-free, and workers were repeatedly reminded by medical professionals that over-medicating Katie was better than under-medicating her. Workers consequently relied heavily on the direction of these professionals regarding the type of relief, dosage and delivery of the morphine-based drugs that were prescribed to Katie. Because Katie was unable to tell workers when she was experiencing physical distress, workers needed a way to determine it for themselves. A pain scale was sourced from the medical literature by the senior practice advisor who then worked with the team to amend the scale, incorporating their knowledge about Katie and how she typically displayed discomfort into a series of observations they could make to determine her pain levels. They would do this by ascertaining changes in her vocalisations, social engagement, facial expressions, activity levels, physiology (such as skin colour), and routines (such as eating and sleeping). Once the pain scale had been reviewed by relevant treating professionals, workers implemented the pain scale, completing it every four hours (and at any other time they suspected Katie was in pain) by reviewing the list of pain indicators and calculating the pain score. The threshold for administering the morphine-based drugs was sufficiently low to increase the likelihood that Katie remained pain free.

One challenge that eluded answer was determining how much Katie comprehended about what was happening to her body and her life. Katie's preferred modes of communication were non-verbal in nature, and workers had no way of determining what she understood about complex concepts like dying. They believed that Katie had learned about her illness, not from what she had been told, but from enacting her own preferred way of understanding – passionate engagement with life. And throughout her illness, workers hailed Katie's fighting spirit. However, a few days before her death, Katie experienced a lengthy and violent seizure

in the shower. Paramedics were called in for support. As Fleur sat with Katie on the floor of the shower while she recovered, she watched as tears tumbled down the face of this fearless woman for the first time in the decade she had known her. Fleur told me that she thought it was in that moment, wrapped in the pure physicality of a body she could no longer rely on, that Katie finally understood: she was *never* going to get better.

Traditional forms of communication were evidently inadequate so Katie's workers did not concentrate on trying to make sure she understood confronting subjects like cancer, terminal illness, spirituality and death. Instead they communicated using the shared language of trust they had constructed over their many years together. Tricia told me, "The best we could do was make sure she knew that we would be there to care for her" and Moira wrote the following about this language of trust they shared:

A specific day that sticks in my mind, is when we were all trying different ways to bandage Katie's entire breast area, whilst chasing her around the bathroom holding the dressing, solutions, bandages etc. required. Katie thought it a great game at first. When whilst singing to Katie, I asked her to hold still and give me a hug so I could unroll the bandages around her. She leant into me, held her arms in the air and stood very still. When done and I was thanking her for being so helpful, she touched her forehead on mine and made long eye contact. I felt blessed for this moment as it helped me feel that although Katie was not of the understanding of the concept of the cancer, she trusted me.

During Katie's somewhat tumultuous transition from institutional living into community life, she had learned that her workers would stand unflinchingly with her during the most savage moments of her life. Similarly, her workers trusted that Katie would eventually understand her mortality in the same way she had pursued living: on her own terms.

As Katie neared her end, she was becoming increasingly frail. Her workers were beginning to injure themselves as they supported her to undertake the simplest of activities such as going to the toilet. And as her personality and demeanour began to change, support workers were no longer confident that their current approaches to identifying pain and administering relief were keeping her sufficiently comfortable, even with continual revisions to the pain management scale. *Was her increased placidity an indication that she was comfortably over-medicated? Or that she had accepted the inevitability of her decline? Perhaps it showed that she had developed an even greater trust in her workers? Maybe the drugs were having little impact and she was simply overwhelmed by pain?* Workers were no longer confident of their answers to these questions, questions which demanded answers if the team was to achieve its objective of a good death for Katie.

By this time, the service had a new manager and it was clear to her that Katie now required a whole new dimension of care. Katie needed mechanical support (the organisation had a no-lift policy), and most staff were not trained in the use of hoists and other assistive devices. While the team understood that Katie's needs were multi-dimensional, the physical requirements of care were becoming increasingly urgent, and the service was not equipped to support them. And becoming equipped was going to take more time than Katie had left.

The service decided to transfer Katie to palliative care so that she could spend the final days of her life as comfortable as possible. As soon as she arrived, a morphine-based drip was inserted directly into her spine. The executive officer of the organisation auspicing Katie's service committed to absorbing the additional cost of paying a worker to be with Katie during her time at the hospice, and workers and family members negotiated a 24-hour roster of 'presence' to ensure that Katie would never be alone during this final leg of her voyage.

Katie died a few days later, in a place without pain and in the company of those who loved her.

Katie's support workers were not a group of credentialed experts with extensive bodies of evidence-based knowledge. Yet they drew on professional and multiple other sources of knowledge available to them, and worked them into a targeted locale knowledge that enabled the team to work towards the collective objective of a good death for Katie. Support workers struggled with not-knowing, multiple dilemmas, and challenges to knowledge use, not the least of which was Katie's own fearless engagement with her body and workers' inability to fully comprehend what Katie knew about what was happening to her. Workers operated within a continually shifting hierarchy of knowledge that was open to multiple ways of knowing, and that sometimes privileged personal experience and sometimes the facts of science. Their task was one of purposefully bringing knowledge together from multiple sources, of shifting knowledge during their individual practice and their collective construction of it, of making it work in the most confronting of circumstances both for them personally and collectively, and for the woman they supported. It was locale knowledge constructed through *doing*.

### **The worth, challenges and implications of locale knowledge in contemporary disability service provision**

Locale knowledge was constructed out of individually and collectively held forms of knowing, and was specific to the local context of support to older service consumers, namely the people, activities, environments, events, values, complexities, systems, objectives and dilemmas that were part of workers' everyday engagement at the coalface. Continually adapted for action, it was used for the achievement of objective in response to the real-life needs and preferences of older service consumers. Locale knowledge was, at its best, an everyday knowledge of doing that workers used to deliver practical outcomes for older people with an intellectual disability, in accordance with their needs and preferences, in ways that supported optimal participation in later life.

Locale knowledge was not, however, invulnerable to poor practice. Katie's story highlights how place-based ways of knowing made positive contributions to people's lives when constructed in line with a sound, ethical objective on which future decisions could be based, collective open-mindedness regarding knowledges that were yet unknown, and a commitment to ongoing review of the effectiveness of the current knowledge. Effectiveness of locale knowledge could, however, be easily undermined by numerous factors including power struggles over which knowledges were higher on the knowledge hierarchy, lack of access to essential knowledges, lack of 'knowledge hunger' (or satisfaction with the status quo), lack of confidence, and 'knowledge arrogance' (rigid determinations about which knowledges are 'best').

Locale knowledge was also undermined by its lack of credibility. As one of Foucault's (1980) subjugated knowledges – bodies of knowing that are ranked relatively low on the knowledge hierarchy – locale knowledges are vulnerable to critique. Backed by the prestige of positivism, evidence-based knowledges are afforded priority status in neo-liberalist-driven contemporary human service provision (Craig & Bigby, 2015), and local ways of knowing – such as the placed-based, locally constructed knowledges of disability support workers – continue to be heavily critiqued by professionals who frequently dismiss them as unscientific. Yet, as Katie's story shows, potent forms of locale knowledge that deliver positive outcomes for service consumers offer their own critique of positivist discourse, and according to Osmond and O'Connor (2006), "best knowledge is considered to be that which is likely to produce positive outcomes for clients" (p. 14).

The successful application of locale knowledge in complex human service delivery has considerable implications for the professional development of frontline workers. Improving

knowledge and practice in contemporary human service provision is often considered from the standpoint of training – that is, providing frontline workers with more and better factual knowledge about how to generate desired outcomes for consumers. Katie's story, however, indicates that existing evidence-based knowledge may not always supply the ready-made answers support workers believe they need when encountering complex consumer crises and the rapidly changing needs of people ageing with an intellectual disability. As Katie's workers discovered, knowledge was not always available in a form they could immediately enact, even when it was delivered as best practice or training by professionals. The findings presented in this paper do, however, indicate that strengthening workers' ability to locate, evaluate, synthesise, enact and review relevant and valuable knowledges that have specific usefulness to unique individuals in unique contexts could potentially be of greater benefit to disability support workers employed in complex human service settings than perpetuating contemporary knowledge accumulation models such as training (see Freire, 2004/1970). While Katie's story suggests that teaching teams of support workers how to construct place-based knowledge may contribute positively to their support of people ageing with intellectual disability, the single vignette presented in this paper should be viewed as an example of what is possible rather than what is typical in contemporary complex disability service provision. More research is needed to ascertain how the intentional construction of place-based knowledge with and for older people with intellectual disability enables support workers to deliver creative, dignifying, socially inclusive, and person-centred responses to the profoundly challenging events that often emerge during later life.

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## **Biographical Notes**

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