

BEING, DOING AND BELONGING AFTER BRAIN INJURY:
AN ETHNOGRAPHIC EXPLORATION OF THE CAPABILITIES APPROACH

Mary Butler

ABSTRACT

The capabilities approach, developed by Sen and Nussbaum, is a way of describing quality of life as a function of what the person is able to be and do. The capabilities approach is used in this paper to fill a distinct gap in the care literature, which has tended to focus on the burden of care, rather than on what the carer actually does. There are various approaches to developing capability sets for specific populations. In this paper a capability set for carers of adults with severe brain injury is arrived at by means of an ethnographic study of five families, carried out over one year. This capability set is further clarified using the heuristic device of 'ideal types' of responses to care, from both the perspective of the carer and the adult with brain injury. It is intended that this research may contribute to the development of a focused agenda regarding the capabilities that this community choose to value.

INTRODUCTION

This paper offers an ethnographic exploration of care and disability from a capabilities approach. The capabilities approach suggests that a person's quality of life is a function of what the person is able to be (e.g. well or poorly nourished) and do (e.g. perform more or less meaningful work) (Sen, 1985: 10). The combination of these functions constitutes the form of life that the person achieves. These functions can be gathered into capability sets that reflect 'the person's freedom to lead one type of life or another' (Sen, 1992: 40). The capabilities in this discussion are not value judgments made by an individual or family about which person to marry or whether to downscale the family dwelling. Rather, they are priorities that affect a larger group, such as a particular community of practice formed by the carers of adults with brain injury. There are various approaches to developing capability sets. For example Nussbaum (2000) advocates a set of 'Central Human Capabilities' that

are 'open-ended and subject to ongoing revision and rethinking'; Sen (1980) argued that capabilities are used for different purposes, so lists of capabilities need to be developed for specific purposes; Alkire (2006) endorses the use of a list specified at the most general level of objectives, such as life, health and security. In this paper all of these approaches have informed the development of a capability set underpinning the care of an adult with brain injury. This is explored using an ethnographic case study, and further clarified using the heuristic device of 'ideal types'. It is intended that this research will contribute to a focused agenda in a participatory planning process about the capabilities that this community choose to value.

The capabilities approach fills a distinct gap in the care literature, which has tended to focus on the burden of care, rather than on what the carer actually does. The analysis of burden experienced by carers has been examined in both the qualitative and quantitative literature. Opie's (1992) sensitive account of caring for elderly people was influential in raising awareness about the negative effects of caregiving in New Zealand. She poignantly described the chronic exhaustion and physical ailments of carers associated with the relentlessness of the experience, together with the sense of being dominated by isolation and feelings of loss. These findings were echoed in Carpinter, Irwin and Rogers' (2000) report where parents described in detail the extent to which their physical well-being was threatened by the extreme behaviour of high needs children who were growing into adulthood. The quantitative literature further elucidates the specific elements of burden in the caregiving experience. The most compelling evidence for health impacts on caregivers is provided in a meta-analysis of studies by Vitaliano (2003), where the health of caregivers was compared with demographically similar non-caregivers. This indicated poorer physical health among caregivers along a range of indicators. More recent research suggests that there may be a double jeopardy in regard to pain for caregivers, who are both more vulnerable to physical pain and also more likely to be experiencing physical pain than the rest of the population (Cummins *et al.*, 2007). The burden paradigm is therefore an expression of how caregivers experience burden in terms of physical and mental health impacts, and also experience stressful social situations in terms of social, financial and employment opportunities (Goodhead & McDonald, 2007; Jorgensen, Parsons, Jacobs, & Arksey, 2010).

This experience is shared by an increasing number of people, and it is estimated that about ten percent of the population is now involved in caregiving (Goodhead & McDonald, 2007). One political response to the growing number of caregivers in New Zealand has been the development of a Carers' Strat-

egy (Ministry of Social Development, 2008), which has a number of objectives including health and education for carers, and the provision of financial support and pathways back to employment. This approach belongs to a body of literature drawing on a human rights perspective to develop policy and legislation that is aimed at administering justice for carers (Clements, 2009; Ministry of Social Development, 2008; Rea, Kenealy, Sheridan, & Gorman, 2010). Much of this work has been targeted at helping carers to find pathways back to employment. In Britain the judgement in *Coleman v Law* was an historic moment for carers internationally, when Sharon Coleman was able to prove that she had been discriminated against by her employers on the grounds of her son's disability. An important aspect of this case was the emphasis on the relationship between the carer and the person with disability. It was acknowledged that discrimination 'by association' in such cases undermined the ability of disabled people to exercise their autonomy.

It is rare to find rulings such as these that highlight the relationship between the disabled person and the carer. Most policy emphasises the individual rights of the carer to work outside the home and to have respite care. Such policy fails to acknowledge the way in which individual health is inextricably linked to the health of the whole family. Policy and legislation that supports the rights of the carer to be paid a full time wage for full time care work are rare and contentious. For example, the Ministry of Health recently fought and lost a Human Rights case that ruled it was discriminatory not to pay family carers. They argued against paying family carers even though funding had been allocated and there was nobody else available or qualified in this case to do the job (Human Rights Review Tribunal, 2010). It is against this background that the significance of a ruling that enabled the payment of family carers should be judged. In New Zealand there was an historic case (*ARCIC v Campbell*, 1995) which permitted the Accident Compensation Corporation (ACC) to pay family carers. The argument was accepted that people with serious disability (caused by injury) should not have to suffer makeshift care arrangements that might put their health and life at risk. From the application of this ruling a culture of expert family care for adults with severe disability evolved over fifteen years. This culture gives a rare opportunity to describe the capabilities of carers in situations where they are not suffering excessively from burden and stress.

As mentioned previously, to date the literature has generally been far more concerned with describing the burden on carers than in discussing what carers actually do. Arksey (2005) did qualitative research with 80 caregivers in the U.K. and enumerated the generic tasks of care-giving, including help with personal cares; mobility; supervision; emotional support; practical tasks, in-

cluding managing finances; and educating others. In addition, parental carers tended to be involved in managing behaviour and providing social stimulation and advocacy. Overarching all of these functions was the need to be flexible. There are also a range of family caregiving skills identified by Mezey (2004), such as the capacity to monitor, interpret, make decisions, take action etc. These lists provide a general sketch of the function sets associated with care, but do not give a coherent perspective of what a capability set for carers of adults with brain injury would look like.

A major problem in developing such a list is the issue of adaptive preferences, which describes a tension around the extent to which carers should be held responsible for the choices that they make. For example, the Turkish ethnographer Uyan-Semerçi (2007) examines how refugee women articulate capabilities as a factor of caring for their family. They express adaptive preferences that value the growth and well-being of their children in ways that seem to deny their own well-being. Yet this preference is a culturally appropriate articulation of mechanisms by which these women achieve status in their community. It is therefore far more valued to stay at home and care for children than it is to travel long distances to carry out low-paid low-status jobs. The capabilities approach questions the extent to which such adaptive preferences should be taken at face value. This is most often articulated as the example of the 'tamed (Indian) housewife', who is satisfied with her situation (despite poor nutrition, poor social status, chronic fatigue, poor physical health, abuse from family members, and the burden of physical labour), since she has no idea of what it is to feel healthy and remains ignorant of the benefits and pleasures of education (Nussbaum, 2001b: 310). Is the seeming satisfaction of this woman an argument against trying to help her and others in her situation? Applying the capabilities approach here begins to address the seeming conflict between human rights and cultural relativity. It is also an exercise that makes it possible to overcome the hurdle of a restricted imagination that would interpret limited capabilities as a natural part of the work of caring.

One way around the adaptive preference limitation is to examine situations where there has been a shift from not having opportunities for particular capabilities to having such opportunities. This paper examines the situation of a family caring for a young man with brain injury who suddenly achieves generous supports after many years of struggling without any supports. It is hypothesized that their situation provides an insight into the capability set that is genuinely valued, as opposed to that which is imposed by circumstance. It is hoped that this analysis may prove to be a useful contribution to a public debate about the capability set that should ultimately be supported for carers

of adults with brain injury.

METHODOLOGY

The story of methodology is [*emphasis in original*] the story of the study (Agar, 2004:19).

The story of the researcher began with a single ethnographic case study of a young man living with brain injury (Butler, 2000) carried out over a three month period in 1998. It was extended through a larger ethnographic study of five families over the course of one year in 2003 (Butler, 2007). The ethnographic process of participant observation shifted across these studies from an emphasis on participation, to one where observation (backed by interviews) became the focus. This paper is therefore informed by a deep and extended engagement with a particular community of practice over the course of a more than a decade. A conglomerate case ('Jamie') has been created from the stories that informed the researcher, particularly during the 2003 collection phase.

'Jamie' had his brain injury as a young boy and his family struggled for fifteen years without any outside assistance. However, they live in New Zealand where such an injury is ostensibly covered by the Accident Compensation Corporation (ACC), and eventually their case was accepted, three years before the ethnographic study commenced. ACC is the no-fault injury compensation system that has been operating in New Zealand since 1974. The funding was paid to Jamie's parents to manage as a care package on his behalf and this case therefore provides a rare insight into the community of practice that developed when care was adequately compensated and flexibly available. Jamie was assessed as requiring over eighty hours of care per week, which transformed both his capabilities and those of the family. His story therefore provides unique insight into a before-and-after scenario. This story is also particularly valuable because the family was strong enough to come through the tough times intact and so is able to provide the perspective of both parents of a person with brain injury.

Each section of the findings describes a particular function set: being, doing and belonging. At the end of each section there is a commentary in the form of 'ideal types' contained in a series of boxes. The aim is to use these 'ideal types' as a heuristic device to clarify the function set of the carer and the person with disability. The boxes therefore add another dimension to the findings section by providing in a single frame: a) the story of before and after receiving the care package; b) the story of both the carer and the disabled person; and c) the

essential capabilities within each of the broad thematic areas of being, doing and belonging. The narrative rationale is that each of these boxes is still based on the conglomerate story of Jamie and his family, but the language shifts to that of 'ideal types' in order to describe the essential elements of the capability being described from a relational perspective. This exercise is a response to the challenge of conveying the kinds of capabilities that are possible under conditions of stress and conditions where the carer feels supported. By placing the stories of the carer and the disabled person alongside each other in this way, the intention is to demonstrate the relational aspect of capabilities and how completely intertwined the capabilities of both parties are. In this way these commentaries make explicit what is largely implicit in the story told by the ethnographic field notes. It is not the intention here to do a gendered analysis of care, so the language used in these commentaries is varied. Both the carer and the disabled person are alternately described as 'he' and 'she'.

FINDINGS

Being: barely surviving

'Being' includes those aspects of life where the family is primarily focusing on survival; it speaks of many of the issues that are described as burdensome in terms of the health of both the carer and the disabled person. 'Being' is the aspect of the human condition that dominates when the carer is not adequately supported and there is a sense of moving from crisis to crisis, without being able to plan.

Jamie was twenty three at the time of the study. He had his brain injury at the age of five, when he ran in front of a truck. Following the injury, his parents (Joanna and Jack) decided to set up a franchise business, which meant that one of them could always be available to Jamie. For fourteen years they looked after him with virtually no assistance, but finally they hit a crisis when Joanna's health broke down. This is a fairly typical description of the carer who had pushed herself beyond her limits: 'Joanna was always the backbone, but well, with her back and her heart she learned that she couldn't be the backbone anymore' (Jack).

Jack was working twenty-hour days to keep the business afloat while Joanna was in hospital, first for back surgery and then with heart problems. Yet even when Joanna was gravely ill in hospital, Jamie still demanded constant access to her. Jamie's injury was completely invisible, which made it difficult for others to understand the intensity of his need for cognitive support in the form

of problem solving, reassurance and talking things through. Even with all of this support things tended to go wrong for Jamie, because he was so easily led astray. He looked like a big man, and it was difficult to communicate how little he could actually be held responsible for his actions during his early adult years. His family frequently found themselves defending him through a lengthening list of criminal proceedings for minor offences. His father described what it was like trying to support him through the scrapes he got into:

Jamie just keeps going full on. He cannot stop for a minute. He is like a truck that is going full steam ahead, and he isn't taking any corners. And we are following up behind trying to keep him out of trouble (Jack).

For example, Jamie could be safe driving on the roads for months at a time, but then he might stop taking his medication, or something else would happen that made it necessary for him to stop driving. His parents were often in the difficult position of trying to enforce boundaries during these periods.

Jamie is all right a lot of the time, but he is not okay when he is manic. And those times he just has to stop driving. But it is hard, because he has got a little bit of freedom and that is tantalising him to want some more' (Joanna).

This unrelenting pressure finally eased when Jamie was admitted for a full assessment to the local rehabilitation unit, and once his parents had him out of the house they refused to take him back. They had no intention of abandoning him, but it was a strategy they felt forced to use in order to confront health professionals with the extent of Jamie's needs. The final report indicated that he needed over eighty hours of care support every week, which corroborated what they had been saying for so long. With this funding the family started to move beyond mere survival. 'If the person with the head injury is adequately compensated, then the family is able to cope. Otherwise they cannot' (Joanna).

The family used this funding to move him out of the house and into a flat, but they still spent several hours every day providing support. Unfortunately, in many ways this funding came too late because they found that Jamie had never become socialized to accept help from anyone but themselves. They still needed to observe very closely every aspect of his life. For example, he stopped taking his medication when Joanna was momentarily distracted, which meant that he became subject to severe mood fluctuations.

I thought it was me not being able to cope with it but it was actually Jamie. He will fire up and you will be sitting there doing something and you might say something and it is, 'Oh you f...'. And then he will back down and be nice as pie five minutes later (Joanna).

The focus on 'being' was a consistent thread in the provision of care to Jamie. During the period before the family had adequate funding this focus dominated and the family felt that they were barely surviving, in spite of their best efforts. Even after receiving funding, there were periods when a momentary distraction meant that Jamie's well-being became problematic again.

Commentary

Being: the burden paradigm	Being: the victim paradigm
<p>The carer is burdened and ground down having too much to do and there is no hope that things will change in the future for the better. She is exploited and abused both by the person she cares for and by others around her. She is blamed for everything, including the suffering caused by the disability and is abandoned by all who might have had an obligation to either her or the disabled person.</p> <p>She goes from crisis to crisis, knowing that this is going to happen, but without the resources to plan. She is sleep deprived beyond exhaustion, yet she cannot afford to get sick because no one else will do her job.</p> <p>What makes it worse is that other members of the household are disadvantaged. There isn't enough money and she is concerned for their safety because the person with disability</p>	<p>The person with disability feels abandoned and his health declines because of lack of care. He may come into contact with the criminal or mental health systems, or may become a victim of emotional, physical or sexual abuse.</p> <p>Sometimes everything is done for him, including things that he has the capacity to do and will do for himself, because it is quicker this way. Other times he is left to his own devices and simply cannot do what is necessary.</p> <p>He is profoundly ungrateful for everything that is done for him and abuses his carer or exploits her whenever possible.</p> <p>He is aware of the level of burden he imposes. He feels guilty and trapped. His life is dull beyond belief and there is nothing to talk about. He has</p>

is aggressive and increasingly dangerous.	no hope of ever getting out of the poverty trap.
Being: good care practice	Being: responsiveness of the disabled person to good care practice
<p>The attitude of the carer to the person with disability can be described as one of 'attentive love'. The carer is able to keep the person he cares for safe, with a degree of comfort and competence that spares her unnecessary suffering. He is both sensitive and respectful in this task. His greatest feat is to rise each morning and start again, without despair. There is a sense of rhythm and playfulness, and a deep connection to the person he is caring for. He has the humility to stand silently beside the pain and suffering that he cannot control.</p> <p>He manages to keep a decent income coming into the house and is able to look after his own needs as well as that of others, now and into the future.</p>	<p>The disabled person has spare capacity in terms of energy, time and cognition after she has assisted with her cares. The support that she is given is sufficient so that she can begin to address the needs of growth and belonging. She feels as though she earns her keep at some level. She may take up more than her fair share of the energy in the house, but no one resents her for this because there is enough to go around.</p> <p>Things are not equal, but everyone gets what they need. There is a great deal of joy and laughter in her care and lightness in what is done for her. The care she receives ensures that she suffers from none of the secondary conditions that so often accompany disability. She is well in herself, as healthy as she could possibly be, and she looks good.</p>

Doing: and productivity

'Doing' in the sense of engaging in productive activity is the aspect of life that tends to be lost when the family is barely surviving; it is that aspect of life that creates a visible product that is not part of the cycle of consumption and survival. A focus on productive activity is particularly important because the nature of brain injury is such that the person forgets much of what they have done. Productive activity may also be the mechanism through which the person with brain injury comes to escape the poverty trap.

Although Jamie was allocated a care package of over eighty hours of care per week, there was nothing in the report that suggested how it should be used. There was a brief attempt to move him into a residential unit for people with brain injury in the community, but the staff was not able to handle his fierce independence or his mood swings. Jamie explained this by saying he was ‘old brain injury’ and they were only used to dealing with ‘new brain injury’. The family were not interested in using the funding to pay themselves for their work, although this would have been their prerogative. The important thing for them was to be able to use the funding flexibly on Jamie’s account: they used it first to pay a handyman to do productive work alongside Jamie. He learned by doing things and he needed to spend a lot of time exploring activities. Having someone to work alongside him in this way gave him a greater sense of competence and it meant that jobs actually were finished. He was incapable of finishing jobs without having someone to help in him in this way:

Jamie is like the crocheted loops at the edge of something. He does one loop and then moves on to the next, and the last one will never be revisited.... So that by the end Jamie is sitting down and I am still working’ (Jack).

The family came to the point where it was not possible to have Jamie living with them and Joanna came up with the idea of getting him a flat of his own. She had previously been given a small amount of backdated attendant care by ACC, which she had saved and was able to use as a deposit on a house for him. Renovating this flat gave a focus for Jamie’s energies, but it also became the kernel of an idea that was to prove very important for his ongoing development and financial security.

One of the reasons why brain injury is so difficult to understand, both for the brain injured person and for others, is because there can be such enormous variability in cognitive capacity over periods of time. This made it virtually impossible for Jamie to maintain regular work hours, because he would go through periods when it was extremely difficult for him to organize the simplest of his daily affairs. This variability meant that he might be able to complete building tasks one day, but be completely unable to carry them out the next. It was not a matter of simply training Jamie to do a task. Another significant portion of the funding was used to pay a builder to allow Jamie to work on site with him. The work of the carer was always about being responsive to the wide variability within what he could do. The quasi-supported employment arrangement with a builder permitted Jamie to have the semblance of work relationships and routine. At the same time Jamie was uncomfortable about

the fact that the builder was actually paid to have him at the site:

I feel as though I am leading a false life sometimes. If I say what I am doing it sounds as though I am better than what I am. I say that I am working on the buildings, but I don't say that I am doing it as a volunteer and that I can knock off any time that I like. I feel like a fraud. (Jamie)

As Jamie's confidence grew he became increasingly frustrated by the knowledge that he was caught in a poverty trap. This is a situation where any increase in income results in a loss of benefits so the person is no better off financially. Successfully renovating his flat suggested to him that he could replicate the experience, and he began a process of planning to buy another property. At this time this was only one among his many grandiose money making schemes, which changed almost weekly. Eventually his parents made the decision to establish a trust so that he could buy houses to renovate and rent out. This seemed to at least offer a glimmer of hope that he might, someday, have an income that was not completely dependent on ACC. There were some unfortunate incidents where he made poor decisions, but gradually he became adept at this business and eventually he began to make an income.

In this section it is possible to distinguish between a) employment; b) getting an income, and c) engaging in productive activities. All of these were very necessary for Jamie, but they were not achievable in a single package by someone with such a serious brain injury. Only the flexibility of the care package enabled him to achieve each of these components in such a way that he was able to benefit from them individually.

Commentary

Doing: the burden paradigm	Doing: the victim paradigm
This part of life does not happen in any positive manner. The carer is too overwhelmed to put any effort into growth, either his own or that of others. Alternatively, he focuses on the growth of the person with disability to the exclusion of his own needs and those of the rest of the family	The disabled person does not know her own potential for growth, nor does she know what resources are available to her. She is not given opportunities for growth because they are not available in her area. Alternatively, she may be given op-

He has to give up paid employment because it is too difficult to juggle the high level of needs of the disabled person with the demands of the work place.

opportunities for growth that bankrupt the family at several levels.

She may be forced and cajoled to grow in ways that may or may not ultimately be for her own good. Whatever choices she has in her life, they do not allow her any sense of control of the direction she might take.

Doing: the perspective of the competent well supported carer

Doing: responsiveness of the individual with disability to the competent and well supported carer

The carer is able to grow in ways that are meaningful to her and that ultimately sustain her individuality.

The disabled person has enough capacity and resources left over from looking after his basic survival needs to be able to engage in those activities that are meaningful to him.

She has the vision and capacity to drive a programme of care and to provide a good quality life for the person with disability. She has a deep knowledge of disability and the capacity to advocate well.

He is given enough freedom and different opportunities to begin to develop a vision of what it is that he wants. He has the opportunity to learn from both positive and negative experiences and to work on projects that meet his need for growth. He knows what he wants to do and is able to be self-directed.

It is hardly surprising that she develops outstanding skills in this area. Professionals and family recognise her expertise and respect her.

The siblings of the disabled person are good citizens, with a finely developed sense of values from a lifetime of living with disability.

He gets enough support to have the benefit of completing things, even when he cannot actually do the whole task himself.

Belonging: and beginning to separate.

‘Belonging’ and separation are ways of expressing how the person with brain injury and the family carer both begin to find their own places in the world. ‘Belonging’ is that aspect of the human condition where the carer and the

disabled person begin to insert themselves into a narrative of their own lives. In doing this they disclose who they are in relation to each other.

Jamie's parents were not wealthy, but they were known as good people with strong social values. They lived through painful years when they felt stigmatized because they had to confront people who had no understanding of why Jamie behaved as he did. Through school they were the parents who had the child who was both bullied and bullying, constantly running away, kicked out of almost every class. He left school without any qualifications. During his teenage years it was not at all certain that they would be able to keep Jamie out of prison and they were intensely aware of the vulnerability of having an invisible disability:

Do you know what it is like to have the police come to you, at five o'clock in the evening, and ask if they can search the premises? Jamie was caught receiving stolen goods' (Jack).

Joanna and Jack continued to coordinate his care when he moved into the flat, and he saw them every day. This worked well and in time Jamie wanted to know whether he could manage at an even further distance to his family. For example he went on an extended holiday to Australia. What Joanna learned was that she could let go of Jamie, once she knew that he was safe. Following this trip her confidence in their capacity to care for him at distance grew visibly. This gave Joanna greater choices in her own life also:

We know that we can manage him, because of his trips to Australia, from a distance. What I am saying is with Jamie we can start stepping back a bit because we know some of his limitations and what some of the input is that we need and how to work things from a distance. (Joanna)

This opened up a whole new set of possibilities for his parents. They had bought a business ten years prior to this, in order to be constantly available to Jamie. Now they put the business on the market and began to plan a life that recognized Jamie as an adult with a life that was separate from theirs. They began to engage in conversations that were directed at imagining what they wanted in their own lives:

We are selling the business mostly because it is time for Joanna and I to do something different. Jamie has moved to a new phase where we can manage him at a distance' (Jack).

Even as they began to find a degree of separation, Joanna and Jack constantly engaged in discussion about how much responsibility Jamie could be expected to take for his own life. There was such rapid change over the period of the study that it was evident that this negotiation sometimes brought them into conflict. Gradually they turned to their own lives and they both found jobs where they were working separately for the first time in nearly two decades. Joanna, in particular, became recognized as a skilled speaker about brain injury. As they established their own lives there was no indication that Jamie was being abandoned by his family. His mother summed up this situation as an ongoing balancing act: 'I am able to hold onto Jamie and let him go at the same time' (Joanna).

Commentary

Belonging: the burden paradigm	Belonging: the victim paradigm
<p>The carer suffers stigma because of her association with disability and is held responsible for this on a spiritual plane. Whatever she does is criticised by those who are closest to her. People say that she does too much or too little for the disabled person. Nobody listens to her and she is denied a sense of identity and authority. There is no one who recognises that she does a good job, or has any inkling of how difficult her work as a carer is.</p>	<p>The disabled person is stigmatised on the grounds of his disability, and where he is included he feels like a burden. Nobody listens to his voice and so he does not develop (or loses) a sense of his own identity. He is discriminated against and is perceived and responded to in terms of stereotypes. He strongly disagrees with what is being managed on his behalf, but he is powerless to effect any change.</p>
Belonging: a positive outcome for carers	Belonging: the response of the disabled person to care that helps them to belong
<p>The carer has a strong sense of his own identity within a community that both recognises and applauds him as an individual. This community understands that he has an identity that stretches far beyond his role as a carer.</p>	<p>The disabled person has a strong sense of her own identity and lives within a community that recognises her for who she is. No matter how difficult communication is she is still able to convey a sense of humour, or some other trait that is intrinsic to</p>

He is truly responsive and is able to represent the best interests and the wishes of the disabled person. He is recognised for his work and is invited to represent carers and disabled people in a wider forum.

He is able to embrace the relationships that are formed by the person with disability, and welcomes whatever changes they lead to.

her personality.

She is confident that the carer really listens to her and is able to represent her interests in the world.

She is able to form and sustain relationships with people who can understand her, and she is able to understand them.

DISCUSSION

The capability approach opens an analytical space in the discourse of care, by indicating that burden is only one of the many faces of care. The voice of carers who insist on the fundamental importance of their relationship with the disabled person is frequently lost in the enumeration of the losses that care brings upon them. Yet these voices are important reminders of what care can bring to lives, where the care is carried out under conditions that make it possible. For example, this is how the philosopher Kittay describes her relationship with her severely disabled daughter (Sesha):

It's perhaps self-delusional to say that I am as dependent on her as she is on me, but perhaps not. Others could take care of her and even love her – in fact, I must think that she will continue to thrive with or without me. But without her, I would wither (Kittay, 2002: 273).

The capabilities approach outlined in this paper is able to extend the discourse about rights for carers by creating a reminder that, for carers, the right to provide adequate care is their first prerogative. This was expressed by Joanna when she said: 'If the person with the head injury is adequately compensated, then the family is able to cope. Otherwise they cannot.' This essential relationship is often forgotten in the drive to provide solutions that will enable the carer to get respite and to remain in employment. These rights are important, but they need to be underpinned by the knowledge that carers will continue to work beyond endurance as long as there are no other solutions available for the person with disability. Legislative force is increasingly being added to routine expressions of care and concern about the plight of carers. However, this will not help carers unless it is accompanied by policy and legislation that

ensures a better quality of life for the person with disability. Without this assurance, there is little point in trying to strengthen the capacity of carers for employment.

This paper provides insight into the lives of carers that are lived beyond the burden paradigm of care. Prior to receiving an adequate care package, Joanna's health broke down under the strain of caring for Jamie, but many accounts would leave their story at this point. Once the family received support, they immediately began to express a much wider range of capabilities. This suggests that the distortions that occur with adaptive preferences (Nussbaum, 2000, 2001a, 2001b) do not operate in this context. The family was not attached to holding Jamie in a state of dependence. On the contrary, once the family members received support they not only moved from a situation of burden, but they were also able to arrive at novel solutions. They were able to respond to Jamie in a variety of ways, distinguishing between his separate needs for employment, income and productive activity.

The success of Jamie's family needs to be set in the context of what was happening to them before they got access to flexible funding. They were following a trajectory that is commonly experienced by families of young men with brain injury: Joanna's health had broken down (Jorgensen, et al., 2010; Vitaliano, 2003), and Jamie was within a hair's breadth of finding himself in prison (Schofield et al., 2006). Eighty hours of care per week may seem a lot, until it is put alongside what the ongoing costs of failure in this family would have meant in terms of healthcare for Joanna and a custodial sentence for Jamie. The family could not have precisely predicted what they were going to do with the funding, but they were highly motivated by their awareness of the costs of failure. The funding placed them in a position where they were no longer simply surviving, and they rapidly moved into lives that reflected a wider spectrum of capabilities for all of them. It should be noted that the funding was paid as wages to the family, but they never used it to pay themselves. Instead, it provided a flexible pool of funding that enabled them to employ a handyman, and to create a quasi-supported employment situation. Eventually they used it to create a trust, so that Jamie could be involved in renovating houses and getting a rental income.

The flexibility of the funding effectively enabled the family in this case to create a solution to the 'poverty trap' that exists for many people with disability. This family was well aware that Jamie was never going to have the skills to fit within an ordinary work environment, so when they got access to flexible funding they were quick to turn it into an entrepreneurial opportunity. This

approach to the flexible use of individualised (i.e. family waged) funding in order to create opportunities for productivity and employment has previously been identified in the New Zealand context (Butler, 2000). The therapeutic advantage of creating such pathways into valued capabilities are so great that this is a strong argument for attempting to find solutions to the poverty trap for people with disability. The capabilities approach strengthens the argument for welfare systems to mitigate against the poverty trap. The capacity to earn a percentage of income before triggering a financial penalty would be an important facilitator of productive activity. This paper demonstrates how building a productivity function set for a person with brain injury creates the possibility of a sustainable future.

The flexible use of funding reveals an approach in which individual health is seen as being inextricably linked to the health of the whole family, in a way that resonates with the Whanau Ora approach (Ministry of Health, 2009). A relational approach to capabilities looks beyond the individual to a family or group perspective. As Joanna once said: 'It is not an individual who has a brain injury, it is a whole family'. An individual perspective on capabilities of either the person with disability or the carer tends to overlook how the disability impacts on the whole family and also the potential for synchronicity when things work positively. A relational approach to the overall capabilities of this small group begins to highlight how they work together to make something that is greater than the parts. It would have been impossible to imagine at the outset just how far this family would be able to take a small amount of funding to increase the capability set of the whole family. The health professionals who worked with Jamie were able to identify that he needed eighty hours of support every week, but as far as Jamie was concerned, none of their suggestions about how that funding might be used were acceptable to someone with 'old brain injury'.

We have much to learn about ways of reasoning philosophically about disability and care in ways that are inclusive, respectful of difference and sensitive to inequality. The aim in this paper is to bring an ethnographic perspective to a philosophical approach. A relational approach to capabilities moves beyond paradigms of disabled victims and burdened carers to provide a robust conception of how families of people with brain injury can effectively work together to enhance the capabilities of every member. This paper provides an ethnographic exploration of three function sets that underpin the overall capability set of someone who is caring in the best and the worst circumstances. This removes some of the arguments about adaptive preferences as an expression of true autonomy, since it demonstrates what the carer does when they

are provided with adequate opportunity. It also shows the value of an approach that enables these capabilities for both the carer and the person with disability. There is a dual benefit if a capability set can be achieved, and a dual hardship in the case of failure.

REFERENCES

- Agar, M. 2004 'We have met the other and we're all nonlinear: ethnography as a nonlinear dynamic system', *Complexity*, 10(2):16–24.
- Alkire, S. 2006 'Public debate and value construction in Sen's approach', in A. Kaufman (ed), *Capabilities Equality: Basic Issues and Problems*. New York: Routledge.
- ARJIC v Campbell. 1995 *The Accident Rehabilitation and Compensation Insurance Corporation v Andrew Frances Campbell, Shane Francis Creighton, Marcel Leigh, Simon John Walshe, Jennifer Sherryl Williams*. Wellington: AP200/95.
- Arksey, H. 2005 *Caregivers' aspirations and decisions around work and retirement*. Leeds: Department for Work and Pensions.
- Butler, M. 2000 *The Man Who Would Not Get Out of Bed*. Unpublished Masters thesis, University of Otago, Dunedin.
- Butler, M. 2007 *Care Ethics and Brain Injury* Unpublished PhD thesis, Otago University, Dunedin.
- Carpinter, A., Irwin, G. and Rogers, G. 2000 *Just Surviving*. Wellington: Ministry of Health.
- Clements, L. 2009 *Carers and their Rights: The Law Relating to Carers*: Carers UK.
- Cummins, R., Hughes, J., Tomy, A., Gibson, A., Woerner, J. and Lai, L. 2007 *The Wellbeing of Australian's – Carer Health and Wellbeing*. Deakin: Australian centre of Quality of Life, Deakin University.
- Goodhead, A. and McDonald, J. 2007 *Informal Caregivers Literature Review*. Wellington: Health Services Research Centre, Victoria University.
- Human Rights Review Tribunal. 2010 *Atkinson v MOH* Reference n. HRRT 33/05.

In the matter of a claim under the Human Rights Act 1993 and its amendments.

Jorgensen, D., Parsons, M., Jacobs, S. and Arksey, H. 2010 'The New Zealand informal caregivers and their unmet needs', *New Zealand Medical Journal*, 1234 (1317).

Kittay, E. 2002 'When caring is just and justice is caring: justice and mental retardation', in E. Kittay and E. Feder (eds), *The Subject of Care: Feminist Perspectives on Dependency*. Oxford: Rowman and Littlefield publishers.

Mezey, M. 2004 'Nurses and their changing relationship to family caregivers', in C. Levine and T. Murray (eds), *The Cultures of Caregiving: Conflict and Common Ground Among Families, Health Professionals and Policy Makers*: 70–86.

Ministry of Health. 2009 *Whanau Ora Tool*.

Ministry of Social Development. 2008 *Carers Strategy*. Wellington.

Nussbaum, M. 2000 *Women and Human Development*. New York: Cambridge University Press.

Nussbaum, M. 2001a 'Adaptive preferences and women's options', *Economics and Philosophy*, 17: 67–88.

Nussbaum, M. 2001b 'The cognitive structure of compassion', *Upheavals of Thought: The Intelligence of Emotions*. Cambridge: Cambridge University Press: 304–327.

Opie, A. 1992 *There's Nobody There*. Auckland: Oxford.

Rea, H., Kenealy, T., Sheridan, N. and Gorman, D. 2010 'Invisible care: do we need a Code of Rights to protect family and informal carers', *The New Zealand Medical Journal*, 123(1317): 5–6.

Schofield, P., Butler, T., Hollis, S., Smith, N., Lee, S. and Kelso, W. 2006 'Traumatic brain injury among Australian prisoners: rates, recurrence and sequelae', *Brain Injury*, 20(5): 499–506.

Sen, A. 1985 *Commodities and Capabilities*. Amsterdam: North-Holland.

Sen, A. 1992 *Inequality Reexamined*. Cambridge, Mass: Harvard University Press.

Sen, A. (ed). 1980 *Equality of What?* (Vol. Tanner lectures on Human Values). Cambridge: University of Utah Press.

Uyan-Semerci, P. 2007 'A relational account of Nussbaum's list of capabilities', *Journal of Human Development and Capabilities*, 8(2): 203–221.

Vitaliano, P. 2003 'Is caregiving hazardous to one's physical health? a meta-analysis', *Psychological Bulletin*, 129(6).