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The impact of these barriers are those reflected in the social model of disability, where barriers oppress and disenfranchise people with disability, impact on agency and reflect inequitable power relations (Oliver 2006; McKenzie 2007).

The limitations of this analysis are that it reflects an interpretation of authors’ contributions to the literature only. The literature is not necessarily representative of the views of people with disabilities, who are primary stakeholders in the discussion and debate about the processes and outcomes of access.

Conclusion

Access is necessary for achievement of social connectedness. Access opens the door to numerous life opportunities and to exercising of agency in pursuing life goals. As an inclusive concept, access is more than gaining entry, exiting or making use of and having the right to do these, which are reflective of normative, ableist views, where the enjoyment of, and responsibility for, access is primarily dependent on agency. Access involves positive engagement and response at every process point so that equality of opportunity is realised. This involves social and political responsibility for addressing barriers that continue to impede access for people with disabilities. An inclusive concept of access should include reference to terms such as ‘provision for’ and ‘accommodation’ to reflect the social and structural response that is required.

Additional research is required to understand better the influences and processes of access. Investigation of attitudes and attitude change and how these impact on, or result from, practices is indicated and would be valuable for addressing social and structural barriers. Understanding the mechanisms used for effective consumer consultation and how to implement these would also address a number of barriers. Clarification of how barriers in each dimension impact on each other, and the consequences of these for the person and their satisfaction, would serve to ‘untangle the web’ and create an effective platform for social, political and economic response, all of which are required for realisation of social inclusion.

2.6 The relationship between undertaking an informal caring role and social exclusion

Sally Savage and Nicole Carvill

The aim of this chapter is to demonstrate the relationship between undertaking an informal caring role and social exclusion. There is a substantial body of literature available on the impact of caring on informal caregivers; however this literature focuses largely on identifying and measuring the impact of the caring role. The negative impact of caring is clear. A recent survey of over 4,000 carers in Australia reported that they had the lowest collective wellbeing of any group surveyed (Cummins et al. 2007). Differences in wellbeing between carers as a group, and non-carers, were reported in the Victorian Carers Program, a population-based study (Schofield et al. 1998). Carers reported less life satisfaction, less positive affect, more negative affect and greater overload compared with non-carers, regardless of age or marital status. More than one-quarter of the 945 carers in the Victorian Carers Program self-rated their health as fair or poor (Schofield et al. 1998) in comparison with 16 per cent of 25,900 Australians in the general population who rated their health as fair or poor in a National Health Survey (Australian Institute of Health and Welfare, 2006). In this chapter we argue that the type of exclusion experienced as a result of caregiving is not a static phenomenon, and that exclusion can be primarily social, financial, or systemic.

A carer or caregiver is someone who is unpaid and provides regular and ongoing assistance and support (physical or emotional) for a person with a physical and/or intellectual disability, mental illness or is frail aged. The person for whom they care is referred to as a care recipient. The number of people in a caring role is growing in Australia due to the ageing population and to people with disabilities living longer.

The data included in this chapter comes from several studies conducted with carers in the Barwon-South West region of Victoria for various projects. In-depth interviews were conducted with: 41 parents of a child aged up to 13 years with a disability (Jones et al. 2003); 77 carers in the areas of aged care, disability and mental illness (Carvill 2008); 42 parents and family carers of adolescents with a disability (Fennelly et al. 2008); and telephone interviews conducted with 142 community-dwelling women aged 70 or over (Ulvestad 2006). The words of the carers interviewed for these projects are used to illustrate points in this chapter.
Exclusion is not static

The situation of carers illustrates that social exclusion is not static; it can occur suddenly, and to anyone. The exclusion experienced by carers is not due to stable factors such as socioeconomic status, geographic location or race, but it results from a change in specific circumstances. This type of exclusion can happen to anyone, for example when a partner or parent becomes increasingly frail or develops dementia, when a child with a disability is born, or when a family member becomes disabled due to an accident.

For some people, the change experienced on becoming a carer affects all aspects of their life, as follows:

I’ve given up my life, my free time, my whole way of life. I’ve gone from easy going and relaxed to on the go and never stopping.

(Carvill 2008: 268)

I can’t visit friends. I can’t go to the craft show, I can’t get out of the house. I’ve given everything up. Your life stops and his life stops too.

(Carvill 2008: 268)

Some carers comment on specific activities that they are no longer able to do, since taking on a caring role. They are no longer able to participate in a range of activities including volunteering and physical activity:

[My] husband’s health limits activity – now cannot do Meals on Wheels, [or] go out.

(Ulvestad 2006: 35)

I used to go to the gym in the morning but I’ve stopped because he needs help with breakfast.

(Carvill 2008: 269)

Thus, many aspects of the previous life of carers may be changed as a result of taking on a caregiving role. Important social connections and health-enhancing activities may no longer be possible.

Social exclusion

An important mechanism of exclusion for carers relates to social exclusion. Some reported that their social network had reduced significantly since the care recipient’s diagnosis, resulting in a sense of social isolation. Many carers described a ‘loss of freedom and spontaneity’ associated with the caring role, which results in social and lifestyle restrictions (Carvill 2008). Such restrictions have the potential to adversely impact on other areas of a carer’s life and result in stress proliferation. The term stress proliferation is used to highlight the influence of multiple stressors and to illustrate how potential lifestyle restrictions associated with caring have the potential to affect other areas of a carer’s life (e.g. employment opportunities, family and peer relationships). Socioemotional support appears to improve carer wellbeing. Socioemotional support is conceptualised as the strength of the connection between the carer and their social network and is measured by a carer’s perception of the availability of someone who helps them to feel good and the presence of a confidant. Conversely, carer perceptions of insufficient social support has been found to be predictive of depression and higher levels of burden for carers of a person with a mental illness (Magliano et al. 1998; Song et al. 1997). The following quotes are from carers with an aged care recipient:

The contact that we used to have socially has gone. I’m more isolated but if people came to visit I could cope [with the role].

(Carvill 2008: 272)

I don’t have as much contact with my family and friends as I used to. I miss it.

(Carvill 2008: 272)

Some carers commented that the social contact they do have is with a new group of people – professional carers. Thus their social contact is linked with their caring role:

I now have social contact with nurses and respite workers.

(Carvill 2008: 272).

Parents who are caring for a child with a disability have expressed similar experiences:

I haven’t got my own time. I can’t do things on the spur of the moment, I always have to be available.

(Carvill 2008: 314)

Friends are really hard. We couldn’t socialise with this child needing twenty-four seven care, plus the stress. I couldn’t be bothered with visitors plus they didn’t understand, not having a clue.

(Jones et al. 2003: 136)

A further result of this impact of caring is the inability to participate more broadly in the community:

We had an active life – lots of social committees and activities – less now. Can’t manage it and husband.

(Ulvestad 2006: 35)
Some carers of a child with a disability describe difficulties they experience when out with their child, particularly if the child displays inappropriate behaviour:

I feel people are looking at me thinking, ooh, she's a bad parent.

(Jones et al. 2003: 77)

I feel like I have to explain myself or my child, but at the same time I feel angry and think, why should I have to explain myself? I constantly feel like there’s an internal battle going on.

(Jones et al. 2003: 80)

This type of experience, in addition to the huge time commitment in caring for the child, can lead to a self-imposed isolation:

At times it is very easy to become a recluse. It is just too hard to get out, just too hard to do this, too hard to talk about. The child tends to dominate the conversations when you’re at home and when you’re out.

(Jones et al. 2003: 136)

Financial exclusion

For many carers, the caring role has significant financial implications. In the recent survey of Australian carers, their satisfaction with their ability to pay for household essentials, to afford things they would like to have, to save money, and to not worry about income covering expenses were all severely compromised in comparison with participants from the general population who completed similar surveys (Cummins et al. 2007). Some carers face severe time constraints and are unable to participate in paid employment. Additional costs are incurred for some carers, particularly those caring for the disabled:

Financially it is hard on us with only one of us working, but with the needs of the children I really can’t work. Anything you need for the disabled tends to be twice the price.

(Fennessy et al. 2008: 196)

The allowance made available to carers is viewed as clearly insufficient by carers:

We get a disability allowance for looking after them, but that works out to about thirteen cents an hour. ... So it’s always going to be a financial burden, which is an awful way of looking at it, but it is.

(Fennessy et al. 2008: 196)

Another carer of a young person with a disability indicated that dealing with the bureaucracy in order to obtain some form of financial assistance was another disempowering experience:

Similarly, in Carvill’s (2008) interviews with carers in the areas of aged care, disability and mental illness, some carers reported either reducing or relinquishing their work commitments to meet the demands of caregiving. Carers who continued to work appeared to need additional support to balance the combination of work and caring. The limitations associated with current support services were also discussed by carers. For example, if the care recipient is unwell there is no emergency support available for the care recipient which would enable the carer to go to work rather than remain with the care recipient.

Systematic exclusion

There is a substantial body of literature on the impact of caregiving, and sophisticated theories explaining the interactions between the stressors experienced by carers and their ability to manage these (Pearlin et al. 1990; Aneshensel et al. 1995; Folkman 1997). However, this knowledge appears to have had little impact on the service system, in relation to how carers are treated. Four ways of thinking about carers and their relationship with formal services have been characterised by Twigg and Atkin (1994), who have argued that how a carer is perceived by organisations and practitioners determines whether their needs are recognised and addressed. The four approaches to carers are:

1. carers as resources in which carers are seen as a means to an end of meeting the care recipient’s needs;
2. carers as co-workers with whom the formal care providers work in parallel with the outcome being focused on the welfare of the care recipient;
3. carers as co-clients where the focus is on relieving the carer of strain or stress; and
4. the superseded carer in which the aim is not to support the caregiving relationship but to transcend or supersede it (Twigg and Atkin 1994: 14–15).

Our research in the Barwon-South West region of Victoria suggests that carers are viewed as resources by most organisations and front line practitioners, but their needs are neither recognised nor addressed consistently. In fact, many support services were clear that the focus of their service was on meeting the needs of the care recipient (Carvill 2008). The following quotes from carers caring for someone with a disability typify a system that is not working cooperatively with carers:
One of the problems is that you are dismissed as a parent, like you don’t know anything. Professionals are thought to be the experts, whereas I think we are.

(Fennessy et al. 2008: 59)

I was told ‘You’re mad’ when I said I wanted [care recipient] home with me. I was told I couldn’t do it and a residential placement was the best option. Because he has high level needs [agency name] won’t provide a service. I have had to fight to get funding and services. The system needs an overhaul.

(Carvill 2008: 309)

Navigating a system that is not user-friendly is also problematic for many carers, and a disempowering experience for them:

Everything is disjointed. If you need something that is out of the norm you have to do lots of phone calls. There’s no central point. No one person to call for information.

(Carvill 2008: 309)

Others commented that ‘Finding services is a nightmare’ (Carvill 2008: 309) and that ‘I have no idea what support is available’ (Carvill 2008: 309).

A number of carers interviewed indicated that there was an expectation that they would be able to specify what type of support they needed in their role, which the carers explained they could not do:

Sometimes I get tired and feel like I need something but don’t know what.

(Carvill 2008: 254)

The hardest question I was asked was by someone from [agency name]. They asked ‘What do you need?’ and I found this very hard to answer.

(Carvill 2008: 254)

Carer self-identification of unmet support needs is problematic as such a process assumes that the carer has a detailed knowledge about the range of support services available and how the services may help to alleviate specific causes of stress. Self-identification of support needs also presumes that the carer can objectively pinpoint all sources of personal stress including both physical and emotional sources. The practitioner’s failure to identify a carer’s needs has important negative implications for the wellbeing of the carer. The existence of unmet needs has been found to have negative implications for the carer’s wellbeing and ability to continue within the role (Gaugler et al. 2005).

Some interviews with carers provide further evidence of the disempowerment of the carer via the language used by professionals to describe the care recipient.

When she was newborn, she was interesting to everybody, so they kept calling her ‘an interesting case’, never by name, just ‘an interesting case’.
I said, ‘She’s my daughter; she’s not an interesting case at all’.

(Fennessy et al. 2008: 211)

Health promotion implications

The negative health impact of social isolation and not being engaged or participating in one’s community is acknowledged (Rosenfeld 1997; Michael et al. 2002). Similarly, the inability to participate in health enhancing behaviours such as physical activity is detrimental to an individual’s health and wellbeing (Bauman et al. 2002; Teychenne et al. 2008). In addition, there is potentially a negative impact for both the individual and the community when volunteering activities are restricted or precluded. Volunteering is a particularly important way of being socially engaged, providing benefits to the community as a whole, to the recipients of the voluntary work, and also to the volunteers themselves. A review of the literature on volunteering suggests that people who volunteer are likely to maintain significantly higher levels of wellbeing, a strong sense of their own worth, and have better functional health than those who do not volunteer (Onyx and Warburton 2003). Importantly, there is evidence that volunteering actually improves wellbeing and functional health: it is not just that healthier people are able to volunteer (Davis et al. 1998; Onyx and Warburton 2003).

There are a number of systemic factors that could be altered to improve the health and wellbeing of carers. A change in the model of service provision so that carers are treated as co-clients rather than as resources, as described by Twigg and Atkin (1994), would be beneficial to carers. Such a change should result not only in more appropriate support for carers, but would also enable carers to feel that they are valued and have an important role to play as carers. They should be empowered and made to feel knowledgeable and proud rather than ignored and foolish. For carers who are in the workforce, greater flexibility in working hours and in rules for taking time off would facilitate a smoother integration of the working and caring role. Finally, more substantial financial support for carers would assist those who experience hardship and find it difficult to cope financially with the additional costs of caring.

At the community level, an enhanced awareness in general of the impact of the caring role on carers could lead to changes that would be of benefit to carers. Small gestures can at times make a substantial difference. For example, a neighbour dropping in and offering even a small amount of help, or simply having a chat with an elderly person caring for a frail aged partner could be an important social event for the carer. Within families, an increased understanding of the relationship between carer and care recipient, and of the impact of the situation on the carer, could facilitate smoother communication and perhaps some assistance from other family members. Within communities,
an increased understanding of disability and mental health in general, and of the role of caregivers for people with a disability or mental health problem, may lead to a level of tolerance and support in the community that would be highly beneficial to carers and their care recipients. Roth et al. (2005) found that addressing carer satisfaction with the social supports available through individual and family counselling altered the stress process by changing a threatening appraisal to a more benign appraisal. This type of carer intervention which is aimed at enhancing the social support of spousal carers of a person with Alzheimer's disease has been found to be effective in reducing the emotional distress associated with the role.

Conclusion

The various ways in which people who provide informal care experience exclusion largely stem from the failure, at various levels, to acknowledge both the importance of, and the impact of, the role played by carers. This occurs at a systemic level and at a community or personal level. The impact of this exclusion undoubtedly contributes to poor health and wellbeing outcomes for carers. The exclusion of carers is also detrimental to the overall community, as it prevents carers from participating in their community at an optimal level.

2.7 Debating the capacity of information and communication technology to promote inclusion

Jane Maidment and Selma Macfarlane

Introduction

Discussion around the use and impact of information and communication technology (ICT) has created polarised debates about the potential of ICT to generate inclusion or exclusion. Computer mediated communication is variously heralded as a means of transcending ‘sociocultural markers such as race and gender ... lead[ing] to a utopian society’, and denigrated for creating ‘impoverished, low-trust relationships at best and social withdrawal, at worst’ (Markham 2005: 794). Similarly, it is argued that the plethora of information available via ICT can break down hierarchical access to information and power previously dependent on social position. Conversely, however, others observe that ICT has created new inequalities based on the information rich and the information poor, and one’s position in controlling, or being controlled by, technological advancements. As Markham (2005) comments, such universalised and dichotomised opinions have been usefully extended to include more specific, context-based analyses, acknowledging a complex range of processes and outcomes associated with ICT in various settings. This chapter explores this diversity and some of the ways ICT has impacted on human service education, professional development, and the provision of services in specific contexts. We attempt to identify ways in which ICT may lead to social inclusion and/or exclusion for social groups with varying access to ICT.

The chapter begins with an exploration of the digital divide in the Australian context. This discussion is followed by an examination of online education, professional development and the capacity of ICT to enhance the well-being of practitioners. The chapter then focuses on the use of ICT in human services and the rise of computer mediated self help and support groups. The potential for ICT to promote and extend political participation is also explored as well as the role of ICT in global development. Throughout, the potential for inclusion and exclusion is highlighted, using examples, and critical analysis for exploring the inclusionary and exclusionary capacity of ICT.