



Caring for independent lives: Geographies of caring for young adults with intellectual disabilities

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ABSTRACT

This paper engages with the emerging disciplinary clash between 'care' and 'independence' within disability studies by examining the geography of home care for young adults with intellectual disabilities. The care system as a whole is viewed as central to disablist structures within disability studies (see Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*, Hampshire: Palgrave Macmillan.). However, despite the theorisation of dependency as being in antipathy to the goals of the disability movement, caregiving at home still continues to dominate community care. The paper attempts to address how family carers are 'caught-in-the-middle' between their 'duty' to care and at the same time, perpetuating dependency; the reality being that parents have to deal with issues of being overprotective and confronting various social assumptions about disability. It examines the narratives from 25 family caregivers in Ireland who provide personal assistance to young adults with intellectual disabilities.

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Introduction

The informal care sector – made up mostly of family caregivers – has for a long time been the largest source of care for adults with intellectual disabilities (ID) (referred to as 'learning disability' in social policy documents and in popular discourse in the UK), even during the 'institutional era', albeit in the shadow of the asylum (Metzel, 2005; Thomas, 2007). In any case, the experience of separation and isolation has continued since the asylums closed and people with ID moved into nearby communities (Dear & Wolch, 1987). People with ID have since faced new entanglements of inclusion/exclusion in the community between 'special schools', 'special' transport, sheltered and group housing on one hand, and mainstream schools, accommodation and types of employment on the other (Hall, 2005).

The definition of an ID is the possession of the following features: intellectual functioning is significantly below

average; there are difficulties with everyday life skills; and the condition is present from early childhood. It is marked by lack of understanding and communication (NAMHI, 2004). While definitions of ID may provide some insight into the impairment itself, it is important that these definitions do not overly label the person and that generalised assumptions are not made. People with ID are a group regarded as being particularly vulnerable to dependency creation on one hand (Swain, French, & Cameron, 2003) yet can be highly independent on the other; depending on the level and type of advocacy provided (Lemon & Lemon, 2003).

The aim of this paper is to conduct an in-depth examination of the daily geographies of carers of young adult children with ID in order to explicate the ways in which they negotiate providing, and are challenged by constructions of, independent living. Independent living is defined as achieving control, choice and self-governance in one's life (Morris, 1993). The paper uses what Hall (2005) refers to as the socio-spatial 'fine print' of the everyday lives of carers of people with ID to question the assumption that this variant of community care guarantees independence

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and autonomy for the young adult with an ID. It attempts to illustrate the ways in which both social and spatial life shape carers' abilities to provide opportunities for independent living. The paper thus briefly documents the wide body of literature on ID, then addresses work within disability studies on the notion of a disciplinary clash between care and dependency (Thomas, 2007). Finally, it examines the recent geographical work on ID, and proposes that a health geography perspective offers important insights to this debate, by focusing on the daily geographies of family caregivers.

The literature review is followed by a detailed exploration of the interconnections between the physical, social and spatial experiences of carers in order to tease out how carers are 'caught-in-the-middle' within this debate. The analysis draws on qualitative data from 25 interviews with family caregivers of young adults aged between 18 and 30 years with ID in Ireland.

Literature review

Intellectual disability (ID) (and the *caregiving* of people with ID) has a long tradition of theoretical and empirical research. One particular project of great significance for people with ID has been Wolfensberger's (1983) concept of 'normalisation', otherwise known as 'social role valorisation' (SRV). SRV is defined as the creation, support and defence of socially valued roles for people who risk devaluation (Dowse, 2001). This principle, however, served to accord professionals "a central role in interpreting disabled people's socially valued roles and activities" (Barnes, Mercer, & Shakespeare, 1999: 74).

In terms of family perspectives, Birenbaum (1971) suggested that family coping becomes more difficult as the child with ID ages and as families face support network shrinkage over time. Similarly, there has been a focus on the health-related stress and depressive symptoms experienced by caregiving mothers of adults with ID (Pruchno & Meeks, 2004). Work has also been done on coping strategies of aging mothers of adults with mental retardation (Seltzer, Greenberg, & Krauss, 1995). An 'adaptation' hypothesis has suggested that people adjust to caregiving over time, and acquire skills and competencies which help them to cope better, even when their own support networks may indeed be more depleted (Seltzer & Heller, 1997).

Despite the breadth of the ID literature, there have been strong calls that this group has been ignored by broader discussions on disability, in particular, the social model of disability. For example, Chappell (1997) makes the plea that writers in the disability movement keep the question of learning difficulty in their minds. Much of the subsequent work on ID in mainstream disability literature has been on how the social model has failed to satisfy people with ID who feel themselves to be excluded by definition (McClimens, 2003). Dowse (2001) goes on to examine why the disability movement's promotion of a strong disabled identity may be difficult to achieve for all its constituents, particularly people with ID. She points out they may have been better served by their own political collective identity (self advocacy in the UK), as well as considering

that ID is not a unitary or homogenous category of impairment in itself. She also acknowledges some people with ID will have cognitive limitations which curtail a broader awareness of the experience of oppression as common to all people with impairments.

As this specific ID and caregiving literature developed, research on 'care' more generally has met a lot of resistance from the disability studies literature, which has been described as 'ideological dynamite' (Oliver & Barnes, 1998). First of all, 'care' has been for a long time synonymous with health/medical care and the medicalisation of disability/impairment, which led to the institutionalisation of people with ID (Metzel, 2005). Since then, with the move away from care in large institutional environments, the concept of community care has been viewed as central to the process of disablism in disability studies (Thomas, 2007). Disablism here refers to a term introduced by Abberley (1987), meaning the social beliefs and actions that oppress/exclude/disadvantage people with impairments. It has been argued that home care can contribute to this process of disablism by impeding the chances of the person with ID achieving the fundamental principles of independent living; control, choice and self-governance (Morris, 1993).

As a reaction to the persistence of disablism within new forms of care, writers such as Oliver and Barnes (1998) have argued that, "constructing the category carer and developing policies in respect of this group has neither enabled disabled people to become independent nor freed other family members from their 'caring' duties" (Oliver & Barnes, 1998). Indeed, Twigg and Atkin (1994) even went as far as suggesting that they may be seen as part of the problem as well as part of the solution. This arose as a result of caregiving research both assuming the need for 'care' as self-evident (thus re-enforcing the notion of dependence) and ignoring the disabling effects their 'duty' to care can have on the individual with the impairment.

While this debate has flourished in disability studies, more recently, geographers have turned their attention to ID and have begun to ask questions about the role of space in understanding dependency which offer important insights into the debate (see Hall, 2005; Hall & Kearns, 2001; Metzel, 2005). This area of study gathered pace with Hall and Kearns' (2001) article on making space for the 'intellectual' in geographies of disability and a subsequent special section on the geographies of ID in Health and Place (2005), documenting their position 'off the map' (Smith, 2005) and being 'outside the participatory mainstream' (Philo & Metzel, 2005).

Of particular relevance to the issue of dependency has been firstly Metzel's (2005) work on the extent that people with ID are still socially and economically controlled in the community by intensive regulation of funding and services, thus leading to ghettoisation and segregation; thereby contributing to the experience of living within an 'asylum without walls' (Dear & Wolch, 1987). Secondly, Hall's (2005) work on the entangled geographies of social exclusion/inclusion for people with learning disabilities has contributed a nuanced account to our understanding of places of exclusion and inclusion. He examines how seeming places of inclusion – sites of paid employment and

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