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Making space for belonging: Critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion

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ABSTRACT

This paper critically reflects on the way in which recent adult social care reform has been evolving beneath the alleged policy goal of prioritising the cultivation of meaningful inclusion and ‘belonging’ in the community. With this goal, there has been a focus away from ‘services’ for persons with intellectual disabilities, to supporting natural connections within the community. This paper draws on a grounded theory study of the perspectives of those responsible for overseeing community living arrangements for persons with disabilities, drawing on interviews and focus groups with service providers and relevant government officials. It examines the socio-spatial implications of the gradual shift towards ‘belonging’ as a disability policy goal, as it has evolved in two discrete settings – British Columbia, Canada and Ireland. The findings identify the complexities involved in facilitating active community connection for persons with intellectual disabilities and reveal important cautionary lessons for other jurisdictions where community living policy has arguably been moving away from communal services towards self-managed supports in ‘real’ communities through personal budgets in an effort to remove barriers to participation. The paper thus critically reflects on the rapid pursuit for transformation in personalised adult social care in government policy, arguing that the process of fostering meaningful community inclusion will and *should* take time.

Introduction

The concept of social inclusion has become ubiquitous in disability policy since the late 1990s and early 2000’s with international and domestic policy prioritising the removal of barriers to social and economic participation. Within England for example, its emergence is marked succinctly by the Department of Health White Paper *Valuing People Now* (2007), which requires intellectual disability (referred to as learning disability in England) services to work towards social inclusion and foster participation in community life. This goal is shared amongst many other countries and has involved a core focus on re-placing people within the community to ensure they have full and fair access to activities, and supporting them so that they can be employed and live in their own home rather than conducting their whole lives within segregated disability services (Bates & Davis, 2004).

During this time, the concept of ‘belonging’ has filtered into the international lexicon of social care policy, and arguably takes the concept of social inclusion beyond narrow understandings and identifies it as not simply the promotion of the increased presence of marginalised persons in society, but rather that such people return to or begin to occupy valued social roles within society and community life (CLBC, 2009; Kendrick & Sullivan, 2009). This thinking has been crystallised in the 2007 UN Convention on the Rights of Persons with Disabilities (CRPD), which mandates that States Parties must ensure that ‘the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of *belonging*’ (preamble, emphasis added). Here the emphasis is on *meaningful* engagement and reciprocal relationships within the community and policies to address the inequalities faced by people with disabilities.

While meaningful social inclusion is not new within the disability literature, the recent generation of policy mechanisms that purport to endorse belonging has arguably become more pervasive, whilst simultaneously promoting an agenda of increased ‘choice’ and personalisation in the form of personal budgets and self-managed support. The international focus on personalisation approaches is now evident across a range of countries including Canada, England, many states in the US, and more recently Ireland, and is increasingly endorsed as a mechanism which can facilitate greater community inclusion (Bigby & Frawley, 2010; Power, 2013).

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While this emphasis on belonging is broadly welcomed, this paper seeks to draw out implications for social policy development in this realm from a study of the experiences of stakeholders involved in facilitating 'belonging' for persons with intellectual disabilities in two international comparative cases – British Columbia (BC), Canada and Ireland. The experiences from these jurisdictions point towards the geographic and socio-relational complexities of promoting a sense of belonging within the community and reveal critical insights into some of the challenges facing the support sector in this field.

In terms of fostering belonging within community care policy, the debate shared amongst many countries has become dominated by disability rights, personalisation and choice, and the transformation of adult social care towards a life in the community (e.g. Department of Health, 2007; 2008). Again, while such goals are laudable, many of the changes are being implemented in a climate of austerity cuts and there is evidence from a number of welfare regimes (e.g UK, Canada) that cuts are specifically being targeted at disabled people (see Rice & Prince, 2013; Taylor-Gooby, 2012). The process has become focused on work participation, personal budgets, self-managed support and anti-discrimination legislation. Meanwhile, there has been a shift away from conventional services such as group homes and day services. According to Hall (2011), the landscape of support has become increasingly decentralised and focused on the normalised spaces of the home, employment and public space, whilst constraining collective and interdependent forms of support. The overall result, according to Sir Bert Massie, former Chairman of the UK Disability Rights Commission (precursor to the Equality & Human Rights Commission) is that:

> The positive developments of the last decade have undoubtedly helped to create a more open road for disabled people to be and do the things they want to in life. But at the same time the public services, resources and support many require to take up these new opportunities have either not materialised, remain at odds with these goals or have gone into decline. Many disabled people have been invited to look to the stars, only to find the ground opening beneath them. (2010)

These concerns highlight the failures, which have beleaguered attempts to cultivate a sense of belonging for people with intellectual disabilities within the community within the current context of personalisation.

In order to contribute to debates over the future of adult social care, this paper draws on a study of the accounts of relevant stakeholders within the disability support landscape in the Canadian province of BC and Ireland relating to their experiences of facilitating 'belonging'. BC serves as a site where all institutional services have been closed and new debates are emerging regarding the failure of this change in supporting people to belong. It points to the importance of developing mechanisms to purposefully build sustainable support networks. Meanwhile, Ireland – a location still grappling with institutionalisation – demonstrates the extent of work needed to build strong and sustainable support arrangements to engender a sense of belonging. While each of the study sites has elements of a community connection focus, they nonetheless should not be interpreted as models of good practice. Rather, their inclusion in this research is primarily to understand the everyday geographical and socio-relational issues experienced by stakeholders in the process of promoting belonging for persons with intellectual disabilities. It is argued that it is not possible to understand the full consequences of adopting this political goal without an adequate understanding of the many and varied implications of this change, in particular in terms of its socio-spatial re-sculpting of the support landscape.

The following section examines the emergence of the political goal of belonging. It asks what it potentially means to create a sense of belonging, in terms of the issues involved in occupying a life in the community.

Tracing the goal of 'belonging'

The concept of belonging finds its roots in deeper understandings of social inclusion (Bates, 2002). While ideas of belonging and social inclusion have evolved for some time, as shall be explored, one of the most common articulations of social inclusion has been to serve largely as a goal to tackle marginalisation and disadvantage, poverty, unemployment and threats to community safety, along with poor access to healthcare and decent housing, as classified under the UK Social Exclusion Unit (1998). This has generally involved a focus on ameliorating poverty through getting people back to work, getting off welfare dependency, and removing barriers to participation. This conception of inclusion has been criticised for being quite narrowly conceived, namely as focusing on employment and independent living (Christie & Mensah-Coker, 1999). Sibley (1995) criticises the 'singular concern' with economic (non) engagement as the marker for inclusion/exclusion, arguing that it masks a far greater complexity of inclusionary and exclusionary situations and experiences.

In terms of policies tackling social exclusion for persons with disabilities, the initial focus was to move people who were deliberately segregated in institutions back into the 'community' (see Mansell, 1993) with a subsequent move away from sheltered employment to open employment, thus demonstrating a similar emphasis on economic (re) engagement as the marker for inclusion (Department of Health, 2001). The scope of this policy initially involved a shift from institutions towards residential group homes situated within the community, as examined by geographers such as Laws and Radford (1998) and Philo and Metzel (2005).

In seeking to promote community living, Nirje (1972) in Wolfensberger's (1972) now classic text on the principle of normalisation, first articulated the principles of creating conditions through which a disabled person experiences the normal respect to which any human being is entitled. Since then, O'Brien and Lyle (1987) conceptualised five accomplishments of normalisation that should be aimed for and ideally met by community-based services: community presence, choice, competence, respect and community participation. In this classification, they clearly distinguish between community presence and community participation, the latter being framed as relationships between people with and without disabilities. It was this key conceptualisation that further prompted ideas about belonging and relationships. Since this time, a number of key texts (Bradley, 1994; Clement & Bigby, 2010; Etmanski, 2000), together with the extensive literature on normalisation, have advanced understandings about creating individual supports to provide necessary accommodations and has formed the basis of current thinking. For the purposes of this study then, belonging is defined as *meaningful* engagement and reciprocal relationships within local neighbourhoods or networks between people with and without disabilities.

As stated at the outset, this thinking has now filtered into the lexicon of official law and policy, which has begun to emphasise these deeper understandings of the concept of social inclusion (CLBC, 2009; HSE 2012). At the heart of this approach is the extent of 'true' belonging within the community – rather than solely the relocation into the local neighbourhood. This goal speaks to the essence of sustaining relationships and the reciprocity inherent in a valued connection rather than solely being included in various aspects of community life (CLBC, 2009). Belonging thus does not solely involve being placed within an environment, but *fitting in* within a specified place or environment. Significantly, geographers