

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

PART I

Towards Active Citizenship for Persons with Disabilities

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

1

Introduction

PURPOSE OF THE BOOK – OUTLINING THE CORE QUESTIONS

Since the origins of welfare, there has been a continual debate over the way in which it has developed, with views of how it ought to be organised and what role, if any, the state should play in its provision. Within this debate there has been a more specific question over the role and actions of the state in relation to the lives of persons with disabilities, particularly given the long and close involvement by the state in their ‘care’. This involvement has been subject to much attention in recent times over how best people with disabilities are supported to ensure they remain active in society. Welfare and services have been criticised for being paternalistic and no longer encouraging ‘independence, social integration and participation in the life of the community’.¹ Accordingly, the general principles of welfare have been called into question by policy makers and disabled people alike regarding how much it promotes and facilitates individual self-determination and participation in society. In considering this agenda, it is important to ask whether or not persons with disabilities should be treated any different from other groups who have traditionally been ‘cared for’ by the state in the past. These central questions guide the core focus of this book – in particular to re-examine the way in which persons with disabilities have been supported by the state at the domestic level, and how this support has been reconfigured and reframed in accordance with a new generation of values and obligations centred on human dignity and independent living.

These guiding questions are ever more relevant today, given the significant economic downturn affecting many countries around the world. At the same time, the values and expectations that people hold are also changing. Many individuals with support needs are now better educated and no longer want a life of passive and enduring dependency. There is a stronger appreciation of the individual and of

¹ As articulated by Article 15 European Social Charter, Council of Europe, 1961.

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

one's right to shape one's own life. There is also a growing unease at the extent of social disparities, which is compounded by an increased exposure to other countries' standards and practices and greater access to information.²

With regard to whether the state has a role in welfare, it is important to revisit the original goals of the concept and purpose of the social institutions of the state. Prior to the beginning of the twentieth century, the overriding philosophy was that economic growth could solve most problems. However, with mass unemployment, gross inequality and widespread deprivation affecting many countries in the Western world, it became clear that growth could also produce costs.³ Affluence and economic change, it was found, also produced 'diswelfares' and deprivation as well as wealth. For example, higher rates of economic growth often resulted in increased inequality, depending on things such as tax rates and the nature of economic growth.⁴ If a society leaves 'the costs where they lie', according to Miller (1987), the least well off often bear the burden for the beneficiaries of growth.⁵ When this is left unchecked, as had previously been the case, there are often further associated problems such as a breakdown in social cohesion, emigration and more widespread poor health. The potential alienation caused can also contribute to a loss of political support amongst those who are affected.⁶ The wellsprings of the concept of welfare originated as a response to these costs. The goal of social institutions was to help achieve full employment, a share in growing prosperity and the satisfaction of certain basic needs to live and participate in society.

As originally conceived, welfare aimed to give people the opportunity to be active citizens – not to enforce dependency. This was the pivot of Beveridge's social welfare programme, as envisaged in his 1942 and 1944 reports.⁷ The welfare institutions he proposed were aimed at increasing the competitiveness of British industry in the post-war period, not only by shifting labour costs like health care and pensions out of corporate ledgers and onto the public account, but also by producing healthier, wealthier and more motivated and productive workers who would also serve as a market themselves for British goods.

Similarly, in Canada, the Canada Assistance Plan in 1966 had two primary objectives according to the 1968 Annual Report of the CAP.⁸ These were to 'support the

² National Economic and Social Council (2005) *Developmental Welfare State*. NESC, Dublin.

³ Mishan, E. J. (1993) *The Costs of Economic Growth*. 2nd Edition. Oxford University Press, Oxford.

⁴ *Ibid.*

⁵ Miller, S. M. (1987) 'Introduction', in Abel-Smith, B. and Titmuss, K. (eds.) *The Philosophy of Welfare: Selected Writings of Richard M. Titmuss*. Allen & Unwin, London. pp. 1–18.

⁶ Clarke, J., Cochrane, A. and Smart, C. (1987) *Ideologies of Welfare: From Dreams to Disillusion*. Hutchinson, London.

⁷ Beveridge, W. (1942) *Social Insurance and Allied Services* (the Beveridge Report); Beveridge, W. (1944) *Full Employment in a Free Society*.

⁸ Canada Assistance Plan Division in the Welfare Assistance and Services Branch (1968) *Annual Report of the Canada Assistance Plan*, Year Ended 31 March.

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

Introduction

5

provision of adequate assistance to persons in need and to encourage the development and extension of welfare services designed to help prevent and remove the causes of poverty and dependence on public assistance'. One of the key factors that supported the development of more effective assistance and welfare service programmes was the growing concern that was being expressed about problems of poverty. It was increasingly recognised that the talents of many Canadians were being wasted because of poverty, illness, inadequate education and training and inequality in opportunities for work.

Meanwhile, in the United States, the 'Great Society' social reforms of the 1960s introduced for the first time general welfare payments, health care through Medicaid, food stamps, special payments for pregnant women and young mothers and federal and state housing benefits. This sought to limit what were seen as dangers in modern American life, including poverty, unemployment and the burdens of widows and fatherless children. With the Welfare Reform Act of 1996, the original emphasis of welfare was revisited and refashioned as 'a finite program built to provide short-term cash assistance and steer people quickly into jobs'.⁹

As originally conceived, there were two interlinked pillars of welfare: *state entitlements* and *social services*. While various mechanisms of state entitlement exist – such as a universal benefit, a means-tested benefit or a tax credit – they are based on a very similar principle that sees welfare as an important agent guaranteeing a minimal level of well-being and social support in order to build a floor under people, on which they can build by their own efforts. Over time, state entitlement increasingly has been given on the basis of contract: that people have to make contributions, that there would be known benefits, that welfare would be much more transparent, and that the cost would be much more clearly designated. The purpose of a non-contributory safety net is to help those who, at various stages in their life, for one reason or another, cannot participate in the contributory mechanisms available.

Alongside this, social services have played an integral part in enabling people to live healthily and to continue to engage in and contribute to society. 'Services' are taken to mean the constellation of actors and organisations necessarily and currently involved in providing supports that are key to social protection, from salaried public employees, to not-for-profit organisations, through to self-employed family doctors.¹⁰ In other words, they offer people the support to move away from a sole reliance on welfare entitlement. In addition to state entitlements, then, access to services – in health, housing, employment, social inclusion and other areas – is also integral to enjoying social protection and becoming active citizens.

⁹ Goldstein, A. (2008) 'Welfare Rolls See First Climb in Years', *The Washington Post*, 17 December, www.washingtonpost.com/wp-dyn/content/article/2008/12/16/AR2008121602978.html (accessed 4 September 2011).

¹⁰ National Economic and Social Council (2005) *Developmental Welfare State*. NESCC, Dublin.

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

Formerly, advances in social protection were largely thought of as a societal dividend which democratic political processes extracted *after* the event from successful economic performance.¹¹ However, when working together, state entitlements and social services can help to minimise effects of turbulent economic times and to ensure that social disadvantage does not become lasting social exclusion. These joint social institutions can help people adapt to pervasive changes and barriers to societal cohesion over time.

This original purpose of welfare and services arguably got lost in the intervening decades – particularly for people with disabilities, whose non-contribution was assumed in the first place, and services continued to seek to remove them from society. This historic peculiarity was later reflective of the broader ‘welfare crisis’ in the 1970s in the United Kingdom and in the 1980s in the United States, which sought a reappraisal of the Fabian vision of welfare – particularly its statist, paternalistic form of intervention. It was found that the way in which welfare had developed tended to encourage and enforce dependency rather than promote social and economic re-engagement in society. In particular, welfare became tainted with earlier institutional forms of care which had evolved since the earlier century. People with disabilities were simply being institutionalised and not given the tools or support to help them engage in employment or exercise their freedom. The systems which had been set up to support them in the end had not helped them to be active citizens, nor supported the development of stronger communities. As a result of this legacy, many services today have become standardised, inflexible and unaccountable to those they serve. Too many people are locked into poverty, dependency, social isolation or destructive patterns of behaviour to which the system seems unable to respond.¹² Indeed, many existing services were created to ‘look after the helpless’ and never sought to promote independence.¹³ The legacies of institutionalisation have meant that many services no longer serve the public interest or the interest of people with disabilities. In the past, the ‘public interest’ served by state funding of such services either was left unsaid or it was simply assumed that passive maintenance was sufficient. Consequently, today, significant erosion has taken place in the legitimacy of traditional sources of such support.

Looking back, one of the key reasons the original welfare effort failed, particularly for people with disabilities, was the uncoupling of state entitlements from social services, which were themselves not supportive of active citizenship. In other words, state entitlements and social services no longer worked in tandem to assist people to become more engaged in society; they had become solely focussed on forcing

¹¹ *Ibid.*¹² See Duffy, S. (2003) *Keys to Citizenship: A Guide to Getting Good Support for People with Learning Disabilities*. Paradigm, Birkenshead.¹³ McConkey, R. (2004) ‘The Staffing of Services for People with Intellectual Disabilities’, in Walsh, P. N. and Gash, H. (eds.) *Lives and Times: Practice, Policy and People with Disabilities*. Rathdown Press, Bray. pp. 30–43.

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

Introduction

7

people into separate and non-active lives. For persons with disabilities, this meant that services which were set up to assist them became in themselves barriers to participation. According to the National Economic and Social Council (2005),

If the social policies adopted are not supportive of continued economic strength, the eventual result will be a return to poor social protection. Part of the challenge to social policy, therefore, is that it facilitate as many people as possible playing a role in the economy and that it provide tangible results – in the form of parallel improvements in the quality of life for everyone – that good economic performance is leveraging the creation of a more just and attractive society.¹⁴

Rather than meaningful participation being narrowly conceived as solely engaging in open competitive employment however, the active citizenship concept refers to a broader engagement in a range of valued forms of participation, either through supported employment, volunteering, peer support and mentoring, undergoing training, partaking in local activities in the community – or indeed the securing of open competitive employment.¹⁵ In response to this challenge, the wellsprings of reform have come from the recognition that the way in which ‘welfare’ and social support developed had ignored the original foundations of welfare; it had failed to give people the opportunity to decide the supports they need to meaningfully engage in society. Instead, the ways in which social structures had been established had caused further dislocation.

Given that people with disabilities form a core part of society which to varying extents may require supports to enable freedom, the question needs to be asked: Should persons with disabilities be treated any different from other people? While the debate over new forms of supporting people has relevance for all, the treatment of people with disabilities has its own peculiarities, as touched on earlier. Consistently, throughout the history of welfare, people with disabilities were not given an opportunity to engage or participate in society – and were generally met with pity or revulsion.¹⁶ As a result, people’s ‘impairments’ were medicalised, and the state felt that people with disabilities were best institutionalised, thereby removing any potential for them to socially or economically participate in society.

The advent of community care in the 1970s and 1980s envisaged a new era of participation and inclusion in the community. Significant amounts of money were given to social services to operate community residential centres. However, the

¹⁴ National Economic and Social Council (2005) *Developmental Welfare State*. NESC, Dublin. p. 1. Please also see pp. xii and 7–11 for a more critical interrogation of how economic and social developments are neither intrinsically opposed nor compelled to occur together in some automatic way. Rather, they *can be made to support each other*.

¹⁵ Gilbert, T., Cochrane, A., and Greenwell, S. (2005) Citizenship: locating people with learning disabilities *Int J Soc Welfare*, 14: 287–296.

¹⁶ Schweik, S. (2009) *The Ugly Laws: Disability in Public (The History of Disability)*, New York University Press, New York.

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

original proponents of community care quickly saw that the same institutional practices, such as depersonalisation, rigidity of routine, block treatment, social distance and paternalism, continued to live on in the new community settings which were built.¹⁷ As a result, there continued to be little chance to guarantee individualised needs-tailored supports and participation and inclusion in the community. Current worldwide trends favour a personalisation of supports to meet real as opposed to assumed need, opening up choice in personal living arrangements and redesigning supports to enable an active life in the community.¹⁸

This change in the philosophy of ‘support’ in the disability field has more recently been recognised by international human rights instruments, such as the recent UN Convention on the Rights of Persons with Disabilities (CRPD),¹⁹ which is calling for a new age of supporting people with disabilities as a core human rights concern. Importantly, Article 19 of the convention deals with the right to ‘independent living and *being included in the community*.’ Among other things it asks States Parties to guarantee the right to ‘have access to a range of in-home, residential and other community supports services, including personal assistance to support living and inclusion in the community’.²⁰ This marks a shift from the earlier philosophy of rights, which previously had focussed on securing rights to services per se, without the principles of participation, inclusion and accessibility, as examined in the next chapter.

The inspiration for reform – that of social and economic re-engagement rather than continuing social protection in itself – should thus be the same for those with a disability as for all people. Therefore, while this book is focussed on social support for persons with disabilities, it nonetheless should have a broader relevance to all persons, in terms of its focus on the reconfiguration of the very idea of welfare for all.²¹ Here, the emphasis is on the idea of ‘active citizenship,’ centred on promoting a life in the community and challenging the socially constructed barriers, behaviours and attitudes which continue to deny full citizenship, and providing the supports needed to enable people to realise their citizenship. Significantly, this change means that people are able to live their own lives as they wish, confident that supports are of high quality, and have choice and control over the shape of that support.

Underpinning this reform agenda is the idea of a ‘developmental welfare state’,²² meaning a shift from a dependency-creating welfare model towards an enabling

¹⁷ European Commission Ad Hoc Expert Group (2009) *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-Based Care*. European Commission, Brussels.

¹⁸ O’Brien, P. and Sullivan, M. (Eds.) (2005) *Allies in Emancipation: Shifting from Providing Service to Being of Support*. Thomson Dunmore Press, South Melbourne Victoria. pp. 3–19.

¹⁹ United Nations (2006) Convention on the Rights of Persons with Disabilities. Hereafter, CRPD.

²⁰ Article 19, CRPD (emphasis added).

²¹ In Scotland, for example, the *Community Care and Health (Scotland) Act* (2002) stipulated that all persons assessed as having ‘community care needs’ would be eligible for a direct payment. This covered persons who are frail, receiving rehabilitation after an accident or operation, are fleeing domestic violence, are a refugee, are homeless or are recovering from drug or alcohol dependency.

²² See National Economic and Social Council (2005) *Developmental Welfare State*. NESCC, Dublin.

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

Introduction

9

welfare state. This change in thinking has culminated in many jurisdictions undergoing reform processes designed to support people to be active citizens, and to develop stronger communities of support. This has focussed on a more personalised, *person-driven* approach to meeting needs, providing greater *choice in living arrangements* and a wider range of supports and opportunities that enable people with disabilities to *live and participate in the community*. Personalisation has come to represent this approach focussed on developing a more individualised way to support delivery and the promotion of choice and control in one's own support. Its fundamental principles are contrary to the traditional service-centred response, where the service provider generally decides on a menu of options provided to groups of people with disabilities in segregated settings, with little or no room for choice or personal autonomy.²³ These core guiding principles form the centrepiece (Article 3) of the recent CRPD, which outlines that States Parties must respect a person's inherent dignity, individual autonomy and independence, including the freedom to make his/her own choices, and full and effective participation and inclusion in society.²⁴ These inform the normative framework of this book.

FOCUS AND SCOPE OF THE BOOK

While the concept of welfare therefore is at a crossroads, the next important question is *how* a state might sculpt such reform, in light of these historical differences in the way people with disabilities have been treated. Achieving such a change suggests the need for reconfiguring traditional welfare structures in such a way as to remove barriers to participation. Examining how different countries have grappled with this reform agenda is the core focus of this book. The central aim is to understand the way in which states have implemented international disability law and policy and reconfigured their systems of welfare and social services in order to facilitate the development of good integrated models of support. To achieve this, the main objectives of the study are to examine:

- the contemporary international and regional (European) disability legal and policy climate, which sets out the moral compass and guiding principles for states to follow;
- the main demand-side and supply-side aspects of reform within the support delivery systems across a comparative sample of jurisdictions including the United States (a selection of states including Wisconsin and Michigan), Canada (British Columbia and Ontario), the United Kingdom (England and Northern Ireland), Sweden and France;

²³ Genio (2009) *Disability and Mental Health in Ireland: Searching Out Good Practice*, Genio, http://www.genio.ie/files/publications/Genio_Report_2009_Disability_and_Mental_Health_in_Ireland.pdf (accessed 23 November 2010).

²⁴ CRPD.

Cambridge University Press

978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. Defranco

Excerpt

[More information](#)

- the context of service delivery within Ireland, a jurisdiction at the cusp of reform, identifying how it has begun to reform its system of support delivery, and the challenges it faces.

In order to inform change at the domestic level, this book is particularly concerned with *how* policy is delivered and implemented. The first consideration in answering this question is how social support is administered by the state. Does the state provide support directly or does it work through intermediaries? Is it operated through a state's health care system or local authority structure? If delivered through intermediaries within the 'independent sector' (non-profit and private agencies), how is the serving of the public interest ensured? More specifically, how do we ensure that the social institutions involved do not fall back into practices which continue to enforce dependency?

In most cases, states have operated a blend of directly provided benefits and services, as well as working through a complex array of intermediaries within the independent sector. To achieve reform throughout this diverse sector, states have had to reconstruct both the demand side of support, by trying to restore power to the consumer, and the supply side of support, by attempting to make the social support market more responsive.

The demand side of reform is seen as pivotal to counteract the effects of people with disabilities being historically devalued and disenfranchised. Without building capacity amongst persons with disabilities, professionals and service managers will continue to reshape their services in ways they see fit, without people themselves being able to insist on the supports they need to guide their own lives. Here, advocacy, independent planning and facilitation in managing one's own support are important mechanisms which can be used, and they are examined in this book. Also, recent welfare policy which has started to gain ground internationally (in the United States, the United Kingdom and Canada), known as 'asset-based welfare policy', where the government fosters saving and asset building, is examined. These policy mechanisms are designed to restore balance to individuals who have previously been left disempowered and solely reliant on the discretion of support providers.

Reforming the supply side is also seen as important in order to carve out new roles for support providers and to inject market forces into service arrangements. This includes an insistence on some form of competitive tendering within the service sector and an enforcement of standards by which they operate. This approach has sought to replace old systems of allocating resources to organisations, which had historically given them unchecked freedom to direct services as they wished. Traditionally, block grants were used to administer funding to the independent sector. These were lump-sum grants of money given to intermediaries to provide loosely defined services to a group of people, without close inspection or state involvement. They therefore did not allow individualised targeting of resources, and as a consequence, individuals were grouped together in depersonalised inflexible service arrangements which were unable to adequately respond to people's wishes