Empowerment and the architecture of rights based social policy

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Abstract  This article considers what the notions of empowerment, rights and citizenship imply in the way of structures and policies. It argues that a coherent model is emerging with recognizable elements. The article begins with a brief discussion of some background and theoretical questions. It then examines four elements: support for people to articulate their claims; support for people to identify, obtain and manage supports necessary to actualize their claims; providing control over resources; and governance. Examples will be drawn primarily from the UK and British Columbia, Canada to illustrate the elements. The article then looks at some of the issues related to successful implementation of a rights or empowerment based model of policy and structures for supporting people labelled as having a learning disability.

Keywords  advocacy; direct funding; empowerment; personal planning; rights

Empowerment has for a decade or more been a keyword in social work and other human services. While definitions vary, the essence of empowerment is about enhancing, securing and/or legitimating the power of oneself, another, or a collective. For people who have been labelled as having a learning disability this is indeed a profound change – and challenge – to a society and service system which have on many occasions either inadvertently or actively sought to diminish, delegitimate, oppress and control those so labelled (see Macnicol, 1989; Stainton, 1998a; Thomson, 1998). The related ideas of rights, choice, citizenship and self-determination have now become well established as a philosophy or value base said to underlie progressive policy and services for people with a learning disability (see DoH, 2001; MCFD, 2002). Exactly what this means in practice and the theoretical imperatives underlying it, however, are somewhat less clear.
This article will consider what these ideas imply in the way of structures and policy and will argue that a coherent model is emerging with recognizable elements. Examples are drawn primarily from the UK and British Columbia, Canada to illustrate the changes. The article will then look at some of the issues related to successful implementation of a rights or empowerment based model of policy and structures for supporting people labelled as having a learning disability. The article begins with a brief discussion of some background and theoretical issues.

**Empowerment, rights and self-determination**

One commonality underlying the most current changes in policy and practice is a move away from a paternalistic model, where we decided ‘what was best for these people’, assuming they were incapable of making choices, or at least ‘good’ choices. Indeed, current initiatives emphasize choice as a central feature of progressive systems. Initially the emphasis has been on eliminating barriers to participation and providing some broad legal protection to citizens with learning and other disabilities. By the 1980s we began to see explicit protection for people with learning disabilities in legal instruments. Notable is the inclusion of ‘mental disability’ within the Canadian Charter of Rights and Freedoms in 1982 which afforded equal protection against discrimination, and the Americans with Disabilities Act of 1990. Similar legislation is now in place to varying degrees in numerous jurisdictions including the UK with the Disability Discrimination Act 1995. These are significant achievements and have been effective in offering protection against everything from involuntary sterilization, denial of the right to vote, medical treatment and unfair discrimination at work to denial of educational opportunities, though effectiveness varies across jurisdictions and for populations of disabled people.

While these fundamental protections have to a lesser degree provided the positive supports necessary for the exercise of citizenship, their impact has been largely in the area of protection against discrimination. What is less clear is how policy structures and instruments needed to change to support the empowerment of individuals to exercise their rights and citizenship. In essence, the question is: ‘What is the architecture for rights or empowerment based policy?’

While it is not possible in the current article to examine the detailed theoretical underpinnings of such an approach, a few comments will help to set the stage for a more detailed examination of the specific policy elements (for a detailed examination of the theoretical issues see Stainton, 1994). Two critical assumptions when considering how we approach the question of policy and structure from an empowerment or rights’
perspective help to distinguish it from previous approaches. First, we are concerned with capacity not outcome. That is, we are concerned with how choices are made, not what choice is made. In service terms this is why self-determination or rights based approaches focus on ways of supporting choice making such as advocacy and independent planning, not on programmes such as vocational or residential services.

Second, we are interested not only in the act of deciding what a person wants to do, but also with their ability to act on that choice. Telling someone they are free to decide to go to a mainstream school but not providing the means for them to act on that choice is no choice at all. This emphasis on capacity not outcome is in my view a critical difference between a rights based approach and other approaches to policy and practice in this area.

One further issue concerns equality. The problem is sometimes called the ‘difference dilemma’, and refers to the problem that what people require to achieve an equal citizenship differs with each individual. In other words ‘equal treatment’ does equate with equal citizenship since different people require different types of treatment to achieve the same basic capacity for participation. For example, a person who cannot use her legs requires different means to achieve basic mobility than does someone who walks. Being concerned with equal capacity requires differential treatment based on differential needs to achieve the same relative capacity for participation and citizenship.

While the example above may be relatively easy to deal with, this dilemma becomes more acute as the nature and complexity of needs increase. This complexity makes it impossible to establish general universal provisions which will satisfy all individuals’ needs. The challenge then for social policy is not to find better services, but to create a structure in which individuals can articulate their demands directly and which allows the state to adjudicate and meet legitimate claims in a manner which does not in itself infringe the person’s potential participation. In essence, what is required is a structure within which an ongoing dialogue on legitimate claims can occur between the individual and the state, as the representative of the collective (Stainton, 1994).

Elements of a rights based social policy

The key elements of such a structure are, I suggest, now fairly clear, with most elements having been implemented to one degree or another in a large number of jurisdictions. They include three key elements which have been previously described (Stainton, 1994):
• support for people to articulate their claims
• support for people to identify, obtain and manage supports necessary to actualize their claims
• providing control over the resources.

A fourth element which has more recently emerged is concerned with governance: that is, issues of who controls decision making within the system, not simply on an individual level, but on a broader structural level. I will briefly consider each of the above and then return to the question of an integrated structure to support the empowerment and rights of people with a learning disability and some of the current challenges of implementation.

Support for people to articulate their claims
The logic of this element is pretty straightforward. If people are to be empowered to control their own lives then they need to be able to articulate their wants, needs and choices. For many people with a learning disability this can be problematic, either because they do not use formal communication methods, or because their voice is suppressed through laws which declare them incompetent, through services which do not listen, or through having been denied the chance to develop self-advocacy skills. The increase in advocacy is one example of how this element has begun to be more formally recognized and incorporated into policy and structures. The advocacy commitment and investment in the UK learning disability strategy Valuing People (DoH, 2001) is a good example; the Australian Advocacy Commission is another.

While governments have been increasingly recognizing and supporting advocacy, including self-advocacy, they have been less keen to recognize the rights of advocates to the tools needed to represent effectively the interests of those they advocate for. Stories of advocates being excluded or challenged by those in authority are fairly common when issues become difficult. The 1986 Disabled Person (Representation and Consultation) Act did contain provisions for personal representatives and gave them equal rights of access to information and participation as the individual. This, however, was scrapped by the government before implementation, and some 18 years later no similar provision has since been put into place.

This leads into more formal arrangements for supporting decision making. Many jurisdictions have been concerned with reforming their guardianship and related laws to provide options which do not involve an automatic loss of rights. Several Canadian jurisdictions have recognized the need for independent personal representation to be recognized in law.
Current initiatives in British Columbia call for the status of personal networks to be recognized in law (MCFD, 2002).

One of the most progressive pieces of legislation in this area is British Columbia’s Representation Agreement Act 1996 which provides a simple, inexpensive means for individuals to formally recognize one or more persons as their representatives for routine health, personal care, financial decision making and legal affairs. The real innovation in this Act is its change to the way capacity is viewed and understood. Rather than a simple common law test of capacity to determine whether one can formally express an understanding of the meaning and consequences of a given decision, the Act relies on expanding the traditional concepts around communication and the nature and quality of the relationship. Section 3 (2) notes that ‘An adult’s way of communicating with others is not grounds for deciding that he or she is incapable of understanding anything referred to in subsection (1).’ Section 8 of the Act states:

1. An adult may make a representation agreement . . . even though the adult is incapable of
   (a) making a contract; or
   (b) managing his or her health care, personal care, legal matters, financial affairs, business or assets.

2. In deciding whether an adult is incapable of making a representation agreement . . . all relevant factors must be considered, for example:
   (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
   (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
   (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
   (d) whether there is a relationship with the representative that is characterized by trust.

The three key shifts which are required are an expanded notion of communication; an emphasis on the quality of the relationship (trust) between persons, so that when people may not be able to traditionally communicate their choices, those best placed to interpret for them, i.e. those who know them best, are empowered to represent them; and recognition that incapacity is often a function of lack of support rather than inherent in the person. This is essential for individuals who cannot directly articulate their wants and needs if they are to avoid having their needs
solely determined by professionals or legal guardians who have little knowledge of who they are as individuals and whose interest in them is structurally professional rather than personal.

The difficulty of shifting this long-standing legal notion of capacity can be witnessed in the long and tortuous road of UK attempts to reform their guardianship and related laws (see Law Commission, 1995; Lord Chancellor’s Department, 1997; 1999). Begun in 1995, at the time of writing a new law is still not in place and the recent Bill (Secretary of State for Constitutional Affairs, 2003) falls far short of the type of reforms required to meet the criteria discussed above. The Attorney General of British Columbia (2004) has also tried recently to replace the Representation Agreement Act but was halted by strong community advocacy from seniors and disability groups.

While advocacy and representation are not new concepts, what is new from a public policy perspective is that the state is increasingly recognizing the structural necessity of independent support for articulating wants and needs and the importance of unpaid personally bonded and committed individuals in the lives of people with learning disabilities. Traditional ideas about competence and capacity are however proving difficult to reverse.

**Support for people to identify, obtain and manage supports necessary to actualize their claims**

Related to this is the second element: the necessity of independent support to assist people to identify, obtain and manage supports necessary to act on their choices. The increasing centrality of independent personal planning support and coordination for people with learning disabilities reflects this imperative to support people to not only identify but also actively pursue and manage their supports. The emphasis on person centered planning in *Valuing People* (DoH, 2001) is one such example. Western Australia’s local area coordination (SCRCSSP, 1998) is another example. Independent planning and support is also a central feature of current reforms in British Columbia (MCFD, 2002). While planning models and support systems such as service brokerage have been around for decades (Salisbury et al., 1987), the key issue, as with the first element, is integration into the system rather than an add-on or an approach pursued by a few progressive people or organizations.

One aspect of this that is less well understood is what is meant by ‘independent’. While most would agree to the benefit of person centered planning and ongoing support, a key structural element is often ignored, namely, the location of the planning agent. Too often the planning support is also responsible for the funding or service delivery, placing them in a conflict of interest position and resulting often in either a service led
approach (Stainton, 1998b) or a lack of well funded, ongoing planning supports being available to individuals and families. A key feature of the proposed approach to the British Columbia model is a strict separation between the personal planning element and the service and funding responsibilities, along with an ongoing right of access to planning support for individuals and families (MCFD, 2002). The value of independent planning support has been confirmed in several studies of UK direct payments projects where independent support provided by disabled people themselves has been highly valued by consumers (Stainton and Boyce, 2004).

Providing control over the resources
The third element of this emerging architecture is the increasingly common use of individualized funding (IF) or direct payments (DP) as a means to ensure control over resources remains with individuals rather than with services or systems (Lord and Hutchison, 2003; MCFD, 2002; SCRCSSP, 1998). The UK direct payments programme is a good example of a comprehensive model integrated into the mainstream social service system. The logic here, simply put, is that if people are receiving resources from the state as a matter of right, then they should have the right to control how the resources are used to meet the agreed needs. There is also an increasingly strong body of research evidence to support the claim that IF/DP enhances both the control individuals and families feel over their own lives and the effectiveness of the support (Dawson, 2000; Lord and Hutchison, 2003; Powers et al., 2003; Rosenau, 2002; Stainton and Boyce, 2004).

Governance
As noted above, governance is increasingly becoming part of the discussion on human service reform. Often not in so many words, but concern with who is involved in decision making about policy, funding distribution and community planning is frequently part of policy reform in the area. This is the macro level equivalent to direct funding and individual planning. The partnership boards that are part of the Valuing People initiative are one such example. On a slightly smaller but more radical scale, the increasing centrality of consumer controlled and directed organizations in the implementation of direct payments in the UK is another example (Hasler et al., 1999; Stainton and Boyce, 2004). This goes one step further than ‘partnership’, and emphasizes the point that those who are best informed about how disability related policy and services are delivered are disabled people themselves and their families. Current reforms in British Columbia called for almost the entire community living service division, with an
approximate annual budget of $604 million Cdn, to be turned over to a community based board with a legislated mandatory majority of self-advocates and family members (MCFD, 2002). Although the government has baulked at mandated self-advocate representatives, once again arguing ‘capability’, they have agreed to a majority of members with a strong personal connection to community living (British Columbia, 2004).

While the state rightfully remains responsible for ensuring taxpayer monies are spent prudently and with reasonable fiscal controls, the notion of governance recognizes that once a legitimate interest or claim is established, those most directly involved in that claim have a further right to determine how best to meet the needs inherent in that claim. As noted above, this is simply the same logic as IF/DP, but on a macro level. It remains to be seen just how far beyond ‘partnership’, which is usually a partnership on government terms, states are prepared to go.

Impediments and direction

As the above indicates, all the elements of a rights based architecture for policy are now relatively commonplace. There are, however, several factors which are inhibiting an effective rights based system from emerging:

- Lack of coordination of the elements into a coherent system.
- Lack of sufficient independence of the elements. For example, in many jurisdictions it is still the fund holders who also support planning and/or provide services, which is a clear conflict of interest.
- Piecemeal or add-on approaches which impair the overall integrity of the system.
- Many jurisdictions have introduced a single element without the others, which in many case reduces or eliminates their effectiveness as instruments to foster equal citizenship.

A good example of how the three elements, when not in concert, can impede progress is the experience of people with a learning disability and direct payments in the UK. The requirement that users must be able to consent to and manage direct payments has been a major stumbling block for people with a learning disability in trying to access direct payments (DoH, 2001; Galsby and Littlechild, 2002). While efforts are currently being made to increase their participation through better guidance to local authorities (DoH, 2004) and proposed changes to the law on capacity, as discussed above, these changes at present do not seem to go far enough to allow comprehensive access to those with a broad range of learning disabilities. The key point here is that when all three elements are present and integrated, the likelihood of true empowerment, participation and meaningful citizenship is increased exponentially. When elements are
introduced in an unsystematic or inconsistent manner, the overall effect on empowerment will be seriously compromised.

Conclusion

This article has briefly outlined the key elements of a policy approach and structure which can support the empowerment of people with a learning disability. It is not a panacea, nor is it a complete answer to the question of how best we can support the full inclusion and citizenship of people with a learning disability. This article has however outlined an architecture for support which is emerging in many jurisdictions, and which, when fully and properly implemented, will create an environment for individuals to fulfil their citizenship aspirations as equal people first.

References


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Date accepted xx/xx/xx