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# Chapter 27

## From care to citizenship?

*Jan Walmsley*

This chapter examines organisations and structures during a momentous period in learning disability history. Organisations and structures alone can be rather dry, so the chapter's theme will be the extent to which citizenship was furthered by the various frameworks in place. We are discussing a basically positive period in learning disability history. ...[I]t was a period when life improved overall for people with learning difficulties, when people had greater opportunities for an ordinary life, and social inclusion, and when citizenship emerged as a policy theme. It saw the virtual ending of large state-run long-stay hospitals as a residential option and the inclusion of children of all abilities in mainstream schools as an attainable goal. However, the chapter will also explore some considerable continuity beneath the rhetoric of policy. The authors of the 1971 White Paper said to their proposed shift from hospital to community care that 'no new policy is involved for local authority services. What is needed is faster progress to overcome the present deficiencies' (DHSS, 1971: 43). Similarly, in 2004, a review of independent living and community care concluded that whilst much of the policy framework was in place to offer independent living to disabled people, including people with learning difficulties, there were major organisational, financial and attitudinal barriers to achieving the vision for individuals (Morris, 2004). Moreover, although it was a period of intense optimism, of a belief that the disadvantages of impairment could be overcome if the right policies, services and attitudes were in place (Walmsley and Johnson, 2003), the same problems as have dogged learning disability policy and services remained, with commentators dubbing some of the aspirations articulated in *Valuing People* 'romantic'. That is, that they represent a model of individualised consumer choice which was ill-suited to the needs of many people whose impairments would always render them vulnerable without strong societal support.

[...]

### The big change: deinstitutionalisation

If it is remembered for anything in learning disability, the last 30 years of the twentieth century will be remembered as the period when most of the large hospitals closed.

Although institutional care had been widely criticised since the NCCL campaign of the early 1950s, in practice the long-stay hospitals had continued to expand in numbers, albeit gradually, until the late 1960s (DHSS, 1971: 19) giving the NHS a near monopoly in residential provision. Indeed, several major hospitals actually opened in this period. It took a long time for the institutional momentum to slow down. Although the 1971 White Paper did not visualise the closure of long-stay hospitals, in the period 1971–2001 those community care solutions advocated throughout the preceding half century became a reality on the ground.

[...] The location of learning disability in social care is not entirely secure – recent proposals are but the most recent of a series of identified threats to social services as the ‘lead agency’ for community care (Means et al., 2003).

The large NHS hospitals were replaced by a host of community-based hostels, later group homes, supported living, independent living funded through Direct Payments, supported employment, along drives to improve access to leisure, to friendships and to sexual relationships. In sum, these were associated with the type of life most people took for granted, an ‘ordinary life’ (King’s Fund, 1980). Fashions about the type of accommodation thought appropriate also changed, with smaller units increasingly preferred over large. Whereas in the 1970s large hostels were the norm, by 1988 the Wagner Review of Residential Care was of the view that ‘although new hostels are still being planned and built, it could be that the present generation of purpose-built hostels is the last. There is a growing feeling that a buildings based service is inflexible’ (Atkinson, 1988: 127). These predictions proved accurate. Hostels fell into disfavour, and the later 1980s, 1990s and early twenty-first century saw trends to smaller units – group homes for up to seven people, individual flats and even owner-occupied houses for some under shared ownership schemes. [...]

The main beneficiaries of the thrust to residential care were the residents of former hospitals. The Wagner Report (1988) noted that little progress had been made towards providing for people who had remained with their families, thus:

There is now an accumulation of adults, some middle aged, with ageing and elderly parents, whose futures are still unplanned and uncertain, and who are at risk of being admitted to a residential setting during a major family and personal crisis. (Sinclair, 1988: 131)

Not much changed in this regard. It was estimated in 2005 that 29,000 people lived at home with parents over 70 (*Viewpoint*, 2005: 18). Similarly there was in 1988 little opportunity for young people to leave home as they reached adulthood (Sinclair, 1988: 131). A lack of statistical data makes it hard to establish a clear picture, though anecdotal evidence suggests that parents in 2005 expected that provision for residential care would be made as their young people approached adulthood (Dumbleton, 2005).

Not only were people living with families not catered for, there has been an increasing acknowledgement that the specific needs of families from black and minority ethnic and cultural groups have been neglected. Following a number of key studies which researched the experiences of such groups (Shah, 1992), concerns began to be voiced regarding the double discrimination often encountered. Families’ experiences of being socially excluded by language barriers and racism, negative stereotypes and attitudes (Baxter et al., 1990; Mir et al., 2001) have emerged as important issues for policy makers, most noticeably in *Valuing People*. However, although there is at the policy level a greater awareness of the needs of people with learning difficulties from Black and

Minority Ethnic (or other minority) groups, there is little in place to ensure that steps are taken to address the issues (*Viewpoint*, 2005).

## Economic factors

[...]

In the 1970s, spending on mental handicap lagged well behind spending on health services for the general population. In 1975–76, for example, per capita funding on beds in mental handicap hospitals was £8.96 per day, compared to between £20.37 and £31.41 in acute hospitals (Ryan and Thomas, 1987: 167). Institutions were increasingly catering for more severely handicapped patients which also increased costs; at the same time the number of mildly handicapped patients who had earlier assisted in the running of the hospitals had dropped (DHSS, 1971: 19).

The 1971 White Paper set aside cash for improvements in community services, £40m for each year 1971–75, but ominously intoned ‘the main responsibility lies with local authorities themselves’, given that, as it said ‘no new policy is involved for local authority services’ (DHSS, 1971: 43–44, paras 198, 206). No money was ring-fenced for the expansion of learning disability services which meant that, as ever, they were subject to considerable local variation.

During the 1970s, hospital closures moved very slowly. Whereas in 1971 there were 58,850 people in hospitals, this figure had fallen only to 51,500 in 1980 (Wright et al., 1994). [...] One of the major barriers to closure was financial. Not only was it almost as expensive to run a half-full hospital as it was to run a fully occupied one, it did not benefit local authorities who were therefore unable to adequately fund new services. Cash savings from hospital closures accrued to Health Authorities whilst the cost fell on local authorities (Johnson, 2005). It was the 1980s which saw acceleration so that by 1990 there were 32,700 hospital beds, 37 per cent fewer than in 1980 (Wright et al., 1994). The acceleration is explained in part by financial factors. [...] Money continued to be an issue throughout the period and undoubtedly will be so for the foreseeable future. Government-funded research has shown that high quality community care is not cheaper than hospital care. Researchers found that while some types of living accommodation were cheaper than a hospital place, on average new types of accommodation were more expensive. At 1992 prices, hospital had cost an average £514 per person per week, whilst after five years, average costs for the same population in community-based housing was £598 per person per week (Cambridge et al., 1993: 72). Local authority responsibility for learning disability services has meant that there has continued to be a wide variation in the type and quality of services available, and the pace of change has been inconsistent (Fryson and Ward, 2004).

Furthermore, financial pressures on the private care sector have led to many smaller providers going out of business, to be replaced by larger firms. In 1992 there were only six private sector providers with 1000 beds or more; in 1998 there were 17 (Laing and Buisson, 1998, 1999). This has implications for service user choice.<sup>1</sup> Further individualisation of care services, under schemes like Direct Payments, are argued by governments to be cost neutral, though it is argued that ‘deconstructing a 20 bed care home offering 24/7 intensive support and dispersing that into 20 individual services will require more money, staff time and adapted housing stock’ (Churchill, 2005: 18).

## Markets, quasi-markets and care management

One major development in terms of organisation was the shift from monolithic provision of services by the NHS or Social Services to the creation of purchasers (later commissioners) and providers of services initiated by the 1990 NHS and Community Care Act. This was one of the most far-reaching and significant organisational changes of the period, affecting all health and Social Services activity. In 1971, virtually all services were directly provided by statutory agencies, funded either by taxation collected by central government in the case of health, or local taxes (successively rates, Poll Tax and Council Tax) in the case of Social Services. [...]

The 1990 Act is one of the landmark pieces of legislation behind the organisation of community care. Although it draws on the moral superiority of community care ideas (Walmsley, 1997) it was in large part motivated by the need to curb social security payments for residential care. The open-ended, nationally funded and controlled Department of Social Security budget for care was replaced by a cash-limited, locally administered budget only for those users who were individually assessed as requiring support. Purchasers purchase care on behalf of clients who have been assessed as requiring them. The services are provided by organisations which tender under a competitive process (initially Compulsory Competitive Tendering, subsequently Best Value) for the privilege. Thus a quasi-market is created. The rhetoric of choice has been extensively deployed to justify this marketisation ...

... [Choosing] done on behalf of individuals by care managers, drawn from a number of existing professional roles (such as social work and nursing) who undertake the assessment, hold the budget and negotiate the care package. Where block contracts are negotiated for a large number of places in care homes or in day services, the semblance of choice is even less convincing, given that in any specific area there are likely to be large-scale providers who dominate provision. Since the introduction of the quasi-market in the 1990s, there have been further developments which emphasize consumer sovereignty. Although hearing service users discussing the price of housing is a marked advance in terms of social inclusion and citizenship, there are indications that people living alone in their own homes can be left to cope with minimal support services, and if they do not have reliable support from family or friends can struggle with maintenance.

[...]

### 'Users'

[...] The user movement of people with learning difficulties began in the UK around the mid-1980s with the establishment of People First London Boroughs. A survey undertaken in 1989 found a considerable number of groups, some 'independent', that is, supported by advisors who were outside services, but many were part of the service system in ATCs and residential care (Crawley, 1989). The user movement in learning disability has been associated with the broader Disability Rights Movement which began in the 1970s, with the

struggle for self-determination and an end to ‘dependency born of powerlessness, poverty, degradation, and institutionalisation’ (Charlton, 1998: 3). Disabled people led a campaign for disability rights legislation arguing, via the social model, that it is society, and not a person’s impairment, that is disabling (Finkelstein, 1980; Oliver, 1983). The vocabulary of services, and of people’s expectations, became more rights based. The right to Direct Payments won in legislation in 1996 can be attributed to effective campaigns by disabled people and their organisations, something from which a few people with learning disabilities benefited.

Self-advocacy organisations have to a limited extent followed the lead of disabled people’s organisations in demanding and expecting rights for people with learning disabilities, and for them to be at the centre of the decision-making process, as illustrated by slogans such as ‘We are the Experts’ and ‘Nothing About us Without Us’ (Chapman, 2005). [...]

The role of users has been enhanced by Government interest in supporting a consumer voice in the development of policy and the running of services. This accompanied the marketisation of services in the 1990s, with service users redefined as consumers or customers (Davies et al., 2005). In line with a general move to increase the ‘user’ or ‘patient’ voice in the development of services, the Government has been broadly supportive of this development. The active inclusion of people with learning difficulties in the development and implementation of *Valuing People* is the most obvious manifestation of the recognition of the user movement, and Government’s positive stance towards it.

There has been criticism of the incorporation of the self-advocacy movement into the organisations and structures of community care. The requirement of *Valuing People* for representation on Partnership Boards (DOH, 2001) has intensified the workload for organisations representing people with learning difficulties, without any obvious practical benefit to the majority (Fryson and Ward, 2004). Issues or representation remain fraught with difficulty, particularly as only the most able and vocal of service users are able to participate meaningfully, and their ability to effectively speak for others, often more severely disabled, has yet to be proven (Concannon, 2004). Furthermore, ‘carers’ and ‘users’ do not often speak with one voice. Indeed, there appears to be an inherent tension between the interests of family members in protecting their sons and daughters (care), often through the maintenance of paternalist service models (such as full-time placement at Day Centres), and the demands of the more radical end of the user movement for independent living (citizenship). Several studies indicate that parents are weary of consultation and fear that change actually means less resource (Tilley, 2001; Concannon, 2004). ... User organisations rarely express such concerns as clearly, though there are indications that the value people accord to their current services is greater than the rhetoric implies (Rolph and Walmsley, 2006), with the role they play in sustaining friendship networks being particularly important (Walmsley, 1995; Rolph et al., 2005).

[...]

## From *Better Services* to *Valuing People*

This period, 1971 to 2001, is framed for England by the publication of the two White Papers. ... As we have noted, it was a period when ‘community care’ finally triumphed as a policy option, both in rhetoric and in reality, and during which public perceptions of learning disability were at their most optimistic for well over a century. The aspirations of

people with learning disabilities to be taken seriously, to be active citizens participating in society and to have a voice both reached the surface and were to some extent fulfilled during this period. Whereas in 1971, the fight was to close hospitals and replace them with hostels and Training Centres (for adults) with a strong 'care' message, and the views of people with learning disabilities were assumed, by 2001, those views were actively canvassed in the preparation of, and follow-up to, *Valuing People*. It is, in short, a quite remarkable story of change.

The background to the White Papers differs. Whereas *Better Services* was in part prompted by revelations of appalling neglect and abuse in long-stay hospitals, which had brought services for people with learning disabilities into the media eye, and put pressure on the Government, by the end of the twentieth century, learning disability was more of a policy backwater. There are indications, however, that this was a success for a group of academics and professionals who had been looking for mechanisms to hasten reform, and who finally found a responsive minister. Civil servants had been making the case for a new strategy in a relatively low key manner. [...] The other important point to note is that it was originally only a strategy, and not a White Paper. As such, it was fairly low profile, low risk. It was only when it became clear that the work had substantial support from the learning disability field, and would be seen as a positive news story, that there began to be political support for its being a White Paper.<sup>2</sup>

...[T]he development and writing of the *Valuing People* strategy was the first attempt by Government to include the voices of carers and individuals with learning difficulties. A Task Group was set up of people with learning difficulties who travelled the country visiting self-advocacy groups and collecting evidence of the quality and often, disparity, of local services. Following on from the launch of the strategy, a National Forum of people with learning difficulties was set up with four representatives elected to the Task Force, the body set up to oversee the implementation of the strategy. This put the voice of people with learning difficulties into the centre of the government process. The force behind *Valuing People* was therefore the active engagement with carers and people receiving services in the development of national policy and the encouragement at the same time of an inter-departmental approach to moving services for people with learning disabilities onto a more mainstream basis. The strategy represented a change in attitude to 'person-centredness', and a more participative approach to policymaking.

[...]

As far as the themes of this book are concerned, *Valuing People* came out championing 'Rights, Independence, Choice, and Inclusion' (DOH, 2001: 3). ... While both White Papers commit to greater spending, their objectives bear close scrutiny. The first and second objectives of *Better Services* (to explain why services needed to be extended and improved and to invite greater sympathy and tolerance on the part of the general public for the 'mentally handicapped') were closely linked to a 'care' theme. The aims of *Valuing People* are not set out as clearly. Rather we are presented with 'A New Vision' and some aspirations which might loosely be called aims. Under the overall heading of 'Better Life Chances for People with Learning Disabilities', we find

- more choice and control for people with learning disabilities,
- supporting carers,
- improving health,
- housing, fulfilling lives and employment and
- quality services. (DOH, 2001: 4–8)

This quite marked difference in approach carries through into the body of the White Papers. *Better Services* is a lengthy document which attempts to set out the situation regarding services in some considerable detail. Whilst one might take issue with the medical framing of some of the data, and the prescription of types of service – no acknowledgment of ethnic diversity, no aspirations for supported living or employment – it is undeniable that setting out an evidence base of whom we are talking about, and what their needs may be, is reassuring. In effect, *Better Services* set out some concrete objectives for local authorities, namely 43,500 more places in ATCs than were in use in 1971; 24,100 residential places for adults; and 2800 for children (DHSS, 1971). We know that these targets were not met in the timescale set (see above). They did, however, set up a major expansion in provision of Day Centre and community-based residential placements.

*Valuing People* had a more challenging job if it was attempting to map provision, for, whilst in 1971 there were few providers which were not either NHS or local authority, by 2001 services were provided by a bewildering array of organisations – private, voluntary and statutory, not to mention hybrids such as Direct Payments, or family carers. Its authors made little attempt to chart this complex picture. Whilst it is stronger on values than its predecessor, *Valuing People* is surprisingly devoid of statistics (DOH, 2001: 15, figure 1). ... However whereas in 1971 there were clear and measurable targets for what was then regarded as improvement, in 2001 any target was vaguely worded, and by any standards hard to measure. Probably the most concrete performance indicator in the White Paper is the aspiration to empty NHS long-stay hospitals by April 2004. This was achieved, though not by the target date. Moreover although commendable, this has not necessarily led to community inclusion or participation for all those who might once have found themselves in hospitals. It also does not address those long-established institutions run by non-NHS bodies which continue to flourish to this day. This means that for some, citizenship is an abstract and distant goal – care and control remain the philosophy.

## Conclusion

This chapter has been an overview of the organisations and structures, primarily in England and Wales, which supported community care for people with learning difficulties between 1971 and 2001. It has, of course, told an over-simplified story. As other social policy analysts have pointed out, the pace of change has been such that it is hard to write a coherent account of policy changes (Means et al., 2003). [...] Rather we are more hesitant about the idea of ‘progress’, acknowledging that while some ‘improvements’ have been made, in other respects the picture is more mixed. For many, particularly those with more severe impairments or with ‘challenging behaviour’, there was less change.

## Notes

- 1 Personal communication with the editors.
- 2 Ibid

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