

# Changing Services II: From Colony to Community – People with Developmental Intellectual Disability

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## Introduction

The fifty years since 1960 cover one of the major periods of change in services for people with intellectual disability as the service model based on colonies, with isolation and ‘protection’, was dismantled and a new model of care in the community enforced. This required a massive change in public attitudes, policy, funding, professional roles and training and in medical and social infrastructure. These various facets have not operated in synchrony, so it has been a prolonged journey through some turbulent waters which has not yet reached the tranquil lake. This chapter briefly discusses some of these issues but concentrates on the policies of England and Wales. The terminology has changed over time from mental deficiency to mental handicap, learning difficulties, learning disabilities and the current intellectual disabilities or disorders of intellectual development. The terminology at the time discussed is used in this chapter, even though the terms used then are seen today as objectionable. The reason for using the terms used at the time is that they referred to varying concepts and subgroups.

## Where Did We Start From?

From 1913 to 1959, the model of care was dominated by the 1913 Mental Deficiency Act, derived from the 1908 Royal Commission on the Care and Control of the Feeble Minded.<sup>1</sup> It concentrated on the need to identify ‘mentally defective’ persons who were not adequately supervised in the community and maintain them in ‘colonies’ operated by local authorities. The purposes of the colonies were later stated in their nurses’ manual to be:

1. A training school for mentally defective children or adults for whom suitable training outside is not available.
2. A shelter for those who are homeless, neglected or otherwise in need of a home and protection.
3. A hospital for those who are of low grade or physically helpless or epileptic and who require nursing care which cannot be provided in their own homes.
4. A place of control for those who are mischievous, destructive or harmful or who are a danger to themselves or to others if left in the community.<sup>2</sup>

With the formation of the NHS, the colonies were removed from the local authorities and transferred to the NHS in 1948 as hospitals. This immediately reinforced the assumption

that 'mental deficiency' was a mental health condition and not a social concept. In addition, having the entire health budget for the country in one pot made governments reluctant to face the increasing cost of need while also facilitating the diversion of longer-term care monies to bail out the more prominent and bankrupt acute hospitals.

The 1957 Royal Commission on Mental Health Law recommended community care and a change in the law. The resulting 1959 Mental Health Act changed the legal concept of social defectiveness contained in 'mental defective' to that of 'mental subnormality', excluding many who were previously included. It also changed the assumption of compulsory admission to that of voluntary admission. The change of law changed the clinical concept. At the start of the 1960s, many of the more able patients became voluntary patients who immediately left hospital and lost contact with their services as they created their own lives in the community.

In 1960, most people with 'mental subnormality' lived in the community but almost all state-provided care for them came via special schools or 'subnormality' long-stay hospitals. These 'hospitals' commonly held 200–400 residents each, but there were 5 reaching more than 2,000. In these, men, women and children were still segregated as in the old Victorian workhouses. Most wards housed 50–60 patients with 2 staff to care for them. Staff would be sacked for mistreatment but keeping order relied on institutional intimidation. Everything had to happen in groups – patients queued for baths or shaving (razor blades changed only after a set number of people had been shaved); there was no personal clothing; and work was mundane. Abuse was widespread. Families were not allowed to visit the wards but were assured their loved ones were well cared for.

## 1960–1980: The Need to Act and First Steps

By 1960, the pressure to change was international and reforms started that still dominate the system. John F. Kennedy's family experiences enabled key legislation in the United States such as the 1963 Maternal and Child Health and Mental Retardation Planning Amendments.

The principles of 'normalisation' were being developed in Scandinavia with Bengt Nirje of the Swedish Association for Retarded Children at the forefront. In 1971, the United Nations' Declaration on the Rights of Mentally Retarded Persons stated such people should have the same rights as others *as far as feasibly possible*, should have economic security and should live in the community with their families.

In the UK, the 1960s saw campaigns for better services for people in the community taking hold. Local authorities started to create large institutional day centres (often called training centres) as well as respite hostels. Activities were structured like a continuation of school, but many centres emulated the new industrial therapy ideas of mental health with the more able attendees spending much of their week on simple assembly lines. The hospitals had lost a lot of the people who operated their farms, cleaned their wards and cared for the less able but were refilled from the long waiting lists of families desperate for care. The inpatient population became more demanding at a time when there were still usually only two staff per sixty residents. They were also universally overcrowded, often holding 20 per cent more patients than designed for. Scandals started to proliferate.

On 20 August 1967, the *News of the World* published allegations of abuse at Ely Hospital in Wales. Farleigh Hospital near Bristol was visited by the police in December 1968. Each triggered a formal inquiry that fed the newspapers sensational news of abuse. These scandals

continued through the 1970s with inquiries at Coldharbour by Sherbourne in 1973; South Ockenden in Essex in 1974; Brockhall in Lancashire in 1975; St Ebba's in Epsom in 1976; Mary Dendy in Lancashire in 1977; and the Normansfield in 1978. In addition, the media published various investigations inspired by the scandals. On 29 May 1972, the prime-time television programme *24 Hours* showed a devastating 20-minute programme on the state of Stoke Park Hospital, showing staff struggling against all odds. The senior staff described parts of the hospital as a slum, comments that echoed around the country. The message was clear and reinforced over ten years: relatives were no longer to trust the old institutions or the reassurances that their loved ones were well cared for. Things had to change.

In England, four new policies emerged:

- The Local Authority Social Services Act of 1970 brought together many of the social care services under the responsibility of local authorities to enable more coordinated care.
- The Education Act of 1971, which in accordance with the UN declaration explicitly included all children as the responsibility of the local authorities' education boards and no longer excluded 'subnormal' children who were in hospital training centres.
- The 1974 reorganisation of the NHS into district health authorities ended the local management separation of the mental handicap hospitals from the acute general hospitals. Local budgets were dominated by the needs of the acute hospitals, but this enabled closer co-ordination with general hospitals and with the coterminous local authorities.
- These structural changes underpinned implementation of the 1971 White Paper *Better Services for the Mentally Handicapped* which set out the new direction for all services. It included the principles of non-segregation, access to 'stimulation, social training and education and purposeful occupation' and wanted residences to be as homely as possible.

The White Paper recommended a large increase in the residential care provided in the community and training centres, alongside halving the hospital beds. It promulgated new 24-bed hospitals scattered around the community with new local authority homes of a similar size. No new hospital should exceed 100 beds and no old large site should be added to (except with temporary buildings to relieve current overcrowding).

At the time, this was a radical plan to move to a lifestyle closer to the ideology of normalisation, but it was still based on using rather large low-staffed units only half the size of the usual long-stay hospital villas. In addition, the White Paper looked only at 'mental handicap' services and did not consider whether the generic services were able to provide a non-discriminatory service.

In 1975, the government created the National Development Team for the Mentally Handicapped to advise their social service planners. Several pamphlets were published, including one describing the creation of Community Mental Handicap Teams and several local services were visited when requested to advise on local service developments. It was recognised that any move from long-stay hospital to local authority residential care would involve the development of care expertise in local authority settings. There were attempts to move nursing staff, along with the smaller health service hostels/hospitals, to local authorities, but this was resisted by the unions, despite the 1979 Jay Report declaring an end to mental handicap nursing.<sup>3</sup>

The changes of the 1970s reflect the impact of scandals in hospital care which produced pressure for local authorities to develop services in the community and to close hospital

wards or at least improve them with temporary buildings. However, they occurred in a decade of financial crisis, so resources were limited. Despite this, by 1980 new financial structures for community care were developing alongside day services and some Community Mental Handicap Teams (using hospital staff). In addition, there were some hospital improvements and some reductions in hospital numbers, particularly removing children from long-stay hospitals.

## 1980–2000: In Search of a New Model As the Old Hospitals Close

In 1980, the Department of Health and Social Security (DHSS) published a review of progress since the 1971 White Paper.<sup>4</sup> It concluded that it had overestimated the need for hospital places and estimated that 3 out of 1,000 of the general population needed special mental handicap services. It noted the problems of finance and the need to explore alternative models of transitioning. The next decade saw investment for new academic departments researching models of care. As a result, the policymakers had more evidence about specific models attracting public campaigns.

The pressure from campaigning groups trying to shape policy increased. The Campaign for the Mentally Handicapped (CMH) had responded to the 1971 White Paper by publishing *Even Better Services for the Mentally Handicapped*. In 1981, it published *The Principle of Normalisation: A Foundation for Effective Services* by John O'Brien and Alan Tyne. O'Brien published his five principles in 1991 and they dominated service design in Britain for the next decade, being cited in almost all local policy and planning documents. The King's Fund also published a series of influential booklets and project papers, including *An Ordinary Life* in 1980 and *People First* in 1984. In 1984, the self-advocacy group People First was founded as the voice of people with 'learning difficulties' – and it was increasingly referred to by government when developing policy. Their campaign, summed up in the 1990s by *Nothing About Us Without Us*, became accepted by most policy organisations. In response to their campaign, the government abandoned the term mental handicap for the new term *learning disability* (LD). The general message from these campaigns was clear: the old colony 'mental defectives' were now *people with learning disabilities* (PWLDs) who were to be treated as equal members of the community and therefore would want to live in ordinary houses and integrated within the community, with useful employment. However, there were alternative voices: The National Society for Mentally Handicapped People in Residential Care (Rescare) was established in 1984 as the national voice of many League of Friends for the old hospitals. They expressed fears about their loved ones moving into the harsh community and advocated turning the hospital sites into residential campuses.

Alongside this, there was a new Education Act of 1981, inspired by the 1978 Warnock Report, with needs assessment to secure the resources to enable a child with learning difficulties to be educated in mainstream schools with additional support or in special schools. This was an advance in integration, which was set back later when school attainment tests reduced the popularity of low-performing pupils. Higher education colleges were also financially encouraged to admit students with severe learning difficulties, though cuts in the next millennium reduced this incentive as well.

The 1980s saw the active planning for closure of most of the large old long-stay hospitals. After ten years of planning, the first large hospital to close was Darent Park in 1988.<sup>5</sup> Financial pressures and bureaucratic problems delayed other closures or

forced some closures to include decanting patients to more local hospitals or large homes.<sup>6</sup> Nevertheless, by 2000 most of the large hospitals had closed or were near to closure.

In the 1980s, central government awarded a standard sum to people moving into community care homes to fund their care and community services. This was independent of need and encouraged many new small care settings, owned by ex-hospital staff, to take the more able out of hospitals. The escalating costs of the funding system changed with the 1990 NHS and Community Care Act, making it the responsibility of local authorities to assess the care and support needs of people and to fund according to need after means testing. The Act also brought in the purchaser/provider split (see also Chapter 10), ending the provision of care by local authorities and enabling a plethora of care providers to develop.

In 1992, the media reported one of the first major care scandals in a community care home. It was revealed that residents of the Long Care group in Buckinghamshire had been systematically physically, emotionally and sexually abused by some staff.<sup>7</sup> The main outcome was to remove inspection from local authorities to a new national social care inspectorate – which, after many reorganisations, has become part of the current Care Quality Commission.

## 2000–2010: Gaining Rights and Tackling Mainstream Services

In this decade, the persistent attitudes of the public and mainstream services came under the spotlight and the rights of PWLDs were consolidated. The White Paper *Valuing People* was published in 2001 (Scotland had published *The Same As You* a year earlier). Both emphasised the need for equality and inclusion in the mainstream community, including in all health services, education, work and accommodation. Person-centred care planning was mandated and advocacy promulgated. *Valuing People* highlighted the fact that most health care for PWLDs had always come from mainstream health services. Now GPs were financially encouraged to identify their patients with LD and to carry out annual health checks. Liaison LD nurses were recommended to facilitate access of PWLDs to mainstream health services. In 2004, the *Green Light Toolkit* encouraged mainstream mental health services to audit how they served PWLDs, as many had continued to see this as the only responsibility of specialist services.

In 2006–7, Mencap publicised how LD patients were neglected by mainstream services and criticised staff attitudes there. The publication of *Their Death by Indifference* forced the government to commission a systematic review of deaths of PWLDs, which confirmed the high rate of potentially avoidable premature deaths. There was also a growth in the number of care scandals in the community. Several NHS Trusts had seconded their staff to community homes rather than transferring their employment and now a series of reports showed the dangers of this producing poor surveillance and allowing institutional abuse.<sup>8</sup>

The 2000s witnessed the growth of supported living as the model for meeting the residential needs of PWLDs. In some cases, this meant care homes legally changed into being blocks of rented bedsits. People with high support needs were often placed in individual placements with dedicated 24-hour staffing. The pressure on local authority budgets escalated dramatically. Day care also followed the trend for more individual services with day care centres being replaced by individually supported activities, though financial constraints often limited the hours and range of activities provided.

There were other legal changes. The Mental Capacity Act of 2005 (changed from the Mental Incapacity Act after pressure from People First) set out a clear legal basis for deciding

care when a person does not have the capacity to decide. The Convention on the Rights of Persons with Disabilities was adopted by the United Nations in 2006 and came into force in 2008. This promulgated the rights of PWLDs to equality of opportunities in education, employment and family life. Its oversight committee advocated supported decision-making rather than substituted decision-making as occurs in the UK. The end of the decade saw the Autism Act 2009 – the only specific disability Act in England. The Equalities Act 2010 highlighted the need to make reasonable adjustments to enable equality of opportunity.

By the end of 2010, all the old long-stay hospital beds had closed, though some of the old sites had forensic beds or new ‘assessment and treatment’ units. There was a rapid increase in private hospital beds concentrated on a few sites for those PWLDs with mental health and/or behavioural problems and challenging needs. As an example, in the Bristol area the 3,400 hospital beds of 1960 had reduced to 12 NHS beds and 24 private hospital beds. In 2011, those private beds in Winterbourne View were closed following widely publicised reports of abuse. This triggered the national Transforming Care project to close most of the remaining private and NHS specialist beds for PWLDs. By 2015, there were no specialist hospital beds in the Bristol area.

## Staff Changes with Community Care

The roles of staff working with people with ‘mental deficiency’ were defined by the operational needs of the colonies. With their closure, professionals working there were forced to redefine their role to work in the community. This was most marked for psychiatry and nursing.

## Psychiatry

The colonies were supervised by the same national board that supervised the psychiatric asylums. This board required a psychiatrist to be in charge of a colony/hospital as in psychiatric asylums. However, the colonies dealt with training and supervision and did not deal with comorbid psychiatric disorders. If you needed psychiatric treatment, you went to the asylum.

When the new Royal College of Psychiatrists was created in the 1970s it considered abandoning ‘mental handicap’ as a psychiatric specialty, as the hospitals were closing. It was decided to transform the specialism into the mental health aspects of ‘mental handicap’. Publications on the special features of mental illness in ‘mental handicap’ started to appear during the 1970s,<sup>9</sup> and over the following years the psychiatry of mental handicap became a flourishing specialty within psychiatry, with its own training schemes, and a subspecialty within child psychiatry was created during the new millennium.<sup>10</sup> However, the specialty has remained defined by its treatment of people with intellectual disability rather than its more general skills in neurodevelopmental psychiatry.

## Nursing

Mental deficiency nursing first became a specialty in 1919 when the Medico-Psychological Association (MPA) developed a training course and qualification. A nursing manual was published in 1931,<sup>11</sup> known as the Green Book to distinguish from the Red Book of psychiatric nurses. The book was mainly concerned with causes of mental deficiency, basic concepts of training inpatients and ward management. Mental illnesses such as depression and dementia were not mentioned in the book and epilepsy took up less than a page.

Nurses were seen as ward managers and carers.<sup>12</sup> The consequence was the 1979 Jay Report into the future of mental handicap nursing, which recommended the specialism change with community care to one based on a certificate in social services. As the hospitals closed, this change seemed inevitable as care homes did not advertise for registered nurses and few could maintain their nursing registration when working in care homes.

However, the Community Mental Handicap Teams still needed nurses, albeit ones who were more versatile. The early teams comprised only a nurse, a social worker and a part-time psychiatrist. Other clinicians and professionals were added later as patients moved into the community. In addition, nurses with expertise in mental illness and learning disabilities were required for the new specialist mental health services and liaison services for physical medicine.

As a result, the profession was transformed. The training courses changed and many existing nurses underwent further training in mental health, epilepsy, dementia care or behaviour modification. Like psychiatry, the nursing specialism changed to be closer to that of other nurses, with additional expertise defined by the health needs of the population they treated.

## Care in the Community

The fifty years covered in this chapter saw the development of a wide range of community services and supports by different organisations. Local authorities now assess and fund care needs and provide safeguarding services rather than direct care. However, few PWLDs are in employment, despite this having been a target for fifty years.

As the LD hospitals closed, the skills of generic health services provided in the community became an issue. GPs are now expected to be able to assess PWLDs. Salaried dentists have increased in number to cater for PWLDs as they present special issues and take longer to treat. Some general hospitals now have liaison nurses to support staff working with PWLDs requiring assessment and treatment.

The early Community Mental Handicap Teams have tended to divide into two: one service providing support to GPs and the work of social workers, usually based within community primary care services; and the other dealing with 'challenging behaviour' and/or mental health aspects of care, often based within mainstream mental health services.

## Conclusion

Just as the name of their condition kept changing (we now have *disorders of intellectual development* in the eleventh edition of the *International Classification of Diseases*, or ICD-11), services for PWLDs were also radically transformed between 1960 and 2010. The service started as one based on the eugenic model of confining and training nuisance 'mental defectives' in institutions built large to reduce costs with little provision for those who lived in the community. Over fifty years, the model became one of total inclusion as equals in the community with equal opportunities in employment, accommodation and family life. Policymakers had to negotiate a massive change of policy, service provision and associated funding mechanisms to do this. The frequent scandals of care probably helped provide impetus and funding.

During this time, there was a massive development in ideological models, including self-advocacy and safeguarding, as well as research into the causes of LD and how to empower PWLDs. Now the issue is how people experience the dream in reality. The law requires equality of treatment and lack of discrimination, but it is not clear if this will eliminate negative attitudes held by others.

For the author, there have been cycles of care: I was first the psychiatrist for a 200-bed hospital but with no empty beds and with little support for community emergencies. Eventually, I had a large supportive community team and an admission unit. Then, the community team came under four different employers who relocated their staff and the inpatient service closed. Continuity of care was lost and admissions could be 100 miles away. Now PWLDs have individualised direct support but the services around them are more fragmented, as is the case for anyone living in the community.

## Key Summary Points

- In 1960, services were based on ‘hospitals’ which had been mental deficiency ‘colonies’.
- The 1970s saw the start of the recognition of a right to live in the community as equals.
- It took thirty years to close the old hospitals and develop an entirely community-based service. This needed changes to policy, funding agencies and the benefits system.
- This also involved changing the skills of previous staff and changing skills and attitudes in mainstream services.
- We now have a rights-based system, which is more fragmented and more challenging for PWLDs to negotiate.

## Notes

1. *Report of the Royal Commission on the Care and Control of the Feeble Minded*, 8 vols, Cd. 4215–4202. London: HMSO, 1908.
2. *Manual for Mental Deficiency Nurses*. London: Bailliere, Tindall and Cox, 1931, p. 2.
3. Jay Committee, *Report of the Committee of Enquiry into Mental Handicap Nursing and Care*, Cm. 7468. London: HMSO, 1979.
4. Department of Health, *Mental Handicap: Progress, Problems and Priorities*. London: Department of Health, 1980.
5. L. Wing, *Hospital Closure and the Resettlement of Residents: The Case of Darenth Park Mental Handicap Hospital*. Avebury, 1989.
6. For a description of the local closure process, see N. Bouras, *Reflections on the Challenges of Psychiatry in UK and Beyond*. Pavilion Publishing and Media, 2017.
7. J. Pring, *Longcare Survivors: The Biography of a Care Scandal*. DisabilityNews Service, 2011.
8. See, e.g., *Joint Investigation into the Provision of Services for People with Learning Disabilities at Cornwall Partnership NHS Trust*. London: Commission for Healthcare Audit and Inspection, 2006; and *Investigation into the Service for People with Learning Disabilities Provided by Sutton and Merton Primary Care Trust*. London: Commission for Healthcare Audit and Inspection, 2007.
9. The first was F. E. James and R. P. Snaith, eds, *Psychiatric Illness and Mental Handicap*. London: Gaskell, 1979.
10. N. Bouras and G. Holt, eds, *Mental Health Services for Adults with Intellectual Disability: Strategies and Solutions* (Maudsley Monograph). London: Routledge, 2010.
11. *Manual for Mental Deficiency Nurses*.
12. Another good example is C. H. Hallas, *Nursing the Mentally Subnormal* (2nd ed.). Bristol: John Wright, 1962, which does cover mental illness over 8 of its 200 pages, as many as is devoted to ‘discipline and special privileges’.