

DEVELOPMENT OF HEALTH SERVICE POLICY FOR PEOPLE WITH LEARNING DISABILITY IN THE UNITED KINGDOM

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ABSTRACT

The evolution of health services for people with learning disability in the UK is reviewed in the context of health policy, with an emphasis on developments since the formation of the National Health Service in 1948.

Key words: *Clinical Governance; Community Care; Learning Disability; Mental Handicap; Mental Retardation; National Health Service; Services*

BRIEF HISTORY

In pre-industrial Britain, people with severe learning disability (severe mental retardation) were looked after by their families, although institutions began to appear from the late 13th century. Those with milder degrees of retardation usually found some suitable work in what was largely an agricultural economy heavily dependent on manual labour. However, following the industrial revolution in the 18th century, there was a large shift of populations into the developing towns and cities. The complexities of urban industrial life soon exposed vulnerable groups of people, particularly the mentally ill and those with learning disabilities. These people were suddenly 'visible' and became a political embarrassment as they gravitated to prisons and workhouses.

Initially, legislation and care provision did not distinguish between the mentally ill and learning disabled. However, by the late 19th century, the onset of compulsory education identified people who could not cope with mainstream educational services (Elementary Education [Defective and Epileptic Children] Act, 1899) and institutions for the training and education of 'defectives' began to appear.

The initial aim of these special services was to return people to the community after a period of training but, by the early part of the 20th century, fears about the high birth rate amongst the 'feeble-minded' and ideas, perpetrated by the eugenics movement, about their high birth rates diluting the quality of the gene pool in the general population, prompted a trend towards longer term care.

The Mental Deficiency Act of 1913 differentiated between 'idiots' (severe learning disabilities), 'imbeciles' (moderate learning disabilities), 'feeble minded' (mild learning disabilities) and 'moral defectives'. Provision was made for statutory institutional care or community care under licence or guardianship for people who could not be cared for in society. Institutions

were also established for 'defectives' with violent propensities. Local Mental Deficiency Committees, run by local government, acted as gatekeepers, providers, and inspectors of institutions. Local Authorities were also responsible for training and daytime occupation.

THE ROLE OF THE NATIONAL HEALTH SERVICE IN LEARNING DISABILITY

1948 TO 1969

Until the onset of the National Health Service (NHS) in 1948, all services for people with learning disabilities were in effect provided by local government in a variety of settings including institutions, residential colonies, and day care settings. The majority of the staff in the institutions were unqualified 'attendants', although some of the larger institutions had part-time medical staff or a medical superintendent.

When the National Health Service was formed, these institutions, housing some 50,000 inmates and varying in size from 20 beds to 2000 beds, were re-designated as 'hospitals' whilst day care services remained under the local government authorities as before.

By the 1960s, the hospital population had peaked at 64,000 patients. Recruitment of specialist staff was increasingly successful and a wide range of medical, nursing psychology, and allied professionals entered the service. Diagnosis, treatment, teaching, and research achieved greater prominence in the activities of institutions. State enrolment of specialist learning disability nurses was initiated in 1964.

The first glimmerings of a shift back towards community care came in 1965 with the publication of a government document *Improving the Effectiveness of Services for the Mentally Subnormal*, which advocated returning people to supported life in the community.¹ Schemes were also suggested whereby hospital sites would be sold to pay for community homes.

However there was little serious political will for change until the publication of two hospital inquiry reports, Ely Hospital in 1969² and Farleigh Hospital in 1971,³ and a sociological study *Put Away*,⁴ which showed a number of serious deficiencies in British learning disability hospitals.

1970 TO 1989

In 1971, the government responded with a white paper *Better Services for the Mentally Handicapped*.⁵ During a period of 20 years, there was to be a massive shift of people from institutions to community care, joint planning between health and local authorities, and involvement of the voluntary sector. Prevention and early detection and intervention were also emphasised along with a strong research base.

Following the Jay Report,⁶ which recommended doubling the number of trained community residential care staff, the Health Ministry issued a consultative document,⁷ advocating the shift of resources from hospital to community.

By the mid-1980s, community learning disability teams were being widely introduced and there was expansion in residential care staff to work in the small group homes, which were becoming the dominant format for community care provision. Large homes with 20 or more residents were, however, still common. Transfer of funding from hospitals to local authorities as patients were resettled into the community was intended to assist the process but did not always achieve the intended result. There was insufficient provision for funding the transition (when both the hospital and the community service had to run in parallel) and both were sometimes compromised as a result.

Although the majority of learning disability hospitals reduced in size during this period, the first large hospital closure, Darenth Park in Southeast London, was not achieved until 1988. The resettlement of the patients was followed up over a 10-year period.^{8,9} Those with the fewest problems left first and others transferred to smaller institutions. The quality of community placements was variable. Smaller units were more restrictive (for safety reasons) than units with large grounds. Small houses found it difficult to cope with behaviour disturbance (challenging behaviour), were not always welcomed by neighbours, and had a high staff turnover. There was little change in handicaps, skills, or behaviours but those with the fewest disabilities gained the most benefit from the opportunities afforded by community care.

As other large learning disability hospitals were closed, hospital-based services for people with learning disabilities concentrated on providing specialist services for those with mental health or severe behaviour problems, forensic patients, those with neuro-psychiatric problems, autism, and individuals requiring high levels of nursing care because of their physical problems or frailty.

For the majority of people with learning disabilities, services are now provided in small units situated on general hospital sites, often with the result that a comprehensive range of specialist services (particularly forensic services) is not possible and patients are referred to other health districts or to the private sector, which has expanded rapidly to meet

demand. Some people with learning disability have access to generic mental health services but it is often difficult to cater to their needs in such settings and they are at risk of exploitation by their more able fellow patients.

1990 TO 2000

In 1990, under the NHS and Community Care Act, Local Authorities were given 'lead responsibility' for assessing need and funding residential and non-residential social care. Health Authorities remained responsible for funding the health care component of the total care package for the individual.

The National Health Service was re-organised as an 'internal market' — Health Authorities, which previously managed NHS hospitals directly were made responsible for commissioning appropriate health care for their population from a mixed economy of provider organisations, either NHS or independent. NHS hospitals were encouraged to become autonomous Trusts taking over the 'ownership' and management of public hospitals and facilities previously managed by the Health Authorities. Trusts had to contract with health authorities for the provision of services for patients in their catchment area or, for patients outside of the catchment area, negotiate a price with the Health Authority of origin (an extra-contractual referral). Primary care underwent a similar change with practices becoming 'fund-holders' or grouping as consortia with the ability to choose where to refer their patients for secondary health care.

The element of competition was intended to improve quality and reduce costs by diverting funding to the most successful services. However, whilst these arrangements made the NHS more business-like and cost-aware, there were also limitations as the overall budget was cash-limited, market forces did not always operate quickly enough to prevent duplication, and there was a tendency towards uneven geographical distribution of specialist services. There was also a reduction in cooperation between health services, with information increasingly being regarded as 'commercially sensitive'.

The change in government in 1997 saw a further evolution (the 'new NHS'), with a shift away from the market system and an emphasis on cooperation within the NHS (and with the private sector), equal access health care irrespective of socio-economic status or place of residence and, most importantly, a desire to emphasise quality and health improvement rather than cost or activity.¹⁰ Primary care doctors were re-organised into self managing 'primary care groups' with funding allocated to purchase the majority of secondary health care (possibly including learning disability services). Health Authorities will remain responsible for more specialist secondary and tertiary care. There is also a greater emphasis on promoting healthy living and the importance of cooperation of health services with other agencies such as education, employment, housing, and social services in securing health improvement for the population as a whole and in particular for vulnerable groups such as people with learning disabilities and those on the fringes of society.¹¹

Signposts for Success was published with the specific aim of guiding both commissioners and providers in the

provision of person-centred services for people with learning disability (whether generic or specialist services) that are accessible, provide good communication and information, assistance with consent issues, continuity of care, commitment to quality improvement, and the use of evidence-based interventions.¹² A year later, a further document *Once a Day* was published with the intention of assisting primary care services in dealing with people with learning disability.¹³

The admission of compliant but non-consenting patients to hospital was challenged in 1998 in the 'Bournwood case' (L. vs Bournwood and Community NHS Trust).¹⁴ L, a patient with autism and profound learning disability, was discharged to a foster family, became disturbed and was returned to hospital. The family's request for his release was refused by the hospital on the grounds of his medical condition. The patient was not attempting to leave but was not in a position to consent to either staying or leaving.

Although the challenge ultimately failed at the House of Lords, the principle that the rights of such patients should be safeguarded was recognised and is to be incorporated into new disability legislation as well as in a proposed new Mental Health Act, currently at the consultation (green paper) stage, and due to replace the current 1983 Mental Health Act within the near future.

CLINICAL GOVERNANCE

On the clinical quality front, a major government initiative was launched in 1998, which introduced the concept of 'clinical governance'. Clinical governance is intended to build on existing activities including clinical audit, continuous quality improvement, investment in training and education, promoting the concept of 'life-long learning' among clinical staff, and the use of evidence-based practice and risk management. The identification and management of poorly performing clinicians is also part of the process as well as implementing lessons learned from mistakes or via complaints.

The intention is to make quality and the critical examination of clinical practice an integral part of all activity within the National Health Service as well as the private sector. In addition to this local clinical governance, national institutions are being established.

The National Institute for Clinical Excellence (NICE) will set standards for services, advise on clinical and cost effectiveness of existing and new treatments, and issue guidelines. It will also develop 'national service frameworks' for major disease areas, which will set out the scope and standards of care to be achieved by provider services. Currently, a *National Service Framework for Mental Health Services* has been published;¹⁵ others are awaited.

A Commission For Health Improvement (CHI) will monitor the implementation of local systems to assure and improve the quality of clinical services, largely through a programme of visits and 'spot checks' and with the power to investigate and work with local organisations on remedial action.

Provider organisations (through the Chief Executive and Board) are now responsible for putting mechanisms in place

to maintain and improve the clinical quality of services provided by their organisation as well as for ensuring that the service achieves its financial targets.

Professional self-regulation of medical staff is also under scrutiny following an unfortunate series of highly publicised medical scandals (notably poor outcomes in paediatric cardiac surgery cases at Bristol, UK, where informal knowledge was not translated into formal action) which has dented public confidence in the medical profession. The General Medical Council has already revised its performance procedures¹⁶ and is currently working with professional organisations and the Royal Colleges on future regulatory mechanisms. These will almost certainly include some form of periodic assessment and revalidation of senior doctors.

CONCLUSION

In conclusion, learning disability services in the UK are now well into the post-hospital era. Most people with learning disability are cared for in the community. There is still much work to be done to improve access to general health services and to make specialist health services more effective, responsive, and sensitive to the needs of the users. Recent government initiatives provide the tools to achieve these aims but, as always in cash limited public services, the challenge will have to be met largely by the creative use of existing resources supplemented by relatively small amounts of additional funding.

REFERENCES

1. National Health Service. Improving the effectiveness of the hospital service for the mentally subnormal. London: Her Majesty's Stationery Office; 1965. Report No.: HM(65)104.
2. Department of Health and Social Security. Report of the committee of inquiry into allegations of ill treatment and other irregularities at Ely Hospital, Cardiff. London: Her Majesty's Stationery Office; 1969. Report No.: Cmnd. 3975.
3. Department of Health and Social Security. Report of the Farleigh Hospital committee of inquiry. London: Her Majesty's Stationery Office; 1971. Report No.: Cmnd. 4557.
4. Morris P. Put away: a sociological study of institutions for the mentally retarded. London: Routledge & Kegan Paul; 1969.
5. Department of Health and Social Security. Better services for the mentally handicapped. London: Her Majesty's Stationery Office; 1971. Report No.: Cmnd. 4683.
6. Department of Health and Social Security. Report of the committee of inquiry into mental handicap nursing and care. London: Her Majesty's Stationery Office; 1979. Report No.: Cmnd. 7468 I and II.
7. Department of Health and Social Security. A consultative document on moving resources for care in England. London: Her Majesty's Stationery Office; 1981. Report No.: HC(81)9.
8. Kornan N, Glennerster H. Hospital closure. A political and economic study. Milton Keynes: Philadelphia; 1990.
9. Wing L. Hospital closure and resettlement of residents. Aldershot: Gower; 1990.
10. Department of Health. The new NHS. Modern. Dependable. London: The Stationery Office; 1997. Report No.: Cmnd. 3807.
11. Department of Health. Our healthier nation: a contract for health. London: The Stationery Office; 1998. Report No.: Cm 3852.
12. Department of Health. Signposts for success in commissioning

and providing health services for people with learning disabilities. London: Her Majesty's Stationery Office; 1998. Report No.: 98CC0157.

13. Department of Health. Once a day. London: Her Majesty's Stationery Office; 1999. Report No.: 98C114/173B.
 14. House of Lords. Judgements in Re L (By his Next Friend GE). Opinions of the lords of appeal for judgement in the cause. 25 June 1998. <http://www.parliament.the-stationary-office.co.uk/pa/ldjudgment/jd98.../inrel01.ht>
 15. Department of Health. National service framework for mental health: modern standards and service models. London; Her Majesty's Stationery Office; 1999. Report No.: L46/01 16575.
 16. General Medical Council. Maintaining good medical practice. London: Her Majesty's Stationery Office; 1998.
1. Day KA, Jankar J. Mental handicap and the Royal Medico-Psychological Association, 1841-1991. In: Berrios GE, Freeman H, eds. 150 years of British psychiatry, 1841-1991. London: Gaskell; 1991.
 2. Day KA. Prudhoe and Northgate Hospitals, a history: 1914-1999. Morpeth, Northumberland: Northgate & Prudhoe NHS Trust; 1999.
 3. Lugon M, Secker-Walker J, eds. Clinical governance: making it happen. London: Royal Society of Medicine Press; 1999.
 4. Spencer DA. Concept of learning disability In: Read SG, ed. Psychiatry of learning disability. London: WB Saunders & Co; 1997.

FURTHER READING:

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