Unit 3 - A history of learning disabilities

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Outline

This unit will:

- Briefly trace a history of learning disabilities from ancient through to recent times. This will be linked to the changing configuration of service provision for this group of people.
- Explore the range of attitudes and beliefs that societies often hold toward people with learning disabilities.
- Consider the range of factors that have underpinned the changing social position of people with learning disabilities in respective societies and will include a consideration of political, social and economic influences.
- Explore the influence of social policy documents and legislation on both the type and quality of service provision for people with learning disabilities.

Introduction

Demonstrating knowledge and understanding of the role of people with learning disabilities in history is vital to you understanding their position in contemporary society. In the past people with learning disabilities have been perceived as objects of fascination and fear, resulting in them being both worshipped and, or, vilified. This unit will explore with you some of the ways in which society has labelled people with learning disabilities, and how these labels have subsequently affected the type and quality care afforded to them. The effects of labelling are particularly important for you as providers of health care to this group. This is because it is known that stereotypical attitudes and beliefs generated about this group from history may result in the provision of poor health quality care. (Fitzsimmons and Barr, 1997)

People with learning disabilities in Ancient Greece and Early Modern Britain

Historically, those with learning disabilities have been labelled differently by respective generations depending on the attitudes and beliefs about the place of this group of people in society at any one time. Such labels have included subhuman organism, menace, unspeakable object of dread, object of pity, holy innocent, diseased organism, object of ridicule and eternal child (Wolfensberger, 1972). Early writings from Ancient Greece would suggest that people with learning disabilities were among a number of social groups considered to have a deleterious influence on developing societies and therefore needed to be eradicated as the following statement suggests:-

"...then this is the kind of medical and judicial provision for which you legislate in your state. It will provide treatment for those citizens whose physical and psychological constitution is good; as for others, it will leave the unhealthy to die, and those whose psychological constitution is incurably corrupt it will put to death."

(Plato, 427 - 347 BC in Lee, 1987)

Similarly in medieval times, the existence of people with learning disabilities in society was linked to people's beliefs about the relative influence of supernatural forces upon respective communities. In the absence of medical knowledge about the cause of disabilities, people's understanding of abnormal pathology was often based upon myth and legend, resulting in people with learning disabilities being both persecuted and fostered. Stratford (1996), for example, has made reference to the reliefs, sculptures and artefacts of the Olmec tribe who lived around the Gulf of Mexico from 1500 BC-AD 300. These depict people with Down's Syndrome as god-human hybrids resulting from sexual intercourse between senior members of the tribe and a jaguar, the sacred totem of the tribe. This led Stratford to conclude that people with Down's Syndrome were probably worshipped by the tribe and given preferential treatment. In support of this Miles (1996) has referred to a shrine in Gurjat, Pakistan where people with microcephaly lived. They were known as 'chuas' and their maintenance as a community was at one time essential as they were deemed to hold religious significance for the country. Eberly (1988) has discussed the influence of disabilities on the portrayal of mythical characters such as those found in Scottish folklore. She concluded that both fairies and hybrids (offspring resulting from sexual relations with non-humans such as supernatural forces or beasts) were more likely than not, based upon the characteristics of individuals with some form of congenital disability.

Examples of this included the *silkies* (seal people) found in the Orkney Isles who had webbed fingers and toes or the *Aberdeenshire Brownies* who had no separate fingers and thumb. Treatment of such creatures was varied. In the case of the Changeling found in Celtic folklore they were deemed to bring either luck to a community or be a bad omen. In the case of the latter, treatment of the Changeling included being placed on a red-hot shovel, pressed into red hot ashes, laid on a red-hot grid, being fed with leather or red-hot iron or being made to drink poison (Haffter, 1968).



Figure 3.1 Illustration of a silkie Reproduced by kind permission of Sigurd Towrie

Despite the beliefs about the nature of people with learning disabilities in earlier times, they were generally still supported within their own communities. State assistance for their maintenance was not to become a feature of their care until early modern Britain where De Prerogativia Regis (1325) gave legal rights to either families or elected guardians to protect the lands of both people with learning disabilities ('idiots' or 'natural fools') and people with mental health problems ('lunatics') ensuring that they remained profitable (Kirman, 1975). Distinction between those individuals with mental health problems and those with learning disabilities was based on a series of tests that included being able to tell one's age, name one's parents and be able to name the days of the week. De Prerogativia Regis could be regarded as the first attempt at state managed community care for people with learning disabilities.

During the 17th century, state care for this group was revised and control was transferred to local parishes. Under the Elizabethan Poor Act (1601) people with learning disabilities were among a number of 'unattached' groups that were deemed to be a threat to the stability of the establishment. State response to this problem was their incarceration in poor houses and these may now considered to be early examples of institutional care for this group.

Essential

Reader Activity 3.1

A range of beliefs have existed about the nature of people with learning disabilities.

- 1) List your personal attitudes and beliefs about people with learning disabilities.
- 2) List the ways in which attitudes and beliefs about people with learning disabilities are initially conceived and then possibly shaped.

Having made these lists spend some time discussing your responses.

Eugenics and the problem of the feeble-minded

The perceived threat of people with learning disabilities on the establishment continued into the 18th and 19th centuries with revised vigour. The need for skilled labour arising from the new demands created by the Industrial Revolution (from about 1760 onwards) ensured greater prominence of the deficiencies in the social and economic skills of people with learning disabilities. As Race (1995) has suggested the Industrial Revolution brought about "the measurement of people by their ability to cope with the new technological and commercial processes." People with learning disabilities were not considered to be profitable members of society due to a lack of skill and intelligence and were therefore considered to be a financial burden. The Poor Law Amendment Act 1834 responded to this situation by ensuring that such groups were segregated in workhouses. However, the subsequent threat posed by people with learning disabilities was to extend beyond their limited usefulness for communities to reflect a belief that this group was one of a number responsible for the dissemination of social ills within the population. This was to result in a new series of strategies being employed to control this group of people.

During the late 19th and early 20th centuries, it was believed that the social ills of criminality, prostitution and alcoholism were closely associated with people with mild learning disabilities (Tredgold, 1909). This group were at that time known as the 'feeble-minded'. It was believed that procreation amongst this group would ensure the spread of these social ills that would gradually erode society's physical, intellectual and moral core, resulting in its eventual collapse. This view is reflected in the following statement:-

" the danger lies in the fact that these degenerates mate with healthy members of the community and thereby constantly drag fresh blood into the vortex of disease and lower the general vigour of the nation." (Tredgold, 1909)

This fear was given all the more credence because people believed that the feeble-minded were among a number of groups deemed to reproduce at a more prolific rate than the rest of the population causing an eventual imbalance between the supply and demand of food (Malthus, 1798). In addition to this, it was the believed that the condition of feeble-mindedness was a hereditary characteristic, like eye colour, passing between generations and resistant to any endeavours that sought its 'improvement' through education and training. Patterns of transmission were often demonstrated in pedigree charts such as the one displayed below that depicts the infamous Kallikak family.

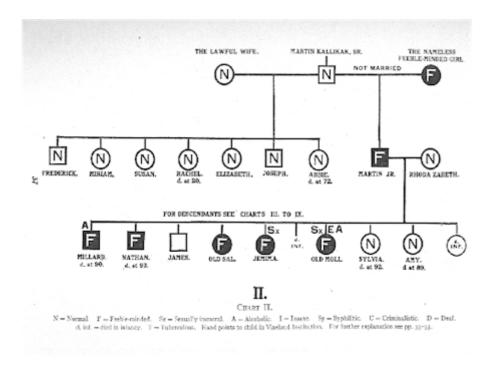


Figure 3.2 The Kallikak Family (Goddard, 1913)

State control of these individuals was again deemed necessary for the survival of society and eugenics was the chosen method of control.

The term eugenics was first coined by Francis Galton in 1883 and was defined as being;

"science of improving inborn human qualities through selective breeding"

(Galton, 1883)

Francis Galton disputed the theory of natural selection provided by his cousin Charles Darwin suggesting that nature could not be relied upon to select the most appropriate characteristics for the survival of the human race. Maintenance of society relied upon the use of artificial methods. He advocated two forms of eugenics; one was to promote procreation in the intellectual classes, a process termed *positive eugenics*, whilst the other was inhibition of procreation amongst classes that were considered to be socially deviant, a process termed *negative eugenics*. Negative eugenics was operationalised in Great Britain in the form of institutionalisation. This was the method advocated by the 1909 Royal Commission set up to investigate the 'problem' of the feeble-minded. In other countries, other methods were employed. This included mass genocide in Germany (Burleigh, 1994) and compulsory sterilisation in the Nordic countries (Tannsjo, 1998). North America at this time also opted for a selective immigration policy.

In 1913 the Mental Deficiency Act was introduced in Great Britain to legalise the detention of individuals with varying degrees of mental defect. It identified four categories of mental defect that provided the necessary diagnostic criteria for the certification of this group. These four categories have been presented in Box 3.1.

Idiots - persons so deeply affected in mind from birth or from an early age as to be unable to guard themselves against common dangers.

Imbeciles - persons who whilst not being as defective as 'idiots' were still incapable of managing their own affairs.

Feeble-minded persons – persons who whilst not being as defective as imbeciles still required care, supervision and control for their own protection or for the protection of others.

Moral defectives - persons who from an early age display some permanent mental defect coupled with vicious or criminal propensities on which punishment has had little or no effect.

Box 3.1 Diagnostic labels of the Mental Deficiency Act 1913

The First World (1914-1918) delayed the implementation of the Mental Deficiency Act, however, the findings of the Wood Committee (1929) resulted in an acceleration of policy with the recommendation that 100,000 individuals suffering from mental deficiency be immediately institutionalised.

Essential

Reader Activity 3.2

Eugenics is a flawed theory conceived of over one century ago but can you think of any contemporary medical or social interventions that are aimed at controlling the type and quality of individuals or groups present within the population?

Life in an institution

Initial attempts at institutional care for people with learning disabilities (early 19th century) included an educational philosophy of care that reflected the belief that mental defect was sensitive to modification. However, later models of institutional care became more custodial and less reforming reflecting the new belief that feeble-mindedness was resistant to change. The emphasis was now on the protection of the wider society.

"You weren't allowed out of the hospital. You had to write up and ask could you leave the grounds. You had to ask the medical or write to the doctor and ask them. You couldn't just go across the road and look at the shops, it wasn't allowed unless you wrote up and asked. I didn't go out because I got so used to not going out. You'd get lost if you're not used to it"

Mabel Cooper - Forgotten Lives (1997)

The Wood Committee (1929) had advocated the formation of self-sufficient 'colonies' that would cater for all groups of mental defect, regardless of age or level of disability. The term 'colony' was to be eventually replaced with the term 'hospital' with the implementation of the NHS Act 1946 under which control of colonies was transferred from local councils though to Regional Hospital Boards.

Lennox Castle is one example of a long stay hospital for people with learning disabilities in Scotland. Opened in 1936 it was initially called 'Lennox Castle Certified Institution for Mental Defectives' and had places for six hundred males and six hundred females. It was the largest institution in Scotland. It initially consisted of twenty dormitory locks with sixty beds in each dormitory. Facilities for male and female patients including dining rooms were segregated. There were also segregated workshops for patients that included a laundry for the females. Many hospitals at this time relied on the labour of inmates for the maintenance of the hospital (Wood Report, 1929). Orme (2002) recalls his experiences of working as a health care assistant in a 'mental handicap' hospital near Edinburgh in the early 1970s. He remembers having to care for 40 patients on one ward, with 3 staff, one bath and two showers. Patients were also expected to share clothes except on a Saturday which was visiting day. He also remembers the use of punishment to ensure conformity to the hospital regime and this was a common feature of institutional care. (Goffman, 1961)



Figure 3.3 Lennox Castle Hospital, Lennoxtown, near Glasgow Crown Copyright: RCAHMS

"Typical punishments took the form of withholding privileges such as cigarettes, or confining patients to the ward. For serious misdemeanours, individuals could be made to stay in bed all day. This was called 'pyjama punishment." (Orme, 2002)

Admission to a hospital such as Lennox Castle could be at the request of the family, or by a number of people in the form of a petition, and was sanctioned on the basis of the signatories of two doctors, one of whom was officially approved for the purpose. Diagnosis and subsequent certification was undertaken using a number of 'tests' to prove the inability of an individual to live in society. These tests included being able to differentiate between a fly and a butterfly or a stone and an egg; to state the similarities between an apple and an orange; to suggest how many feathers there were on a chicken or how many miles it was to America (National Council for Civil Liberties, 1951; Potts and Fido, 1991). It would appear that little attempt was made to assess a person's individual capabilities so it could be concluded from this that institutionalisation was an inescapable outcome for many people.

Essential

Reader Activity 3.3

Refer to the narratives and look for Alan's stories. You can see he spent many years in a long stay hospital. He moved to accommodation with support and is now in temporary accommodation with a voluntary organisation while he waits to return to his refurbished accommodation.

He recalls:

"When I was younger I saw two nurses, a male and female threatening other patients by shouting and bullying them. I reported this, yet nothing was done about it. I saw an incident where a guy couldn't get out of bed and the nurses were being very rough with him. They were threatening him saying they would hurt him if he didn't get out of bed."

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Using this case study and the recommended reading material at the end of this chapter try and formulate a picture of the lives of people with learning disabilities in long stay institutions. This may tell you something of why some people with learning disabilities are frightened of hospitals and the people who work in them.

The introduction of the concept of community care and the principles of normalisation.

During the 1950s and 1960s a number of significant events brought the appropriateness of institutional care for people with learning disabilities into question. These events began to pave the way for the eventual introduction of community care for this group and included the increasing influence of the human and civil rights movements that culminated in the European Convention on Human Rights (1950). Attention was also being paid to the damaging effects of institutionalisation on the development of the individual. In the 1960s, a number of reports into the state of institutional care in Great Britain identified impoverished and squalid living conditions, lack of privacy for patients, an emphasis on predominantly physical care and custodial attitudes among staff. The most famous of these was the 'Report of the Committee of Enquiry into Ely Hospital' (Howe Report, 1969). In addition to this, these reports followed a number of sociological studies undertaken in the 1950s that demonstrated that a significant number of people living in institutions had both the intellectual and social capabilities to live adequately in the community. (Race, 1995)

The above changing social influences were to be consequently reflected in a modified social and political agenda. In 1957, the recommendations of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency were to pave the way for the new Mental Health Act 1959 that ended compulsory certification enabling the discharge of many people with learning disabilities from long stay institutions. In 1971 the White Paper 'Better Services for the Mentally Handicapped' was introduced in Great Britain that advocated a 50% reduction in hospital places by 1991 and an increase in the provision of local authority based residential and day care. It also called for an end to custodial methods of care in hospitals and recommended the retraining of hospital staff. In 1979 The Jay Report re-emphasised the need for local authority led care, and importantly, a service philosophy based on the principles of normalisation.

The concept of normalisation was initially defined as;

'utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible'

(Wolfensberger, 1972)

In the 1980s it was redefined as 'social role valorisation' to include reference to strategies used in the creation, support and defence of valued social roles for people at risk of devaluation (Wolfensberger, 1998). In Great Britain, the principles of normalisation adopted were those interpreted by O'Brien and Tyne (1981) as the five service accomplishments. These have become the

developmental goals to which organisations then and organisations now strive towards and have been summarised in Box 3.2.

Community Presence - ensuring that service users are present in the community by supporting their actual presence in the same neighbourhoods, schools, workplaces, shops, recreation facilities and churches as ordinary citizens

Choice - ensuring that service users are supported in making choices about their lives by encouraging people to understand their situation, the options they face and to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do.

Competence - developing the competence of service users by developing skills and attributes that are functional and meaningful in natural community environments and relationships, i.e. skills and attributes which significantly decrease a person's dependency or develop personal characteristics that other people value.

Respect - enhancing the respect afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, and forms of dress and use of language promote perception of people with disabilities as developing citizens.

Community participation - ensuring that service users participate in the life of the community by supporting people's natural relationships with their families, neighbours and co-workers and, when necessary, widening each individual's network of personal relationships to include an increasing number of people.

Box 3.2 O'Brien and Tyne's Five Service Accomplishments (1981)

Since the introduction of the O'Brien and Tyne's Five Service Accomplishments into Great Britain, there has been a steady stream of policy and legislative documents that have influenced service provision for people with learning disabilities. In 1989 the White Paper 'Caring for People' confirmed the government's commitment to the development of locally based health and social care services. Following on from this, the government introduced The NHS and Community Care Act 1990 to provide the necessary support structures to enable, where possible, people to remain in their own homes thereby reducing the demand for long term care. These structures included an increase in the range of domiciliary, respite and day services including the promotion of independent care options and a greater emphasis on supporting informal carers. Central to these developments was the provision of a service that would be tailored to the needs of individuals and

the introduction of community care assessments that would be undertaken by social services with the assistance of health care professionals.

It is the case that the rate of deinstitutionalisation for people with learning disabilities residing in long stay hospitals in Scotland has been a much slower process than observed in other parts of Great Britain. This has been attributed to a diversity of reasons. These include: the initial absence of a national closure programme; funding disputes including resource transfer; poor interagency collaboration; opposition from parent and professional groups; and the debate over the future service configuration for those people with learning disabilities and additional complex needs such as challenging behaviour (Stalker and Hunter, 1999). In 2000, however, the first Scottish White Paper on learning disabilities was published. 'The Same as You' (Scottish Executive, 2000) detailed a comprehensive review of services for people with learning disabilities in Scotland and included a series of recommendations for future development. In addition to changes in day care provision and the opportunity for people with learning disabilities to have more control over their lives through the introduction of personal life plans and direct payments, it also outlined plans for the closure of Scotland's remaining long stay institutions by 2005. Whilst criticism continues to be lodged at the speed to which this process has been undertaken (Mitchell, 2001), it is clear that the range of services available to people with learning disabilities in Scotland continues to grow and reflect the diversity of needs associated with this group (Atherton, 2000). In addition to this recent legislation implemented has sought to consolidate the human and civil rights of this group of people. The Adults with Incapacity (Scotland) Act (2000) is a piece of legislation yet to be replicated in other parts of Great Britain and is therefore unique to Scotland. It seeks to protect the decision-making rights of people with learning disabilities and ensures the appropriate support to those without the necessary capabilities.

Conclusion

It is the case that attitudes and beliefs about people with learning disabilities have been the subject of change throughout history and have consequently affected the configuration and delivery of services to this group. Traditional models of institutional care have eventually been replaced by models of community care and social inclusion, reflecting a greater appreciation of the human and civil rights of people with learning disabilities. Whilst the rate of change in Scotland has been relatively slow as compared to other parts of Great Britain, it could be argued that this has enabled a more accurate assessment and response to the needs of people with learning disabilities. In addition to this, recent policy and legislation reflects a clear commitment to a more person centred approach to care than previously observed in this country. Since the major recipients of changes in services are people with learning disabilities themselves, the final word is taken from a former patient of Lennox Castle Hospital. Ernest Bell spent 36 years in long term care and now has his own home.

"My life is better now....I like the fact that I have my own space if I want.....But one of the nicest things would be that there is a bit of love and a lot of laughter in my home"

(Bell, 2002)

Essential

Reader Activity 3.4

The history of people with learning disabilities is punctuated with a number of key developments that have provided the basis for current service provision.

Draw a timeline that depicts the key milestones in the history of learning disabilities.

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Plates

Illustration of silkie, available at http://www.orkneyjar.com/folklore/selkiefolk/index.html - retrieved 02/9/03.

Pedigree of the Kallikak family (Goddard, 1931).

Photograph of Lennox Castle reproduced with kind permission from The Royal Commission on the Ancient and Historical Monuments of Scotland.

Resources

Resources on the history of idiocy

http://www.personal.dundee.ac.uk/~mksimpso/

Image archive on the American eugenics movement

http://www.eugenicsarchive.org/eugenics

Learning disability history

http://www.open.ac.uk/shsw/Research/Idsite/index.html

A history of mental disability 1000AD-2000AD: from idiocy to intellectual disability

http://caslater.freeservers.com/disability1.htm

Disability History Museum

www.disabilitymuseum.org