Unit 2 - A brief history of learning disability

Dr Helen Atherton - Lecturer in Learning Disabilities (University of Leeds)

Overview

Unit 2 will:

- Explore the range of attitudes and beliefs that societies often hold towards people with learning disabilities.

- Consider the range of factors that have underpinned the changing social position of people with learning disabilities in respective societies, including 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 disability in history is vital to understanding their position in contemporary society, particularly within the context of healthcare delivery systems.

In the past, people with learning disabilities have been perceived as objects of fascination and fear, resulting in them being both worshipped and, sometimes, vilified. This unit will explore some of the ways in which society has labelled people with a learning disability and how these labels have subsequently affected the type and quality of care afforded to them. The effects of labelling are particularly important for people who provide healthcare to this group. This is because it is known that stereotypical beliefs and attitudes towards this group may result in the provision of poor health quality care (Fitzsimmons and Barr, 1997).

It should be remembered that for some people with learning disabilities, this history of poor healthcare provision is their own history; in some cases it continues to be very much a part of their lives. Memories of poor healthcare in the past may directly affect how individuals perceive healthcare professionals and the kinds of services available to them (see Unit 3). We know that many of the people with learning disabilities with whom you will come into contact may have lived in institutions, which reflected different societal attitudes. Their memories of the past are likely to affect their interactions with you in the present.
A time line of the history of people with learning disability

Those with learning disability 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: ‘sub-human organism,’ ‘menace,’ ‘unspeakable object of dread,’ ‘object of pity,’ ‘holy innocent,’ ‘diseased organism,’ ‘object of ridicule’ and ‘eternal child’ (Wolfensberger, 1972). At various points in history, they have been misunderstood and the term has been conflated with witchcraft, lunacy, mental illness, and criminality. In Figure 2:1, a timeline is presented depicting some significant events in the history of people with learning disabilities. Study the timeline and attempt to undertake the reflective exercise that follows.
Figure 2:1 Time line from the 1400s to present

<table>
<thead>
<tr>
<th>1400</th>
<th>1500</th>
<th>1700</th>
<th>1800</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lunatics admitted to hospitals; treatment consisted of chaining and whipping.</td>
<td>Earlier laws against witchcraft are abolished. Regulation of Madhouses Act 1774</td>
<td>1794 Malthus noted imbalance between rate of population growth and rate of increase of food supply. Feeble-mindedness considered to be transmitted through the generations. The feeble-minded considered to be a group reproducing at a greater rate than the general population. Rogues, Vagabonds, and other Idle and Disorderly Persons Act (1744) makes distinction between lunatics and vagrants/ paupers. Treatment includes bleeding and emetics.</td>
<td>1828: Lunatic Asylum Regulation Act. Poor Law Amendment Act (1834) separated people considered unable to contribute to the economy into workhouses. The Idiots Act 1886 was the first time the needs of the mentally handicapped were specifically addressed by legislation. In addition to workhouses, people with learning disabilities were often admitted to lunatic asylums, and prisons. The Act introduced registration, inspection and admission to specialised asylums. The Lunacy Act (1890), however, did not discriminate between the ‘mentally ill and the mentally retarded.’ Most care provided by family, social networks and religious organisations. Development of Darwinian theory and belief in natural selection and the deterioration of intelligence. Eugenics, the ‘science of improving inborn human qualities through selective breeding’ first coined by Francis Galton in 1883. Negative eugenics (inhibiting procreation amongst classes considered socially deviant) brought about by institutionalising.</td>
</tr>
</tbody>
</table>

Witchcraft linked to madness (which included learning disabilities at that time).
<table>
<thead>
<tr>
<th>1900 - 1947</th>
<th>1947 - present</th>
</tr>
</thead>
<tbody>
<tr>
<td>1909 Royal Commission set up to investigate the ‘problem’ of the ‘feeble minded.’</td>
<td>1947 National Health Service Act. Treatment becomes free at point of access.</td>
</tr>
<tr>
<td>1913: Mental Deficiency Bill. People with learning disabilities now identified as distinct from the mentally ill.</td>
<td>1959: Mental Health Act. Further distinctions between mental illness and a new term, 'mental sub-normality.'</td>
</tr>
<tr>
<td>The Mental Deficiency Act 1913 legalised the detention of individuals with varying degrees of mental defect. The Act established four classes of mental deficiency: idiot - unable to guard themselves against common physical dangers such as fire, water or traffic; imbecile - could guard against physical dangers but were incapable of managing themselves or their affairs; feeble-minded - needed care or control for protection of self or others and moral defectives. The First World War (1914-1918) delayed the implementation of this but the findings of the Wood committee reporting in 1929 resulted in the acceleration of policy recommending that 100,000 individuals suffering from mental deficiency be immediately institutionalised. The Wood report also noted the reliance institutions had on the labour of inmates for maintenance.</td>
<td>European Convention on Human Rights (1950), Mental Health Act 1957, Howe report (1969) and recommendations of the 1971 White Paper 'Better Services for the Mentally Handicapped' advocating a 50% reduction of hospital places by 1991, reflect different attitudes and contribute to new thinking on learning disability.</td>
</tr>
<tr>
<td>The Mental Deficiency Act 1927 gave Local Authorities statutory responsibility for providing occupation and training. Mental deficiency was ‘a condition of arrested or incomplete development of mind existing before the age of 18 years whether arising from inherent causes or induced by disease or injury.’</td>
<td>1980s/90s: many people discharged from old long-stay hospitals in response to White Paper of 1971.</td>
</tr>
<tr>
<td>1930s: compulsory sterilisation considered in the UK for people with learning disabilities. Mid 1930s-mid 1940s: Nazi German exterminates 'undesirables,' such as those with learning disabilities.</td>
<td>2000 - Present. Many more people now living in community and supported settings.</td>
</tr>
<tr>
<td>Review of services for people with learning disability, Scottish Executive 2000 'The same as you?'</td>
<td></td>
</tr>
<tr>
<td>2003: Mental Health (Care and Treatment) (Scotland) Act</td>
<td></td>
</tr>
</tbody>
</table>
Reflection point 2.1

The introduction stated that people with learning disabilities have been perceived and portrayed variously at different points in history as: ‘a sub-human organism’, ‘menace,’ ‘unspeakable object of dread,’ ‘object of pity,’ ‘holy innocent,’ ‘diseased organism’, ‘object of ridicule’ and ‘eternal child’ (Wolfensberger, 1972). With reference to the timeline, consider each of the centuries described and try to identify, from significant legislation and the way in which services were constructed, how people with learning disabilities were perceived in each period.
Life in an institution

The perception held by many establishment and authority figures in the eighteenth and nineteenth centuries was that people with learning disabilities presented a threat. The Industrial Revolution (from about 1760 onwards) created new demands for skilled labour and it was apparent that people with learning disability did not have the social and economic skills required. 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 disability were not considered to be profitable members of society, due to a lack of skill and intelligence and, therefore, they were 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 attitude towards people with learning disability; that they had limited economic usefulness for communities, evolved further to reflect a belief that this group was one of a number of groups responsible for the social ills within the population. This resulted in a series of strategies employed to control this group of people.

Through the late 19th and into early the 20th century, it was believed that the social ills of criminality, prostitution and alcoholism were closely associated with people with mild learning disability (Tredgold, 1909); a group which, at that time, were referred to as ‘feeble-minded.’ It was believed that procreation amongst this group would result in the spread of social ills that would gradually erode society’s physical, intellectual and moral core, resulting in its eventual collapse. A 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 led to the inevitable segregation of people with learning disability from the rest of society, including institutionalisation. Initial attempts at institutional care for people with learning disability (in the 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.’

(Cooper, 1997)

The Wood Committee (1929) accelerated the policy of institutionalisation and 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 National Health Service Act (1948), under which control of colonies was transferred from local councils to Regional Hospital Boards.

Lennox Castle is an 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 [Figure 2.2]. It was the largest such 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 including 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) has recalled his experiences of working as a healthcare assistant in a ‘mental handicap’ hospital near Edinburgh in the early 1970s. He remembers having to care for 40 patients on one ward, with three staff, one bath and two showers. Patients were also expected to share clothes, except on Saturdays, which was visiting day. He also remembers the use of punishment to ensure conformity to the hospital regime, a common feature of institutional care (Goffman, 1961).

Reflection point 2.2

Locate an old learning disability hospital that was based relatively near to where you currently practice or live. Spend some time reflecting on how this institution might have affected contemporary services and attitudes towards people with learning disabilities.
‘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. Institutionalisation was thus an inescapable outcome for many people.
Getting it right together - Unit 2 - A brief history of learning disability
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 disability into question. These events began to pave the way for the eventual introduction of community care for this group and were undoubtedly affected by the increasing influence of the human and civil rights movements that culminated in the European Convention on Human Rights (1950). There was increasing recognition of 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, a 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 which 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 social influences listed above 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 paved the way for the new Mental Health Act (1959). This 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, advocating 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 re-training 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 a:

‘[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, this 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 the UK, 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 which organisations then and now strive towards and are summarised in Box 2.1.

**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 2.1 O’Brien and Tyne’s Five Service Accomplishments (1981)

Since the introduction of O’Brien and Tyne’s five service accomplishments into the UK, there has been a steady stream of policy and legislative documents which have influenced service provision for people with learning disability. 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 this, the Government introduced The NHS and Community Care Act (1990) to provide the necessary support structures to enable (when 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, as well as the introduction of community care assessments that would be undertaken by social services with the assistance of healthcare professionals.

The rate of deinstitutionalisation for people with learning disability residing in long stay hospitals in Scotland has been a much slower process than that observed in other parts of the UK. A wide variety of reasons have been suggested for this, including:

- the initial absence of a nationwide closure programme;
- funding disputes including resource transfer;
- poor inter-agency collaboration;
- opposition from parent and professional groups;
- the debate over the future service configuration for those people with learning disability, and
- addressing additional complex needs such as challenging behaviour (Stalker and Hunter, 1999).

In 2000, however, the first Scottish White Paper on learning disability was published. ‘The Same as You?’ (Scottish Executive, 2000) detailed a comprehensive review of services for people with learning disabilities in Scotland, including a series of recommendations for future development. In addition to changes in day care provision and the opportunity for people with learning disability (through the introduction of personal life plans and direct payments) to have more control over their lives, 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 disability in Scotland continues to grow and reflect the diversity of needs associated with this group (Atherton, 2000). In addition, recently implemented legislation has sought to consolidate both 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 the UK and is therefore unique to Scotland. It seeks to protect the decision-making rights of people with learning disabilities and ensures appropriate support to those without the necessary capabilities.
Conclusion

Attitudes and beliefs concerning people with learning disabilities have changed throughout history. This has affected the configuration and delivery of services to this group. Models of traditional institutional care in the UK have 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.

Scotland has taken a considered approach to change that has enabled a more accurate assessment of 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. There is a commitment in NHS Scotland to identify a best practice statement on access to healthcare for people with learning disabilities. Its purpose is to ensure that people with learning disabilities have access to consistently good health care. This is a laudable aim, but ultimately it will be for people with learning disabilities and their families to decide if such a document has been translated into reality or whether it might become consigned to history. Those who wish to find out more about the work in this area might like to refer to this web page:

http://www.nhshealthquality.org/nhsqis/qis_display.jsp?pContentID=2073&p_applic=CCC&p_service=Content.show&amp;#2

Since the major recipients of changes in services are people with learning disability 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)
References


Mental Deficiency Act 1913. London: HMSO.
Mental Health Act 1959. London: HMSO.


NATIONAL COUNCIL for CIVIL LIBERTIES (1951) 50,000 outside the law: an examination of the treatment of those certified as mentally defective. London: National Council for Civil Liberties.


Poor Law Amendment Act 1834. London: HMSO.


Human Service Planning, Leadership and Change Agentry (Syracuse University).
Recommended reading


Plates

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/

Learning disability history
http://www.open.ac.uk/hsc/ldsite/index.html

A history of mental disability 1000AD-2000AD: from idiocy to intellectual disability
http://caslater.freeservers.com/disability1.htm

Disability History Museum
http://www.disabilitymuseum.org