Barriers to Empowerment for People with Learning Disabilities

By Emily Baker

Introduction

- Explore the definition of learning disability (LD) and empowerment.
- Examine the treatment of those with LD historically and inequalities that they face today.
- Compare the medical and social model of disability and consider how each perspective impacts practice.
- Consider barriers to empowerment such as the responsibility of practitioners to protect, barriers in communication, coerced decision making and challenges in healthcare.
- Furthermore, possible solutions to disempowerment will be considered such as legislation and policies to protect LD individuals and other strategies.

What is a learning disability?

People with a learning disability may:

- may find it challenging to understand information, particularly if complex (NHS, 2022; Department of Health, 2001, Magotra, 2024).
- may struggle to develop new skills (NHS, 2022; Department of Health, 2001).
- may struggle in social situations (Department of Health, 2001).
- may not be able to live independently (although many people with LD do achieve this) (NHS, 2022).

What is a learning disability?

- Cannot be ‘cured’ and is experienced differently by everyone who has one (NHS, 2022; Public Health England, 2023).
- Caused by changes to the brain during pregnancy, birth or early childhood (NHS, 2022; Public Health England, 2023; Magotra, 2024).
- Down's syndrome, meningitis or cerebral palsy may cause or involve a learning disability (Public Health England, 2023).
- Some people are diagnosed when they are very young and others are diagnosed in adulthood (NHS, 2022).
- Impacts a person to different extents (Public Health England, 2023).
- Those with profound and multiple learning disability (PMLD) may have difficulties with their senses, speaking, moving, eating and personal care (NHS, 2022).

Empowerment and Power

- To understand empowerment, we must first understand the concept of power (Page and Czuba, 1999; Chaudhuri, 2016).
- March (1957) power is to be able to influence others and restrict the outcomes of a situation.
- Dahl (1957) and Weber (1947) agree that power is the ability to make someone do something that they would not otherwise do.
- Chaudhuri (2016) argues that to empower is to give power to.
- Thus, one may argue that to empower someone is to give them the ability to influence others or the outcome of a situation.

Empowerment: Associated Concepts

- Control over your health and opportunities (Tegland, 2008).
- Self-esteem, autonomy and ultimately the freedom and ability to make your own decisions (Tegland, 2008; Page and Czuba, 1999).
- Belief in oneself (Cattaneo and Chapman, 2010).

Photo: Vision Propositions, 2024

History: Pre-1971

- Mental Deficiency Act (1913) - detainment in long-stay institutions (Jingree and Finlay, 2012; Race, 2002).
- Belief LD must be removed from society as they were the cause of social issues such as crime and poverty (Debenham, 2022).
- Male and female segregation to stop chance of reproduction (Race, 2002).
- Children with LD were deemed ineducable and had no entitlement to education (Race, 2002).
- Concern around how people were being treated (Stainton, 2000).

Post-1971

- Government formalised plans to close these institutions in a White Paper in 1971 called Better Services for the Mentally Handicapped (Department of Health, 1971).
- Principle of normalisation (Department of Health 1971) - people with LD should experience 'normal life' to the highest degree possible (i.e. live in 'normal' places and occupy themselves with 'normal' activities) (Debenham, 2022).
- Led to people with LD normally being cared for in the family home (Bowey and McGlaughlin, 2007).

Inequalities Faced by LD People

- 5.1% of LD adults in England in paid employment (NHS, 2021, p. 20).
- 31% of LD adults live in poverty (18% for non-LD adults) (Tinson et. al., 2016, p. 1).
- 70% of LD people do not have friends outside of their families and those who are paid to care for them (Department of Health, 2001) and around half of people with LD experience chronic loneliness (Gilmore and Cuskelly, 2014).
- 6% - control over who they live with (Department of Health, 2001).
- 1% - control over who cares for them (Department of Health, 2001).
- Median age of death - 62 years old for LD people, 82.7 years old for general population (Public Health England, 2023).
- 1200 people with LD die per year when access to good quality care could have prevented their deaths (Glover and Emerson, 2013).

Medical Model: Inequalities are Inevitable

- Inevitable vs Due to society -- medical vs social model of disability.
- Medical model locates the disability within the person (Race, 2002).
- Disability is a personal tragedy (Race, 2002; Goodley, 2001).
- Differences are seen as inherently negative (Johner, 2013).
- Their symptoms are seen are resulting from their 'disorder' rather than from the way they are treated in society (Goodley, 2001; Coles, 2001).

Social Model: Inequalities are Socially Constructed

- First applied to LD in 1956 - ‘we need to see mental defectives in terms of the general theory of social problems’ (Dexter, 1956, pp. 10–11).
- It is the way people are treated in society that creates disablement (Coles, 2001; Goodley, 2001).
- It is societies failure to provide appropriate accommodations not the person that needs to be fixed (Coles, 2001).
- Physical and attitudinal barriers must be removed - e.g. writing information in an easy read format (Race, 2002).
- Diagnosis and incarceration hides the need for social reform (Goodley, 2001).
- Some behaviour that may be viewed as challenging is rational when one is put in harmful environments (Goodley, 2001).
- However, Crow (1996) - negative experiences of disability itself should not be ignored.

Protection VS Empowerment

- Staff that look after people with LD have a responsibility to provide care but also to promote choice and control (Finlay et. al., 2008).
- It can be disputed that these agendas conflict (Finlay et. al., 2008).
- Blow (2008, np) argues that due to this focus on caring for the individual, people with LD are often treated as though they are 'eternally children'.
- Fundamentally, services have the power to override service users decisions and this power is asymmetrical (Finlay et. al., 2008; Jingree and Finlay, 2008).
- This means the person does not have full autonomy (Jingree and Finlay, 2008).

Coerced Decision Making

- People supporting those with LD may (in)advertently influence the decisions made by the person (Finlay et. al., 2008).
- The way supporters question LD people about their choices may cause the LD person to change their choice (Jingree and Finlay, 2008).
- Because of the differences in the LD person and their carer's knowledge and status, they may not be given the opportunities to make choices that are truly their own (Jingree and Finlay, 2008).
- Staff also have the choice to ignore the utterances and desires of the LD person in a way that the disabled person does not (Jingree and Finlay, 2008).

Barriers in Communication

- People with LD may experience difficulties producing speech and understanding the speech of others (Public Health England, 2023).
- When people have communication difficulties it may be difficult for their supporters to understand what they are intending to communicate (Edge, 2001; Grove et. al., 1999).
- This may lead to their preferences not being taken into account (Finlay et. al., 2008).
- People working with those with LD may not have the skills or training to create effective dialogues with service users (Blow, 2008).
- Evidence that professionals may rely on using speech, even if the client does not seem to prefer this method of communication and other methods such as sign language may be more effective (e.g. Finlay et. al., 2008).
- Furthermore, in some settings the speech of those with LD is ignored (Prior et. al., 1979).
- LD people may struggle more to communicate in environments that are noisy or when others are not attentive to their attempts (Mathers et. al., 2011).

Healthcare of Learning-Disabled People

- People with LD may struggle to understand information given to them about their health - particularly if it is given to them in an inaccessible manner (Public Health England, 2023).
- People with LD are legally entitled to reasonable adjustments when visiting healthcare settings (Mencap, 2020a; Health and Care Act, 2022).
- After the death of Oliver McGowan and many others with learning disabilities there is now mandatory training for healthcare workers in autism and learning disabilities (Mencap, 2020a).

Healthcare During COVID

- 1 in 4 nurses said they had seen examples where LD people were not allowed an accompanying carer and some were not allowed to bring essential documents such as a hospital passport (Mencap, 2020b).
- Hospital passport - provides information about the LD person including the way the person likes to communicate and the things that can be done to make them feel safe and comfortable (Mencap, 2020a).
- Although later amended, guidance was given out which told healthcare workers not to provide ventilators to those with LD who could not manage everyday tasks (Mencap, 2020a).
- 54% - high risk of people with LD receiving unneccessary DNACPR on their records - may unknowingly have them now (Mencap, 2020b).
- 4 in 5 of nurses stated reasonable adjustments were not always made (Mencap, 2020b).

Legislation Involving LD People

- Human Rights Act (1998) - LD people and all other people have inalienable rights such as the right to life and freedom from degrading treatment and discrimination.
- Equality Act (2010) - employers and healthcare settings must make reasonable adjustments to ensure LD people are not disadvantaged.
- Health and Care Act (2022) - all health and social care provides must be trained in learning disabilities and autism.
- Mental Capacity Act (2005) - decisions made for a person who is deemed as not having capacity must be made with the person's best interests in mind and must involve the person's participation and wishes as far as possible.

Valuing People (2001)

- Advocacy provisions should be expanded (£1.3 million/year for three years).
- People should be involved in decisions that impact their lives - more people should receive direct payments.
- A person-centred approach should be used when planning care and services.
- People should be given information in a format that they can understand.

All information from:
Department of Health, 2001

How Successful Was Valuing People?

Successful	Unsuccessful
Between the periods of 2000-01 and 2003-04: • 850% increase in the number of LD adults receiving direct payments • 850% increase in social service expenditure on direct payments • Social services expenditure on home care increased by 58% • 27% increase in use of overnight respite care • Number of people admitted to inpatient hospitals decreased by 20% • 34% increase in spending on residential care homes • 24% increase in spending on day services	Between the periods of 2000-01 and 2003-04: • Number of emergency admissions increased by 19% • 20% increase in spending on secure beds in NHS hospitals

(Hatton, Emerson and Lobb, 2005)

Conclusion

- People with LD may struggle with understanding information and developing skills.
- LD are caused by changes to the brain and are experienced differently by each individual.
- To empower someone is to give them the ability to influence others and the outcome of situations.
- It involves control over health and opportunities, self-efficacy, autonomy and freedom.
- Historically, individuals with LD were incarcerated, however after 1971, there was a drive to move LD people into community settings.
- Despite this LD people still face inequalities in employment, social class and health, among other areas.

Conclusion

- Some people argue that viewing LD as a social issue rather than as a medical one leads to better outcomes for LD people.
- LD people face barriers to empowerment, as often their decisions are influenced or overridden by others, they may struggle to get their voices heard and they may not receive the same standard of healthcare as non-LD people.
- Legislation such as the Equality Act (2010) and the Health and Care Act (2022), as well as government publications such as Valuing People (2001) aim to protect LD people.
- Other practices such as using simpler language and visual aids can help LD people to be empowered.

References

- Blow, B. (2008). ‘Empowering to disempower: a dilemma when working with adults with learning difficulties’, *Anthropology Matters*, 10(1).
- Bowey, L. and McGlaughlin, A. (2007) ‘Older carers of adults with learning disability confront the future: issues and preferences in planning’, *British Journal of Social Work*, 37, 1, pp. 39–54.
- Cattaneo, L. B., & Chapman, A. R. (2010). ‘The process of empowerment: A model for use in research and practice’, *American Psychologist*, 65(7), pp. 646 -659.
- Chaudhuri, A. (2016). ‘Understanding ‘Empowerment’.’, *Journal of Development Policy and Practice*, 1(2), pp. 121-141.
- Coles, J. (2001). ‘The Social Model of Disability: what does it mean for practice in services for people with learning difficulties?’, *Disability & Society*, 16(4), pp. 501-510.
- Crow, L. (1996) ‘Including all of our lives: renewing the social model of disability,’ In: J. Morris (ed.) *Encounters with Strangers: Feminism and Disability*. London: The Women's Press.
- Dahl R. A. (1957). ‘The concept of power’, *Behavioural Science*, 2, pp. 201–215.
- Debenham, L. (2022). *Normalisation and Learning Disabilities*. Available at: https://www.aboutlearningdisabilities.co.uk/normalisation-learning-disabilities.html [Accessed 22/04/2024]
- Department of Health (1971) *Better Services for the Mentally Handicapped*. London: HMSO
- Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century.* Available at: https://assets.publishing.service.gov.uk/media/5a7b854740f0b62826a041b9/5086.pdf [Accessed 22/04/2024]

References

- Dexter, L. A. (1956). ‘Towards a sociology of the mentally defective’, *American Journal of Mental Deficiency,* 61, pp. 10 – 16.
- Edge, J. (2001). *Who's in control?: Decision-making by people with learning difficulties who have high support needs*. London: Values Into Action.
- *Equality Act 2010 c. 15* Available at: https://www.legislation.gov.uk/ukpga/2010/15/contents [Accessed 23/04/2024]
- Finlay, W. M. L., Walton, C. and Antaki, C. (2008) ‘Promoting choice and control in residential services for people with learning disabilities’, *Disability & Society*, 23(4), pp. 349–360.
- Gilmore, L and Cuskelly, M. (2014). ‘Vulnerability to loneliness in people with intellectual disability: an explanatory model’, *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), pp. 192-199
- Glover, G. and Emerson, E. (2013), “Estimating how many deaths of people with learning disabilities in England could be prevented by better medical care”, *Tizard Learning Disability Review*, 18(3), pp. 146-149.
- Goodley, D. (2001). ‘'Learning difficulties', the social model of disability and impairment: challenging epistemologies’, *Disability & Society*, 16(2), pp.207-231.

References

- Grove , N. , Bunning , K. , Porter , J. and Olsson , C. (1999). ‘See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities’, *Journal of Applied Research in Intellectual Disabilities*, 12, pp. 190 – 203.

- Hatton, C., Emerson, E. and Lobb, C. (2005). *Evaluating the Impact of Valuing People*. Available at: https://www.lancaster.ac.uk/staff/emersone/FASSWeb/Hatton_05_EvalVP_R1.pdf [Accessed 23/04/2024]

- *Health and Care Act 2022 c. 31* Available at: https://www.legislation.gov.uk/ukpga/2022/31/contents [Accessed: 23/04/2024]

- *Human Rights Act 1998 c. 42* Available at: https://www.legislation.gov.uk/ukpga/1998/42/contents [Accessed: 23/04/2024]

- Jingree, T., & Finlay, W. M. L. (2008). ‘"You can’t do it … it’s theory rather than practice": staff use of the practice/principle rhetorical device in talk on empowering people with learning disabilities’, *Discourse & Society*, 19(6), pp. 705-726.

- Jingree, T. and Finlay, W.M.L., 2012. “It’s got so politically correct now’: parents’ talk about empowering individuals with learning disabilities’, *Sociology of Health & Illness*, 34(3), pp.412-428.

- Johner, R. (2013). ‘Disability and poverty: Stories that resist attitudinal barriers to inclusion’, *Canadian Journal of Disability Studies*, 2(3), pp. 31-54.

- Magotra, A. (2024). ‘Teachers empowerment: A transformative approach to mental health, learning disabilities, and inclusive education’, *Indian Journal of Medical Sciences*, pp.1-4.

References

- March J. G. (1957). ‘Measurement concepts in the theory of influence’, *Journal of Politics*, 19(2), pp. 202–226.

- Mathers, A.R., Thwaites, K., Simkins, I.M. and Mallett, R. (2011). ‘Beyond Participation: The practical application of an empowerment process to bring about environmental and social change’, *Développement Humain, Handicap et Changement Social*, 19(3), pp. 37-57.

- Mencap. (2020a). *My Health, My Life: Barriers to healthcare for people with a learning disability during the pandemic.* Available at: https://www.mencap.org.uk/sites/default/files/2020-12/MyHealthMyLife_COVID%20report%20%281%29.pdf [Accessed 17/04/2024].

- Mencap (2020b). *Learning Disability Nurses' Experience During The COVID-19 Pandemic: Survey Findings.* Available at: https://www.mencap.org.uk/sites/default/files/2020-12/Learning%20disability%20nurses%E2%80%99%20experiences%20during%20the%20COVID-19%20pandemic_survey%20findings%20%286%29.pdf [Accessed 23/04/2024]

- *Mental Capacity Act 2005, c. 9* Available at: https://www.legislation.gov.uk/ukpga/2005/9/contents [Accessed 23/04/2024]

- NHS (2021). *Measures from the Adult Social Care Outcomes Framework: England, 2020-21.* Available at: https://files.digital.nhs.uk/57/AB0038/meas-from-asc-of-eng-2021-ASCOF-report.pdf [Accessed 23/04/2024]

- NHS. (2022) *Learning disabilities*. Available at: https://www.nhs.uk/conditions/learning-disabilities/ [Accessed 17/04/2024]

References

- Page, N. and Czuba, C.E. (1999). ‘Empowerment: What is it’, *Journal of extension*, 37(5), pp. 1-5.
- Prior M., Minnes P., Coyne T., Golding B., Hendy J. & McGillivary J. (1979). ‘Verbal interactions between staff and residents in an institution for the young and mentally retarded’, *Mental Retardation*, 17, pp. 65–9.
- Public Health England. (2023). *Learning disability - applying All Our Health*. Available at: https://www.gov.uk/government/publications/learning-disability-applying-all-our-health/learning-disabilities-applying-all-our-health [Accessed: 17/04/2024]
- Race, D.G. (2002). *Learning disability: a social approach*. Abingdon, Oxon: Routledge.
- Stainton, T. (2000). ‘Equal citizens? The discourse of liberty and rights in the history of learning disabilities’, In L. Brigham, D. Atkinson, M. Jackson, S. Rolph and J. Walmsley (eds.) *Crossing Boundaries: Change and Community in the History of Learning Disability.* Kidderminster: BILD Publications.
- Tengland, P.A. (2008). ‘Empowerment: A conceptual discussion’, *Health Care Analysis*, 16, pp. 77-96.
- Tinson, A., Aldridge, H., Born, T. B. and Hughes, C. (2016). *Disability and Poverty*. Available at: https://www.npi.org.uk/files/7414/7087/2444/Disability_and_poverty_SUMMARY_REPORT_FINAL.pdf [Accessed 23/04/2024]
- Weber, M. (1947). *Theory of Social and Economic Organisation*. New York: Oxford University Press.
- Vision Propositions (2024). *Leadership Empowerment*. Available at: https://visionpropositions.com/leadership-empowerment/ [Accessed 23/04/2024]