# **Chapter 10 Health and Disability in Adults**

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# Introduction

Many adults in the world live with a disability. It is, however, a somewhat nebulous term which collectively refers to individuals with different experiences, such as being born with a cognitive impairment or becoming disabled as a result of chronic illness or accident. Irrespective of the type of disability, it is widely accepted that living with a disability can have significant impact upon individuals' lives contributing to health inequity and lack of access to health and social care. This chapter examines current evidence with regards to prevalence of disability as well as contemporary guidelines re defining disability. The chapter develops by examining the historical management of adults with a disability and how this contributes to the different ways in which disability is perceived. Moving on, the chapter presents contemporary challenges that adults living with a disability face in the 21<sup>st</sup> Century and how health and social care professionals can inadvertently perpetuate vulnerability of these individuals.

Chapter objectives:

- Investigate definitions of disability extending beyond that of individuals born with either an intellectual or physical impairment;
- Explore the historical management of adults living with a disability and how this has influenced contemporary discourses regarding disability;
- Consider wider social influences and how these impact upon health and well-being of adults living with a disability;

- Examine health inequalities of adults living with a disability;
- Identify professional practice suggestions to working with adults living with a disability.

### **Prevalence and definitions**

Current estimates of people living with a disability vary, the World Health Organisation (WHO 2019) estimate the figure to be over a billion people equating to 15% of the world population; whereas Hosseinpoort *et al*, (2016) estimate that the prevalence of adult disability to range between 15.6 and 19.4%. These differences occur due to the complexity of defining what is meant by the term disability. The World Report on Disability (WHO, 2011) identify that rather than being a homogenous group, adults living with a disability are diverse and heterogeneous ranging from individuals who are wheelchair users, individuals born with congenital conditions (such as cerebral palsy, Down syndrome), individuals who lose a limb due to a traumatic event, individuals living with a chronic debilitating illness (such as arthritis or dementia), individuals living with a specific learning difficulty (such as dyslexia, dyspraxia and so forth). As such, disabilities can be permanent or temporary, visible or hidden, single or multiple events and can have a significant impact upon the individual and their family (WHO, 2011).

One particular group of people who are increasingly finding themselves 'disabled' are adults living with a long term conditions, this is due to both a growth in ageing population as well as a growth in chronic illnesses (WHO, 2018). Long terms conditions are identified as medical conditions for which there are currently no cure and which are managed by medications and other treatment (George and Martin, 2016) and include conditions such as dementia, arthritis, osteoporosis, chronic obstructive pulmonary disease and chronic heart failure. There is also a significant growth in the numbers of adults living with not just one but multiple chronic conditions referred to as co or multi morbidity and this has a significant impact not only on financial healthcare costs but also human costs such as quality of life (Goodwin *et al,* 2010). In light of this, it could be argued that every single one of us will at some point in our adult lives experience impairment or disability.

Disability has been defined by the World Health Organisation (2001) as an 'umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between the individual (with a health condition) and that individual's contextual factors (environmental and personal factors)'. Whilst this definition is now 18 years old it is still the most commonly used international definition of a disability. Vornholt *et al*, (2018) argues that this definition recognises that people can be disabled not only by their bodies but also be environmental factors, and that disability is not equal to medical concepts of impairments but rather to the relationship between the person and their environment.

It is important to note when this chapter refers generically to an adult living with a disability it is inclusive of all of these particular groups of individuals exploring the wider health issues related to living with a disability.

## **UK Historical Overview**

In order to understand some of the prevailing discourses surrounding disability, there is a need to explore how adults living with a disability were perceived and treated in the past. What follows is a brief history adapted from Historic England (2018). During the Medieval Period of 1050-1485 adults with a disability had a highly visible presence in society. Types of disability prevalent during this period included sensory impairments ('blynde', 'deaff', 'dumbe'), intellectual disabilities ('fools') mental illness ('lunaticks'), physical impairments ('lame', 'creple') as well as what we would commonly refer as medical conditions today such as leprosy ('lepre'). Leprosy (Hansen's disease) is a chronic infectious disease affecting the nerves and skin that was extensive during the medieval period and at that time there were no effective treatments. Perceptions of adults living with a disability were mixed; some perceived that the disability was a punishment from God whilst others saw it as a blessing as the individuals were in fact living in purgatory on earth and as such their transition to heaven would be smoother. As there was no state provision for support, if adults could not work then they were largely supported by their family, local community, by begging or by the church. Many churches provided the first hospital type care for people living with leprosy especially in the aftermath of the Black Death where fears of contagion were widespread, resulting in greater isolation for people living with leprosy. It was also during the medieval period that the first mental institution in England was established to manage adults living with mental illness.

During 1485-1660 there was the dissolution of monasteries by Henry VIII and this led to many of the religious hospitals closing and adults living with disabilities found themselves homeless, forced to live on the street. These attacks on the church and the catholic faith shifted the focus of care from a religious to a civic duty in towns and local communities and it is here that hospitals began to be built. Henry VIII reign also saw an increase in infectious diseases such as the sweat, plague and smallpox and this was coupled with an increased fear of contagion leading to the development of 'Pest houses' where people living with contagious diseases were forced to live, isolating themselves and their infection from wider society. Perceptions towards disability was also changing, there was the introduction of a variety of Poor laws reflecting the very negative societal view of the poor, adults living with a disability were perceived as 'impotent poor' which resulted in them being provided with some charitable financial relief. During 1660-1832 adults living with a disability still largely lived in their own homes and communities and support continued to be based upon charitable and civic duty. However, during this time there was a real expansion of medicine and with it the development of large hospitals developing greater knowledge and study of health and illness. Embryonic ideas began to emerge that institutions were right place for adults living with disabilities however it wasn't until the 19<sup>th</sup> century that there was a real growth in asylums and the introduction of workhouses where increasing numbers of adults living with a disability found themselves located. These institutions developed largely due to the very negative societal attitudes to the poor and destitute, as such workhouses were designed to root out individuals who did not want to work and live productive lives resulting in poor living conditions and harsh work environments.

The first half of the 20<sup>th</sup> century (1914-1945) saw the growth in the Eugenics movement which perceived disability as a defective threat and burden to society. This led to the development of rural communities for people with disabilities isolating them from wider society. This began to be challenged at the end of the First World War as many returning soldiers returned home with a physical disability as a result of the conflict, yet these soldiers had very high societal regard as they had served their duty to their country. This led to advances in science, especially the prosthetic movement, striving to find ways to enable the soldiers to return to work. However, there was also an increasing epidemic of adults living with a disability due to childhood infectious diseases such as skeletal tuberculosis, poliomyelitis and rickets. It wasn't until after the Second World War with the general public's increasing knowledge of the mass killing of people with a disability in Germany that the Eugenics movement really subsided. This collapse was supported by more returning soldiers with disabilities, men who had become disabled in their fight to protect the nation and this led to an increased social awareness of the right of people with a disability which culminated in the 1944 Disability Employment Act and, in part, the introduction of the NHS in 1948.

It is evident that some of the prevailing perceptions of adults living with a disability that were prevalent in the UK before the  $19^{th}$  century are still apparent in other parts of the world today. Research by Bunning *et al*, (2017) on perceptions of disability amongst local communities in Kenya identified that disability occurs due to witchcraft, demons, evil spirits as well as it being God's will. However this tends to focus on cognitive and physical disabilities rather than disability as a consequence of old age. Yet a review by Hosseinpoort *et al*, (2016) of 48 low to middle income countries identified an statistically significant likelihood of disability associated with women as well as age; in that 1 in 5 people aged 50-59 identified as having a disability rising to 3 of 5 in people aged 80+.

#### Models of Disability

As can be seen from the historical overview, the 'medical model' of disability largely developed from the 19th Century onwards reflecting societies growing interest and knowledge in science and medicine as well as the introduction and growth of the number of asylums and larger hospitals. In the medical approach there is a focus on 'pathologising' the disability and in classifying the impairments with a view that treatments could then focus on helping the patient manage those impairments (Larkin, 2009). Disabled people were therefore seen as 'abnormal' and treatment really relied upon institutional care. The medical model of a disability was the prevailing view until the later part of the 21<sup>st</sup> century where the civil rights movement in America inspired many disabled groups to take action against the discrimination and inequity they experienced. This led to the development of a social model of disability arising from the social movement of disabled activists during the 1980s who argued their impairments did not make them disabled, instead it was wider social factors and attitudes which curtailed their opportunities and capabilities resulting in them being disabled from engaging (Larkin, 2009). In part it can be argued that in order to really understand an individual's experience there is a need to incorporate both the medical and social needs as an individual's disability is an interaction between the features of the person and the context in which that person lives (World Health Organisation, 2002). The International Classification of Functioning, Disability and Health (Figure 10.1) was developed to provide a universal classification of disability and health in health and health related sectors (WHO, 2001). This classification incorporates a biopsychosocial model of disability recognising that an integration of biological, individual and social dimensions in understanding disability.

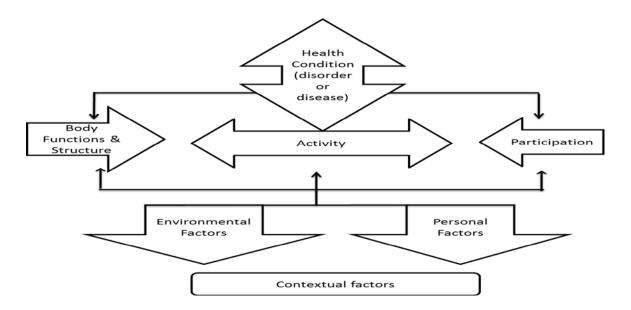


Figure 10.1 Adapted from the International Classification of Functioning, Disability and Health (WHO, 2001)

Whilst this international classification was developed in order to address the challenges of defining disability, there are still numerous issues for Bogart and Lund (2018) identify that not all individuals who would meet the criteria of having a disability under the ICF would self-identify as having a disability. Healthcare research by Morris *et al*, (2018) with all new outpatient visits at a clinic asked patients if they were disabled and those who responded yes were asked to describe their disability. Of the 14,908 participants who identified as having a disability; there was a difference in their categorisation of their disability. Adults tended to describe their disability in terms of activity limitation (56%) whereas children tended to describe a diagnosis (83%). In contrast, research by Eccles *et al*, (2018) in a higher educator sector identified that many higher education students also experienced difficulty in identifying what is meant by disability and as a consequence did not self-identify as disabled on university application forms. Their difficulties related to three different areas; firstly, they had normalised their 'disability' seeing it as part of who they are and therefore did not perceive it as a disability; secondly, they struggled with identifying the range of

impairments together as a disability often viewing disability in terms of traditional physical impairments such as being blind or being a wheel chair user rather than chronic illnesses. Lastly, the students identified discomfort in identifying a disability to others due to fear of stigmatisation. Not only are their issues with individuals self-identifying as disabled, but a scoping review by Gulley *et al*, (2018) exploring how disability and chronic conditions are defined and measured in healthcare access, quality utilisation and costs from a professional perspective identified that disability tended to be assessed through a variety of functional assessments such as activities of daily living and functional limitations whilst chronic illness were defined by the existence of a medical diagnosis. What these studies identify is that individuals living with a condition and/or the health and social care professionals working with them may perceive their disability status differently and this can influence the degree of support and services received. Moving forwards, Gully *et al*, (2018) argues there needs to be more focus on the development of assessment methods which account for both chronic illness and disability.

Not only are there challenges related to the identification of a disability, the ICF model still largely perceives disability as an issue or challenge to be resolved. This linking of a disability as a negative constraint can result in the person with the disability being perceived as 'less' than other people (Ellis-Hill *et al*, 2008). Recently, this notion of perceiving disability negatively has been challenged through the introduction of the Affirmative model of a disability. Swain and French (2000, p569) define this as '...essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experience of

being impaired and disabled'. Arguing that rather than perceiving disability as a negative tragedy it could be seen as a blessing which enable individuals to be more fully themselves (Goble, 2010). This affirmative model is developing traction, largely in challenge to the continued negative perceptions of a disability.

## Wider social influences and disability

In order to fully appreciate the wider factors that can influence a person's experience of living with a disability let's explore the experience of two older people (see case studies 10.1 and 10.2).

## Case Study 10.1

Peter is an 85 year old gentleman living with his wife and extended family in an urban area. Peter lives in a four bedroom house which was the family home; down the road live Peter's children and grandchildren and they regularly visit Peter and his wife. Peter is a retired GP who is enjoying an active retirement, playing golf, attending his local sailing club as well as being an active member of his local church. Peter's wife Mary has become increasingly concerned regarding Peter's health as he has recently lost weight and has reduced energy levels resulting in him feel unable to go out and attend his local groups and activities. Peter has also recently become unsteady on his feet and has fallen recently. He has been seen by his GP who has diagnosed Peter to be at risk of falls and frailty.

## Questions:

1. What factors influence Peter's current ability to remain living at home?

2. What support do you feel that Peter needs?

## Case Study 10.2

Mary is an 87 year old widow living alone in a very remote rural community. Mary lives alone in a three bedroom house. Mary admits to feeling isolated at times, as many of her friends from the village have passed away and she finds is difficult to walk the 10 minutes' walk into the village. Mary has two children but they live around a two hour drive away and whilst they try to visit regularly, they also work full time. Mary used to be a part-time cook in the village school and she will often talk about missing her work, the companionship of the other women and seeing the children at the school. Mary's next door neighbour tries to pop in at least three times a week to check on Mary. He is concerned that she is not eating and is spending more time in her nightgown and sleep on the sofa. He calls the GP as Mary had fallen during the night sustaining a laceration to her lower right leg. The GP visits with the District Nurse, he feels that Mary is becoming increasingly frail and is at risk of falls.

#### Questions:

- 1. What factors influence Mary's current ability to remain living at home?
- 2. What support do you feel that Mary needs?

It is evident from reviewing the example of Peter and Mary that both have experienced the same symptoms (weight loss, increased tiredness and falls) and could be identified as frail. Frailty is defined as a progressive ageing related, multi-system clinical state characterised by loss of physiological reserves and diminished capacity to withstand exposure to stressors (Gibson and Crowe 2018). However the management of these cases may be very different, in that it is more likely that Peter will remain at home whilst it is more likely that Mary may require additional support. Frailty is an increasing disability experienced in old age. It is these wider personal and environmental factors in the International Classification of Functioning, Disability and Health (WHO 2001 figure 10.1), that need to be explored further. Within public health there has been recognition of the wider social factors that impact upon health. Whilst there are numerous models exploring this, the most commonly used is that of Dahlgren and Whitehead 1991 (Public Health England, 2017), see figure 10.2

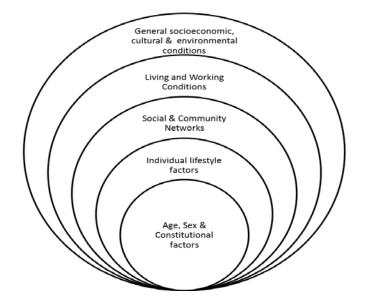


Figure 10.2 Adapted from Dahlgren and Whitehead 1991 cited Public Health England 2017

Fig 10.2 consists of five concentric circles. At the heart of the model is personal biological factors such as age, sex and constitutional factors; both Peter and Mary are of a similar age (85 and 87), an age group where 9% experience frailty, although Mary, as a woman, is more likely to experience frailty (Clegg *et al*, 2013). Looking at the individual lifestyle factors, Peter lives with his wife whereas Mary lives alone and admits to feeling socially isolated at times. Research by Gale *et al* (2018) with 2187 people aged over 60 highlighted that social isolation

was more common in those who were older, less educated and less wealthy resulting in an increased risk of physical frailty. In aspects of living and working conditions, whilst both are retired their working lives would have impacted on their finances in their retirement. For example, there is a significant difference in the wages Mary would have earned as a part-time school cook compared to Peter as a partner in a GP practice. Part time work is estimated to result in a 47% reduction in women's pensions (Now Pensions 2019), so it is more than likely that Mary has less disposable income to spend on leisure activities resulting in reduced social contact as well as reduced physical activity, both of which perpetuate frailty. In terms of the social and community networks not only is Mary more socially isolated than Peter she also lives in a rural area, which often have less public transport than in urban areas making it more difficult for her to get out in her local community. Within the general socioeconomic and cultural as well as the financial difference previously mentioned, Peter as retired GP will have a better understanding of navigating health services in comparison to Mary.

As health and social care professionals it is really important that we consider the impact of these wider social factors and how this can influence very different experiences even though an adult may have the same 'disability'. It is also important that we spend time assessing parents/carers knowledge and understanding of statutory services; as health and social care personnel it is easy to forget how complex the interplay of such services are and this can result in significant confusion for the lay public. A key aspect of our role is educating and sign posting to other statutory services.

#### Discrimination, Disability and Health Inequity

People with disabilities are one of the most socially disadvantaged groups experiencing disadvantage (Bigby *et al*, 2018; Palad *et al*, 2016). In order to address this 2006 saw the introduction of the Convention on the Rights of Persons with Disabilities ((CRPD) United Nations, 2006). This convention promoted full integration of people with disabilities within society and asserted the importance of international collaboration in addressing the rights of persons with disabilities. To date, 177 countries have ratified the CRPD, which carries the force of national law (World Bank, 2018). Within the CRPD there were eight agreed principles regarding the rights of people with a disability including:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- 2. Non-discrimination;
- 3. Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- 5. Equality of opportunity;
- 6. Accessibility;
- 7. Equality between men and women;
- 8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

In 2014, the Global Disability Action Plan 2014–2021: Better Health for all People with Disability (WHO 2015) was published, this has an overall goal of achieving health, wellbeing and human rights for people living with a disability.

In spite of these global action plans there is a wealth of evidence that people with disabilities experience discrimination and inequity. With regards to education, despite similar educational aspirations between disabled and non-disabled young people (Burchardt, 2005), there are educational attainment gaps in that young people with a disability are less likely to complete secondary level education than their non-disabled counterparts (Male and Woden, 2017). This gap in educational attainment of young people with a disability has long term effects of their lives as adults, in that adults with a disability are twice more likely to be unemployed than their non-disabled counterparts (Vornholt *et al*, 2018). This has significant long-term health implications as the link between formal education and improved health is well established (Baker *et al*, 2011) as well as implications for long term financial security and pensions as well identified earlier.

In health, article 25 of the CRPD specifically focuses upon the rights of people with a disability to attain the highest standard of healthcare (United Nations, 2006). Notwithstanding this, people with disabilities are more likely to seek access to healthcare yet conversely report greater unmet health needs (WHO, 2018) resulting in higher morbidity and rates of premature death (Tracy and McDonald, 2015). Sakellariou and Rotarou (2017) highlight that people with a disability experience worse access to healthcare due to physical and attitudinal barriers (Hanon and Payne, 2017). These have resulted in reduced access to screening for common cancers including prostate, cervical, breast and bowel (Merten *et al*, 2015). Not only are there issues with accessing health care but experiences of care are also worrying. Numerous reports have examined poor care experiences of people living with a disability in health and social care including Death by indifference (Mencap, 2007), Six Lives (Parliamentary and Health Service Ombudsman, 2009) and Winterbourne View (Department

of Health, 2012); all of these reports highlight significant failures in health and social care which resulted in people with a disability experiencing suffering, abuse and inappropriate care. More recently, a systematic review of exploring hospital experiences of people with an intellectual disability highlighted that despite 20 years of research and government initiatives little has changed and that people with a disability still have poor experiences of hospital care (lacono *et al.* 2014).

### Application to social work professional practice

We have previously explored the recent shift towards the affirmative model of disability promoted by disability writers and activists, yet this has yet to integrate fully into mainstream societal thought. Largely the predominate perceptions of disability remain negative, perceiving disability as a slowing action, a lack of independence and impairment (Friedman and Owen, 2017) and this perception of a disability can have a direct impact upon health and social care professionals response to the disability. Focussing upon the negative attributes of a person highlights their vulnerability and in doing so their risk to harm (Heaslip and Hewitt-Taylor, 2014). Professional responses therefore tend to focus on the amelioration of risk and protection of the person, making them safe and making decisions for them. Consequences of this are a reduction in the ability of the individual to self-assess and manage their own risk, a reduction in their personal autonomy and reduction of their citizenship. They became 'something' which must be protected rather than 'someone' with an equal voice. A scoping review of empirical research published by social work authors in Australia identified that social work research tends to focus upon the negative attributes of a disability continuing to describe the problem, drawing attention to the disadvantaged

position and service inadequacies whilst very few research studies have tested the efficacy of interventions or evaluated services model (Bigby *et al*, 2018). There is a need to move away from such paternalistic practices towards more inclusive person centred practices which value and promote the individuals voice. Goble (2010) identified that in order to achieve this practices much focus on:

- 1. A dialogue based approach, drawing on the expertise and experience of individuals in constructing joint narratives about their health.
- 2. A strengths and abilities focus, focussing on strengths, and capabilities rather than deficit and weakness to create opportunities for engagement.
- 3. Creating a collaborative culture, focussing on communication which foster positive inclusive relationships

In a dialogue based approach, there is a need to recognise the expertise of individuals who are living with a disability. Examples of this can include the inclusion of individuals in the training and education of health and social care professionals as this can directly challenge hidden beliefs, values and stereotypes of individuals living with a disability, as the person with the disability is presented as the expert rather than the human service professional. Key to this is the focus and recognition of the need to focus upon strengths, and capabilities of individuals rather than deficit and weakness and elegantly challenging discriminatory beliefs and values. This serves to create a culture of collaboration, however here there is a need to focus on positive communication which develops inclusive relationships. This positive communication has to include all individuals living with a disability so needs to include a variety of communication techniques such as verbal, non-verbal and appropriate assistive technology ensuring participation of all parties. Key to this is both the valuing and accepting of the others lifeworld. Ellis-Hill *et al* (2008) developed a life thread model which can be used to understand the lived experience of a disability. In this model she explains that "life threads represent the variety stories that we tell about ourselves. They represent past memories and future plans" (p152). Some life threads remain consistent such as roles (e.g. daughter, granddaughter) but others are transient for example winning a football match aged 10 whilst significant then may not remain so in 59 years' time. It is these life threads which create our sense of identity, our understanding of our current situation as well as our future possibilities, however these threads are not fixed as one's sense of identity is constantly shifting influenced by societal interactions and life experiences. In this model we see much more of a holistic picture of the experience of living with a disability. For example someone living with a disability as a result of a traumatic event can find that their life threads become broken as people find themselves redefining who they are and who they will be in the future (Ellis-Hill *et al*, 2008). Consider for example the fictional story of Still Alice (Case study 10.3)

## Case Study 10.3

Still Alive is a movie based upon the book written by Lisa Genova. In this story, Dr Alice Howland, a linguistic university professor at Columbia University who finds herself forgetting words and becoming increasingly disorientated in her daily life. Throughout the film and book you follow Alice's life through her story as she finds herself with a diagnosis of early onset Alzheimer's shortly after her 50<sup>th</sup> birthday. In this you see how her previous life threads were tied in with her cognitive and linguistic capabilities, her job, her role, the academic papers she has written, yet her life threads shift as she becomes aware of her

diagnosis and deteriorating condition; she finds herself having to redefine who she is in the present as well as coming to terms that this redefinition will also shift as her cognition declines.

#### Questions:

- Consider yourself and your life threads, how do you define yourself and what is important to you
- 2. Consider how you would feel if you found yourself forgetting your words, feeling lost in your own home and losing your sense of who you were

Ellis-Hill et *al* (2008) argues that it is vital that we, as health and social care professionals, respond to adjusting life threads by respecting personhood and enabling people to tell their stories. In this we recognise we may not be able to resolve the issues the person is experiencing or indeed make the situation better yet Ellis-Hill *et al* (2008, p156) argues it is equality important that we listen and enable people to tell their stories, we recognise that 'being with somebody is just as important as doing something for them'.

This chapter has considered wider definitions of disability and examined how some of the current discourses surrounding disability have emerged through society's historical treatment of adults with a disability. It is these wider influences that have resulted in adults living with a disability experiencing health inequities and this is, in part, perpetuated by attitudes towards them. Lastly, different ways in which we as health and social care professionals can strengthen the ways in which we work with adults living with a disability to value them as equal partners have been presented. The reflective questions posed next provide you with an opportunity to consider your personal values, beliefs and practices

when working with people with a disability as well as the service in which you work and how this could be developed to ensure for equitable provision.

## **Reflexive Questions**

- 1. Consider the words that spring to mind when you think of disability and what does this tell you regarding your definition of a disability and what has influenced this?
- 2. Reflect upon your experiences of adults with a disability through personal/professional exposure or what you have seen through media such as television and films. What has been the predominant presentation of the person with a disability?
- 3. Critically reflect upon the degree to which your assessment process captures the wider determinates of health and how this can influence the experience of the individual. How much of your service actually addresses the wider issues?
- 4. Consider the service in which you work, what services are in place to ensure that the voices of people with a disability are heard in service development and enhancement. How could you develop this further to include the voices of people who may have a communication difficulty?

## **Further Reading**

 Read more on the Life Thread Model and explore how this can influence your practice and that of your colleagues – see Ellis-Hill, C., Payne, S., Ward, C., 2008. Using stroke to explore the Life Thread Model: An alternative approach to understanding rehabilitation following an acquired disability. *Disability and Rehabilitation* 30(2) 150-1594-5

- Read more about discrimination and disability exploring why people with a disability experience discrimination and the impact it has upon them - see - see Temple, J., Kelaher, M., and Williams, R., (2018) Discrimination and avoidance due to disability in Australia: evidence from a National Cross Sectional Survey. *BMC Public Health* 18:1347 <u>https://doi.org/10.1186/s12889-018-6234-7</u>
- 3. Read the Convention on the Rights of persons with a disability and critically question the degree to which this is having an impact on the individual lives of adults living with a disability – see United Nations., 2006. Convention on the Rights of Persons with Disabilities. Available from https://www.un.org/development/desa/disabilities/convention-on-the-rights-ofpersons-with-disabilities.html
  - Read the ICF see World Health Organization. 2001. The International Classification of Functioning, Disability and Health (ICF). Geneva, WHO available from <a href="http://www.who.int/classifications/icf/en/">http://www.who.int/classifications/icf/en/</a> additional reading thoughts

## References

- Baker, D., Leon, J., Smith Greenway, E., Collins, J., and Movit, M. (2011). The education effect on population health: a reassessment. *Population and Development Review* 37(2), 307–332.
- Bigby, C., Tilbury, C., and Hughes, M. (2018). Social work research in the field of disability in Australia: a scoping review. *Australian Social Work* 71(1), 18-31.
- Bogart, K., and Lund, E. (2018). Disability pride protects self-esteem through the rejectionidentification model. *Rehabilitation Psychology* 63(1), 155-159.

Bunning, K., Gona, J., Newton, C., Hartley, S., (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PLoS One*. 2017; 12(8): e0182214.
doi.org/10.1371%2Fjournal.pone.0182214

- Burchardt, T. (2005). *The education and employment of disabled young people*. Joseph Rowntree Foundation; Bristol.
- Clegg, A., Young, J., Rikkert, MO., and Rockwood, K., (2013). Fraility in elderly people. *Lancet* 2; 381(9868):752-62. doi: 10.1016/S0140-6736(12)62167-9
- Department of Health (2012). *Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report.* Department of Health: London
- Eccles, S., Hutchings, M., Hunt, C., and Heaslip, V. (2018). Risk and Stigma: Students' Perceptions and Disclosure of 'disability' in Higher Education. *Widening Participation and Lifelong Learning* (Forthcoming).
- Ellis-Hill, C., Payne, S., and Ward, C. (2008). Using stroke to explore the Life Thread Model: An alternative approach to understanding rehabilitation following an acquired disability. *Disability and Rehabilitation* 30(2), 150-159.
- Friedman, C., and Owen, A. (2017). Defining Disability: Understandings of and Attitudes towards Ableism and Disability. *Disability Studies Quarterly*, 37(1), 2.
- Gale, C., Westbury, L., and Cooper, C., (2018). Social isolation and loneliness as risk factors for the progression of frailty: the English Longitudinal Study of Ageing. *Age Ageing*, 47(3), 392–397
- George, J., and Martin, F. (2016). *Living with long term conditions*. British Medical Association: London.

- Gibson, J., and Crowe, S., (2018). Frailty in Critical Care: Examining implications for clinical practices. *Critical Care Nurse 38*(3), 29-35.
- Goble, C. (2010). Celebrating disability (chapter 5; 55-65). In Gaine, C., Equality and Diversity in Social Work Practice. Learning Matters; Exeter.
- Goodwin, N., Curry, N., Naylor, C., Ross, S., and Duldig, W. (2010). *Managing people with long-term conditions*. Kings Fund: London.
- Gulley, S., Rasch, E., Bethell, C., Carle, A., Druss, B., Houtrow, A., Reichard, A., and Chan, L.
  (2018). At the intersection of chronic disease, disability and health services research:
  A scoping literature review. *Disability and Health Journal* 11 (2), 192-203.
- Hanon, E., and Payne, D. (2017). Cervical screening for women with physical disabilities. *Kai Tiaki Nursing New Zealand* 23(11), 22-44.
- Heaslip, V., and Hewitt-Taylor, J. (2014). Vulnerability and risk in children living with a physical disability. *Nursing Children and Young People* 26(10), 24-29.
- Historic England. (2018). A history of Disability from 1050 to the present day. Available from <a href="https://historicengland.org.uk/research/inclusive-heritage/disability-history/">https://historicengland.org.uk/research/inclusive-heritage/disability-history/</a> [accessed 11<sup>th</sup> October 2018].
- Hosseinpoort, A., Bergen, N., Kostanjsek, N., Kowal, P., Officer, A., Chatterji, S., (2016). Socio-demographic patterns of disability among older adult populations of lowincome and middle-income countries: results from World Health Survey. International Journal of Public Health 61; 337-345
- Iacono, T., Bigby, C., Unsworth, C., Douglas, J., and Fitzpatrick, P. (2014). A Systematic
   Review of Hospital Experiences of People with Intellectual Disability. *BMC Health Services Research* 14, 505. Available from <a href="https://doi.org/10.1186/s12913-014-0505-5">https://doi.org/10.1186/s12913-014-0505-5</a>
   [accessed 19th November 2018].

Larkin, M. (2009). Vulnerable groups in Health and Social Care. Sage: London.

- Male, C., and Wodon, Q. (2017). The price of exclusion: Disability and Education, disability gaps in educational attainment and literacy. Global Partnership for Education.
   Available from <a href="https://www.globalpartnership.org/download/file/fid/61180">https://www.globalpartnership.org/download/file/fid/61180</a>
   [Accessed 17<sup>th</sup> October 2018].
- Merten, J., Pomeranz, J., King, J., Moorhouse, M., and Wynn, R. (2015). Barriers to cancer screening for people with disabilities: A literature review. *Disability and Health Journal* 8(1), 9-16.
- Millward, G. (2017). 'A matter of common sense': the Coventry poliomyelitis epidemic 1957 and the British public. *Contemporary British History* 31(3), 384–406.
- Morris, M., Inselman, J., Rogers, J., Halverson, C., Branda, M., and Griffin, J. (2018). How do patients describe their disabilities? A coding system for categorizing patients' descriptions. *Disability and Health Journal* 11(2), 310-314.
- Now Pensions (2019). *Facing an unequal future: Closing the gender pensions gap*. London: Now Pensions.
- Palad, Y., Barquia, R., Domingo, H., Flores, C., Padilla, L., and Ramel, J. (2016). Scoping review of instruments measuring attitudes toward disability. *Disability and Health Journal* 9(3), 354-374.
- Parliamentary and Health Service Ombudsman (2009). *Six lives: the provision of public services to people with learning disabilities*. Stationary office; London.

Public Health England (2017). *Health profile for England*, available from:

https://www.gov.uk/government/publications/health-profile-for-england/chapter-6social-determinants-of-health [accessed 13th October 2018].

- Sakellariou, D., and Rotarou, E.S. (2017). Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data. *BMJ Open* 7:e016614. doi:10.1136/bmjopen-2017-016614.
- Swain, J., and French, S., (2000) Towards an Affirmation Model of Disability. *Disability & Society*, 15(4), 569-582.
- Temple, J., Kelaher, M., and Williams, R., (2018) Discrimination and avoidance due to disability in Australia: evidence from a National Cross Sectional Survey. BMC Public Health 18:1347 https://doi.org/10.1186/s12889-018-6234-7
- Tracy, J. and McDonald, R. (2015). Health and disability: Partnerships in healthcare. *Journal of Applied Research in Intellectual Disabilities* 28(1), 22–32.
- United Nations (2006). *Convention on the Rights of Persons with Disabilities*. Available from <a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html</a> [accessed 11th October 2018].
- Vornholt, K., Villotti, P., Muschalla, B., Bauer, J., Colella, A., Zijlstra, F., Van Ruitenbeek, G., Uitdewilligen, S. and Corbiére, M. (2018). Disability and employment – overview and highlights. *European Journal of Work and Organizational Psychology* 27(1), 40-55.

World Health Organisation (2019). Disability and Health.. Available from

https://www.who.int/news-room/fact-sheets/detail/disability-and-health [accessed

17.09.2019]

World Bank (2018). Disability Inclusion. Available from:

https://www.worldbank.org/en/topic/disability [accessed 11th October 2018].

World Health Organisation (2018). Disability and Health. Available from

http://www.who.int/news-room/fact-sheets/detail/disability-and-health [accessed

17th October 2018].

World Health Organisation (2015). WHO Global Disability Action Plan 2014-2021; Better health for all people with disability. Available from

https://www.who.int/disabilities/actionplan/en/ [accessed 18<sup>th</sup> September 2019]

World Health Organisation (2011). World Report on Disability. Geneva, World Health

Organisation.

World Health Organisation (2002). *Towards a Common Language for Functioning, Disability and Health*. Geneva, World Health Organisation.

World Health Organization (2001). *The International Classification of Functioning, Disability and Health (ICF)*. Geneva, WHO available from

http://www.who.int/classifications/icf/en/ [accessed 11<sup>th</sup> October 2018].