People with intellectual disabilities

This opening chapter is designed to sketch some of the terrain concerning people with intellectual disabilities before we begin to discuss health inequalities and public health approaches to the health of people with intellectual disabilities in the following chapters. We begin by outlining the major ways in which the construct of intellectual disability has been understood and operationalised, and discuss the implications of these different ways of understanding intellectual disability for how the health inequalities experienced by people with intellectual disabilities are to be understood and addressed. We describe the major issues concerned with identifying and classifying intellectual disability, followed by an overview of the research concerning the epidemiology and causes of intellectual disabilities.

Understanding intellectual disability

Frameworks for understanding disability in general and intellectual disability in particular are constantly developing and hotly contested (Buntinx and Schalock, 2010; Officer and Groce, 2009; Open Society Institute, 2006; Thomas, 2007). It is important to sketch out how different frameworks conceptualise intellectual disability, as they have very different implications for how we understand the health inequalities experienced by people with intellectual disabilities and what can and should be done about them.

The medical model

Within high-income countries (and within some low- and middle-income countries too; see Emerson, Fujiura and Hatton, 2007), the dominant framework for understanding disability in the last 100 years has been what has been described as the ‘medical’ or ‘individual’ model (World Health Organization, 2001). This characterises the inequalities experienced by people with intellectual disabilities (for example in the areas of work or health) as an inevitable function of the long-standing ‘deficits’ located within individuals. In this model, the duty of society is to
work towards the eradication or prevention of the conditions ‘causing’ intellectual disabilities (for example, through genetic screening programmes), to work on rehabilitating individuals to reduce the magnitude of their ‘deficits’, and to ‘care’ for this section of the population in comfortable conditions. Notions of striving for social justice through notions of social equality do not apply here as they are viewed as unrealistic, unachievable and irrelevant to the societal tasks at hand.

The social model

In explicit contrast to the medical model is the social model of disability (Stalker, 2012; Thomas, 2007). The social model makes a conceptual distinction between impairment (an injury, illness or condition that is associated with long-term differences and/or limitations in potential functioning) and disability (the economic, social, physical and cultural barriers that exclude people with impairments from fully participating in society as equal citizens). This model characterises the inequalities experienced by people with intellectual disabilities as the expression of societal oppression and exclusion rather than being the inevitable consequence of a person’s impairment. Therefore political action is required to eradicate the economic, social, physical and cultural structures and processes that oppress people with intellectual disabilities, and to ensure that human rights are afforded to people with intellectual disabilities (Barnes, 2012). It is important to note that the social model is primarily a framework for political change rather than a fully elaborated theory (Barnes, 2012), and there are current debates about the importance or otherwise of recognising the ‘reality’ of impairments and the direct and indirect effects they may have on a person’s health and well-being (Stalker, 2012; Thomas, 2007).

The biopsychosocial model

Various attempts have been made to reconcile the medical and social models, the most influential of which is the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (World Health Organization, 2001, 2007b). Despite the medical and social models being in explicit conflict with each other, the ICF ‘is based on an integration of these two opposing models’ (World Health Organization, 2001; p.20).

In the ICF, functioning and disability are conceptualised in terms of the complex interplay between bodily functions/structures (and the immediate impairment effects of these), activities (and activity limitations), participation (and participation restrictions) and environmental factors. Environmental factors (such as living conditions, social attitudes and practices, service systems and policies) are explicitly recognised as having a crucial effect on a person’s functioning and social participation (or social inclusion). As such, disability arises when people with impairments are confronted by social conditions (or environmental barriers) that reduce their everyday activities and/or social participation (World Health Organization, 2001). Disability is not seen as a characteristic of a person.
Chapter 1: People with intellectual disabilities

Neither is it seen as an inevitable consequence of a particular disease or health condition. Rather, it is viewed as a socially determined outcome resulting from the operation of disabling and discriminatory cultural, social and environmental conditions.

The ambition of the ICF is to create an overarching framework, or 'language', within which the full complexity of disabled people's lives can be captured and classified. However, in spirit and operation the ICF can resemble a medical model on to which social model aspects have been grafted. For example, the construct of human rights is not an integral part of the ICF framework (Bickenbach, 2012). Furthermore, the very complexity of the ICF does not readily lend itself to the identification of clear priorities for identifying and eliminating the inequalities experienced by people with intellectual disabilities.

Mapping models of intellectual disability on to health and health inequalities

The models outlined above clearly conceptualise intellectual disability very differently, with very different actions recommended as a consequence. What do these models of disability have to say about health and health inequalities?

The medical model of disability is consistent with (and possibly arose from) a bio-medical model of health. Health is conceptualised as the absence of disease, where disease is created by physical causal agents (genes, bio-chemicals, damage to the body) leading to changes in the structure and function of the physical body and brain, with interventions (typically medication or surgery) directed to these physical agents. Because the medical model views intellectual disability itself as a series of functional deficits caused by physical causal agents, this model in effect fuses the constructs of impairment, disability and poor health/disease. For the medical model, reducing the health inequalities experienced by people with intellectual disabilities compared to others in society is an irrelevant goal – the goal is to reduce the poor health experienced by people with intellectual disabilities who will, however, always remain in poorer health than the general population.

The social model of disability views health inequalities as one expression or indicator of the oppressive ways in which societies treat people with intellectual disabilities. Although this is becoming increasingly contested (Barnes, 2012; Shakespeare, 2006), the social model makes clear conceptual distinctions between impairment, disability and health. An impairment is not inevitably equivalent to poor health or illness, although there is increasing discussion amongst disability studies theorists that there can be direct ‘impairment effects’, which have an impact on health (Scambler, 2012; Shakespeare, 2006; Thomas, 2007). Whilst the political action required by the social model to achieve equal civil rights and empowerment includes eliminating inequities in access to effective health services and changing societies to eliminate the disablism that can result in poorer health and well-being, achieving civil rights and empowerment would be the primary goal of the social model.
Chapter 1: People with intellectual disabilities

The biopsychosocial model of disability is consistent with a more holistic conception of health, such as that adopted by the World Health Organization: 'Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity' (World Health Organization, 1946). This definition emphasises health as positive well-being within a broad social context, rather than health as being the absence of disease within an individual. Using this holistic conception of health means that good health or poor health are distributed across the components of the ICF in terms of how bodily functions/structures (and the immediate impairment effects of these), activities (and activity limitations), participation (and participation restrictions) and environmental factors interact (Buntinx and Schalock, 2010). Biopsychosocial frameworks such as the ICF certainly allow for the identification of health inequalities (and would identify a much broader range of inequalities as falling within the 'health' domain compared with the medical model). The ICF, however, is studiously neutral on what the ultimate goals of policy and practice concerning the health of people with intellectual disabilities should be, and what the priorities are for achieving them.

The capabilities framework

An increasingly influential framework for documenting, understanding and addressing inequalities in society is the capabilities (or capability) framework (Nussbaum, 2011; Sen, 2001). The capabilities framework has arisen out of work on the economics of developing countries, with an original ambition to move beyond a country's Gross Domestic Product (GDP) as an indicator of how 'well' a country is developing. As many authors have pointed out (Nussbaum, 2011; Sen, 2001; Wilkinson, 2005; Wilkinson and Pickett, 2009), a nation with higher or rapidly increasing GDP can also be a nation with huge levels of inequality that suppresses the rights of its citizens.

The capabilities framework (or more properly frameworks, as its most high-profile proponents disagree on many aspects of the framework) has a number of characteristics that make it an encouraging approach for understanding the health and other inequalities experienced by people with intellectual disabilities and prioritising societal action to address these health inequalities. Still in development, there is increasing recognition that a capabilities framework may have substantial utility for disabled people generally (Burchardt, 2004; Wolff, 2011), including people with cognitive impairments (Nussbaum, 2009; Wolff, 2009).

As Nussbaum (2011) describes the central focus of a capabilities approach:
- The key question to ask, when comparing societies and assessing them for their basic decency or justice, is, 'What is each person able to do and to be?' In other words, the approach takes each person as an end, asking not just about the total or average well-being but about the opportunities available to each person.
Chapter 1: People with intellectual disabilities

- It is focused on choice or freedom, holding that the crucial good societies should be promoting for their people is a set of opportunities, or substantial freedoms, which people then may or may not exercise in action: the choice is theirs. It thus commits itself to respect for people’s powers of self-definition.

- The approach is resolutely pluralist about value: it holds that the capability achievements that are central for people are different in quality, not just in quantity; that they cannot without distortion be reduced to a single numerical scale; and that a fundamental part of understanding and producing them is understanding the specific nature of each.

- Finally, the approach is concerned with entrenched social injustice and inequality, especially capability failures that are the result of discrimination or marginalization. It ascribes an urgent task to government and public policy – namely, to improve the quality of life for all people, as defined by their capabilities (pp. 18–19; italics in the original).

It is important to note that capabilities are not synonymous with skills or abilities. For Nussbaum (2011), capabilities ‘are not just abilities residing inside a person but also the freedoms or opportunities created by a combination of personal abilities and the political, social, and economic environment’ (p. 20). Nussbaum calls these substantial freedoms or combined capabilities, as meaningfully exercising these capabilities requires both internal capabilities (states of the person amenable to change, including learned skills but also states such as self-confidence) and the social, political and economic conditions in which people can develop and apply their internal capabilities.

These combined capabilities are conceptually distinct from people’s basic capabilities (the ‘innate equipment’ that makes development possible). Because capability frameworks are focused on ‘What is each person able to do and to be?’ in terms of freedoms for each and every individual, no minimum threshold of basic capabilities is required and no one is excluded on grounds of cognitive impairment from the responsibilities of societies to facilitate the individual exercise of combined capabilities (Nussbaum, 2009; Wolff, 2009).

Combined capabilities are also conceptually distinct from functioning (how capabilities are realised in people’s lives). The exercise of self-determination via combined capabilities will result in different people choosing different ways of living their lives.

The capabilities framework and health inequalities

To make this rather abstract discussion more concrete, we will take as an example the inequalities in physical activity levels experienced by people with intellectual disabilities (Bartlo and Klein, 2011; Robertson et al., 2000b) and discuss how different models approach this issue.

The capabilities framework is centrally concerned with ensuring that each and every person with intellectual disabilities has the combined capabilities to exercise self-determination in terms of physical activity. This would include ensuring
that a person has been supported to develop relevant internal capabilities, such as knowledge about the health and other consequences of physical activity or inactivity, and self-efficacy in terms of perceived control over levels and types of physical activity. It would also include the person living throughout their life in environments that actively support and do not hinder the exercise of self-determination in relation to physical activity. For children, this may include local schools that facilitate a wide range of sports and other physical activities that would be accessible and potentially enjoyable to the person, interpersonal environments free of bullying or negative reactions to the person engaging in physical activity, and anti-poverty social policies to support families in facilitating physical activity for their children.

For the capabilities framework, the aim is for people with intellectual disabilities to be able to exercise substantial freedoms in terms of physical activity. Different people may make different choices in terms of the level and type of physical activity (so their functionings may be quite different), but it is crucial that they have not made these choices due to the curtailed development of their internal capabilities or unsupportive environments. It is also important to note that a person's basic capabilities will have an influence on how their combined capabilities are to be achieved (for example for a person in a wheelchair compared with an ambulant person), but the duty of societies aiming for social justice is to achieve combined capabilities for all people with intellectual disabilities.

This example highlights some of the strengths and challenges of the capabilities framework as applied to the health inequalities of people with intellectual disabilities.

First, there is a question about what we should measure to determine whether people with intellectual disabilities are living in a just society with regard to health. Some capability framework theorists argue that it is the combined capabilities or substantial freedoms that are crucial (Nussbaum, 2011) – that people with intellectual disabilities are in a position to genuinely exercise substantial freedom with regard to their health. This places capability frameworks firmly in line with human rights frameworks (Burchardt, 2008), where human rights can be seen as another way of describing important domains of substantial freedoms. It also means that capability frameworks are not compatible with quality of life approaches to evaluating the lives of people with intellectual disabilities, with their emphasis on assessing quality of life in hedonic and materialist terms (Hatton, 1998; Buntinx and Schalock, 2010). However, direct assessment and measurement of substantial freedoms (as with human rights) is notoriously difficult (Wolff, 2011).

Other authors using capability frameworks argue that we can see whether substantial freedoms are being exercised through the functionings that result from the combined capabilities that people have at their disposal (Wolff, 2011; Wolff and De-Shalit, 2007). This might be particularly relevant to the health of people with intellectual disabilities, where stark inequalities in functionings related to health are clearly visible. However, even if health functionings are taken as the end point, it is still crucial within a capability framework to understand how these
inequalities in health functionings have arisen (particularly by investigating people's internal capabilities and the social, political and economic conditions within which they live) to inform societal action. An attempt to operationalise a capabilities framework within a UK policy context recommends assessing capabilities in terms of autonomy, treatment (both aspects of substantial freedoms) and functionings (Burchardt and Vizard, 2011).

Second, capability frameworks are concerned with social justice as it applies to each and every individual, rather than an approach that is concerned only with inequality at an aggregate level (Wolff and De-Shalit, 2007). In terms of addressing the health inequalities of people with intellectual disabilities, this would not necessarily mean ensuring that the health functionings (or the combined capabilities) of this group as a whole were similar to those of the general population – a stated goal of many policies designed to reduce or eliminate health inequalities. Instead, it would mean ensuring that each and every person with intellectual disabilities met or exceeded minimum thresholds in terms of health functionings (Nussbaum, 2011). Achieving population equality would be inadequate if some people with intellectual disabilities did not meet minimum thresholds in terms of health, although there is debate about how such minimum thresholds should be set and whether they should be absolute or relative, for example when considering hardship and poverty (Wolff and De-Shalit, 2007). Of course, assessing health inequalities between people with intellectual disabilities and the rest of the population is important for understanding the scale and nature of disadvantage experienced by people with intellectual disabilities but, according to the capability framework, eliminating health inequalities is not necessarily the ultimate goal of social policy.

A third characteristic of capability frameworks is that they are pluralist about value – in other words, every domain of combined capabilities (or possibly functionings) is important in its own right, rather than being reducible to a single scale (Nussbaum, 2011). For example, both access to effective cancer screening services and healthy levels of physical activity are important for people with intellectual disabilities to experience, and achieving exceptional levels of physical activity would not absolve society of responsibility for accessible cancer screening services just because a pooled measure of 'health' averaging across these domains might turn out as satisfactory. In this sense it is clearly in opposition to quality of life approaches to assessing the lives of people with intellectual disabilities (Buntinx and Schalock, 2010), which explicitly include the facility to combine domain scores into a single quality of life index score for an individual. It also makes clear that there may be trade-offs or 'tragic choices' to be made between different capabilities in certain circumstances (Nussbaum, 2011): for example, the family of a child with intellectual disabilities may feel they have to make a trade-off between their child attending a segregated school and the child receiving no education at all if no inclusive education is available to their child.

Finally, additions to capabilities frameworks have highlighted additional concepts of potential value when understanding the health inequalities experienced...
by people with intellectual disabilities. This includes the concept of ‘capability security’ – individuals feeling secure that societies will not withdraw the supports and conditions essential to the achievement of substantial freedoms (Wolff and De-Shalit, 2007). For example, people with intellectual disabilities and their families may feel considerable anxiety about benefits and/or services being withdrawn, reducing the potential positive impact that they could make of current benefits and services (Wilkinson, 2005; Wolff, 2011). The same authors (Wolff and De-Shalit, 2007) also discuss the concept of ‘fertile functioning’ where one area of capability may promote others (for example, people with intellectual disabilities who are physically active may also be more socially connected and able to access employment), and the concept of ‘corrosive disadvantage’ where one area of unmet capability may block others (for example, people with intellectual disabilities who are depressed are blocked from enjoying a whole range of substantial freedoms in other domains).

Taken together, these central features of capability frameworks provide a potentially coherent and useful way of both understanding the health inequalities of people with intellectual disabilities and guiding public policy towards improving the public health of this group. A capability framework is compatible with the social model of disability, embedding the central insights of the social model within a broader conceptual framework without losing the political importance of striving for social justice (Burchardt, 2004). It is also compatible with human rights approaches, again embedding human rights within a broader conceptual framework whilst retaining the importance of individual and indivisible human rights (Burchardt and Vizard, 2011). In contrast with both the medical model and the ICF, capability frameworks are explicitly concerned with social justice and the responsibility of societies to ensure that each and every individual is in a position to exercise substantial freedoms. The emphasis on the importance of each dimension of substantial freedoms and on these freedoms themselves also makes capability frameworks incompatible with quality-of-life approaches.

Which capabilities are important?

An essential part of the capabilities framework is trying to determine which capabilities are the central ones for people with intellectual disabilities, with capability theorists taking different approaches. Nussbaum (2011) has developed ten ‘central capabilities’ from a priori philosophical principles, which she argues apply to all humans. In contrast, Sen (1999) argues that central capabilities should be determined democratically in response to societal concerns, although he does recognise that this may lead to capabilities that are ‘trivial’ or even ‘bad’. Hybrid approaches have also been tried; these start with a set of capabilities derived from human rights principles then empirically develop these capabilities through processes of deliberative consultation (Burchardt and Vizard, 2011; Wolff and De-Shalit, 2007).
Chapter 1: People with intellectual disabilities

As far as we are aware, the development of a specific set of central capabilities for people with intellectual disabilities has not been attempted, although there has been a substantial international research effort to develop quality-of-life domains for disabled people generally (Power, Green and Grp, 2010) and people with intellectual disabilities in particular (Wang et al., 2010; Claes et al., 2010), and a set of central human rights for disabled people has also been developed (United Nations, 2006b).

Table 1.1 below presents an initial attempt at a crosswalk comparing the central domains of life proposed in: (1) quality-of-life models for people with intellectual disabilities and disabled people generally; (2) the UN Convention on the rights of persons with disabilities; (3) Nussbaum's ten central capabilities; and (4) the 'valuable capabilities' developed partly empirically with members of the public in the UK. This definitively non-definitive crosswalk aims to comparatively map the major central domains of life as described by each approach, although many of the major central domains (and particularly the sub-domains described as constituting them) are described and grouped in ways that make this difficult.

Nevertheless, there is considerable consistency across these approaches, particularly at the level of sub-domains. For our purposes, there is a clear recognition across all the approaches of the importance of good health, in terms of not dying prematurely and experiencing good bodily health and emotional well-being. Despite differing emphases, there are also considerable commonalities in other central domains of life that could be considered as the internal capabilities and social, political and economic conditions that facilitate good health, such as good interpersonal relationships, legal security and equality before the law, material well-being, inclusion as a full member of society, having a productive role in society, and being supported to achieve substantial freedoms in terms of knowledge, skills and the capacity for meaningful self-determination. These broader factors that facilitate (or hinder) the exercise of substantial freedoms in terms of health are as much of a concern as access to effective health services for those seeking to improve the health of people with intellectual disabilities.

A recent attempt to operationalise central capabilities within a UK policy context, building on the ten 'valuable capabilities', suggests the adoption of 'spotlight indicators' (Alkire et al., 2009; Burchardt and Vizard, 2011). These are pragmatic, in that they are typically based on statistics already being collected, and they are not designed to be comprehensive across all aspects of the valuable capabilities or across the three aspects of capabilities they propose to assess (autonomy, treatment and functionings). Potential spotlight indicators for England that directly assess health capabilities and that are potentially relevant to people with intellectual disabilities are listed in Table 1.2. However, it should be noted that almost all the other spotlight indicators can be considered as either internal capabilities of the person or aspects of the person's social, economic and political conditions, all of which will have a profound effect on the person's autonomy, treatment and functionings in relation to health.
Table 1.1 Central domains of experience according to: (1) quality-of-life framework for people with intellectual disabilities; (2) World Health Organization (WHO) quality-of-life framework including a disability module; (3) UN Convention on the Rights of Persons with Disabilities; (4) the ‘central capabilities’ derived by Nussbaum from fundamental principles; and (5) the ‘valuable capabilities’ developed for the Equality and Human Rights Commission (EHCR) on the basis of codified human rights and a deliberative consultation process

<table>
<thead>
<tr>
<th>Central domains of life (with sub-domains) according to each approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>QoL for people with intellectual disabilities (Wang et al., 2010; Claes et al., 2010)</td>
</tr>
<tr>
<td>Overall QoL derived from combining subjective and objective QoL scores in each sub-domain</td>
</tr>
<tr>
<td>Physical well-being, health (functioning, symptoms, fitness, nutrition)</td>
</tr>
<tr>
<td>Activities of daily living (self-care, mobility)</td>
</tr>
<tr>
<td>Healthcare</td>
</tr>
<tr>
<td>Leisure (recreation, hobbies)</td>
</tr>
</tbody>
</table>