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1

Understanding intellectual disability

The most fruitful distinction with which the sociological imagination works is between ‘the personal troubles of the milieu’ and the public issues of social structure. (Wright Mills, 1970, p. 14)

Disability is always an interaction between individual and structural factors. Rather than getting fixated on defining disability either as a deficit or a structural disadvantage, a holistic understanding is required. The experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself. (Shakespeare, 2006, p. 55)

Intellectual disability is the contemporary term that describes the phenomenon that has also been known as learning disabilities, mental retardation, mental handicap, idiocy, subnormality, and mental deficiency. Most people will have an immediate and common-sense understanding of intellectual disability and who people with intellectual disabilities are, based on their own particular life experiences. This chapter aims to move beyond such common-sense notions, derived from personal experience, the media, film, or fiction and explore a little further the meaning of intellectual disability. It will look at questions such as: What is intellectual disability? Does it have a basis in reality? How is it socially created and constructed in western society at the beginning of the twenty-first century? By unpacking the complexity of intellectual disability, it aims to show social workers that the experiences of people with intellectual disability can be understood both as the personal troubles of the milieu and the ‘public issues of social structure’ (Wright Mills, 1970, p. 14); and to help them recognize that just as in any other field of social work practice, there are multiple ways to work, at both the individual and structural levels to redress disadvantage, improve quality of life and bring about social change to reduce discrimination and oppression that result from the ‘social problem’ of intellectual disability.

In understanding the nature of intellectual disability, it is crucially important not to conflate this characteristic with a person's whole being. As the self-advocacy movement points out, people with intellectual disability are People First, each has his or her own unique personality, experience of emotions, and potential for development. Most importantly, people with intellectual disabilities have the same intrinsic human worth and rights as all other citizens. Though people with intellectual disability share some common characteristics, they are a diverse rather than homogenous group, which includes people with a wide spectrum of impairments and abilities 'from people who, with some gentle support are able to earn their own living, or at least live pretty independent lives, to people who require assistance with the most basic tasks of living – eating, moving, communicating' (Walmsley & Welshman, 2006, p. 6). This diversity is illustrated by the three vignettes about Dominic, Grace, and James.

Dominic

My name is Dominic. I am 18 years of age and live with my mother. I was born in a small country town, my mother was a single mother and apparently the birth was not easy and I was premature. Before my mother took me home from hospital the doctors told her it was likely that I would be blind but they could not be sure at such a young age. As the days and months passed it was clear to my mother I could not see but the doctors said there was nothing that could be done to help me, they would just have to wait and see how I developed. In these early years my mother also noticed that I wasn't doing the things that other babies were doing. I was not making any sounds, I didn't feed very well and I cried a lot. Over time it was clear that I could not see and I was not learning how to talk. My mother took me to lots of doctors and other health professionals but nobody could say what was 'wrong' with me. I was definitely visually impaired but nobody could assess how much or what I could see because I could not speak. I have no verbal language just a range of sounds, people who know me well can understand what feelings I am expressing with these sounds and what they mean. I have been called autistic, mentally retarded early on and now intellectually disabled. My mother says I am 'differently able' and my level of disability depends on how well my immediate environment suits me and how well people understand me. I can't look after myself at all and do not know much about what is going on around me. I need help with dressing, bathing and all other everyday things and do not make decisions for myself. Even though I am 18 I still love to jump on the trampoline. I also enjoy listening to and humming along to music, walking and moving along fast like on a bike that someone else is riding and the smell of different foods cooking. I love to be with my mother and she spends a lot

of time with me doing the things I like. I don't really relate that well to other people but if they are like my mother, patient, softly spoken and able to guess how I am feeling I am usually pretty happy. I don't like having to do things but I don't like being left with absolutely nothing to hear, smell or feel.

Grace

I have Down's Syndrome my name is Grace. I know other people with Down's Syndrome and they are not much like me apart from some physical features like the shape of our eyes, the gap between our big and second toes, the line down the middle of our palms our large tongues and the fact that most of them like me are called intellectually disabled. I live with my family and I am 40 years old. I speak with a really high fast voice that not everyone can understand and my doctor keeps telling me I am overweight – by a lot. She is also worried about my heart because some people with Down's Syndrome have heart problems, but I don't think I do. I am an artist and go to work each day at an art studio with other artists who are also called intellectually disabled. Some of them can't speak, some are in wheelchairs, and some are really independent and live on their own and do their own thing. I will never be like that because even though I can do a lot of things for myself I really can't remember how to do the big things like shopping, cooking, looking after my money and making decisions about my money. I cannot read and I don't know many people apart from the people I work with and my family. I am pretty good at showering myself and choosing which clothes to wear and of course I am really good at art. The other thing I am really good at is singing and I am in a choir. My parents make a lot of decisions for me and look after my money and make my health appointments. I don't cook because Mum has never let me in the kitchen because she is scared that I will burn myself or cut myself. At the art studio I make my own cup of tea and sometimes heat up food in the microwave. I travel to the art studio on a local bus. Each morning I walk to the bus stop, buy my ticket from the bus driver and get off at the studio. I love doing this by myself because I am on my own and it shows that I am an adult. I went to Special School then a day centre with lots of other adults with intellectual disabilities and physical disabilities. I was really glad when this centre changed and sold the big centre and bought lots of smaller places like the art studio, a gardening nursery and an office where staff work and organize sport and recreation things to do in the community. I don't do any of these because I just like working on my art, having exhibitions and going places to look at other art. When I am on holidays I stay at home or go on holidays with my family. I have been overseas with others from the art studio a couple of times to show our art in other countries. That has been great. I like people to listen to what I want to do in my

life but I don't really know much about the world around me. I do know what I like though and that I want to keep doing art forever.

James

I was born in 1957 and was put straight into an orphanage. My name is James but I don't think that is what I was called when I was born. I do not know how long I was in the orphanage but it must have been a few years because the only photos I have seen of myself with my family, the family that adopted me, was when I was about 3 or 4. Something happened when I was about 16 because my family that adopted me sent me away to an institution for people with disabilities. I really do not know why. They visited me there sometimes but I never knew why I couldn't go home. I stayed in different institutions until I was about 30 years old then I was moved into group homes and eventually I got a flat of my own. All this time I wanted to be back with my family but it never happened. Luckily though I still saw my parents who had adopted me and my adopted brother and sisters. They never forgot me. I thought that if I tried really hard at the school at the first institution I would get out of there but we didn't really learn anything. Usually we only went in the afternoons because we did jobs in the mornings like washing in the laundry, mopping the floors and sometimes work in the gardens. By the time we got to the school we were really tired and we did a lot of sitting around singing, some words and reading and packing things like clothes pegs. They called that the school. I liked the words and reading and tried to keep them in my head, that is why I am pretty good at reading now. I was really angry all of those years and I used to get in a lot of trouble because I would answer the staff back and sometimes fight them and other residents. I got moved a lot because of that but it wasn't right what they were doing. I was smart and I was locked away with all sorts of people. One day they just came and told me I was leaving and to pack my case. I ended up in a house with five other people who had lived in the institution with me. Two of them I didn't like at all and we had never got on, but at least we were out. I had been locked away so long I didn't know what to do. They got us jobs at a gardening place, I loved it but I got in trouble at home because I couldn't get on with some of the others. We punched each other and one day one of the staff punched me. That was it I had to move on and they let me go. I got a case manager and he found me a flat to live in close to some of my family. I had to learn how to cook, clean and look after myself but luckily my brother helped me with my money and taking me to the doctors. I ride my bike everywhere now and feel so free. I am not independent but I live by myself, love reading the paper and listening to the radio and following the football. I have a part time job in a factory where nobody else is called intellectually disabled and

sometimes I work for the government or a self-advocacy group running sessions for other people with disabilities about their rights. I do my own thing and stand up for myself. I really enjoy going to my self-advocacy group meetings and talking about our rights.

Inherently different or just labelling and life chances

It can be argued that intellectual disability has a little or no basis in reality but is socially created and constructed; the product of social arrangements, language, discourse, culture, and ideas. This is suggested by the following propositions:

- At some times and not others during their life course a person may be labelled as having an intellectual disability. For example, the prevalence of intellectual disability is highest in the age group 10 to 20 years, and some people no longer attract this label when they leave school (American Association on Mental Retardation – AAMR, 2002).
- People with similar characteristics may be labelled as having an intellectual disability at one historic time and not another, or in some cultures and not others. For example, in the United States in 1959, the definition of intellectual disability changed from 1.5 to 1.0 standard deviations from the mean on an IQ test which increased from 3% to 16% the proportion of the population considered to have intellectual disability (AAMR, 2002).
- A person's social and intellectual development can be adversely affected by the social conditions in which they live. Mild intellectual disability is more prevalent among people who live in poverty (Emerson, Hatton, Felce, & Murphy, 2001), and is substantially increased among children of socio-economically disadvantaged mothers (Emerson & Hatton, 2007).
- Being labelled as having an intellectual disability is stigmatizing and affects a person's self-esteem as well as their life experiences, and social, educational, and vocational opportunities available to them. People with intellectual disability are often cast into negative roles, such as being subhuman or eternal children, and these social expectations become self-fulfilling prophecies (Yates, Dyson, & Hiles, 2008, p. 248). Ferguson (1987), for example, considered that people with intellectual disability 'are saddled with socially created valuations that are discriminatory, demeaning and unnecessary' (p. 54).

Although all these propositions have some truth, the logic that intellectual disability is a social construction should not lead us to the

conclusion that it has no basis in reality and that if the material, ideological, and cultural nature of society changed sufficiently intellectual disability would not exist. Irrespective of where an administrative line is drawn, which label, if any, is applied to a person, the impact of that label or the nature of social conditions, there will always be people in any society who have a lower than average intellectual capacity and poor adaptive skills – people who master basic skills more slowly, find it difficult to think in abstract concepts, and have difficulty problem-solving and engaging socially in the world. This is the group generally labelled as having an intellectual disability.

On the basis of intellectual and adaptive capacity alone some people then are markedly different from others. This difference in capacity is not of the same order as other common differences between people, such as sex, race, or eye colour. Differences between males and females are not by their nature inherently disadvantageous, they only become so through the interaction with society, when for example socially generated gender stereotypes can lead to sexual inequality. But because of the inherent nature of low intellectual capacity, and its complex interaction with the social world, having lower than average intellectual and adaptive capacity is a disadvantageous difference. Ferguson (1987) put its inherently disadvantageous nature bluntly when he wrote that it would be easy to imagine a world where gender or skin colour had no inequalities attached, but hard ‘to imagine a world where it would not be preferable to be capable of abstract thought. Indeed, the very act of imagination required therein contradicts the world we would have to conceive’ (p. 54). Ferguson hastened to add, however, that such inherent disadvantage should have nothing to do with the intrinsic value of people who happen to have a low level of intellectual capacity. Moreover, too often the discriminatory way that society has understood and treated people with low intellectual capacity compounds their inherent disadvantage and deprives them of rights, respect, and dignity.

Impairment and disability

The fundamental distinction between impairment and disability lies at the core of understanding intellectual disability. Impairment refers to the type of differences in intellectual capacity described above, which cause difficulty in everyday functioning and are inherently disadvantageous. Shakespeare (2006) used the term ‘predicament’ to illustrate the trying nature of impairments and the intrinsic difficulties to which they lead in engaging with the world. Importantly, such difficulties occur irrespective of social arrangements – though clearly social circumstances may ameliorate or aggravate the difficulties experienced. In contrast

disability represents the complex interaction between impairment and social processes in society, and is a social problem caused by social process. 'It is not physical, cognitive or sensory impairments that cause disability, but rather the way in which societies fail to accommodate natural aspects of difference between people' (Priestley, 2003, p. 13). Understanding intellectual disability requires then an understanding of both intellectual impairment and disability.

Impairment

Impairments are defined as problems in body function or structure such as a significant deviation or loss that affect a person's capacity to function (World Health Organisation – WHO, 2001). People with sensory impairment, for example, have problems with structure of eyes or ears that affect their capacity to see or hear. People with intellectual impairment have problems with the functioning or development of the mind that affects their cognitive (memory and learning) processes and capacity. Along with other health conditions that lead to impairments, intellectual impairment is defined in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (AAMR, 2002). It uses the now discarded term, 'mental retardation' and states it is

[a] condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition. (ICD-10)

Such language is now somewhat dated and seldom used. More often intellectual impairment is defined by its consequences for a person's functional capacity, such as '[s]ignificant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills that occurs before the age of 18 years' (AAMR, 2002), or the concurrent existence of:

- (a) significant sub-average general intellectual functioning; and
- (b) significant deficits in adaptive behaviour – each of which became manifest before the age of 18 years. (Disability Act 2006 Victoria, section 3)

The defining elements of intellectual impairment are the level of intelligence and adaptive behaviour during the developmental phase of a person's life. In considering whether or not a person has an intellectual impairment, account must be taken of what is typical for their age, peers,

and culture, that limitations coexist with strengths and with appropriate supports a person's functioning is likely to improve over time. Before going further it is worth briefly considering 'intelligence' and 'adaptive behaviour' and translating what limitations in these areas mean for everyday life (see Boxes 1.1 and 1.2).

Box 1.1 Intelligence

Intelligence refers to general mental capacity – a person's capacity to reason, plan, remember, solve problems, think abstractly, comprehend complex ideas, learn quickly or from experience, to make sense of things, figure out what to do or overcome obstacles by talking and communicating. People with low intelligence will find it difficult to do some or all of these things, do them more slowly or are simply not be able to do them at all. The concept of intelligence and its methods of measurement are social constructs and have changed over time. Some researchers suggest that intelligence has multiple dimensions, such as analytical, creative and practical, or conceptual practical and social (AAMR, 2002). The early development of IQ tests in the 1950s used the idea of mental age as a measure of intelligence. For example, anyone considered to have a mental age of 12 or less was labelled as 'feeble-minded'. Now intelligence measurements are represented as an IQ score. IQ scores are based on a 'normal distribution' or bell curve, which means that most of the population have a score around the mean (100), and fall within narrow parameters. Currently in Australia and the United Kingdom below-average intelligence is represented by a score of 2 or more standard deviations below the mean, which is 70 or 75 or below on a standardized intelligence test such as the Stanford-Binet or The Wechsler scales.

Source: AAMR, 2002; Disability Act Victoria (2006).

Box 1.2 Adaptive behaviour

Adaptive behaviour is the conceptual, social, and practical skills that enable people to function in everyday life and the ability to respond to life changes and demands from the environment. Conceptual skills are about cognition, communication, and academic tasks, such as self-direction, use of language, reading,

and writing. Social skills involve the conduct of interpersonal relationships, responsibility, gullibility, and self-esteem. Practical skills are connected to activities of everyday living such as eating, mobility, toileting, and dressing and instrumental activities of every day living such as cooking, shopping, household management, use of transport, money management and occupational skills. People with poor adaptive behaviour will have difficulty exercising many of these skills and thus require support to manage their everyday lives. Adaptive behaviour is measured using standardised tests such as AAMR Adaptive Behavior Scale – School and Community or Vineland Adaptive Behavior Scales (AAMR, 2002). There is no precise relationship between IQ and adaptive behaviour, a person may have a high IQ and low adaptive behaviour or vice versa, which is why a score for both is required in administrative definitions of intellectual disability. Adaptive behaviour skills are not static, and most people can learn to improve their adaptive skills with good teaching and, even if they cannot do things independently with appropriate support, can participate in many of these activities of daily living.

Degrees of impairment

The degree of intellectual impairment varies considerably among the group of people who fall into the category of having sub-average intellectual functioning and significant deficits in adaptive behaviour. Most commonly they are divided into people with a mild impairment who score between 50 and 69 on an IQ test and people with a severe impairment who score less than 50 on an IQ test (Emerson, Hatton, Felce, & Murphy, 2001), although the ICD-10 has four categories of intellectual impairment, mild, moderate, severe, and profound. Using this classification in relation to the vignettes earlier in the chapter, Dominic and Grace would probably be considered to have a severe impairment, and James a mild impairment. The nature and degree of support a person requires to achieve personal outcomes and participate in the community may vary for different parts of their life, but it is a useful way of thinking about the severity of impairment. For example, the AAMR (2002) identifies different types of support intensity.

- *Intermittent*: Support is on an 'as needed basis', it is required on an episodic or short-term basis, related to specific life course transitions or incidents such as leaving school or losing a job. When required, support may be high or low intensity.

- *Limited*: The intensity of support required is consistent over time and time-limited but not intermittent (e.g., employment training or support to find social activities in the community).
- *Extensive*: Regular, often daily, support is required in at least some environments such as home or work and is not time-limited (e.g., daily support to manage household tasks such as cooking).
- *Pervasive*: Consistent, high-intensity, support across environments, which is of a potentially life-sustaining nature (e.g., daily personal care, monitoring for safety, and well-being).

The causes of impairment often vary with the degree of severity. It is now clear that the major cause of more severe intellectual impairment is found in biology, primarily genetically based syndromes and conditions such as Prader Willi, Fragile X, and Down's Syndrome. In contrast, up to half of all mild intellectual impairment is socially created, caused by social factors such as poverty, poor nutrition, or health care (AAMR, 2002).

Impairment as an incomplete picture

It is difficult to avoid the conclusion suggested by McClimens (2006) that impairment belongs to the 'real world'. Irrespective of social context, how society views and interprets, supports or hinders people who are different, intellectual impairment has real-world implications for how people learn, what they understand, and their capacity to make choices, judgements, and manage the tasks of everyday living. Understanding the nature of intellectual impairment is one important piece in the jigsaw of intellectual disability. It is a very important piece for social workers, as it influences the type of problems people with intellectual disability may experience, the type of support or advocacy they may need, and shapes possible styles of communication and working together. For example, persons with severe intellectual impairment are unlikely to be able to explain in words their feelings or preferred choices. However, understanding and responding to impairment per se is not as core to social work as it is to other professions such as educators, psychologists, speech therapists, and doctors who are often concerned with teaching skills, understanding behaviour, supporting communication, and preventing and treating health conditions. Nevertheless, understanding the roles of other professions in respect to impairment can also be critical to social work assessments, interventions, or making appropriate referrals.

Intellectual impairment gives only a partial picture. The 'significance of these differences depend on how we view and interpret them. We may distinguish between intellectual characteristics on the one hand,

and social definitions and concepts on the other' (Bogdan & Taylor, 1989, p. 77). The concept of disability is central to understanding how the experiences and opportunities available to people with intellectual impairments are shaped. Intellectual disability is concerned with the relationship between intellectual impairment and society. It occupies a less certain space than impairment and is far more contested (McClimens, 2006).

Ways of thinking about disability

Disability Studies is a growing field of academic study in its own right and there are multiple models of disability, each based on a particular social-scientific paradigm with specific assumptions about the nature of reality and society. Mercer (1992), for example, explored the application of seven models of disability to the situation of people with intellectual impairment: medical, psycho-medical, social systems, cultural pluralism, conflict, cognitive, and humanist. Our aim here is not to examine each of these in detail, but to illustrate broadly contrasting individual and social models of disability, and draw attention to the implications each has for thinking about intellectual disability. We note, however, that models are a simplified representation used to emphasize particular features of social phenomena, which are deeply embedded in much more complex understandings and social theory. Finally, we consider the recently reformulated WHO, 2001 model of disability, which in many ways acts as a meta-model.

Individual models of disability

Individual models of disability focus on the functional, medical, or psychological impact of the impairment. They see a linear connection between impairment and disability, *impairment* causes *disability*. Impairment is seen as 'lacking part of or all of a limb or having a defective, limb, organ or mechanism of the body' (Oliver, 1996, p. 22), that restricts or limits the ability to perform an activity in the manner considered normal for a human being. Intervention then is focused on the individual or their immediate environment, and their adjustment to the impairment, through skill development, medical treatment, various therapies, psychological counselling, behavioural programs, or physical/environmental modifications.

Thus, for example, an individual/functional model would see the problems experienced by a person with Down's Syndrome in participating in expected social roles or relationships, such as securing a job or making friends, as a consequence of their inability to read or use

symbolic language to communicate, stemming from their intellectual impairment. Intervention might take the form of social skills training, or job analysis. The individual/psycho-medical model is concerned with biological causes of intellectual impairment and other health conditions that might be associated with the impairment. Thus, the health problems, insatiable appetite, and obsessive behaviour of a person with Prader Willi syndrome would be understood in terms of their genetic origin and intervention might take the form of health monitoring and treatment and behavioural programming or medical research to prevent this syndrome. Other individual models are concerned with psychological aspects of impairment; how people experience and adjust to their impairment and the impact it has on their identity. In this model the focus is on the person's interpretation of their situation and the psychological mechanisms they use to manage their identity, rather than the cultural origins of social attitudes and stigma they must adjust to. Thus, for example, for a young person with mild intellectual impairment who lacks self-esteem and does not want to go to a club for people with disabilities, this model is concerned with understanding how she has come to terms with her awareness of the limitations, whether she is denying her identity as a person with a disability, and what her ambitions might be. Intervention might take the form of psychological counselling, or mutual support through a peer group.

Individual models of disability are concerned with the 'physical or psychological concomitants of impairment' (Priestley, 1998b, p. 75), and tend to portray disability as negative, marked by some sort of inferiority or loss for the individual. Oliver (1996) captured these assumptions by referring to 'personal tragedy theory of disability' that underpins these models. These models are concerned with the private troubles encountered by individuals as a result of impairment and generally point to the need for professional intervention to help deal with them.

Social models of disability

Social models of disability draw attention to the way disability is socially constructed by the interaction of impairment with the structural and cultural aspects of society. Disability is conceptualized as all things that impose restrictions on people with impairments, thus people are disabled by society

ranging from individual prejudice to institutional discrimination, from inaccessible buildings to unusable transport systems, from segregated education to excluding work arrangements, ... the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled

people as a group who experience this failure as discrimination throughout society. (Oliver, 1996, p. 33)

While impairment is a personal attribute, disability is seen as the collective experience of people with impairments created by society and as a form of oppression, similar to racism and sexism. To understand disability, the political economy, built environment, social policies, institutional practices, and culture of a particular society must be examined. It is at these social arrangements rather than the individual that actions to achieve change must be levelled. It is important to acknowledge, however, that as well as the removal of disabling barriers, social models recognize the need for individual support with tasks that people cannot carry out independently due to impairments. Commensurate with the model's analysis is that such support is delivered in a way that empowers individuals to run their own life; it is provided as a right and controlled by the individual.

Social models of disability are not as aligned with professional intervention as individual models and owe much of their development to the work of disabled academics and activists. They take an explicitly political as well as explanatory stance and have a deeply embedded human rights perspective. Commenting on the importance of a social model of disability Barnes suggested that it is 'a way of demonstrating that everyone, even someone who has no movement or sensory function... has the right to a certain standard of rights to be treated with respect' (Barnes, Mercer, & Shakespeare, 1999, p. 31).

Social models of disability are aimed at achieving the acceptance by society of individual difference and maximizing independence, choice, and control of disabled people over their own lives. For example, outcomes sought have been summarized as being enabled to

- function in an ordinary way without special attention or being singled out;
- mix with others, and not being ignored in friendship networks;
- take part and contribute to society in paid work or volunteering;
- realize one's own potential; and
- direct one's own life (Shakespeare, 2006).

Central is that reliance should not be placed on 'special arrangements' for people with disabilities to participate and be included in society. For instance, universal access would ensure that all buildings and transport systems are as accessible to people with mobility impairments as well as those without and multimodal signage and publishing could take into account the different ways of expressing and receiving communication. For example, accessibility to culture and information by people with

intellectual disabilities could be addressed by initiatives centred on the production and active dissemination of easy-to-read books producing 'easy to read public information' and 'Plain Text' news programmes on public radio (Bigby, 1999).

Social models of disability also pay attention to the impact of the cultural representations of impairment on the experiences of people with impairment and argue that these are experienced at the collective as well as individual psychological level. This perspective, for example, understands negative social attitudes and stigmatizing stereotypes of people with impairments not as natural but as socially created and examines their impact on the collectivity of people with impairments. This variant of the social model has been more widely understood as applicable to people with intellectual impairments. It is illustrated by work on labelling and deviancy amplification by sociologists such as Becker and was drawn upon by Wolfensberger to develop his theory of social role valorization (Wolfensberger, 1985). As the quote from Ferguson earlier illustrates, the very act of labelling changes the way persons are regarded by others in society and begins a process that amplifies their difference, setting in motion a self-fulfilling prophecy. For example, when children with intellectual impairment are labelled as such, they are assigned to a different type of schooling that congregates them with others similar to them and segregates them from children without disabilities. As a consequence, they are not exposed to children with 'normal' social skills, which reduces their opportunities to learn social skills thus amplifying their original deficits.

UK social model of disability

The most common social model is that from the United Kingdom, which originated with the work of the Union of Physically Impaired Against Segregation in the 1970s and was developed by writers such as Oliver and Finkelstein. 'Disability stems from the failure of the structural social environment to adjust to the needs and aspirations of citizens with disabilities rather than from the inability of the disabled individual to adopt to the demands of society' (Barnes, 1996).

This model uses a Marxist political economy analysis to trace the marginalization of people with disabilities to the development of a capitalist mode of production which effectively excluded and rendered them useless in a system that had no need of unproductive workers. The model is concerned both with immediate factors in the built environment and institutional practices, as well as the deeper values and social structures of the political economy that exclude or fail to take into account people with impairments. Simple graphic examples of exclusion are the

inaccessibility of buildings, buses, or theatres to people with mobility impairments. Illustrative barriers experienced by people with intellectual rather than physical impairments do not spring as easily to mind and are much less common in the literature. However, examples may include:

- reliance on the written word by most institutions and public places to communicate and conduct their business;
- increasing reliance on technology rather than people to conduct banking, ticket purchases, and as the interface of public enquiry systems;
- removal of conductors and station staff from many forms of public transport;
- an education system that does not equip teachers or provide resources to cater for children with the whole range of abilities;
- an employment system that results in vastly unequal wages often based on productivity or formal qualifications rather than time or effort exerted; and
- a social security system organized around disincentives to reliance on government income support and lesser eligibility of those who cannot work.

Removing barriers such as these requires significant change to institutions and their practices.

People with intellectual disabilities have largely been left out of the development and application of the social model. Some of the reason for this is the suggested hierarchy of disability, summed up in the phrase, 'just because I'm can't walk doesn't mean I'm stupid', which places people with intellectual impairment at the bottom. Goodley (1997) for example, suggested intellectual disability continues to be seen from primarily an individual/functional perspective, an impairment-related bio-medical phenomenon.

The relative exclusion of intellectual disability from the social model has meant that little attention has been paid to the social arrangements that particularly disadvantage people with intellectual impairments, and the distinct types of social change or support they might require have not been adequately differentiated and subjected to advocacy. This is clearly illustrated in Australia by government disability action plans, which have concentrated on physical accessibility, and the very few actions about discrimination on the basis of intellectual impairment, which have been dealt with under disability discrimination legislation. Importantly too, Ferguson suggested that the visions of inclusion, participation, choice, and independent living for disabled people envisioned by the social model of disability do not extend to a picture of what might be possible for people with severe and profound intellectual disability.

Little has changed in this respect in the past 30 years. Recent research in group homes suggests that the question of what social inclusion looks like for a person with profound intellectual disability is still poorly conceptualized in both policy documents and by support staff. For example, when a house supervisor discussed ‘inclusion’ for the men with severe intellectual disability in the group home it typically reflected the goal of community presence rather than social participation. She said:

It’s many things, being included, how you are included. When we first went to the supermarket people stared, now they don’t. When we first moved here the men were intimidated. Last week we wandered around Bunnings [a home improvement store]. Seven to eight months ago we couldn’t do that. The men have developed confidence. People like to go for a drive, to go for a walk along the beach. That’s what we did on ANZAC Day [a public holiday]. (Clement & Bigby, 2009b)

The explanatory power of social models of disability does not extend to all the difficulties of everyday living experienced by people with impairments. Social models cannot, for example, take into account the inherent personal restrictions, such as the inability to think in abstract terms or use language to communicate, that stem from intellectual impairment, which will not be changed by removing social barriers or changing social attitudes (French, 1993). In defence, however, it has been argued that the social model does not ignore impairment but rather concentrates on what can be changed (Sheldon, Traustadattor, Beresford, Boxall, & Oliver, 2007). Additionally, it has been repeatedly pointed out that even if society made significant commitment to inclusion and social change, it could not accommodate, as a matter of course, to the breadth of adjustments required for inclusion of people with all types and severity of impairments unless a completely fundamental change occurred to culture and the political economy. Core values such as independence would have to be replaced by those of interdependence and relationships. Without such changes, the inability of people with severe and profound impairments to be part of the workforce would continue their exclusion (Ferguson, 1987; Priestley, 1998a; Shakespeare, 2006). As writers such as Clapton (2009) have pointed out, the extent of change required for society to achieve inclusion of all people with intellectual impairment is so far reaching that the concept of inclusion would no longer be meaningful.

A rights perspective

Social models of disability like individual models have limitations but provide a key lens through which to understand the experience of people with intellectual disability, as a public issue to be tackled by structural

and cultural change. Moreover, the political and human rights perspective embedded in social models is an important component, which individual models lack. This rights perspective, shared by the social work profession, provides a way through the difficulties of adjusting society to accommodate every difference and thus enable unfettered and unaided inclusion. By arguing that all people have equal moral worth, the view is adopted that all people regardless of their impairment have the right to be included in society and to have outcomes equal to other citizens. Thus, even if institutional or structural change falls short of enabling inclusion in the workforce, for instance, people with intellectual disability have the right to individualized support that compensates for their disadvantaged position, enables participation and inclusion in aspects of their own life and the community, and a quality of life similar to that of other citizens. A rights perspective is more concerned with creation of equal outcomes than equal opportunities. Treating people who are different equally does not address inequalities, and some people will never be able to compete by the rules designed for the majority. What the social model and a rights perspective also do are to link the situation of people with intellectual disabilities with other socially disadvantaged groups highlighting the need for redistributive social policies to achieve social justice. This connection enables social workers to see the broader possibilities for work in the field of intellectual disability.

Meta-models: WHO International Classification of Functioning

The reformulated WHO (2001) model of functioning combines understandings of impairment and disability derived from individual and social models of disability, and provides a common framework that is understood across professions and national boundaries. The International Classification of Functioning (ICF) (WHO, 2001) suggested three coexisting and complementary foci for understanding disability: capacity to function (the body and impairments), activity limitations (skills), and restrictions on participation (opportunity). Capacity to function emphasizes physiological and psychological impairments concentrating on diagnosis of characteristics such as IQ and genetic make-up. It offers a description of limitations and is commonly identified with the medical model. Despite being deficit-based and narrowly focused, this perspective provides an alert to the health characteristics associated with intellectual disabilities and helps to draw attention to group-based, health-related needs relevant for service planning, staff training, and individual support plans. The activity perspective focuses on skills

and limitations in a person's ability to undertake tasks of everyday living in order to inform what support is required and how best it might be provided. This perspective is associated with the functional model and based on the assumption that difficulties can be compensated by strategies such as aids, environmental modification, individual support, training, or education. The participation perspective locates restrictions to participation in typical social roles, the exercise of choice and self-determination in the social processes, and structures of society rather than the individual. It is akin to understandings derived from the social model of disability that change is required to social structures and processes to remove barriers to participation. The solutions it proposes are political, namely, reform of social structures and individualized control of personal support (Fyffe, 2007).

The ICF model neither privileges nor disparages a focus on health, skills, behaviour, or social change. Rather, each perspective illuminates a different strategic lens to achieve policy goals of rights and social inclusion for people with intellectual disability. As Figure 1.1 suggests, its utility too is that, like social-ecological frameworks commonly used in social work, it draws attention to personal/family characteristics and broader social factors that mediate and interact with impairment, activity limitations, and participation restrictions, and thus increases possibilities of multiple levels of intervention.

Conclusion

Individual and social models should not be regarded as 'either' 'or' explanations, each contributes important insights to understanding the nature of intellectual disability. Increasingly, the complexity of disability and the value of perspectives that take different levels of analysis, mechanisms, and contexts into account is recognized (Danermark & Gellerstedt, 2004). In attempting to bring together different models, Sim et al., as cited in Shakespeare, 2006, suggested that disability is a

combination of a certain set of physical or mental attributes in a particular physical environment within a specified social relationship, played out within a broader cultural and political context which combines to create the experience of disability for any individual or group of individuals. (p. 98)

It is generally agreed that between 1% and 3% of the population has an intellectual disability and, for many, intellectual impairment coexists with physical impairment or mental health problems (Emerson et al., 2001). The combination of the disadvantageous nature of intellectual impairment and socioeconomic and cultural factors mean people

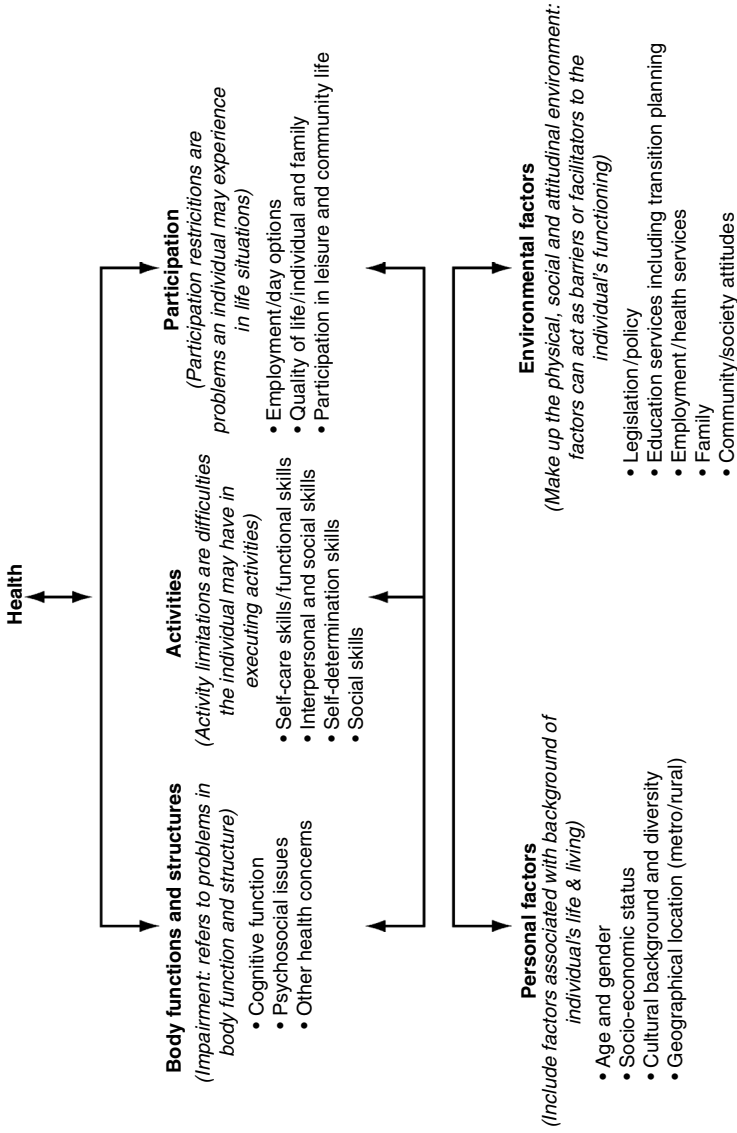


Figure 1.1 WHO International Classification of Functioning

with intellectual disability are particularly disadvantaged in contemporary western society, as illustrated by a brief glimpse of key social indicators.

Employment and income

- '11% of people with intellectual disability have wages or salary as their principal source of income compared to 47% of all persons' (Australian Institute of Health and Welfare – AIHW, 2006).
- 'The median income of households with a disabled adult is over 23% below that of a household with no disability' (Saunders, 2005, pp. 6 & 9).

Appropriate housing and support

- 'In Victoria 2559 people with disabilities are on the service needs register for a place in shared supported accommodation, of whom 1051 are classed as being in urgent need' (Department of Human Services – DHS, 2005).
- 'The number of people waiting for accommodation services, the majority of whom have an intellectual disability, and who are classified by the department as having urgent or high-priority needs, is currently equivalent to approximately 19% of those receiving services' (Auditor General of Victoria, 2000, p. 3).

Social inclusion

- 'Only five of the 27 residents relocated to the community had contact with a family member over a period of 12 months; and only five of 27 residents had regular contact with a friend or advocate who was neither a family member nor a person with intellectual disability' (Bigby, 2008).
- 'The incidence of sexual assault of people with an intellectual disability is up to three times higher than for the general population' (Sobsey, 1994).
- 'The fact is inescapable that physical or intellectual disability today equates almost ineluctably with lesser opportunities, services, social inclusion and quality of life that the rest of the community takes for granted' (Commonwealth of Australia, 2007, p. 99).

An understanding of the complexity of disability and the multiple factors that contribute to the social disadvantage of people with intellectual

disability is critical if social workers are to draw on the multiple potential strategies social workers may use to redress their inequality.

putting it into practice

Consider the stories of Dominic, Grace, and James in this chapter. Although each person has been assessed by the disability service system as having an intellectual disability, as their stories show they are quite different to each other.

- What do they have in common?
- Think about their ages and what you know about the different ways intellectual disability has been understood over time. What historical factors might have influenced the way they have experienced their disability? (policy, practices, medical and social views about intellectual disability)
- What would you consider to be each person's impairments, and what would you describe as more socially constructed aspects of their experiences of disability?
- Apply the ICF model in Figure 1.1 to each person to understand more fully how their intellectual disability impacts on their lives.
- What are the main factors that have led to these people being considered to have an intellectual disability?
- Consider one person and use one of the models (medical, social, rights) to argue for supports and services for that person.
- If you were involved in working with this person, what goals might you envisage they could have at this stage of their lives?

Further reading

Bogdan, R., & Taylor, S. (1982). *Inside out. Two first person accounts of what it means to be labelled as 'Mentally Retarded'*. Toronto: University of Toronto Press.

This is one of the first books to recount the lived experience of people with intellectual disability – poignantly written by two giants in the field. It may now only be available in libraries. An alternative equally powerful account based in ethnography is Edgerton, R. (1993) *The cloak of competence. Stigma in the lives of the mentally retarded*. California: University of California Press.

Oliver, M. (1990). *The politics of disablement*. MacMillan Press: Basingstoke.

This book is in the Critical Texts in Social Work and the Welfare State series and can be regarded as the classical groundbreaking text on the social model of disability. It provides a clear exposition of the implications of the social model for policy makers and practitioners.

Shakespeare, T. (2006). *Disability, rights and wrongs* Abingdon, UK: Routledge. Written many years after Oliver's exposition this controversial book critiques the absence of impairment effect in the social model of disability and provides a comprehensive up-to-date discussion on different perspectives on disability, service provision, and ethical issues. Its critique is debated in a series of Letters to the Editor in the *Disability and Society*, volume 22, issue 2, 2007, pages 209–234.

World Health Organisation (2001). *International Classification of functioning, disability and health (ICF)*. Geneva: WHO and Beginners guide, available at <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>.

This guide sets out a full explanation and the potential uses of the WHO's framework of disability. The ICF is particularly useful in providing a common language used across disciplines for all aspects of disability.

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