Thinking About Disability: Implications for Practice

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People with disabilities are a very diverse group, which is reported to make up around 15% of the world's population. The group includes people with functional limitations, impairments or health conditions which differ in terms of cause, severity and impact on their everyday lives. It includes people with different diagnostic labels, personal characteristics and identities, who live in different social and economic contexts. Despite these differences, people with disabilities share common experiences of disadvantage many of which are created by society and compromise their quality of life and exercise of rights.

We think about disability in different ways—how it is described, measured and understood. This can be confusing when we talk about how many people have disabilities. More importantly perhaps, different ways of thinking about disability lead to competing views about the types of laws, policies, services and practices that should be put in place. For example, whether to talk about people with disability in general or specific impairment groups, what language to use ('disabled person' or 'person with a

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disability') and whether government disability policies should be directed at segregation, social inclusion, care or supporting the exercise of human rights. All of these are subtly different.

This chapter explores some important conceptual issues. The chapter reviews differing descriptions and socio-demographics of disability. It compares and contrasts some of the ways of thinking about disability and describes the context of disability practice. The chapter points to the value of *Both/And* thinking for practice (that is, holding multiple perspectives about disability at the same time) and the potential dangers of *As If* thinking (accepting as true something that is known to be untrue to further social change) (Appiah, 2017; Smith et al., 2016). The author's expertise is in research with people with intellectual disabilities: where examples are given, they will usually relate to intellectual disability. The circumstances of people with intellectual disabilities are sometimes different to those of people with physical and sensory disabilities and can provide an important way of testing ideas about disability services, programmes and practice.

Describing Disability

Governments use broad descriptions of disability from international bodies, such as the World Health Organisation (WHO) or the United Nations (UN) to show who is included in the disability group. The WHO description of disability is part of the International Classification of Functioning (ICF) and can be summarised as:

> Disability is a difficulty in functioning at the body, person or societal level, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors. (Leonardi et al., 2006, cited in Bickenbach, 2019)

The UN Convention of Rights of Persons with Disabilities (CRPD) describes disability as an evolving concept and Article 1 states that:

> Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (United Nations, 2006, Article 1)

Very simply both the WHO and CRPD describe disability as the interaction between individual characteristics and social contexts. However, the language, purpose and values of each of these descriptions are different. The ICF uses the language of health. Its purpose is a universal classification system, a model for understanding the creation of disability and ways of improving human functioning. In contrast, the CRPD's description of disability does not use the language of health. It uses the language of humanity and equity rather than functioning. The values in its description are explicit and its purpose is not scientific understanding but advocacy and pointing to the social change needed to achieve equality and human rights for people with disability.

COUNTING DISABILITY

Leaving models of disability aside for the moment, governments and service providers need more precise definitions of disability to collect information about people with disabilities, develop laws or design social programmes. Creating precise criteria and pinning down exactly the number of people with disabilities is not straightforward—it requires decisions about who is included. For example, governments may want to use broad criteria when they report national expenditure on disability to the UN or plan at the population level for health, education or transport services. Governments may want to use narrower criteria to determine individual eligibility for programmes such as transport subsidies, income support or social care. For example, the commonly reported figures that 18% of the Australian population or 4.4 million people have disabilities of whom 32% (1.4 million) have severe or profound disabilities are very different from the much smaller figures of 610,502 people eligible participants in the National Disability Insurance Scheme (NDIS, 2023) or 746,000 recipients of disability support pension (AIHW, 2022).

Knowing who has been included is important when figures about disability are reported, as they may refer to:

- a nation's whole population and the prevalence data (the number or proportion of the population with disabilities),
- particular age groups and the age-specific prevalence data (proportion of a specific age group with disabilities) or

- data about specific subgroups of people with disabilities, categorised, for example, by type or severity of disability, location or eligibility for or use of particular types of services.

How the data to calculate figures about disability were collected and by whom are also important. In Australia, for example, the Survey of Disability Aging and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS) is the gold standard for identifying and capturing information about disability (AIHW, 2022). It provides comprehensive and detailed data about people with disabilities of all ages across the whole of Australia. The survey sample is large and representative. The survey uses 120 questions to identify disability. They reflect a functional definition: 'having at least one limitation, restriction or impairment to everyday activities which has lasted for at least 6 months'. The survey specifies ten types of limitations such as self-care, communication, property maintenance and meal preparation. When people surveyed are identified as having disabilities they are categorised by severity (mild, moderate, severe or profound) according to how many and what types of activities they need help with. They are also grouped into six disability groups (sensory and speech, intellectual, physical, psychosocial, head injury and stroke and other).

Many of the other surveys that give data about people with disabilities focus on subgroups in terms of age (children or youth), location (state or locality) or service sector (housing, health, education). Criteria used to identify people with disabilities often rely on self-identification, and differ from those of the SDAC, particularly in terms of the number of limitations a person has and length of time they have had them (see AIHW, 2022).

Age is a critical dimension for counting how many people have disabilities. The prevalence of disability increases exponentially by age. On some counts 50% of people with disabilities are aged 65 years or older, and people 85 years and older are twice as likely to have disabilities compared to those aged 65–69. Sometimes reports separate people by age; labelling those under 65 years as people with disabilities and those over 65 years as older people. At other times reports put all age groups together and use the label people with disabilities. If only people below the cut-off for 'older' are included, the number of people with disabilities is much smaller 9% rather than 18% of the Australian population or 2.2 m rather than 4.4 m. As this illustrates, administrative decisions can change who and how many people have disabilities. Interestingly, in Australia service systems are divided on the basis of age and the aged care and disability sectors have different standards and funding.

DISADVANTAGE AND DISABILITY

People with disabilities do much worse on all indicators of disadvantage compared to people without disabilities. This is the case no matter how the group is defined or the data collected. Table 2.1 compares adults with and without disabilities and, where the information is available, people with severe or profound disabilities, on key indicators of disadvantage. The source of these data is Australian Institute of Health and Welfare (AIHW, 2022) which explains in detail the criteria used and how they were collected. All figures have been rounded up or down.

These data show that people with more severe levels of disabilities experience even greater disadvantage. More detailed data show that people with psychosocial or intellectual disabilities often experience more disadvantage than other groups of people with disabilities. For example, people with intellectual disabilities aged under 65 years are less likely to use most health services, other than dental, than all other disability groups and have much higher rates of unemployment (AIHW, 2022).

Large-scale government surveys that collect representative or statistically robust samples are important for planning and gaining broad snapshots of people with disabilities compared to other groups. Such surveys do not include hard-to-reach groups—such as those with severe cognitive disabilities—or provide in-depth pictures of people's lives. This is what scholarly research does, often using smaller and more targeted samples of subgroups of people with disabilities. Some researchers use qualitative methods, asking people to talk about their experiences or observing them, which gives a richer picture of what life is like for people with disabilities. For example, focusing just on death rates of people with intellectual disabilities, researchers showed the much shorter life expectancy of this group and the high rate of deaths that could have been avoided by proper health care compared to the general population (Heslop et al., 2014). All types of data are valuable and provide different insights into the group of people with disabilities.

There are dangers of concentrating on disability status alone. Focusing only on disability hides what is referred to as *intersectionality*. That is the other personal characteristics or identities people with disabilities have that may compound the disadvantages they experience as a person with disability. For example, data shows the higher rates or different types of disadvantages experienced by people with disabilities who are women, from

Table 2.1   Comparing adults with and without disabilities on key social indicators

Social indicator	Adults with disability 25–64 years	Adults with severe or profound disability	Adults without disability
Health			
Self-rated fair or poor health	42%	62%	7%
Insufficient physical exercise	65%		48%
Delay in access to GP	8.7%		4.1%
Delay in access to dental care	32%		20%
Material wellbeing			
Government payment primary source of income	43%	69%	7.9%
Low income	20%		9%
Financial stress	38%	51%	27%
Cannot raise $3000 within one week in an emergency	42%	28%	10%
Went without meals in a week	8%		2%
Education#			
Studying post-school	9%	2%	15%
Barriers to post-school study or work goals	64%		48%
Intending to go to university	48%		66%
Economic participation			
In the labour force	53%	27%	84%
Employed	48%	24%	80%
Unemployed	10%	13%	5%
Part-time work	41%	52%	32%
Satisfied with job	54%		61%
Discrimination and safety			
Not satisfied with personal safety	12%	22%	5%
Lifetime experience of sexual violence*	21%		10%
Social connections			
Experiences social isolation	17%	24%	9%
Experiences loneliness	28%	37%	16%
Member of a club	28%	20%	36%
Dissatisfied with local community	39%	46%	27%
Difficulty getting places	23%		17%
Living situation			
Lives alone	19%		8.%
Not satisfied with home	14%	20%	8%
Moved for health reasons	8%		1%
Life satisfaction			
Satisfied or totally satisfied	51%		69%

* Centre of Research Excellence in Disability and Health (2021)

includes young people 16–25 as well

culturally and linguistically diverse backgrounds, First Nations people, live in remote and rural locations, or identify as LGBTQI (AIHW, 2022).

The following sections move away from describing disability and counting how many people have a disability. These sections consider different models or ways of understanding disability. Each has its own way of understanding why people with disabilities experience the disadvantages already described and how to tackle these disadvantages.

Value of Understanding Different Models of Disability

Models are ways of making sense of complex things and help to organise our thinking. Understanding models of disability is not just an intellectual exercise. Each model emphasises different aspects of disability, giving different perspectives about what might be important to people with disability, what needs to change to support them and different types of policy and practice. Understanding different models of disability is helpful because each model provides insights and suggests strategies that are not mutually exclusive and can be used together. The three models considered are the social model of disability, the individual deficit model of disability and the emerging critical realist model.

These models are described in the following sections as *ideal types* to show the differences between them; in practice the types are not always as distinct from each other.

Social Model of Disability

Definition

The social model of disability was developed in the late 1970s by UK disability activists. Many were people with physical disabilities with first-hand experiences of individual deficit models of disability (discussed in the following section). The social model separates impairment from disability, defining impairment as "lacking part of or all of a limb or having a defective, limb, organ or mechanism of the body" (Oliver & Barnes, 2012, p. 22). In contrast, disability is conceptualised as:

> The disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in mainstream of social activities. (Oliver & Barnes, 2012, p. 22)

In this model disability is created by the way society is organised, as it is not designed to include people with impairments and excludes them. For example, disability results from the design of infrastructure such as buildings and public transport, the organisation of the labour market, the design of services such as education and health, and stigmatising social attitudes that devalue and exclude people with impairments. Hence people with impairments are disabled by society and use of the term disabled people is appropriate. This model has a strong human rights approach.

What Needs to Change

Concentrating solely on disability rather than impairment, the social model shows that changes are needed to the way societies operate rather than changing people with impairments. Social model thinking focuses attention on extrinsic rather than intrinsic factors: that is, it looks outwards to society rather than inwards to people with impairments. It provides strong and clear but very broad messages about what needs to change to include people with impairments in society.

Disability activists using the social model initially emphasised change to improve physical and sensory accessibility and social attitudes. For example, removing obstacles such as the lack of alternatives to stairs to enter buildings, public toilets that were too small for wheelchairs or lack of audible signals at road crossing. Much later, advocates applied social model thinking to people with intellectual disabilities and ideas of cognitive accessibility. For example, the obstacles to access posed by complex digital systems to answer phone calls that require responses to many automated options before reaching a customer service person, electronic touch on touch-off cards for transport systems or complex text as the primary form of communication by service systems.

One of the guiding questions in applying social model thinking is how does the problem facing a person with impairment stem from their social situation and how can this be changed?

Questions Important to Applying the Social Model of Disability

Is the reason a person cannot use public transport because they use a wheelchair for mobility or because of the design of buses and trains?

Is the reason a person does not use a local gym because of their lack of social skills and motivation to keep fit or is it because of the way other patrons stare at them, the unwelcoming attitudes of the receptionist and the need to produce a driving licence to prove their identity?

Is the reason a person cannot secure a well-paid job because of their lack of skills and poor literacy or because the labour market system values jobs requiring complex skills and multi-tasking more highly than those requiring little training or repetitive tasks?

Some of the changes suggested by social model thinking are increasingly taken for granted in Western societies. These include, for example, provision of lifts, ramps, access to all facilities for guide dogs, requirements for physically accessible public buildings and facilities, anti-discrimination laws and multiple methods of communicating in public broadcasts. They are indicative of the success of using the social model to advocate for change, although some would argue such changes only begin to scratch the surface of what needs to change.

Pros and Cons

The social model promotes leadership by people with disabilities in policy and service provision, recognising that people with disability are experts about their own experiences. Universal human rights are integral to the model. The social model helps to identify the common interests of people with disability by focusing attention away from different types of impairments. This avoids splitting people with disabilities into different interest groups, bringing them together as one group to advocate for change. The clear messages of the social model are easily adapted to single-issue advocacy. On the other hand, the broad-brush nature of the social model does not give detailed prescriptions about the many and different types of change needed to make society accessible. It is also criticised for neglecting changes that are more specific to people with intellectual disabilities.

It is further criticised for paying too little attention to impairment. Particularly, neglecting what is often seen as the intrinsic and direct impact of some impairments such as pain, restricted movement or capacity for learning or quick thinking. Making a distinction between impairment and focussing on disability means that impairments are seen as medical issues, and associated with individual genetics, lifestyle or accidents rather than the organisation of society. Consequently, social model thinking gives little attention to the social conditions that may create impairments, such as poverty, pollution or unequal access to health care.

At its most pure, the social model envisages a society that is inclusive of all people, where everyone can participate regardless of their impairments and where separate provisions are unnecessary for people with impairments. The extent of change required to achieve this would be so far-reaching that inclusion as a concept would no longer be meaningful—all people would be included all the time (Clapton, 2009).

Implications for Services

The primary focus of the social model is changing all levels of society, including the organisation and delivery of services. It focuses policy on making mainstream services accessible but also the provision of individualised personal care and support to enable people with disabilities to participate. The model has a strong rights perspective, and advocates for public funding of services to assist people with disabilities to have greater independence, choice and control over their lives, and to be treated with respect. The early social model activists founded the 'Movement for Independent Living' that promoted the right to personal assistants, to assist people with disabilities to achieve independence and dignity. They envisaged that personal assistants would be directed by people with disabilities as would the organisations that employed and managed this workforce. This movement foreshadowed individualised funding for services as a way of promoting choice and control of personal care and support by people with disabilities.

The social model holds key messages about people with disabilities leading and directing both services and service organisations. It makes assumptions that people with disabilities can self-direct support and consequently devalues training and skills needed for the practice of direct support work. However, at the practice level, if applied well the social model does draw attention to ways of working that support physical and

cognitive accessibility. For example, supporting decision-making by making information accessible or supporting participation in meetings by slowing the pace and taking breaks.

INDIVIDUAL DEFICIT MODEL OF DISABILITY

Definition

Individual deficit models of disability (referred to as individual models) are often used to show differences to the social model of disability. There is no one body of writing associated with individual models. They focus on individuals and the impact of impairments on a person's health and functioning (physical, cognitive or psychological). The connection between impairment and disability is direct and straightforward—impairment leads to disability—therefore people are disabled by impairments rather than society. These models emphasise 'defective limbs, organs or mechanisms of the body' (Oliver & Barnes, 2012, p. 22). It is argued that it is these 'defects' that restrict or limit an individual's ability to perform activities or participate in society. Advocates refer to this as a deficit approach, as it highlights what individuals with impairments cannot do and how they are different from 'normal' people. Disability is seen as a tragedy within individual deficit models. In the past application of individual models led to the separation of people with disabilities from society and segregation (putting them together in one place) so they could be educated, treated or protected, or in some instances so society could be protected from them.

What Needs to Change

Use of individual models sometimes still leads to specialist or separate services. But more recently, these models are also used to find ways to improve the functioning of individuals with impairments. For example, optimising physical movement, improving skills, sight, hearing or speech or assisting a person to adjust psychologically to the experiences of acquiring an impairment or practically to impairment-related restrictions. This may involve medical treatments, allied health therapies, training and education or supply of prostheses (artificial limbs), hearing aids or glasses. It may also mean using knowledge about a person's health or genetic condition to improve their health, ensure they get appropriate and timely treatment, avoid future risks of poor health or understand behaviour. The

models can, for example, help us in understanding that, among other things, Prader-Willi syndrome is associated with an insatiable appetite that means that no matter how much a person eats they will not feel full, or that Down Syndrome is associated with high risk of premature ageing and early onset of Alzheimer's dementia.

The primary focus of change to improve quality of life is the individual, but may also extend to change in their immediate environment. This may involve modifying a person's home to take account of impairments and make it safer, by installing rails or ramps or providing equipment or technologies to make tasks easier to do, such as smart devices that raise or lower blinds, provide sound reminders about medication or give spoken instructions for operating machines. These types of change are tailored to each individual and referred to as adjustments or accommodations. They are not necessarily concerned with system-wide changes to accommodate all those with similar needs. The type of change foreshadowed in individual models relies heavily on the expertise of allied health, medical and psychological professions.

Pros and Cons

Application of individual models may have a direct and positive impact on a person's wellbeing and quality of life and assist their participation in activities and social interactions. The focus is on reducing or removing the direct negative effects of impairment—reducing pain, mental anguish or improving mobility. By attending to impairments, a person's health or functioning may be improved, and actions may be taken to respond to identified health risks, treatments or explanations for behaviour that improve quality of life. For example, increasing the skills of a person with intellectual disability may increase their chances of getting a job (in tandem perhaps with social model approaches of reducing discriminatory attitudes), and understanding genetic factors associated with Down syndrome may sensitise those around a person to their higher risks of heart defects to prompt regular monitoring and early interventions.

On the other hand, individual model thinking draws attention away from what people with disabilities have in common and the disadvantages this group experience. The focus on individual differences may create competition for scarce resources, such as specialised services, research or

therapy. Individual models are also criticised for medicalising disability, devaluing or stigmatising people with disabilities, by marking them out as special and different. The emphasis on specialist needs, treatment, knowledge and adjustments has at times led to provision of poorer quality services compared to those available to the rest of the population. For some people this model is associated with a readiness approach, that is, delaying participation until a person has the necessary skills or physical capacity to participate rather than providing immediate assistance to participate that compensates for difficulties in functioning, such as individual support or equipment.

Implications for Services

Individual models do not have a strong rights perspective, but they are concerned with ensuring all people have opportunities to function to the fullest and participate in society. The focus of policy and services is on improving functioning. This means investment in research to find evidence about the best types of interventions. This might be medical treatments or therapies, technologies to replace tasks and support functioning, or methods of teaching skills. Policy will be directed to development of specialist services for specific diagnostic or functional groups and the training and credentialing of professional groups to deliver services.

At the practice level expert knowledge about the needs of different groups of people with disabilities and nature of impairments is emphasised. The focus is on working with individuals and using professional skills to provide individualised care and support and adjust immediate living or working contexts.

CRITICAL REALIST MODEL OF DISABILITY

Definition

A critical realist model of disability is evolving. It is a realist model because it accepts the reality that, for example, some people have bodies that hurt or brains that function differently to others. It is a critical model because, like the social model, it challenges the idea that disability is a deficit. The

model has a strong rights-based values stance, hence, the name 'critical realist model'.

A critical realist model is characterised by interactions between factors intrinsic and extrinsic to individuals. In this model disability is understood as the:

> Interaction between individual and contextual factors which includes impairment, personality, individual attitudes, environment, policy, and culture. … [Disability is created through] the 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. (Shakespeare, 2014, pp. 77–78)

It considers a much wider range of factors about individuals and society than the social model. The critical realist model is sometimes also described as an interactional or relational model, particularly in the Scandinavian literature. It is sometimes confused with bio-psycho-social or social-ecological models which also look at individuals and social contexts but do not have such a strong rights stance.

What Needs to Change

Concern with the interaction between impairment and social structures as well as other individual and contextual factors make this model more complex than either social or individual models. It has multiple targets for change. It draws attention not only to individual or collective experiences of people with disabilities but also to the issues common to particular subgroups such as the difficulties with decision-making often shared by people with cognitive impairments but not experienced by people with physical or sensory disabilities. This highlights that people with different types of impairment often face different obstacles and helps to identify the different strategies needed to remove them.

Examples of the Application of the Critical Realist Model of Disability

Most societies use written words and visual signs as the main way of sharing information. This relies on visibility—people being able to see words and signs. It creates an obstacle for people with vision impairment who cannot see words or signs.

The strategies to remove this obstacle are both structural and individual. They include using additional ways of conveying information. Such as spoken words, sounds or tactile symbols. For example, sounds at traffic lights, braille on automatic teller machines, and technology for individuals to turn digitally written words into spoken form, such as JAWS (software that reads information on screens aloud). These types of strategies are now common in some societies.

A critical realist model highlights that strategies such as these will not be effective for all people with impairments. Some people, with different kinds of impairment or identities, face more complex obstacles created by reliance on written words. For example, translating words into spoken language will not be effective for people with vision impairment who are also deaf. Neither will direct translation from written to spoken words be effective for some people with intellectual disabilities. For this group the obstacle is not visibility of written words but keeping up with the speed that people talk and understanding the meaning of what they say. Some people with intellectual disabilities need a different type of translation, one that slows the pace and simplifies the language be it spoken or written.

Even translation to makes things more understandable will not make information accessible for those with profound intellectual disabilities. For this group it is the very use of symbols and abstract concepts that pose the obstacle to access. For this group strategies for making information accessible have to be individualised, relying on skilled workers or others who know a person well to judge the relevance of the information to the person's situation or interpret their preferences about options it contains.

Pros and Cons

The critical realist model avoids the type of *either/or* thinking of the social and individual models that concentrate either on society or impairment. It uses *both/and* thinking, paying attention to both impairment and society. The model suggests that it is "only by taking different levels, mechanisms and contexts into account" that the complexity of disability can be understood and action taken (Danermark & Gellerstedt, 2004, p. 350). Going back to the example above, strategies to remove obstacles for a person with intellectual disability and low literacy created by reliance on written words may include training to improve the person's literacy *and* regulations that require translation of all written information into plain English.

The critical realist model is concerned with *what exists* and the ways *we think about it*. The model does not try to hide the intrinsic disadvantages of some impairments. For example, some disadvantages are real and intrinsic to intellectual impairment including difficulties with time or abstract concepts, problem-solving, making decisions or assessing risk. Some of these disadvantages will not be removed by changing either the individual or their social context. This would require fundamental changes to society. They may however be reduced by providing good support or changing social contexts. Critical realists argue what is important is how we (our society) think about people with intellectual impairment. They argue that people with intellectual impairment should be valued, regarded as equal human beings with the same rights to dignity and respect as all others in society. What we think (social values) influences government actions and the distribution of resources. For example, government investment in learning and development programmes, individualised support and changing social systems to be more inclusive may not completely remove the disadvantage of intellectual impairment but will strongly influence people's quality of life. Thus, the disadvantage experienced by people with intellectual impairment stems from, among other things, the interaction of impairment with social values. Too often in the past the intrinsic disadvantages of intellectual impairment have been made worse by social values that dehumanise and devalue people with intellectual disabilities. They have been considered as 'not rational', and experienced being stigmatised, feared, excluded or discriminated against. These experiences are not intrinsic to intellectual impairment they are created by interactions between impairment and society and can be removed by changing society's values.

Implications for Services

The implications of the critical realist model for practice and service design are far-reaching. It points to the importance of considering all possibilities to reduce disadvantage experienced by people with disabilities. It helps to understand that different goals, types of interventions and strategies lend themselves to different levels of society including the individual directly. The critical realist model shows what might be achieved at which level of society and assists in identifying all possible strategies when making judgements about the best use of resources and where to intervene.

For example, it helps to make judgements about when it is appropriate to explicitly acknowledge the differences between people with disabilities and when to concentrate on what the group has in common. At the risk of using jargon, the concepts of *differentiation* and *dedifferentiation* are useful here. Differentiation distinguishes between people with disability on the basis of the type of their impairment. Dedifferentiation on the other hand says that no distinctions should be made. Judgements about which strategy is appropriate must take account of the context and level of potential intervention. The NDIS provides a good example.

Differentiation and Dedifferentiation in the NDIS
The campaign for the NDIS aimed to bring significant change to disability policy and disability service systems. The target for change was at the national level. It used a dedifferentiated approach that glossed over differences between people with disability. This approach successfully unified people with disability by highlighting what they had in common.

A dedifferentiated strategy was much less successful at the level of practice in the NDIS, for things such as planning with people for individualised packages of support. Here a differentiated strategy would have worked better. To plan effectively for supports to enable people to exercise their rights to choice and control in their lives, planners needed to understand the differences between people with disabilities in terms of communication, decision-making, and support needs and know about impairments. Planners lack of knowledge led to poor quality plans and frustration on the part of people with disability. For example, people with genetic conditions were reported to feel disrespected by staff who asked inappropriate questions about how long their condition would last.

Critical realist and social model thinking share similarly strong perspectives about the rights of all people with disability regardless of the severity or nature of their impairment. Critical realists take an approach to practice that emphasises people's strengths. But they also consider it is important to understand the *real* impact of a person's impairments to make sure they get the right type and amount of support they need to exercise their rights. Thus, assessment and planning with people with disabilities and people that know them well is considered, and drawing on multiple sources of information including expert knowledge is important to getting the right support (see Chap. 11). Critical realists avoid using *as if* ways of talking that represents people with disability *as if* they do not have impairments or *as if* their impairments are less severe than they are. This type of misrepresentation is often used to demonstrate everyone is equally human and may help in advocating for rights and status. But at the practice level it gets in the way of understanding support needs and the types of adjustments a person may require to participate successfully.

Similarly, critical realists are more likely to promote *interdependence* rather than simply independence: that is, how people rely on each other and the importance of relationships to the quality of care and support. They also recognise the long-term and continuous support needs of some people. This helps to avoid representing people's support needs *as if* they are short term or transitory. This often happens in behavioural support services, where, for example, good support and trusting relationships may help to reduce a person's incidents of challenging behaviour, but this does not mean the person no longer needs a high level of support. Too often if support is reduced it is likely that challenging behaviour will return.

At the practice level critical realist thinking is more likely to argue that recognising individual or group differences is important so that support is tailored to every individual or the group they belong to. This type of thinking brings together many of the strategies offered by individual and social models, but by emphasising *both/and* thinking encourages judgement about the strategies that are most appropriate for each person or each group at a particular time in a particular context. At the policy level critical realist thinking is more likely to emphasise issues common for all people with disabilities to secure the redistribution of resources and high-level change to ways of doing things that are necessary to achieve equality of human rights for people with disabilities.

Table 2.2 summarises three models of disability showing the perceived advantages, shortcomings and implications for policy and practice of each model.

Table 2.2 Summary of disability models

Disability definition	Perceived advantages	Perceived shortcomings	Implications for policy and practice
Social model Disability is the "restriction or disadvantage caused by contemporary social organisation that takes little or no account of people with impairments and excludes them from participation in mainstream activities" (Oliver & Barnes, 2012, p 22).	• Attention to changing social structures and processes that create disadvantage. • Simple and strong messages for advocacy. • Promoting common interests and solidarity among people with disability and diverting attention from individual differences. • Leadership by people with disabilities. • Human rights perspective. • Individual support for personal care or participation needs controlled and directed by people with disabilities. • Focussed on independence, choice, control and dignity of people with disability.	• Focuses more on physical and sensory accessibility with less attention to cognitive accessibility and types of obstacles experienced by people with intellectual disabilities. • Neglect of the downsides of some impairments such as pain or fatigue. • Broad and simple messages about change rather than detailed prescriptions for change at multiple levels. • Blind to other intersecting identities of people with disabilities. • Unrealistic expectations that society can be organised for universal access given competing types of obstacles and change people with impairments require. • Blind to issues of interdependence and supports some people need to exercise choice and control.	**Policy** • National and State laws and regulation about discrimination, accessibility, such as design of buildings, public places, public transport, mainstream services. • Systemic change to social processes to accommodate people with disability, such as mandated training for professions across all service systems including legal, health and financial systems as well as social care. • Building systemic approaches into programmes to taking account of needs of people with disability, such as flexibility for longer consultations. • Mechanisms to fund individualised care and support as a right. **Practice** • Adjustments to ways of working, such as slowing down, taking breaks, producing and using multiple modes of communication, ways of interactions. • Personal assistants directed by people with disabilities.

Table 2.2 (continued)

Disability definition	Perceived advantages	Perceived shortcomings	Implications for policy and practice
Individual deficit model Disability is what accompanies impairment: the "physical or psychological concomitants of impairment" (Priestley, 1998, p. 75), and is portrayed as negative, marked by some sort of inferiority or loss for the individual.	• Identifying differences in individual needs. • Attending to direct and negative impact of some types of impairment. • Reducing health risks. • Improving individual functioning, skills or health. • Adjustments to environment based on individual need. • Specialisation and use of evidence and expertise.	• Focus on deficits. • Readiness approach: rehabilitation or learning enables the person to be ready in the future rather than supporting participation here and now. • Special and different provisions are often of poor quality or lead to exclusion or segregation. • Little attention to systemic change of the social structures and processes. • Dominance of professional and scientific expertise.	**Policy** • Focus on ways to improve functioning. • Investment in evidence-based interventions, such as medical treatments and therapies. • Investment in technologies to replace tasks and support functioning. • Investment in learning and teaching. • Investment in specialist services for specific diagnostic or functional groups. **Practice** • Importance of expert knowledge about needs of different groups of people with disability and nature of impairments. • Focus of professional skills for individualised care and support and adjustment of immediate social context.

Critical realist model
Disability is the outcome of "interaction between individual and contextual factors which includes impairment, personality, individual attitudes, environment, policy, and culture" (Shakespeare, 2014, p. 77).

- Unpacks nuanced and complex nature of disability.
- Promotes Both/And thinking able to incorporate aspects from social and individual models.
- Recognises diversity within the disability group and similarities within subgroups.
- Recognises that types of obstacles and thus changes needed depend on the types of impairment and other individual and contextual factors.
- Attention to both impairments related and socially created obstacles and disadvantage.
- Avoids *as if* thinking such as representing all people with intellectual disability as if they only have mild impairments which obscures different types of support needs.
- Rights perspective.

- Facilitates complex understanding of disability.
- Multiple potential strategies for change meaning there are no simple messages for change.
- Requires judgements to determine appropriate levels of intervention and strategies.
- Focus on deficits as well as strengths.
- Requires skilled support to enable choice and control for some people rather than relying on only worker values or direction by people with disabilities.

Policy
- Attention to potential for intervention and change at multiple levels—law, regulation, community and individual.
- Multiple concurrent programmes and strategies for intervention focussed on system change to benefit all people with disability, for particular subgroups, and for individuals.
- Mechanisms for individualised funding for care and support that include provisions to enable people with cognitive disability to use these effectively to exercise rights.
- Investment in skills training for disability support workers, and practice leadership.

Practice
- Tailored to individuals based on knowledge about multiple facets of an individual and their social circumstances.
- Emphasis on understanding of impairment differences and intersectionality.
- Focus on interdependence and support relationships as well as independence and instrumental support.

Supporting Rights and Quality of Life

The overarching aims of disability policy and practice are to reduce the disadvantages experienced by people with disabilities: ensuring people have a good quality of life, can exercise their human rights and are protected from discrimination or abuse. Rights and quality of life are key indicators of success. They are broad umbrella terms which include other policy visions for people with disabilities, such as social inclusion, community participation, choice and control, independence and self-determination.

Rights

Rights have become more important since the United Nations adopted the CRPD in 2006. The CRPD is an international convention that aims to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (United Nations, 2006, Article 1). The CRPD sets out and explains the meaning of the human rights of people with disability in articles: statements that outline the purpose, definitions and principles of the convention. These include:

- Equality before the law without discrimination (Article 5)
- Right to life, liberty and security of the person (Articles 10 and 14)
- Equal recognition before the law and legal capacity (self-determination) (Article 12)
- Freedom from torture (Article 15)
- Freedom from exploitation, violence and abuse (Article 16)
- Right to respect physical and mental integrity (Article 17)
- Freedom of movement and nationality (Article 18)
- Right to live in the community (Article 19)
- Freedom of expression and opinion (Article 21)
- Respect for privacy (Article 22)
- Respect for home and the family (Article 23)
- Right to education (Article 24)
- Right to health (Article 25)
- Right to work (Article 27)
- Right to adequate standard of living (Article 28)

- Participation in political and public life (Article 29)
- Participation in cultural life, recreation, leisure and sport (Article 30)

Governments around the world that have signed up to the CRPD promote and protect rights through the types of strategies discussed earlier in this chapter that flow from various models of disability. They include for example:

- anti-discrimination and equal opportunity laws,
- policies requiring local governments and public bodies to make disability action plans,
- regulations about building accessibility,
- standards or guidelines for web accessibility or plain language,
- programmes such as supported decision-making and
- services and individualised supports to people with disabilities.

Abuse, homelessness, unemployment and poverty are stark indicators of failures to protect rights of people with disabilities. Positive indicators of rights are more difficult to find. Legislation and policy often assert people with disability have rights but this is rarely enough. Many people need resources and skilled support from family, friends or services to exercise their rights effectively. This is often referred to as putting policy into practice or making rights real. The outcome of a person exercising their rights also depends on individual preferences. For example, one person may use their rights to self-determination and to live in the community to choose to live with their parents into middle age, another may choose to live in a group home, and another in their own in a flat.

Quality of Life

In a similar way to Rights, *Quality of Life* provides a common language for talking about visions for life, and outcomes that might be expected from service systems. Although relevant to all people, the application and measurement of quality of life has been most comprehensively developed in the field of intellectual disabilities where international consensus about its eight domains has been reached (Schalock et al., 2002). Quality of life has eight domains that apply to everyone and everyone's quality of life looks different. The eight domains are:

- Interpersonal relations,
- Emotional wellbeing,
- Personal development,
- Physical wellbeing,
- Self-determination,
- Social inclusion,
- Rights,
- Material wellbeing.

While there is close alignment between quality of life domains and CPRD rights, tools for assessing or measuring quality of life are much further advanced. This means that for individuals quality of life may be a more useful indicator of success of legislation, policy or practices. Quality of life can be judged in various ways: against a person's own goals, against indicators tailored to the particular subgroup a person belongs to or, for some domains, against objective indicators. For example, using a method called goal attainment scaling, progress on each of a person's goals can be measured every six months, and scores compared over time (Shankar et al., 2020). Of course, this depends on how well goals were developed and reflect a person's preferences. However, this is a much more useful indicator of change than simply asking a person how satisfied they are with their life or their services, as most people are satisfied most of the time no matter what is happening to them (Schalock et al., 2002).

Table 2.3 further describes the eight domains and some of the indicators developed for people with more severe intellectual disabilities (Bigby et al., 2014). You will see that many of these rely on practice: that is, the quality of support a person receives.

Quality of life is an umbrella term that includes the aims of inclusion or choice that are often singled out in policy or mission statements of disability support organisations. Every service that delivers good support contributes to a person's overall quality of life but some services focus more strongly on some domains than others. For example, a community access service is likely to pay particular attention to supporting social inclusion and interpersonal relationships, compared to an advocacy service that will concentrate on rights and self-determination.

Table 2.3 Quality of life domains and exemplar indicators

Domain	*Indicators*
Interpersonal relations	**Individuals**
	• experience positive and respectful interactions.
	• are supported to have regular positive contact with their family.
	• know people other than paid staff and family.
Emotional wellbeing	**Individuals**
	• appear content with their environment, activities and staff support.
	• appear happy and take part relatively willingly in a range of activities with the right support.
	• are at ease with staff presence and support.
Personal development	**Individuals** are supported to
	• engage in meaningful activities and social interactions in various areas of their life.
	• try new things, experience success and develop their skills.
	• be competent and develop confidence and self-esteem.
Physical wellbeing	**Individuals** are supported to
	• have a good diet and regular exercise.
	• have access to regular health checks appropriate to age.
	• have pain or illnesses recognised and responded to.
Self-determination	**Individuals** are supported
	• to express preferences and make choices about their lives.
	• by someone who knows them well and can help others to understand their preferences.
	• to understand information through appropriate communication.
Social inclusion	**Individuals** are supported to
	• use local community facilities.
	• take part in activities with people with and without disabilities.
	• have a valued role, to be known or accepted in their communities.
Rights	**Individuals**
	• are treated with dignity and respect in all interactions.
	• have someone who advocates for their needs and interests.
	• have access to transport and community facilities.
Material wellbeing	**Individuals**
	• have their own possessions around their home.
	• are supported to manage their finances.
	• have access to sufficient funds to make purchases of their choosing.

DISABILITY SERVICES AND PRACTICE

Disability practice is the application of knowledge, values and skills to supporting people with disabilities to have a good quality of life and safeguarding their rights. Disability practice takes place in the context of services and programmes. For example, a support worker may be directly employed by a service user to assist them to participate in sport, they may work in a programme delivered by an organisation that provides leisure and recreation services for people with disabilities, or in a mainstream leisure service that is adjusting its programmes to include people with disabilities. A support coordinator or case manager may practice as a sole private practitioner, or as part of a support coordination service, or in a support coordination programme in a disability support organisation that delivers other programmes (such as supported accommodation or community access), or as part of a mainstream service such as the social work department of a public hospital. Together, services such as these make up health and community service systems. These systems are complex and shaped by government priorities, policy and funding. Some professional practices, such as social work, rely on a deep knowledge of service systems but most do not. Nevertheless, some understanding of the broader context of practice is helpful in seeing how the services a person receives fit together.

Health and community service systems have changed significantly in recent years. They are becoming more *person centred*, putting service users at the centre of everything they do and giving them greater control. In some parts of service systems the shift towards person-centeredness has changed funding arrangements from block funding of services to individualised funding. That is, rather than money going directly to organisations which decide what services to provide and who will use them, the money goes directly to individuals to spend on the services they choose. Individualised funding needs four elements:

- *Sufficient individual funding* for each individual to purchase the services they want.
- *Flourishing markets* where there are sufficient services available, which are of the type people want, in the places people want them,

so people can choose which services to purchase and change services if they are not happy with what they get.

- *Savvy consumers* where people with disabilities know what services they want, where and how to get them and are confident to manage and coordinate them and change services if they are not happy with them.
- *Effective regulators* that set and monitor the standards of services—preferably in an evidence-based or evidence-informed way—and promote compliance both by positive strategies to promote learning and improvement and by enforcement action when needed.

Of course, individualised service systems are much more complicated than this, and there are many other processes in each element. For example, individual planning is needed to determine the allocation of funding to each individual and once allocated to plan what to purchase; markets need to be encouraged to develop particular types of services or supply them in isolated places where demand is low; many people with disabilities need supported decision-making or advocacy to be good consumers and to articulate their needs, or choose and manage their services; and regulators must identify what information to collect about the quality of services, determine where to set standards and how to judge quality.

Most of these processes rely on skilled disability practice by those who work directly with people with disabilities and others who are important to them, who lead and supervise direct workers, and who design and manage programmes. The Australian NDIS is one of the most fully developed individualised funding schemes for disability services. It is administered by the National Disability Insurance Authority (NDIA) and almost all government funding for disability services is allocated as part of the scheme to individuals with disabilities to spend on the services they choose. This means that services rely on the NDIS money that each individual service user brings with them for all of their income. If they do not attract enough services users to cover their costs they will go out of business. There is now excellent material on the NDIA website that explains how the scheme works and a recent book by Cowden and McCullagh (2021) provides both description and commentary about the NDIS.

There are aspects of the health and community services system that are not suited to individualised funding. The individual consumers of some services are not easily identified and may be a wider collective of individuals, or be groups or communities. Thus advocacy, community

development or projects to make mainstream services more accessible should continue to be funded directly by governments. It is also argued that governments need to play a significant role in strategic planning and commissioning of services, to ensure all the needs of people with disabilities are well understood and met rather than leaving this to markets alone. The NDIS is unique in this respect in that unlike some individualised schemes it directly commissions only a very few services although it does try to influence the market through price and policy.

Around the world health and community service systems are continually adjusting to meet the competing demands of economic sustainability, ideology and government priorities. There is no doubt that service systems influence the context and nature of disability practice but fundamentally the quality of practice and thus support for people with disabilities to have a good life relies on the knowledge, values and skills of those who carry out practice.

Take Home Messages

- People with disabilities are a diverse group who are significantly disadvantaged on all social indicators.
- The different ways of describing and measuring disability determines the size of this population which if you use prevalence is as large as 18% (4.4 m) of the population in Australia, or as small as 610,502 people who are eligible for the NDIS.
- Three of the most common ways of understanding disability are the social model, the individual deficit model and critical realist model—each gives different insights into ways of improving the lives of people with disabilities. Both/And thinking suggests that all of these are useful in disability practice.
- The social model emphasises the need for change to the structures and processes of society so be inclusive of people with disabilities, the individual model emphasises the finding ways to improve the functioning of individuals often through specialist services, and the critical realist model is concerned with the interaction between people with disabilities and society, focusing both on maximising individual functioning and development and adjusting the social structures of society to be more inclusive.
- The concepts of quality of life and rights are useful ways of thinking about what disability policy, services and practice are trying to achieve for people with disabilities.

References

AIHW. (2022). *People with disability in Australia 2022.* Australian Government.

Appiah, A. (2017). *As if: Idealization and ideals.* Harvard University Press.

Bickenbach, J. E. (2019). The ICF and its relationship to disability studies. In J. E. Bickenbach (Ed.), *Routledge handbook of disability studies* (pp. 55–71). Routledge.

Bigby, C., Knox, M., Beadle-Brown, J., & Bould, E. (2014). Identifying good group homes: Qualitative indicators using a quality of life framework. *Intellectual and Developmental Disabilities, 52*(5), 348–366.

Centre of Research Excellence in Disability and Health. (2021). *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia.* A. Royal Commission into Violence, Neglect and Exploitation of People with Disability.

Clapton, J. (2009). *A transformatory ethic of inclusion: Rupturing concepts of disability and inclusion.* Sense Publishers.

Cowden, M., & McCullagh, C. (2021). *The National Disability Insurance Scheme: An Australian public policy experiment.* Palgrave Macmillan.

Danermark, B., & Gellerstedt, L. C. (2004). Social justice: Redistribution and recognition—a non-reductionist perspective on disability. *Disability and Society, 19*(4), 339–353. https://doi.org/10.1080/09687590410001689458

Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *The Lancet, 383*(9920), 889–895.

NDIS (2023). NDIS Quarterly Report to disability ministers.

Oliver, M., & Barnes, C. (2012). *The new politics of disablement* (2nd. ed.). Palgrave Macmillan.

Priestley, M. (1998). Constructions and creations: Idealism, materialism and disability theory. *Disability and Society, 13*(1), 75–94. https://doi.org/10.1080/09687599826920

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation, 40*(6), 457–470.

Shakespeare, T. (2014). *Disability rights and wrongs revisited* (2nd ed.). Routledge Publisher.

Shankar, S., Marshall, S. K., & Zumbo, B. D. (2020). A systematic review of validation practices for the goal attainment scaling measure. *Journal of Psychoeducational Assessment, 38*(2), 236–255.

Smith, W. K., Lewis, M. W., & Tushman, M. L. (2016). "Both/and" leadership. *Harvard Business Review, 94*(5), 62–70.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities (CRPD).* UN General Assembly.