Introduction

This chapter gives an overview of the main issues related to the situation of adult persons with disabilities in society. This includes key concepts, perspectives and empirical facts related to the diverse life courses of persons with disabilities, and the main types of efforts by various actors, including disabled people themselves, to achieve social recognition, equal participation, and the legal and material conditions for independent living and personal fulfilment for persons with disabilities.

Core concepts, perspectives – and some basic facts

Until recently, individual-oriented or bio-medical understandings of disability have dominated perceptions of persons with disabilities and the provisions to assist. According to these understandings, a medical condition or impairment (i.e. a reduced functioning of the person’s bodily, mental or intellectual capacity) is the cause of the disability. For a long time, such deficiency-oriented understandings of disability have played a key role in defining eligibility for cash benefits and services, often with the stated purpose of compensating for the effects of reduced individual functioning.

In this context it is notable that some scholars have argued that historically the notion of disability was invented to mediate the ways in which traditional poor laws distinguished rather harshly between the deserving and non-deserving destitute (e.g. Stone, 1985; de Swaan, 1990). By defining or categorising destitute persons of working age as ‘disabled’ (usually other and more derogatory terms were used), local authorities could legitimately exempt these persons from the general duty to work and be economically self-sufficient. In this way, some destitute persons escaped the brutal treatment and compulsion that the non-deserving poor experienced.

With the advent of the welfare state and social security provision from the end of the nineteenth century and onward, the use of impairment-oriented disability categorisation was refined and developed further. Gatekeepers tended to assess disability in an absolute and binary way; they deemed a person as either disabled or not. The authorities gave the main emphasis to how
the person’s impairment influenced his or her capacity for paid employment and being economically self-sufficient, to avoid that person becoming a ‘burden for society’.

In other words, the concept of diminished work capacity (or earnings capacity) is synonymous with neither the concept or disability nor the concept of impairment. A person’s ability to perform in a given job or occupation depends on a number of factors. One of these factors is whether the person has relevant and sufficient vocational qualifications for the job, or whether the person has a necessary command of the language(s) to use in the job. Other factors include the extent to which the person has an impairment or disability affecting his or her ability to perform in this particular job, and whether the actual or potential employer provides the appropriate workplace accommodation or adjustments allowing the person to use his or her qualifications, experience and capacity.

Significantly, a second approach to conceptualising disability originated from the experience of large-scale war, especially after the two World Wars (Amos, 1943; Obermann, 1967; Liachowitz, 1988; Grahame, 2002; Ross, 2008; Linker, 2011). The great number of persons wounded and injured in war action tended to be young men, with or without work experience before they were mobilised. Widely regarded as ‘national heroes’, the war injured were a highly legitimate group and represented an important labour potential in reconstruction after war. Apart from privileging war-injured servicemen by providing better financial support and services than for those who had been injured in work, these factors contributed to the invention of vocational rehabilitation services and workplace adjustments to accommodate veterans’ injuries.

After governments had introduced them for injured servicemen, provisions of vocational rehabilitation and workplace accommodation were later generalised to encompass all who had been born with or who later acquired an impairment affecting their prospects of finding or continuing in work.

For instance, in order for a person with an impairment to be able to fill a job for which he or she is best qualified, practical changes in the work situation or improved accessibility to the workplace or other premises may be required (Häikiö and Hvinden, 2012). In other cases, persons with impairments may need flexible working time arrangements, the modification of equipment, training procedures, reference manuals, procedures for testing and assessment, an assistant (reader or interpreter) or supervisor, reorganisation of work tasks, or the reassigning of non-essential duties to other employees.

Gradually, two different approaches merged; on the one hand, vocational rehabilitation services provided by work medicine, physiotherapy and occupational therapy, and on the other, a systematic analysis of work operations to achieve a good fit between job demands and workers’ capacities – ‘ergonomics’ – carried out by engineers or technicians. This combination contained the germ of what became the relational or relative understanding of disability (Tøssebro, 2004; Shakespeare, 2006). This understanding sees disability as ‘a mismatch between the person’s capabilities and the functional demands of the environment or in terms of a gap between individual functioning and societal/environmental demands’ (Tøssebro, 2004). According to this understanding, bodily, mental or intellectual impairments do not determine in themselves how disabled or incapacitated a person will be, but the interaction or relationship between the person’s impairment and the person’s social, cultural and physical context.

If governments decide to build their approach on this understanding of disability, their task would be twofold:

- Reducing the gap between the individual’s capacities and the demands of the environment, by improving his or her capacities through education or retraining and other relevant provisions (technical aids, adjusted housing, transport, personal assistance, etc.).
• Requiring employers to modify the demands of jobs and the work environment to achieve accessibility and various forms of social and organisational accommodation, and, if necessary, to contribute to employers’ costs related to such accommodation.

Although such public–private cost-sharing is rare, it does take place in some countries, for instance, by means of direct public grants or tax credits or tax incentives. Under the European Union Framework Employment Directive 2000/78/EC (EC, 2000), the possibility of public funding is one factor to consider when assessing whether to provide reasonable workplace accommodation for a person with a disability would represent a disproportionate burden for an employer. KMU Forschung Austria (2008) presents a survey of European experiences on the need and possibility for such public–private cost-sharing.

While governments’ policies have given different relative emphasis to the two main forms of interventions, it is still notable that many governments have moved towards adopting a relational or relative understanding as the framework for their disability policies more generally. Arguably, this is also the case with the 2006 UN Convention on the Rights of Persons with Disabilities (UN, 2006) where Article 1 gives the following definition:

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.

A third conceptualisation of disability originated within the international social movement of persons with disabilities and was first codified by scholars who themselves had experience of living with a disability. This social-contextual understanding frames disability in terms of oppression, systematic discrimination, exclusion and segregation, i.e. redefining disability as socially and culturally created (Oliver, 1990; Barnes, 1991). The social-contextual understanding is set in clear opposition to bio-medical understandings of disability and involves a strong criticism of conventional welfare state arrangements building on such understandings, claiming that these arrangements contribute to the margin position, passivity, segregation or even exclusion of persons with disabilities.

Proponents of this social-contextual understanding – often referred to as ‘the social model’ – call for broad social changes to enable persons with impairments to participate in society on an equal footing with others, live independently in the community and exercise self-determination. Key demands include removing barriers for participation by making accessibility legally required, and combating discrimination and exclusion through legal and other instruments. A distinct strand of disability studies and research in the United Kingdom and a number of other countries has elaborated the social-contextual understanding and the related demands for social change. Inspired by the social-contextual understanding, broad alliances of organisations of persons with disabilities have successfully mobilised and campaigned for the adoption of accessibility and non-discrimination legislation both on national and supranational levels.

In their turn, both the relative and social-contextual understandings of disability have been criticised. For instance, one of the objections against the relative understanding has been that it gives indeterminate or insufficient guidance for decision-making and therefore has had limited practical effect. The relative understanding advocates a reduced mismatch between the individual’s capabilities and the environment’s demands but does not tell us how to calibrate overall public efforts on strengthen the individual’s qualifications and capacities versus putting pressure on employers to provide accessibility and other forms of on-the-job accommodation. Cynically, one may predict that governments will follow the road of least resistance; mainly seeking to
change individuals’ qualifications and capacities while being more reluctant when it comes to confronting employers and challenging their traditional prerogatives. Similarly, criticism of the social-contextual understanding observes that the distinction between impairment and disability has become reified, denying the impact of bodily difference and the ways in which not only disability but also impairments may be socially created or shaped (Shakespeare, 2006; Thomas, 2007).

Other writers have criticised the simple binary division between persons with and without disabilities. These writers have outlined what they call a universalist perspective on disability, claiming that everyone experiences – or at some point will experience – limitations in his or her physical and mental capacity (e.g. Zola, 1989; Bickenbach et al., 1999; Bickenbach, 2012). According to this perspective, to have an impairment or chronic illness is a matter of degree rather than a clear dichotomy. Rather than being stable and fixed categories, we are talking about highly changeable characteristics locating all of us at diverse and variable points on a continuum from disabled to non-disabled. Arguably, this is particularly striking when we consider mental health issues that may be long-term but still fluctuating in severity.

Finally, the term ‘disability’ conceals a great diversity of specific impairments and their practical impact upon everyday life. The heterogeneity of the adult population living with substantial impairments is illustrated by the different degree of participation in economic life. According to a study carried out in 51 countries across the world, the average employment rates were 53 per cent for men with disabilities and 20 per cent for women with disabilities, compared to 65 per cent for men without disabilities and 30 per cent for women without disabilities (WHO and World Bank, 2011). Largely for the same reason, across the world persons with disabilities tend more often to live in economic hardship, poverty and bad health, and be denied basic human rights and security, than persons without disabilities (ibid.).

The OECD stipulates that in the mid-2000s the average employment rate of persons with disabilities was just above 40 per cent, while the average rate of persons without disabilities was close to 75 per cent in member states (OECD, 2009). In Europe, the European Union Statistics on Income and Living Conditions (EU-SILC) for 2014 suggests an average employment rate for persons with disabilities of 49 per cent in member states (Grammenos, 2017).

However, and in contrast to what one might intuitively assume, the EU-SILC data do not indicate that the average employment rate of all persons with disabilities at the EU level decreased because of the Great Recession. One reason for this is the relatively high average age of persons with disabilities. For young people both with and without disabilities, the employment rate deteriorated during the period 2008 to 2013, and for young people with disabilities the employment rate continued to decrease in 2014 (Grammenos, 2017, p. 7).

Moreover, a range of studies show that persons with mental or intellectual impairments tend to have considerably lower employment rates than persons with other impairments (OECD, 2015; Halvorsen et al., 2017). For a long time persons with mental or intellectual impairments were also more often than other persons with impairments placed in large institutions, isolated and hidden from the rest of society, and in many cases exposed to demeaning and degrading treatment and abuse. While many Western countries have carried out a programme of closing down the large institutions and seeking to integrate people into the community, other countries, for instance, post-communist societies, are still lagging behind with this deinstitutionalisation.

According to current estimates, more than a billion people in the world live with some form of disability, of whom nearly 200 million experience considerable difficulties in functioning (WHO and World Bank, 2011). These and similar estimates must, however, be interpreted and used with caution for reasons related to the challenges of conceptualising and measuring disability in a valid, consistent and comparable way in cross-national statistics (Tossebro and Hvinden, 2017).
Despite the wider acceptance of relative (relational) or social-contextual concepts of disability, social surveys aiming to measure the proportion of a given population who has a disability, and how this disability affects the situation and well-being of the person, tend to be oriented towards individual impairments or restrictions in functioning or activity. This is partly because surveys generally use probability samples of individuals in order to estimate the distribution of characteristics in entire populations, rather than trying to interview all members of these populations. This procedure means that the individual’s replies to a set of questions about whether he or she has an impairment or experiences a restriction in everyday life are used as a screening device to identify him or her as a person with a disability. Moreover, one has to seek information about the individual’s relationships to his or her physical, social or organisational environments through the replies of the individual.

Unfortunately, we still have limited comparative, representative and reliable data about the agency and participation of persons with disabilities. For instance, Eurostat, ILO, OECD and the European Social Survey programme have sought to collect or compile such data. The European Community Household Panel (ECHP) study, the European Labour Force Survey (LFS), Eurostat’s Ad hoc Modules 2002 and 2011, and the EU-SILC and the European Health and Social Integration Survey (EHSIS) have all included disability-related questions. These attempts to produce comparative data are faced with the fundamental issue of how to define disability for the purpose of official statistics and research.

Unlike demographic characteristics such as age and gender, whether a person has a disability or not is a characteristic where national statistical authorities can rely on existing registers. Knowledge about whether a person has a disability or not has to be collected through statistical surveys, based on interviews or questionnaires and large-scale representative samples of the whole population. Since the basis for this approach is screening and self-identification, a source of error is the reluctance of some respondents to disclose to a stranger that they have an impairment or disability.

Another complicating factor is that, despite the goal of producing strictly comparable data from different countries and translating terms as precisely as possible between different languages, it is unavoidable that the terms used may have somewhat different associations or connotations for respondents in different countries. Possibly the availability and scope of a country’s disability provisions – both of the redistributive and social regulatory kinds (see below) – influence respondents’ inclination to identify themselves as having an impairment or disability (Tøssebro and Hvinden, 2017). Moreover, different demographic structures of countries will affect their proportion of citizens with disabilities.

Anyway, the striking and surprising differences in the proportion of respondents from different countries who report that they have a disability compound attempts to collect comparative data. For instance, in the 1996 wave of the ECHP this proportion varied from 8 per cent (Italy) to 23 per cent (Finland), whereas in the 2012 EHSIS the proportion varied from 6 per cent (Italy) to 20 per cent (Norway). In the EU-SILC data for 2014, the span in the proportion of persons with disabilities ranged from 5 per cent (Malta) to 28 per cent (Germany) (Grammenos, 2017, p. 35). There are no obvious reasons for expecting that the difference in actual disability prevalence between these countries should be so large.

**Presentation and analysis of these elements**

A basic and general mechanism behind the over-representation of persons with disabilities among groups experiencing disadvantage and hardship is the tendency of human beings to favour the common (‘normal’), ordinary, conventional, familiar and recognisable. The more
narrow and strict notions of normality, the more exposed to separation and exclusion will be persons who are perceived to be different or deviating. More specifically, we tend to have clear standards for the ways in which one should look, appear and act. In our culture, we have a long tradition of celebrating facial and bodily beauty, and idealising the young, well-trained and perfect body. Generally, this idealisation tends to put persons who look, talk, walk and behave differently than others at disadvantage and risk of being neglected, disparaged, stigmatised, excluded or segregated from the rest of society.

A second mechanism is the general necessity of human beings to work in order to live and the related norm that one has to contribute in order to enjoy the gains of work (Stone, 1985; de Swaan, 1990). While the necessity and social duty to work is modified and mediated in modern and highly differentiated societies, the perceived ability to perform and carry out one’s share of the work is still an important criterion for our judgement of our fellow-beings (and ourselves) and a significant source of social recognition and respect (and self-respect). The elaborate differentiation of our societies means that performance expectations are particularly strong and dominant in the economic sphere, the market and the work organisation. Broadly speaking, this performance orientation puts persons with reduced work capacity at a disadvantage in economic life, especially if the reduction is of a long-term nature.

A third mechanism is our tendency to make untested assumptions about other people, about what they are like or what they are able to do or achieve. Often our knowledge is more limited than we would like to admit and we make judgements based on weak or flimsy evidence, or limited experience. As a result, persons with disabilities tend to experience prejudice, stereotypes or unwarranted generalisations. Thus, an employer may disregard a well-qualified job applicant with a particular impairment, on the basis of the untested belief that the person would be less able to carry out the job or be less productive, even if the impairment is completely irrelevant to the person’s ability to undertake the tasks of the job. Such disregard would represent a case of (direct) discrimination on the part of the employer.

Whereas we in everyday life tend talk to talk about discrimination as if it involved dislike, bad will or deliberate adverse intentions towards another person or group of people, the legal concept of discrimination is broader, encompassing both intended and unintended effects of human action. Article 2 of the UN Convention of the Rights of Persons with Disabilities defines discrimination as follows:

‘Discrimination on the basis of disability’ means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

(UN, 2006)
Redistributive provisions have for a long time and in most countries played a more dominating role than social regulatory provisions.

Redistributive provisions have offered income maintenance or replacement for persons who have been unable to find work or who have had to give up working. Such cash benefits have, for instance, been called disability or incapacity benefit (pension). The exact construction of disability-related cash benefits has varied considerably between countries (or, over time, within countries) in terms of eligibility criteria, associated training requirements, generosity (replacement rates) and duration. Despite this huge variation in design, national governments as well as supranational organisations like the Organisation for Economic Cooperation and Development (OECD) have been worried about increasing numbers of disability-related beneficiaries and the associated burden on public budgets. A recurring concern has been whether the availability of such cash benefits creates disincentives to work (meaning that ‘work does not pay’), especially for people who are likely to find themselves at the lower end of the income distribution. Although there is some evidence for such disincentive effects, there are disagreements about how great and significant they are, for instance, compared to the strictness of medical and work capacity testing, the frequency of and efforts invested in reviews of granted benefits, and the amount of resources spent on vocational rehabilitation, training, active job guidance and monitoring of job-seeking efforts.

Arguably, not only have people with disability had advantages of disability benefits. Perhaps the gains for the economy and the whole society have been even greater. The studies by Rege et al. (2005) and others suggest that the availability of disability benefits has contributed to ease the restructuring and modernisation of economic life, by providing socially acceptable avenues out of work for those of us who become redundant and who are unlikely to find new jobs. Technically, some employees at risk may receive offers about severance pay that they dare not turn down. After some time, people who have lost their jobs because of downsizing or plant closures may have their status administratively redefined from being ‘unemployed’ to being ‘disabled’. If people who have lost their job realise that they are unable to get a new job, some may change their own self-perception in a similar way and apply for a disability pension (Rønsen et al., 1993). While this (ab)use of disability provision may appear convenient for the directly affected (including the employer) and others, some observers maintain that it effectively means ‘purchasing the absence of the other’ and creating an additional mechanism for excluding persons with disabilities.

As already suggested, many governments spend substantial amounts of resources on measures to strengthen the capacities of persons with disabilities by improving their qualifications, and, through this, their labour market prospects. Evaluations of such welfare-to-work measures have given mixed findings about effects. Some fear that such measures remove participants from the labour market for too long or that having participated in such measures is scarring the person in the eyes of potential employers. It is worth asking whether one might have put some of these resources to better and more effective use by ensuring that young people with disabilities succeed in completing their education as planned and with sufficiently solid results to make them competitive in the labour market. Several studies have found that persons with disabilities on average have lower educational achievements than persons without disabilities and that this difference contributes to the gap in employment rates (e.g. Molden and Tøssebro, 2012).

Some redistributive provisions target persons with disabilities involving long-term or permanent reduction of work capacity. Such provisions include various forms of financial incentives for employers to hire these persons (wage subsidies, tax deductions, etc.) and the possibilities to combine a part-time job with a graded disability pension. In some countries, companies over a particular size are obliged to have a certain quota of employees with reduced work capacity,
serving some of the same functions as wage subsidies. While wage subsidies and quotas appear relatively successful in promoting employment for persons with permanently diminished work capacity, some observers argue that they distort the normal functioning of the labour market through displacement of other job seekers or redefinition of already employed persons. One could probably avoid such unintended effects if one improved arrangements for assessing the extent to which the person’s work capacity is actually diminished, and possibly reviewing whether this is still the case after a certain period.

In most countries, redistributive provisions include social services to assist and care for persons with disabilities. The nature, quality and scope of these services have changed considerably over time (e.g. from placement in large total institutions to services provided in the local community and aiming to create conditions for the privacy, independence and self-determination that citizens generally expect to have in modern societies). Even if the enjoyment of these goods are defined as basic rights under international human rights conventions (e.g. UN, 2006), they are not a matter of course in all societies. In some countries we still find large institutions, whereas in other countries family and kin are still the main providers of care for persons with disabilities (Halvorsen et al., 2017). Meanwhile, in countries where deinstitutionalisation has been almost completed, one can see worrying signs of re-institutionalisation through the establishment of large ‘group homes’, driven by efforts to cut public expenditure. Similarly, local cost-cutting exercises or ‘austerity’ may threaten the provision of personal assistance, vouchers or direct payments to enable persons with disabilities to hire assistance, undermining or reducing possibilities for independent living.

As already indicated, new social regulatory provisions first of all involve giving employers, public and private actors operating buildings, transport, communication and information systems the duty to ensure full accessibility (i.e. preventing and removing barriers to equal access, use and participation). Second, such provisions generally seek to promote equal treatment by prohibiting discrimination of the ground of disability or impairment, for instance, in relation to employment and occupation. Third, the provisions give employers the duty to offer reasonable accommodation to job applicants or employers with disabilities who may require such accommodation. In this context, ‘reasonable’ means that the accommodation should be appropriate and relevant in relation to the person’s requirements but should not represent a disproportionate burden for the employer. As already mentioned, some countries have public arrangements covering part of the costs related to accommodation, making it harder for employers to claim that accommodation would represent a disproportionate burden.

In 2017, most European countries had introduced accessibility and non-discrimination laws owing to their membership or association with the European Union. The EU includes accessibility requirements in its legal regulations for the internal market. All member states had to transpose their national legislation in accordance with the EC Directive 2000/78 on equal treatment in employment and occupation (EC, 2000), while associated countries have decided to introduce shadow legislation to match the Directive.

In the broader international context, equal treatment, accessibility and non-discrimination have been given a strong boost through the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) (entry into force 3 May 2008). In the summer of 2017, 173 countries and entities across the world, including the EU, had ratified the Convention.

It is notable that the international social movement of persons with disabilities has vigorously campaigned for the adoption of equal treatment, accessibility and non-discrimination legislation in the national, regional (e.g. European) as well as the global context.

Observers disagree on what impact the new social regulatory provisions have had in terms of improving the situation for persons with disabilities. So far the practical impact appears to be...
greater in relation to accessibility than in relation to non-discrimination, for instance, in employment. Even in countries that introduced non-discrimination legislation relatively early, for instance, the United States (1990) and the United Kingdom (1995), the evidence on impact is mixed. Overall, the legislation appears to have been most successful in preventing discrimination of persons who are in a job and who acquire a disability than in preventing discrimination of persons outside work seeking to get a job.

Some early studies indicated that the Americans with Disabilities Act (ADA) led to diminished employment rates for persons with disabilities. These studies suggested that employers sought to avoid litigation by not hiring persons with disabilities or that the obligation to provide reasonable accommodation deterred employers from recruiting job seekers with disabilities. Other researchers questioned these findings, arguing that the work disability measure used did not accurately reflect the coverage under the ADA. Later studies have found that while the employment rate of persons with disabilities diminished in the early 1990s, the cause was not the introduction of ADA but a new definition of disability in the income maintenance system.

Research in the United Kingdom indicates that the DDA did not have any impact in the first period after its introduction and that it even contributed to a decrease in the employment rate of persons with disabilities. The DDA may have influenced employers to avoid firing employees who had acquired an impairment but to a less extent have had a positive impact upon recruitment practices.

There may be additional reasons for the lack of positive and robust effects of non-discrimination legislation. One reason may be methodological; for instance, with the data to which researchers have had access, it may not have been possible to control for the effects of potentially counteracting factors. Or researchers may lack data of the extent to which non-discrimination legislation is effectively implemented and enforced in the sense mentioned above; through a system of awareness raising, information, supervision and enforcement, aiming at a combination of preventive measures and sanctioning of actual cases of discrimination. This aspect may be particularly important when comparing the effect of non-discrimination legislation in different countries.

However, non-discrimination legislation has some limitations. For instance, we will only have a case of direct discrimination if a person with a particular disability is equally qualified and able to perform the core tasks of a job (with appropriate accommodation) as a person without that particular disability, and the person with this disability is treated less favourably on the grounds of having this disability. We will not have a case of discrimination if the person with this disability, for instance, is turned down for a job because he or she has less relevant education, training or work experience than another applicant and the latter gets the job. To the extent that persons with disabilities on average have less education, training and work experience than persons with disabilities, this difference may explain a considerable part of the employment gap between the two groups. Finally, non-discrimination legislation leaves it to the person who has experienced discrimination to file a complaint and may incur considerable economic losses if he or she loses a court case against the employer.

For these reasons, policy efforts to improve the employment prospects of persons with disabilities need to combine elements of regulatory and redistributive provisions, rather than seeing these as alternative approaches.

Conclusion

Despite governments’ stated aims of ensuring that persons with disabilities enjoy the right to live in the same way as others, the daily reality for a great number of persons with disabilities is
different. While we find large variations in the living conditions of persons with disabilities across different countries and kinds of impairment, neglect, ignorance, stereotypes, prejudice and discrimination are still preventing too many people with disabilities from enjoying a life of security, dignity, respect, independence and self-determination. Most countries’ provisions to address the situation of persons with disabilities appear insufficient or misdirected, or both. Significantly, the adoption of the UN Convention of the Rights of Persons with Disabilities has created a new optimism and belief in change across the world, in rich, emerging and poor economies. The Convention is likely to stimulate change from different national and regional points of departure but pointing in the same direction.

References


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