**Bioethics and Disability: report for UN Special Rapporteur on Disability**

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1. **Introduction**

In this background report on Bioethics and Disability, our aim is to show how bioethics’ engagement with disability reflects and shapes the social and cultural backgrounds of the people involved in the discussion. This means that bioethical thinking has both direct and indirect effects on the lives of people with disability, as well as broader implications for creating equal and just societies.

**Bioethics as a field of activity**

Bioethics is an academic discipline and professional sphere that considers the ethical, legal, and increasingly the societal issues raised by medicine and the life sciences. Its focus tends to be less on the everyday aspects of these areas (some of which are covered by medical ethics) and more on innovation and cutting-edge developments that raise, or appear to raise, novel ethical difficulties for healthcare, scientific research and society in general. Bioethicists come from a wide range of backgrounds including moral philosophy, law, social science, social policy and medicine, and so can apply a variety of theoretical and empirical approaches [[1]](#footnote-1) [[2]](#footnote-2).

Bioethicists are frequently called upon to examine the implications of a clinical or public health innovation: judging whether it is ethically right, how research and practice should be regulated through legislation and professional guidelines, whether public money should be used to support it, and so on. Sometimes, bioethicists operate as consultants in hospitals, advising on particular clinical dilemmas or research projects. In this way, bioethics often provides a moral bridge between biomedical practice and regulation or policy. Alongside the practical implementation of new biomedical technologies, bioethicists are also concerned with the ethical consequences of the ways that developments in scientific *understanding* can change how societies think about human lives and values.

Bioethics is a comparatively recent development, dominated by high-income countries, although the International Association of Bioethics has met in cities such as Singapore (2010), Mexico City (2014) and Bengalaru (2018) and has members from 40 countries.

In the United States the development of bioethics has been shaped by the Belmont Report of 1979, establishing the principles of respect for persons, beneficience and justice at the heart of the ethics of medical research. Also in the USA, the President’s Council on Bioethics and the Hastings Center for Bioethics have been particularly influential. The Nuffield Council on Bioethics offers an independent perspective on UK debates but also has wide international influence. More formal national bioethics committees operate in France, Germany, Switzerland and other countries[[3]](#footnote-3).

Many of these bioethics committees consult with members of the public. For example, almost all Nuffield Council on Bioethics working parties operate a consultation to gather lay views. In its 2017 enquiry on non-invasive prenatal diagnosis (NIPT), efforts were made to gather the views of people with Down syndrome. The French national bioethics committee, Comité Consultatif National d’Ethique pour les sciences de la vie et de la santé[[4]](#footnote-4), runs an even more extensive consultation process to gather lay views, particularly for the periodic revision of the national law on bioethics.

**Why is bioethics of particular relevance to disabled people?**

From the outset, bioethics has had a strong interest in disability. This is because medicine traditionally sees disability as a deviation from a norm of health[[5]](#footnote-5). In this view the task of medicine is to intervene when bodies deviate from the norm and to use medical knowledge and techniques to restore them to normal functioning and health, or ideally to prevent such deviation happening in the first place. As discussed below, this understanding of disability and of the role of medicine has been strongly challenged by disabled people and disability scholars[[6]](#footnote-6). Bioethics is interested in the moral permissibility of using particular medical interventions to prevent or treat disability, and is often called upon to give ethical guidance to discussions about setting healthcare policy and law.

The greatest involvement of bioethics with disability has been in areas that are very directly about life and death. For example, key topics of bioethical interest include the ethics of using prenatal diagnosis (PND), preimplantation genetic diagnosis (PGD) and preconception screening to prevent the birth of children with disabilities [[7]](#footnote-7) [[8]](#footnote-8); the reproductive rights and freedom of disabled people (especially when disabled people want to use reproductive medicine to become parents); and issues at the end of life, such as assisted suicide, euthanasia and decisions about continuing medical treatment when a person is seriously ill or dying[[9]](#footnote-9) [[10]](#footnote-10). Alongside these ‘life or death’ areas bioethics has also contributed to the discussion of more mundane topics such as: healthcare rationing as it affects disabled people, or the use of biomedical technologies to normalize anomalous bodies or minds, especially in the very common situations where parents make choices about the bodies and minds of children: limb-lengthening surgery for children with restricted growth [[11]](#footnote-11), for example, or cochlear implantation into infants or very young children, among others [[12]](#footnote-12). Several of these points are discussed in more detail in later sections of this report.

Disability is generally considered to be an undesirable state (though see below for an outline of different definitions and models of disability), and most societies view it unfavourable. Physical or mental anomaly is considered to be a misfortune that means a person with disability, and often their family, experiences suffering and disadvantage. From a bioethical perspective, then, preventing or ameliorating disability is a morally good thing to do. It is not however an *absolute* moral good, in the sense that it overrides any other consideration. For example, the compulsory sterilization of people with genetic conditions could prevent the transmission of some kinds of genetic disability between generations, but it would also raise very significant questions of justice and of the individual right to autonomy. Many people also have serious ethical concerns about widely used methods of ‘managing’ disability: these include the termination of pregnancy because of foetal anomaly; diverting limited healthcare resources towards research for rare disabling conditions; or providing the means of assisted suicide in the context of disability. Bioethical analyses aim to provide guidance for clinical practice in contested situations like these.

When they are asked to make judgements about the moral permissibility of termination of pregnancy for foetal anomaly, withdrawal of life-sustaining treatment, or normalizing surgery, bioethicists are effectively also judging *the quality of disabled people’s lives*: they are weighing up the impact of an impairment on an individual’s lived experience, sometimes also the family’s and community’s experience, against the ethical cost (and sometimes the economic and resource cost as well) of making this particular intervention, or not. Whether they choose subjective measures of quality of life (what people with lived experience say) or objective measures (what economists, public health specialists, ethicists or others say) is relevant to the judgement they make.

**Changing contexts**

Bioethics has relevance to disabled people’s lives for other reasons. One of these is that recent advances in biomedicine, and especially the power of new selective and therapeutic technologies, have *changed the frame of reference* within which disability is understood and interventions to prevent or ameliorate disability are evaluated. Medical knowledge has always been used to minimize the risk that individual people will become disabled as a consequence of illness or trauma. Since our knowledge of genetics has grown throughout the twentieth and twenty-first centuries, medical genetics has also been used to minimize the transmission of genetically associated disability from one generation to the next. In those parts of the world where health services are wealthy enough, there is an expanding repertoire of genomic technologies offer new options for preventing disability, whether through the prenatal identification of genes associated with disabling conditions or through postnatal treatment targeted to specific genetic profiles (see sections 3 and 4) [[13]](#footnote-13) [[14]](#footnote-14) [[15]](#footnote-15). These technologies drive sociocultural changes, as increasing options can shift *attitudes* towards disability that in turn become the grounds for concrete *actions*.

Interacting with the sociocultural changes are changes in the *social and political status* of people with disabilities. Over approximately the last 50 years, attitudes towards disabled people have altered dramatically in many parts of the world [[16]](#footnote-16). This is for several interconnected reasons. For one thing, there is greater awareness of disability, partly because of demographic changes experienced across the globe as communicable diseases give way to non-communicable diseases, people live longer, populations age, and so individuals experience more age-related impairment. Advances in medical care have also led to more people surviving premature birth, severe illness or major trauma, but often with lifelong disabilities.

Another factor is that global disability activism has led to the development of various forms of anti-discrimination legislation, and instruments of national and international law, that aim to protect the rights of disabled people and to enable them to live in equality with their nondisabled peers. Among the first of these instruments was the Americans with Disabilities Act (ADA) of 1990[[17]](#footnote-17). Others now include the UK’s Disability Discrimination Act (DDA) of 1995[[18]](#footnote-18) (replaced by the Equality Act of 2010[[19]](#footnote-19)), and the United Nation’s Convention on the Rights of Persons with Disabilities (CRPD) of 2006 which articulates principles of dignity, autonomy, non-discrimination, equality of opportunity, full and activation participation and inclusion, and respect for difference and human diversity.

These and other factors have combined to produce an overall more accepting attitude towards difference and disability, and normalization of the presence of people with disabilities in public life in many parts of the world[[20]](#footnote-20). They also bring into play the sometimes complex intersection of bioethics with civil and human rights approaches to disability.

**Tensions between disability rights activism and bioethics**

Because of its close association with biomedicine and, increasingly, with selective technologies that offer prenatal identification of genetically related disability, many disability rights activists are profoundly suspicious of bioethics. There is concern that bioethical analyses are used to give an ethical justification for a covert form of eugenics that has been termed ‘new’ or ‘liberal’ eugenics: not the state-sponsored coercive eugenics of the Nazi stereotypes, but a neoliberal form developed under late capitalism in which individual parents are encouraged to aim for ‘the best possible child’[[21]](#footnote-21) [[22]](#footnote-22) [[23]](#footnote-23). In the late 1980s/early 1990s, protests by disability activists in mainland Europe prevented the bioethicist Peter Singer from speaking in public. Singer had controversially argued that the euthanasia of disabled neonates could be morally permissible in some circumstances[[24]](#footnote-24). US disability activist Harriet McBryde Johnson famously debated face-to-face with Singer[[25]](#footnote-25). Views like Singer’s are probably now less mainstream within bioethics (although certainly still present)[[26]](#footnote-26), but some of that resistance lingers on in parts of the activist world and in disability studies.

**Mainstream bioethics and disability**

The discipline of bioethics grew out of moral philosophy, theology and law. In the United States and the United Kingdom it has been dominated by Anglo-American analytic philosophy and especially utilitarianism, while other schools of philosophy, such as Kantian deontology and postmodernism, are more popular in mainland Europe. Globally, theological perspectives have a greater profile in bioethical debates. Despite this diversity of forms within so-called ‘mainstream bioethics’, from the point of view of disability all mainstream approaches share some deficiencies.

One of these is a very limited *conceptualization or definition of disability*. Once again, this is the result of bioethics’ necessarily close ties to biomedicine: from one perspective, bioethics can be viewed as a service industry to clinicians who realised that traditional medical ethics was inadequate for the complex moral and social issues thrown up by medicine of the mid to late twentieth century[[27]](#footnote-27). But this close relationship means that bioethics has traditionally mirrored biomedicine’s thinking on key concepts, including disability. In the so-called*medical model* (which is more of a discourse of over-medicalisation) disability is a *nominative pathology*: a defect or deficit determined by reference to a norm of physical or mental structure and function, and located in an individual. The parameters of the norm are given by biomedical science (today, this increasingly means in the form of genomic data). In this view, disability is a deviation from a biomedically determined standard of form or function; the cause of the deviation lies in the biology of the individual; and the aim of medical intervention is to restore the individual body to the norm.

However, a strong body of disability scholarship over the last 40-50 years combined with the work of disability activists has argued that this is a partial, and inadequate, model of disability. A family of *social or social-relational models* see disability not as a purely biological phenomenon, but as a situation that results from the (mis)match between the body and its material and social environment. Leading among these, the ‘strong social model’ developed in UK disability studies, emphasises the distinction between an embodied *physical or mental anomaly* (i.e. the impairment), and the *social response* to the impairment. According to the original strong social model, it is the problematic social response that causes disablement, for example through the lack of environmental adaptations, and not the body per se[[28]](#footnote-28) [[29]](#footnote-29) [[30]](#footnote-30). While impairment is a biological manifestation where a limb or organ functions in a substandard way, as for example in hearing loss, disability is the “disadvantage...caused by a contemporary social organization which takes no or little account of people who have physical impairments and hence excludes them from participation in the mainstream of social activities.”[[31]](#footnote-31) This differentiation enables disability theorists to challenge the assumption that unfamiliar kinds of physical or mental embodiment are *necessarily* disabling, and to question whether the ‘problem’ is caused by the degree of physical or mental difference itself or by the particular social and cultural responses it elicits. Although the minority group model is somewhat distinct from the UK social model, it certainly emphasises that physical and mental differences are not the cause of the oppression experienced by persons with disabilities.

The stronger versions of these social accounts of disability have been heavily criticised more recently for its failure to account for all forms of disability experience. Current social-relational approaches argue more broadly that the extent to which an impairment is disabling depends on how the culturally and historically located communities in which people live make sense of disability and difference[[32]](#footnote-32). Disability is the result of environmental, social, cultural, political and economic factors interacting with an individual’s unusual embodiment, in ways that can be more or less disabling[[33]](#footnote-33). These approaches do not exclude or minimize the real effect of a ‘variant’ body, but neither do they neglect the contribution of factors beyond the individual’s body to the lived experience of disability. They appear to be consistent with the human rights approach to disability as epitomised by the Convention article on definitions, with its emphasis on the interaction between people with impairments and the environment.

**Alternative approaches to disability bioethics**

Although mainstream bioethics has been dominated by a relatively narrow set of theoretical perspectives, there are alternative approaches that offer fruitful perspectives on the bioethical questions related to disability. Among the most influential of these are:

* feminist bioethics;
* care ethics;
* communitarian approaches;
* global or developing world bioethics.

**Feminist bioethics** has been particularly influential for several reasons. First, it starts from the premise that the dominant way of doing bioethics marginalizes the lives and interests of an oppressed social group (women)[[34]](#footnote-34), and many feminist bioethicists have argued that this marginalization is paralleled by mainstream bioethics’ handling of other social and political minorities – including disabled people[[35]](#footnote-35). A second reason is that feminist bioethics is well known for its powerful, critical examination of reproductive medicine and the technologies of assisted conception developed since the late twentieth century. Among these are the biomedical technologies that enable prenatal selection for foetal anomaly that, as section 3 details, is a central and controversial area of bioethics’ engagement with disabled lives.

Beyond this, feminist bioethics also adopts distinctive theoretical and methodological positions that have proved helpful to thinking about disability[[36]](#footnote-36). In sharp contrast to the mainstream, feminist bioethical approaches place emphasis on relationality as an intrinsic part of moral lives, and this has led to a significant reframing of some foundational ethical concepts. For example, mainstream moral philosophy and bioethics hold ‘respect for individual autonomy’ or self-determination as a core moral principle, but their conceptualizations of what autonomy actually is tend to idealize a picture of humans as inhumanly detached agents with as few practical or emotional dependencies as possible. By contrast, feminist bioethicists have elaborated a model of *relational autonomy* in which it is argued that it is precisely the relationships between people in a community that provides the support enabling them to be genuinely self-determining[[37]](#footnote-37) [[38]](#footnote-38). This understanding of autonomy opens up the possibility of recognizing that many disabled people are fully capable of exercising their autonomy even though the processes through which they do so may be unfamiliar. People with disabilities may be more dependent than nondisabled adults on direct or indirect help from others, but this is not in principle any different from the interdependency that everyone has to others within a community.

**Care ethics** is an approach that holds a significant place within feminist bioethics (although feminist ethics is about more than care, and not all care ethics is feminist). Care ethics is an approach to moral issues that emphasises the distinct ethical importance of relationships involving care of various kinds, and ranging from interpersonal interactions to systemic and global structures[[39]](#footnote-39) [[40]](#footnote-40). For example, Eva Feder Kittay[[41]](#footnote-41) criticises the influential contractarian approach to justice of John Rawls, because it does not allow for the fact that some people will always require care to flourish (in other words, they will never be in a position to enter into a mutual contract of reciprocal care). In addition, those who are givers of care may face restrictions on their own ability to participate in society, and as a result their own dependencies are also changed. Care ethics is distinctive in acknowledging that many of the most morally important relationships that people can have are unbalanced, i.e. the interactions between care giver and care recipient are usually not reciprocal.

For disability bioethics this enables an analysis of the nonreciprocal relationship between, say, a disabled person and their personal assistant (PA) in terms that value the particular characteristics of that relationship rather than seeing the need for care as necessarily a problem in itself[[42]](#footnote-42). Paid assistance relationships may appear reciprocal, because the disabled person can exchange hourly wage for the support they receive from the PA. However, some critics are concerned that the application of care ethics in a disability context will reinforce the implication that disabled people are *inevitably* in need of care, or at least more care than nondisabled people. But properly understood the ethics of care understands that the need for care is ubiquitous, not restricted to certain groups of people, and also highlights the less obvious forms of care that may be hidden by more familiar dependencies. So a full care ethics analysis of the relationship between a disabled person and their PA may also reveal that the disabled person is caring for the PA, in less apparent but nevertheless significant ways.

**Communitarian approaches to bioethics**[[43]](#footnote-43) began to emerge in the 1990s following a general development in political philosophy. Communitarian bioethicists are critical of bioethics’ traditional focus on the isolated, decontextualized individual. Instead, they see people being born into communities that offer existing relational networks of values, traditions, norms, and taken for granted understandings of what is good or right. They are sceptical of attempts to find universal truths or solutions, arguing that moral norms have to be understood in the context of the traditions and ‘landscapes’ of particular societies. In terms of disability, communitarianism’s emphasis on the social aspects of healthcare inevitably shifts the focus of ethics and policy away from the individual and the ‘problem’ of their disabled body, and towards the collective responsibility of a society to establish mechanisms that, in collectively endorsed ways, care for and support its disabled members.

**Global or developing world bioethics** does not entail distinctive theoretical framings in the same way that feminist, care or communitarian bioethics do. However, consciously refocusing bioethical attention on the problems faced by low or middle income countries (LMICs) inevitably raises distinctive issues that may be unfamiliar to bioethics but that are highly salient to those countries[[44]](#footnote-44) [[45]](#footnote-45). Even a cursory look at the published bioethics literature shows that by far the most attention has been paid to the ethical problems raised by the kind of healthcare and research that is only available to the populations of wealthier countries. A shift of focus to LMIC means that considerations of distributive justice become more prominent than principles of autonomy; closer attention may need to be paid to relationality in cultures where familial or clan bonds are highly valued[[46]](#footnote-46); while in some countries, histories of colonialism continue to play an influential role in shaping responses to paternalism and agency in the context of health care and research[[47]](#footnote-47). The familiar ethical conundrums of assisted conception, organ allocation, or personalized genomic medicine are largely irrelevant to the majority of the world, and that makes the bulk of bioethics’ current work irrelevant to it as well [[48]](#footnote-48).

**Distinguishing between bioethics of disability and disability bioethics**

Scully has distinguished between the bioethics of disability and disability bioethics[[49]](#footnote-49). The *bioethics of disability*is what might be called bioethics done from an outsider perspective on disability. Using one or more of the well known ethical frameworks or approaches described earlier, it considers areas of biomedical or life science innovation that have particular relevance to disability or disabled people. Just as in other areas of bioethics, over the last decade or so there has been growing acknowledgement that a bioethics of disability often lacks enough of a empirical grounding in the realities of disabled people’s lives to be confident that it has a reliable basis for theoretical ethical reflection and policy making. There are very few bioethicists whose writing on disability is informed by direct lived experience of it: they include Scully, Shakespeare, and Teresa Blankmeyer Burke. While some bioethical writing on disability is sympathetic to disability concerns, and a proportion has begun to show the imprint of the work coming out of disability studies itself[[50]](#footnote-50), it is still overwhelmingly produced from the standpoint of *outsiders to the experience* being written about. In addition, advances in biomedicine and biotechnology mean that there are now forms of disabled living that are socially and ethically unfamiliar: the long-lived tetraplegic, the person with cystic fibrosis who lives into middle age rather than dying in early adulthood, the cochlear implant wearer. Their novelty means that there are few resources within the cultural imaginary for nondisabled bioethicists to draw on in trying to evaluate quality of life, making their judgements about the moral permissibility of various interventions highly contentious.

In contrast to a bioethics of disability, then, *disability bioethics* starts from within the experience of disability. It pays close attention to disabled people’s own voices about their lives, their needs and their ethical choices. Of course, this does not mean that *only* people with disabilities can speak about disability; the perspectives of family members, healthcare professionals, and others in society can all be considered to be parts of understanding disability as a complex, multifaceted social phenomenon. But disability bioethics recognises that much of bioethics’ work so far has been based on thin or inaccurate understandings of the diversity, complexity, and socially embedded nature of disability, and therefore of the bioethical questions that concern people with disabilities and their families.

The ‘disability experience’ results from the interaction of the body’s features, personal factors, and social and environmental factors. While disability in general correlates with disadvantage, not all people with disabilities are equally disadvantaged. People with more severe impairments often experience greater disadvantage, and there is also a hierarchy of types of impairment, so that for example school enrolment rates of children with physical impairment are generally higher than those with intellectual or sensory impairments. Most excluded from the labour market are often those with mental health difficulties or intellectual impairments. Disability also interacts with external factors: women with disabilities experience gender discrimination as well as disabling barriers, while the higher the social class and the wealthier a person is, the more likely they are to be able to obtain the devices and other support that they need. The background cultural approach to disability also plays a role in attitudes and the quality of life a person with disabilities will enjoy.

1. **Bioethics and quality of life**

Many debates in bioethics come down to contrasting views about the quality of life of persons with disabilities. For example, one of the main arguments in favour of prenatal testing and selective termination of pregnancies affected by disabilities is that this avoids the birth of a child who it is assumed will go on to have a poor quality of life. Similarly, it is the (assumed) poor quality of life with disability that underpins arguments for voluntary euthanasia or assisted dying for people with disabilities. Therefore it is relevant to understand, and sometimes challenge, the evidence and arguments about quality of life used in bioethics.

Notwithstanding the impact of a health condition, and even in a world that is not designed to facilitate the wellbeing let alone full participation of people with disabilities, the empirical evidence and anecdotal testimony shows that for many people with disabilities, life is surprisingly good. In a now classic paper on what they call *the disability paradox,* Gary Albrecht and Patrick Devlieger[[51]](#footnote-51) marshal the evidence that reveals that the majority of persons with disabilities consistently report a quality of life as good as, or sometimes even better than, that of nondisabled people.

What reasons can be found to explain the disability paradox? Some would cast doubt on the reports of good quality of life. Bioethicists sometimes describe these self-reports in terms of the ‘happy slave’ idea: people think they are happy because they do not know any better. People with disabilities are simply not telling the truth, it could be claimed. Perhaps these cheerful people with disabilities are deluding themselves and others. It may be just too humiliating to think of oneself as inferior and suffering, or it may be impossible to incorporate the damage into a positive sense of self. Therefore people are in denial. Or perhaps people with disabilities secretly really do feel that disability is awful, but they are not prepared to admit that to others. They do not want to be thought of as inferior or to be pitied , and therefore they dissimulate about their own lives. Perhaps in private they admit to misery, while in public they put on a brave face. These explanations do not seem reasonable, but patronizing or even offensive. Psychological research has supported disabled people’s self-reports of good quality of life, rejecting the scepticism of bioethicists among others[[52]](#footnote-52). We need to find better ways of understanding what is going on.

First, it appears that human beings are capable of adapting to almost any situation, finding satisfaction in the smaller things they can achieve, and deriving happiness from their relationships with family and friends, even in the absence of more worldly success. Resilience is an ordinary human capacity, available to everyone, not the extraordinary quality of a rare individual (the so-called ‘super crips’). This account offers a less demeaning explanation of the psychological processes that go on in the mind of a person with disability. In his discussion of Disability Adjusted Life Years (DALYs), Christopher Murray[[53]](#footnote-53) distinguishes three related process of adaptation, coping, and adjustment. Adaptation means finding another way to do something: for example, the paralyzed person might wheel rather than walk. Coping is when people redefine their expectations about functioning over time. They decide that a stroll of a half a mile is fine, whereas previously they would have only been content with a ramble of ten miles. Accommodation is when someone learns to value other things: they decide that rather than going for walks in the country with friends, the really important thing in life is being able to go to great restaurants with them. Note, however, that none of these explanations implies that being paralyzed, for example, is not a negative experience: adaptation, coping and accommodation merely explain how someone may come to terms with their limitation over time.

Second, it appears to be the case that our appraisal of life with impairment may have less to do with actuality than with fear, ignorance , and prejudice, all of which make the experience appear worse than it actually is. That is to say, we have a distorted view of disability, one made more graphic by the ways cultural representations of disability play on our fears of impotence, incapacity, and dependency[[54]](#footnote-54). Catriona Mackenzie and Jackie Leach Scully[[55]](#footnote-55) warn us of the dangers of relying on our imagination when it comes to disability: we tend to exaggerate, project, and mistake what life is really like for people with disabilities. We wrongly assume that difficulties for people result in misery for people[[56]](#footnote-56).

Third, even to the extent that health conditions and impairments do entail suffering and limitation, other factors in life can more than compensate for them: conversation, culture, work, leisure. Assuming access to networks and resource, individuals can find plenty of opportunities to enjoy what life can offer, notwithstanding the restrictions that impairment places on him or her. By contrast, it is plain to see that someone can have a fully functioning body or mind and yet lack the social networks or the personality necessary for living a happy and fulfilled existence.

Fourth, most disabled people have the potential to enjoy much of what gives life meaning. For example, if modern humans might sum up their life goals in terms of ‘job, partner, family’ there is every possibility of most disabled people experiencing those achievements. Empirically, it is clear that many disabled people have sexual partners, become parents, and earn a living, in both developing countries and developed countries[[57]](#footnote-57). It is certainly the case persons with disabilities face barriers that mean that they are less likely to achieve these goals, but it would be wrong to conclude these goals are impossible for them. The notion of disabled people being asexual and incompetent is certainly a myth.

People born with an impairment have nothing to which they can compare their current existence. Someone lacking a major sense has never experienced music or birdsong, visual art, or a sublime landscape. Someone born with restricted growth has always been that way: even if life is sometimes hard, they are used to being how they are. Somebody with intellectual disability may not consider themselves different at all, and may resist attempts to label them stupid or a second-class citizen. For people with congenital impairment, disability is part of their sense of self and becomes identity constituting[[58]](#footnote-58). Only in rare cases, for example when a person has a degenerative disease (see section 4) does an individual regret his or her form of embodiment . To want to be nondisabled is, essentially, to want to be a different person, which is a psychological and cognitive dissonance few human beings seem able to enter into. The weight of evidence from quality of life studies and from case studies and other autobiographical reports suggests that human flourishing is possible without a major sense, without legs, without average intelligence.

People who become disabled tend to go through a similar trajectory. Immediately after injury or disease has rendered them disabled they may feel profoundly depressed, to regard their life as over, and even to contemplate suicide. Yet after a period of time, they adapt to their situation, reevaluate their negative attitude to the disability, and start making the most of their situation. Often they are driven to greater achievements than before. Usually, their quality of life returns to approximately what it was before the trauma struck. This phenomenon, which also explains why lottery winners revert to their previous state of happiness after the thrill of riches has worn off, is known as hedonic adaptation[[59]](#footnote-59). For disabled people, impairment usually makes little difference to their quality of life. The research shows, for example, that overall levels of life satisfaction for people with spinal cord injury are not affected by their physical ability or limitations[[60]](#footnote-60). Furthermore, the clinical fact of whether the spinal lesion is high or low, complete or incomplete – all aspects that affect functioning – has a weak and nonsignificant relationship with quality of life[[61]](#footnote-61). The major factor is time since injury (or diagnosis): after people have come to terms, their quality of life reverts to their former state.

It seems reasonable to conclude that on balance of evidence, disability usually does not have to equate to exclusion from most of what makes life good. We can perhaps agree with Michael Oliver[[62]](#footnote-62) and other authors in the disability rights tradition when they reject the ‘disability as tragedy ‘ assumption. However, we are not thereby compelled to accept the ‘disability as difference ‘ or even the ‘disability as positive variation’ argument, in which impairment is a neutral or even advantageous characteristic. In other words, an impairment does often make life harder, you might not want others to develop the impairment, and you might even accept a cure for the impairment, if it was available. For this reason, Shakespeare has suggested that seeing disability as a predicament[[63]](#footnote-63) appears a workable and realistic judgment. Importantly, life with impairment can be good, and certainly far less bad than ill-informed observers perceive.

1. **Beginning of life**

Ethical questions at the beginning of life concern efforts to detect illnesses and impairments prenatally and to offer prospective parents the option of selective termination. Another question is whether it is right for persons with disabilities to have children.

Even the most common prenatal conditions, such as Down syndrome, are rare, so it is not efficient to test all pregnancies, especially as diagnostic testing is not only costly but also has an associated chance of miscarriage. So screening to find pregnancies at higher chance of a birth anomaly is usually adopted, where a simple test is offered to all pregnant women free of charge, or at added cost, depending on the health system. Because conditions such as trisomies (such as trisomy 21 causing Down syndrome) are more common in older women it may be that screening is particularly aimed at women over 35. But screening is relevant to all women.

Common forms of screening include ultrasound; blood tests for hormones that are raised in affected pregnancies; and now a non-invasive test that can detect cell-free foetal DNA in the mother’s blood, and thus convey information about the genome of the foetus. None of these are generally diagnostic: they give information about raised chances. However, they can give definitive information about the sex of the foetus.

Women found by screening to be at higher chance of a condition, or women from ethnic groups with raised probabilities of particular conditions, or women whose family is known to be affected by a genetic condition, can be offered diagnostic testing, either chorion villus sampling or amniocentesis. These tests usually give a definitive answer. Women found to be carrying an affected pregnancy might be offered termination of pregnancy, in a health system where termination is legal. Alternatively, they may have an illegal termination or go abroad to a jurisdiction where termination is permitted. And of course they might continue with pregnancy and give birth to an affected baby, or experience a miscarriage or stillbirth.

In ethnic groups where there is a high chance that individuals are carriers of particular conditions, it is theoretically possible to have pre-conception testing to reveal carrier status. For example, In the most usual cases of recessive genetic conditions such as Thalassaemia (which affects people of Mediterranean origin) or Tay Sachs disease (affecting people of Ashkenazi Jewish origin) or Sickle Cell anemia (affecting people of sub-Saharan African origin), there is a one in four chance of having an affected pregnancy. Individuals can then choose not to partner with another carrier, can have prenatal testing and selective termination, or can choose not to have children of their own.

Where resources and health expertise allows, a couple known to be at higher chance of a genetic condition could opt for preimplantation genetic diagnosis (PGD). Here, IVF techniques are used to create one or more embryos which are then tested for the condition the couple wish to avoid, and only non-affected embryos are implanted into the woman’s womb. Although IVF techniques generally have about a 1 in 3 success rate, this route offers a reasonable chance of having a non-affected offspring, although it is much more costly and laborious than ordinary conception.

What is the response of persons with disabilities to prenatal testing and selective termination? Note that the foetus, depending on the legal situation in the jurisdiction, is not regarded as a person in law. Therefore the protection of the Convention on the Rights of Persons with Disabilities does not apply to the foetus, and prenatal testing cannot be regarded, in a legal sense, as literally discrimination against the foetus. However, undoubtedly the prospective parents are choosing not to have a disabled baby, preferring to try again later and have a non-disabled baby, and so this appears, in a figurative sense, to be discriminatory to some observers with disabilities.

Some commentators have regarded prenatal testing as *eugenic****.*** This criticism refers back to the very commonly accepted approach of the late nineteenth and early twentieth century, where people with disabilities – particularly people with intellectual disabilities and psycho-social disabilities – were prevented from reproducing. The obnoxious aspects of eugenics were the combination of policies to improve the quality of the population, with a coercive approach. However, it is not hard for modern clinicians to repudiate this criticism. They highlight that the modern obstetric or genetic service is not at all coercive. Nor does it operate at a population level. Individuals and their partners are offered genetic testing to facilitate informed choice. This seems different to eugenics, and therefore acceptable – at least to those who do not condemn all abortion as murder of the foetus. In many jurisdictions abortion is not permitted, so for example in Brazil, mothers whose pregnancies are affected by the Zika virus have no choice but to continue pregnancy and have a child with microcephaly. However even there, women with financial resources can access illegal abortion, or travel to a country with more permissive abortion law.

Notwithstanding that most current prenatal services are not obviously coercive, that there does not appear to be any explicit government plan to eradicate disability, and that it is very rare to have prominent thinkers espouse eugenic thinking (unlike in the early twentieth centry), there are genuine and well-founded fears[[64]](#footnote-64). Generally, it is unacceptable for clinicians and economists to justify prenatal diagnosis and selective termination in terms of saving the costs to society of life-long support of people with disabilities[[65]](#footnote-65), although this is the ‘elephant in the room’[[66]](#footnote-66). The effects of individual choice, increased screening, and prejudiced against disability, among both clinicians[[67]](#footnote-67) and wider society, will inevitably mean fewer births of persons with disabilities[[68]](#footnote-68).

Phrases such as ‘emergent eugenics’[[69]](#footnote-69), ‘backdoor eugenics’[[70]](#footnote-70) and ‘laissez faire eugenics’[[71]](#footnote-71) capture how, while there may be no explicit government population policy, nevertheless the effect of many individual choices are to produce eugenic outcomes. Nor are those choices as free as they might appear, for several reasons. First, there is generally no balanced information offered about the relevant health conditions. Inaccurate, biased or medical-dominated accounts of e.g. Down syndrome are provided, with the voices of affected individuals and families rarely being heard. Second, the counselling or advice provided by clinicians (midwives, nurses, obstetricians) is not always unbiased. In many parts of the world, clinicians adopt quasi-eugenic beliefs[[72]](#footnote-72). Finally, the context can push pregnant women and their partners towards particular choices[[73]](#footnote-73), particularly when practices such as screening become a routine part of healthcare[[74]](#footnote-74). As well as any particular harms, there is a wider risk of disability being re-defined in terms of avoidable deficits and individual problems, rather than cultural difference and minority politics.

Some other commentators avoid the ‘eugenic’ criticism. But they might focus on the context in which testing is offered. A climate of geneticisation[[75]](#footnote-75) might exacerbate stigmatisation and devalue disabled people, although the original simplistic account has been challenged[[76]](#footnote-76). The hurtful messages that could be conveyed by increased availability of prenatal screening – particularly if care is not taken over language, imagery and representation of disabled lives – has been summed up in the phrase ‘the expressivist objection’: in other words, public investment in more extensive screening expresses sends the message that it would be better if disabled people were no longer born[[77]](#footnote-77). Even the fact that the public health system regards testing as a priority suggests it is promoting selective abortion. Variations of this claim focus on the so-called ‘synecdoche’ of viewing a disabled person not holistically, but in terms of one faulty body part or underlying genetic mutation, or on the discrimination which occurs in jurisdictions such as the UK, when termination is prohibited after 24th week gestation except in cases where the foetus is ‘handicapped’ in which case the pregnancy can be terminated up until birth[[78]](#footnote-78).

One imaginative disabled critical theorist has argued in terms of ‘conserving disability’[[79]](#footnote-79), using an implicit analogy with biodiversity, and describing disabled people as ‘narrative resources’. Another critic, father of a son with Down syndrome, has argued in favour of the ‘giftedness’ of children and the virtue of acceptance[[80]](#footnote-80), and most recently another father has challenged the ethics of screening[[81]](#footnote-81) (Kaposy 2018).

In some European countries such as France, Spain and Switzerland, high screening uptake rates have already been associated with significant reductions in the number of babies born with Down syndrome over the past 25 years[[82]](#footnote-82). In countries such as Iceland and Denmark, almost all women who accept the offer of screening go on to terminate: however, a minority continue to refuse the offer of tests, and a small number of babies continue to be born in both countries. It will be important to watch what happens to Down syndrome support, services and research in these countries over the next 10 years. As they are countries with smaller populations, the impact of prenatal screening is more obvious.

Decisions about whether or not to use prenatal testing or selective termination cannot be separated from attitudes and beliefs about bringing up a child with that condition within the particular social context[[83]](#footnote-83). In many low and middle income countries, social and educational support for disabled people is very limited[[84]](#footnote-84) and even in wealthy countries stigmatising attitudes are pervasive[[85]](#footnote-85). Negative stereotypes about disability, and attitudes towards disabled people are known to be associated with intentions to test for and terminate an affected pregnancy[[86]](#footnote-86) .

Absent from most debates are the perspectives of people with disabilities themselves. Despite a lack of research about the viewpoints of disabled people, some evidence is available: for example, adults with Down syndrome can, understandably, find the idea of aborting babies because they have Down syndrome upsetting. It is also easy to understand that people with Down syndrome can view the widespread offer of testing to pregnant women as offensive or an expression of their being unwanted[[87]](#footnote-87).

*“Because it makes me feel like I’m not wanted in society. And no one loves us…* [my family love me] *But the government doesn’t love me, because if they did love me they wouldn’t do this”* ….*“I think it’s a very sad choice that people are terminating.*” (Sophie, woman with Down syndrome[[88]](#footnote-88), quoted by Barter 2017)

This position was expressed by Frank Stephens, a man with Down syndrome who testified to the United States Congress in 2017[[89]](#footnote-89) . In a consultation about NIPT with adults with Down syndrome some participants were aware that having a baby with the condition may come as a ‘shock’ to parents and that having a prenatal test could help them prepare. Others feel that women have a right to choose whether or not to terminate a pregnancy for Down syndrome or any other reason:

*“They are getting rid of it if they’re finding out it’s Down syndrome because they don’t want that life for their baby or something. I mean it’s a personal choice. I’m a pro-choice person. I believe what the woman wants she should get. If she doesn’t wants a baby with Down’s syndrome she doesn’t have to… It’s a woman’s rights.”* Helen, woman with Down syndrome[[90]](#footnote-90)

Attitudes towards prenatal testing for Spinal Muscular Atrophy (SMA) held by adults with the condition have been found to be linked to the severity of the symptoms they experience and time of symptom onset[[91]](#footnote-91). In a survey of over 80 individuals with SMA the majority were in favour of prenatal genetic screening for the condition. However, those with early onset SMA and more severe symptoms were less supportive of prenatal testing than those with late onset and milder symptoms. The group with the more severe types of SMA also viewed their experiences of disability more positively than those who had experienced life as a non-disabled person or had less significant symptoms. Individuals with relatively static impairments present from birth tend to adjust better to their condition and identify with it in comparison with those who have experienced an alternative life ‘before disability’ or experience periods of decline and change – being disabled is not an identity they want[[92]](#footnote-92). For this group, prenatal testing is not viewed as a rejection of disabled people, rather a rejection of the negative aspects associated with impairment. This points to how a genetic condition or impairment is not always ‘identity affecting’, particularly if it has not been congenital[[93]](#footnote-93). Similarly, a study of adults with achondroplasia found that positive attitudes towards the availability of prenatal testing was associated with perceptions of a lower quality of life[[94]](#footnote-94).

In one of the rare studies from low income settings, approximately 41% of people personally affected by sickle cell disease (SCD) in Cameroon would use prenatal diagnosis, while 48% would reject it[[95]](#footnote-95) ; 95% of parents of children with SCD would request it, and 65% would terminate pregnancies. Reasons for people with SCD screening pregnancies include fear of having an affected child (89%) and poor quality of affected child’s life (82%). However, in Camerooon, as in much of Africa, it is illegal to terminate pregnancy unless the life of the mother is in danger.

People with genetic conditions themselves make reproductive decisions, and some may choose to try to avoid having children sharing their genetic disability, particularly if they understand disability in terms of illness, rather than in terms of social barriers[[96]](#footnote-96).. Alternatively, people with genetic conditions may seek to use prenatal diagnosis to avoid more severe outcomes of their conditions, for example instances where a fetus inherits the condition from both parents, resulting in a non-viable outcome.

Perspectives from disability rights commentators, parents and people with the conditions usually contrast with mainstream bioethical thinking. For example, the utilitarian bioethicist Julian Savulescu[[97]](#footnote-97) talks about procreative beneficence and the parental obligation to produce the ‘best possible child’, at least in the context of pre-implantation genetic diagnosis, although his thesis has been widely challenged[[98]](#footnote-98). His colleague Jeff McMahan similarly uses what he calls the impersonal comparative principle[[99]](#footnote-99) to recommend the same approach. Peter Singer, mentioned earlier, has advocated not just for prenatal diagnosis, but also for a parental right to request euthanasia for newborn babies with severe impairments[[100]](#footnote-100).

Several arguments and assumptions clearly conflict here. Centrally, the disability rights approaches are influenced by the evidence that disabled people have a good quality of life, and the argument that disability is a matter of social barriers and oppression, not intrinsic biological deficit. Conversely, the utilitarian advocates of prenatal selection consider disability to be a harmed condition[[101]](#footnote-101) or to lead to restricted opportunities or less chance of flourishing. If they also do not consider the fetus to be a person or to have any rights or interests, then it seems logical avoid a negative outcome and to prefer a non-affected foetus in a subsequent pregnancy. Importantly, the selective termination cannot be said to benefit the affected foetus[[102]](#footnote-102), except in the rare circumstance that it would better not to exist than to exist with the impairment.

The way forward here might be a middle way. First, accepting that if abortion is permissible, then it is consistent to enable women to have terminations on the grounds of significant impairments detected prenatally, on the same basis that they might access terminations for social reasons. It seems inconsistent to allow the latter but not the former. Many disabled commentators would argue that except in very rare cases (pregnancies not compatible with life), there should not be termination after the point of viability. Society should be neutral about this very personal choice: women should be supported to test and terminate, but also to refuse tests or terminations. However, public health systems should offer a basic suite of prenatal screening to all women, because otherwise only richer individuals could access testing via commercial clinics.

Second, ensuring that women are able to make their own informed choices, supported by their health professionals, whatever they decide; on the basis of balanced and accurate information not just about tests, but also about life with the particular condition for which screening is offered. Health services should not pressurize pregnant women and their partners. Society should welcome and support disabled babies, just as it should welcome all babies. In particular, the voices of disabled people should be heard, and there should be more information available about their lives. Most people think that health services, private or public, should not offer prenatal testing for non-medical issues, nor should they go on a ‘fishing expedition’ to test a pregnancy for any minor difference. The danger is of reducing tolerance for human variation, increasing anxiety about pregnancy, and fuelling a commercial testing market that is unlikely to improve human wellbeing.

**4. Treatment and cure**

Biomedical research aims to find ways either to prevent disabling conditions before they happen, reducing their impact, or treating them once they occur. (Using social model terminology, the medical goal focuses on preventing *impairment* or treating its effects rather than addressing *disability*, which as discussed above is considered to be caused by social responses to impairment.) Although the goals of prevention, amelioration or cure seem at first sight to be unproblematically good ones, the rise of disability rights activism and the emergence of disability identity politics have complicated the picture. This section considers this complexity, as well as summarising some areas of notable bioethical interest in the context of treatment and cure.

**Ethics of cure, disability identity and diversity**

Not surprisingly, people with disabilities themselves hold a wide variety of views about curing disability itself. The key reason for this is that the subjective experiences of impairment are diverse, reflecting not only the effect of the impairment but also that of the community, society and environment in which people live their lives. As already noted, people with stable impairments that have been present from birth will generally experience this as their normality, and often as part of their identity. This is particularly the case when they are otherwise healthy, and the impairment is also linked to a strong collective identity; classic examples are the culturally Deaf community (who may consider deafness as a sociolinguistic feature rather than an impairment), people with restricted growth, and the Down syndrome community. Many people with these disabilities, and their families, find the notion of cure irrelevant or even offensive. Meanwhile, people who acquire impairments relatively late in adulthood are much more likely to see them as disruptive rather than identity-constituting. Conditions that worsen or degenerate over time are associated with different experiences again. In these situations people tend to consider their disablement as a loss and are in favour of cures, frequently forming patient advocacy groups to support biomedical research. There is further diversity in the way that some people and cultures view age-related impairments as unwanted disablements for which there should be treatment, while others see them as a normal part of the life-course.

It is important to remember that there is a hierarchy of impairment: different impairments have different impacts, and the same impairment can have different effects for biological, social and cultural reasons. If there is a supportive and flexible environment prepared to respect and value difference, mild to moderate impairment may not be a difficulty for anyone. However, severe forms of impairment will often cause considerable problems and limitations, and a level of suffering and distress for the individual and their families that cannot be made tolerable by any amount of social adjustment. The importance of promoting cultural respect and social acceptance for people with impairment should not obscure the importance of mitigating or preventing impairment via individual medical or psychological therapies.

Complete elimination of impairment is not possible for most disabled people, but a range of other interventions can radically alter the overall experience. For example, advances in medical treatment up to and including the possibility of lung transplants have significantly improved the life expectancy of people with cystic fibrosis[[103]](#footnote-103). In other cases it is changing attitudes towards disability rather than medical breakthroughs that are the key. In the past, the assumption that it was not worth prolonging the lives of children with Down syndrome meant that they were often not treated for the heart defects associated with the condition; today, active treatment would be the norm in most countries[[104]](#footnote-104).

Many interventions aim to improve function or the quality of life for people with disabilities rather than to cure impairments. Some of these genuinely therapeutic interventions are readily distinguishable from those intended solely to make a disabled person appear more ‘normal’ and be better accepted by their community. For example, surgery to straighten bow legs or reshape joints has enabled people with restricted growth to be more mobile and avoid worsening of their conditions. By contrast, limb lengthening surgery is more often done to address social or environmental barriers rather than the disabling effects of the impairment[[105]](#footnote-105). From a disability rights perspective, an individual – or their family members – who faces negative social reactions is seeking medical help in order to fit in: rather than solving the problem by changing society, the individual is corrected to align with the norm. However, many interventions have both functional *and* social benefits, and people’s motivations for using them can be mixed. The bioethical evaluation is therefore complex.

A small number of disability rights advocates argue that trying to cure any disability is *fundamentally wrong* because it results in the loss of a distinctive disability identity, and also because it expresses a hostile attitude towards disability and/or disabled people. In line with this, some of these critics hold that there is an intrinsic positive value to disability. This is a minority opinion among bioethicists, however, and most would argue from the basic premise that disability is an undesirable state, and so preventing or removing it is a good thing. But nevertheless they would also probably agree that the *medicalization of disability* raises some morally serious issues. For example, there is a broad concern about the effects of prioritising purely medical approaches to disability and neglecting more socially contextual ways of making disabled people’s lives easier. One consequence of (over)medicalization is that, because medical research always needs to attract support and funding, there is a tendency to over-hype the power of research, i.e. to make excessive and misleading claims about what a treatment can achieve, and thereby raise unrealistic expectations in affected groups. Bioethics still remains quite polarized between a focus on the promise of biotechnological innovation, and the more socially contextualized analyses that are produced by feminist and communitarian bioethicists and that are likely to be more compatible with and supportive of disability rights.

Another ethical problem is that the cost of new therapies usually places them well beyond the means of most of the people who need them. The commercial pharmaceutical industry prioritises potentially profitable therapies, and/or prices ‘orphan drugs’ at very high costs, pressurizing public health systems to pay. Given that people with disabilities are disproportionately represented in the lowest income groups in their respective countries, the result is *increased inequality*, whether that is because only the wealthiest disabled people can afford access to a treatment or because a public health service spends a significant amount of its budget on cutting-edge cures for a few affected people rather than (for example) making simpler assistive devices available to many more. To address this adequately, disability bioethics will need to take a more overtly social justice perspective than it has previously tended to.

There may also be unjustifiable *opportunity costs*. At its simplest, investing in research for a cure for muscular dystrophy can mean there is less money available to support the lives of people with the condition, and their families, in the community. Some bioethicists would argue that, since there can never be a 100% guarantee that research will produce a cure, affected people who are alive *now* are unjustly harmed by the diversion of finite resources towards a possible cure for as-yet non-existent affected people in the future. Sometimes, low-tech treatments – such as nocturnal home ventilation for people with muscular dystrophy – can prolong more lives far more effectively than research in complex genomic medicines.

Finally, in a version of the *expressivist argument* already mentioned, and associated with disability scholars Adrienne Asch[[106]](#footnote-106) and Marsha Saxton[[107]](#footnote-107), the act of directing major investing heavily in the eradication of a disabling condition rather than support for people living with it now ‘sends out a message’ that the quality of life with that disability is so intolerable that getting rid of it is worth any amount of investment. This contradicts the empirical evidence that the subjective quality of life of people with disabilities is often much better than outsiders predict.

While the disability rights community may have reservations about preventing or curing disabling impairments such interventions will undoubtedly continue to be a priority for medicine, particularly in LMIC which have fewer resources available to support people with impairments well. From an ethical point of view it is important to be clear that *taking steps to avoid or mitigate disabling health conditions is not an attack on the rights or integrity of persons with disabilities*. Nor is it contradictory to aim both to support persons with disabilities to lead better lives, and to prevent others developing disabling illnesses or impairments. Encouraging disability scholars, activists, and policy makers to take a broader, more inclusive stance will enable both disability activism and bioethics to engage more positively in this complex area.

Although disabled people and their families respond to the prevention, treatment or cure of disability in complex and varied ways, bioethical arguments have tended to be more uniformly positive about treatment or cure, because (i) they are based on the premise that all disability is something we would be better of without, but also because (ii) there is a lack of appreciation of the diversity of impairments, of the diverse social, familial and economic contexts within which impairment is experienced, and so the diversity of possible responses to life with disability. This is one of the major weaknesses we identify in bioethics’ engagement with disability. Nondisabled bioethicists have found it particularly hard to comprehend the possibility of a positive disability identity – whether that is an individual’s sense of their impairment as a positive part of their sense of self, or a collective political identity. For bioethics to recognise more often this diversity of disabled experience and identity as part of its ethical analyses would be an important step forward in the support of respect for the inherent dignity of people with disabilities, and the right for children with disabilities to preserve their identities as stated in Article 3 of the United Nations Convention on the Rights of Persons with Disabilities.

**Novel versus familiar treatments**

Bioethics has a tendency to assume that familiar therapies and cures are ethically uncontroversial, while novel, high-tech medical innovations present new ethical difficulties that bioethicists can help resolve. This may well be mistaken, as some work on ‘everyday bioethics’ suggests[[108]](#footnote-108) [[109]](#footnote-109). As a result the bioethical literature on disability shows a strong bias towards the analysis of cutting-edge technologies. Some recent examples include:

*Psychiatric medication:* A third of all global disability is in some form of mental illness[[110]](#footnote-110), including disorders of mood such as depression and anxiety, schizophrenia, or dementia. Many people with physical impairments, as we saw earlier, have turned to a version of the social model that understands ‘disability’ not as a biological problem, but a more complex phenomenon with both physical and social elements. Conversely, some people with psychiatric illness find the biological model to be more practically and conceptually useful than social explanations, and crucially also makes them less subject to stigma and blame. Others prefer to see ‘psychosocial disability’ as generated by negative social reaction, and maintain that they are ‘different’ not ill[[111]](#footnote-111).

Although psychotropic medications to manage states of mental illness or distress are now relatively commonplace, in the 1990s and 2000s there was significant debate in the bioethics community about the ethical issues raised by their use. These include the capacity of people with mental health difficulties to consent to treatment or research participation[[112]](#footnote-112); the vulnerability of people diagnosed with a psychiatric illness to overmedication; the medicalization of ‘normal’ distress; the medication of challenging behaviour, particularly in children; and profound questions of authenticity and identity, such as whether a person is their ‘real self’ when they are taking psychotropic drugs to enable their everyday life[[113]](#footnote-113). As pharmaceutical interventions become more sophisticated, questions of how to balance treatment with respect for disabled people’s right to self-determination become ever more complex. ‘Smart pills’ that contain both a pharmaceutical and a tracking device to monitor compliance are a case in point[[114]](#footnote-114).

*Corrective interventions****:*** Traditional bioethics places a focus on the individual and their autonomous agency but tends to neglect the familial and social context within which autonomy is exercised and decisions are made. This is particularly problematic when considering interventions in childhood to minimise or cure disability. The example of children with restricted growth being offered *surgery to lengthen their limbs*has already been mentioned. Importantly, the decision for surgery has be taken in the early teenage years while limbs can still be lengthened, and so it is the parents who must consent on behalf of the child. Parents may believe that having more ‘normal’ limbs will increase their child’s acceptance by society and that this benefit outweighs the physical, emotional and financial personal costs of surgery. Meanwhile, children who agree to limb-lengthening surgery may be influenced both by their non-disabled parents’ attitudes and broader cultural messages about disability.

An important class of medical-technological interventions for disabled people consist of various kinds of *implants*. Some have been available for long enough to be relatively familiar. Artificial cardiac pacemakers, available since the late 1950s, are implanted devices that generate electrical impulses to maintain an adequate heart rate in people with potentially fatal abnormal heart rhythms. Implant technology is also being developed to address sensory impairments: ocular implants for visual impairment are familiar in the form of artificial lenses to cure cataracts, but more sophisticated ‘bionic eyes’ for severe impairment are still experimental[[115]](#footnote-115). In deep brain stimulation, electrodes implanted in the brain have the potential to treat drug-resistant depression, epilepsy, and some of the symptoms of Parkinson’s disease[[116]](#footnote-116) [[117]](#footnote-117). Also under development are various forms of prosthetic devices coupled to the nervous system or the brain (neuroprostheses and brain-computer interfaces) that could offer mobility, communication or the capacity to control their environment to people with profound neurological impairments. Here, bioethicists have raised ethical concerns, some of which are common to all pioneering interventions (eg to do with obtaining informed consent from prospective patients for experimental technologies whose safety cannot be estimated), and safety issues associated with the potential for infections and other problems in implanted devices. For implants involving the brain there are risks of inadvertently affecting an individual’s personality or identity[[118]](#footnote-118). And as always there is the unavoidable problem of global justice, since these technologies are likely to be limited to the wealthiest citizens of high income countries.

A notably controversial example is provided by *cochlear implants (CIs),*devices that function as aids to hearing using an electrode array that is inserted surgically into the inner ear. They have been available since the 1970s and there are an estimated 500 000 cochlear implant users worldwide cochlear implants. Originally provided mostly to adults with profound hearing impairment they are increasingly given to young children, again because it is currently believed that the earlier the intervention, the greater the benefits to the child. While many affected individuals and parents find CIs beneficial, the bioethics of CIs has also noted that some parts of the culturally Deaf community, who reject the idea that deafness is a disability at all, are concerned that such early use of CIs in very young children is damaging because it can hinder their acquisition of sign language, and so eventually threaten the survival of the Deaf community into the future [[119]](#footnote-119). There are also worries that, for the reasons raised above, the success of CIs is overhyped[[120]](#footnote-120).

An even more controversial and complex intervention is the so-called *‘Ashley’ treatment*. In 2012 it was reported that the parents of the pseudonymous Ashley, a pre-pubertal child with severe developmental disabilities, had consented for her to have a hysterectomy, removal of breast buds and appendix, and oestrogen treatment to attenuate her growth. The combined interventions were intended to improve her quality of life, both directly (by preventing her undergoing the discomfort and distress of menstruation) and indirectly (by hormonal growth attenuation to ensure she remained small enough to be easily moved by her caregivers). The procedure has been ethically criticised by disability rights activists as well as some bioethicists, on a number of grounds, including: that it fails to respect Ashley’s autonomy; that non-medical interventions would have been equally effective; that the interventions were primarily to benefit the parents, not Ashley herself; and that the procedure is discriminatory against and disrespectful of people with intellectual impairments. Other bioethicists however have attempted to counter these criticisms, arguing that Ashley’s disability made her unable to give or withhold her consent in any meaningful sense; that the reduction in distress and discomfort means that Ashley benefited at least as much as her parents; and that whatever form the treatment of an individual disabled person takes, it has no implications about discrimination or disrespect for the whole class of disabled people. Parallel arguments can be applied to other examples of major surgical or medical interventions aiming to improve the quality of life of people with impairments[[121]](#footnote-121) [[122]](#footnote-122).

*Genomic medicine* offers a final, and very prominent, example of bioethical debates about novel biomedical technologies with enormous implications for people with disabilities[[123]](#footnote-123). There have been striking advances over the last several decades in our understanding of how genes and genomes influence biology. Genomic medicine attempts to make use of this knowledge to prevent, treat or cure disabling conditions. Although accusations of over-hyping are particularly salient in this area, it is also true that various kinds of genomic medicine are very likely to feature prominently in the lives of people with disabilities in high-income countries and possibly some LMIC as well[[124]](#footnote-124). For example, the goal of precision medicine (sometimes called personalized medicine) is to use information from an individual’s genetic profile not only to characterize any genetic sequences that might underpin disabling conditions in the present, but also to make longer term prognoses about that person’s health and to make more accurate predictions of how they will respond to treatment (pharmacogenomics). These developments are so recent that little is yet known about how they affect people with disabilities or the views of different disabled people[[125]](#footnote-125).

Genomic information plays a central role in the identification before birth of foetuses affected by disabilities with a genetic basis, whether through prenatal testing, preimplantation genetic diagnosis, or preconception testing. The ethical issues here, as discussed earlier, are primarily to do with the moral permissibility of ending a pregnancy, or preventing pregnancy altogether, if the foetus affected by a disabling anomaly. However, bioethicists have also discussed the potential harms suffered by people whose genetic disability is identified through *postnatal* genetic testing. Among the many issues raised are the need for adequate counselling about living with an identified condition (this is becoming particularly important with the growing availability of ‘over the counter’ (OTC) commercial gene testing, usually without accompanying counselling), and the risk that people carrying genes associated with a disabling condition, whether or not they are significantly affected by it, will face prejudice and discrimination in employment, education, insurance, housing and so on.

Most recently another facet of genomic medicine has attracted attention. Direct manipulation of the genome to eliminate ‘harmful’ genes and, possibly, introduce ones associated with desired ones has been discussed as a *theoretical possibility* since the 1970s. The advent in the early years of the twentieth century of effective and efficient *gene editing* technologies such as the CRISPR-Cas 9 system means that these possibilities are becoming reality. A key rationale driving the development of these technologies is the potential to ‘edit’ putative disabling genes out of the genome of an individual and -- crucially -- all their descendants as well.

What distinguishes this ethical debate from that of PND and PGD is that it does not entail the ending of a pregnancy or the possible disposal of unwanted embryos. Gene editing would involve the active ‘repair’ of disability-associated genes in a person, rather than the elimination of people carrying those genes. Alongside the familiar ethical issues that always arise with innovative technologies to do with safety, difficulties of informed consent when so little is known about possible risks, and the exacerbation of social divisions because of the cost of interventions, the additional question here is whether it is morally permissible to make genetic changes that may be irreversible and that will have serious consequences for subsequent generations[[126]](#footnote-126). This is often known as reproductive gene editing, as opposed to the somatic gene editing that only affects one individual.

If parents have the ability effectively to design their children as they wish, the likelihood is that they will prioritize a very restricted set of characteristics that are socially approved of and that will not be a hindrance to the future child’s happiness. Similarly, research will focus and commercial markets will develop for certain applications, not others. There is concern among bioethicists and disability activists that the result will be an overall decreased tolerance for diversity and difference, especially where that difference is considered to be disabling. Hence genome editing might help to foster eugenic thinking, without being actively eugenic itself[[127]](#footnote-127).

Ways forward here would again include listening to the voices of people with disabilities themselves, rather than making assumptions about their quality of life; promoting the importance of respect for diversity; refusing to reduce complex social experiences to simple ‘genetic spelling mistakes’; but also benefitting from medical advances, where they genuinely improve quality of life. Disability is always a social and cultural phenomenon, but it is also about particular forms of embodiment, some of which may be painful, restrictive or otherwise problematic for individuals and their families.

**5. End of life and assisted dying**

Since approximately 2000, several jurisdictions have introduced assisted dying legislation, and this has attracted considerable controversy, particularly from persons with disabilities and their organisations, as well as from the Catholic Church. Some jurisdictions – such as the US states of Oregon, Washington, Montana, Vermont, California, or the Australian state of Victoria – offer assisted dying restricted to adults who are terminally ill. Assisted dying in these limited cases is contrasted with suicide, which remains discouraged. In Europe, Belgium and The Netherlands offer assisted dying for people who are suffering irredeemably, even in some cases to young people. Approximately 4% of Dutch deaths each year are the result of euthanasia. Meanwhile, the Swiss canton of Zurich has organisations such as Dignitas which will support people to die if they have terminal illness or indeed physical or mental illness[[128]](#footnote-128), and they have a medical certificate and evidence that they have freely chosen to ingest suicide drugs provided.

When it comes to assisted dying, there are important distinctions to be made. Often, clinical medicine draws an ethical distinction between offering palliative medicine, including sedation that might hasten death, and the act of killing or facilitating death. The former is justified in terms of “the doctrine of double effect”: the drug is not intended to kill, it is intended to ease suffering. There is also an important and related distinction, according to some bioethicists, between actively killing, and letting die, for example through non-intervention. In the latter case, there is no intention, on the part of the doctor, to end someone’s life. But according to utilitarian thinkers, intention does not matter: if the effect is the same, there is no difference morally between the two behaviours. Finally, there are debates about end of life. Some would say everyone is terminally ill, in the sense that we are all ageing, becoming more impaired, and inevitably going to die. But others have shortened life spans due to degenerative disease, and are likely to die significantly earlier. But someone with cystic fibrosis or spinal muscular atrophy is likely not to see themselves as terminally ill. When it comes to defining who is terminally ill, it can be very difficult. Doctors do not agree about prognosis: some people live for weeks, months, even years, when it was predicted that they would imminently die. Therefore, it is very difficult to define ‘terminal illness’ in legislation. Medical assistance in dying law in Canada, for example, talks about ‘death reasonably forseen’, which ducks the difficulty of defining what ‘terminal illness’ might entail.

In the assisted dying scenario, it may be helpful to distinguish three groups of individuals with disabilities. Disability is defined by the WHO as a decrement in functioning. The first group comprises those people who are in the advanced stage of a *terminal illness*, such as cancer or motor neurone disease. Depending on the development of the symptoms of the illness, this group of people will have functional limitations and should be considered disabled[[129]](#footnote-129). The second group is disabled people with a *degenerative impairment or illness* which may ultimately kill them, but which they will live with for decades: they may be reliant on others, or even on medical technologies such as ventilator or tube feeding, but they are not in imminent danger of death. Muscular dystrophy, spinal muscular atrophy, multiple sclerosis can be examples of such conditions. The third group is disabled people who have a *static impairment* which may reduce their functioning but will not, in the normal course of events, lead to their death. Stroke, spinal cord injury, cerebral palsy or achondroplasia are examples of these conditions. People may change their attitude to their condition, and they may age faster than non-disabled people, accruing additional complications, but their condition is not intrinsically progressive.

These three groups may have very different ideas about autonomy. The first group have not long experienced disabling symptoms. For example, they may regard having to use a wheelchair as a violation of autonomy. The second and third groups may be very familiar with wheelchairs, personal assistants and possibly supportive medical or communication technologies. They may consider that they lead autonomous and independent lives, despite their reliance on people and technologies to maximise their functioning and participation in society. The second and third groups are more likely to subscribe to disability rights movement thinking, but not all disabled individuals accept these ideas. In particular, newly disabled people are less likely to subscribe to disability rights thinking, because they have been brought up to believe that disability is a tragic, negative state of dependency, not a viable and positive alternative form of life. In many cases, fit, young men acquire impairment through trauma, and find themselves in a situation they have never even considered, where they are reliant on others and no longer powerful.

Applying the principles of autonomy and equality to the area of assisted dying might suggest that disability rights advocates should not be in opposition, at least in principle[[130]](#footnote-130). The disability rights movement supports disabled people's choices in every area of life. If people are entitled to a choice over where to live, who to live with, who to support them and so on, it seems inconsistent that the disability rights movement would deny people the right to end their own life. This might be related to a utilitarian account of the value of life, which suggests that the value of life should be self-determined. John Harris, for example, would argue that “Persons who do not want to live are not on this account harmed by having their wish to die granted.”[[131]](#footnote-131).

In most jurisdictions, disabled people who are dependent on medical technology or care are already able to request the withdrawal of these medical interventions, even where the outcome will be their death. For example, the UK case of Miss B, who was ventilator dependent, in pain from arthritis, and wished to have the machine switched off so that she could die: the Court permitted this[[132]](#footnote-132). Other disabled people, such as Diane Pretty (who had motor neuron disease) or Debbie Purdy (who had multiple sclerosis) or Tony Nicklinson (paralysed after stroke), also in the UK[[133]](#footnote-133) , were not able to exercise this autonomous choice to die, because they were not dependent on medical technology. The UK Courts refused their requests for assistance in dying (Nicklinson) or for their carers to be immune from prosecution in the event of assisting them to travel to Zurich to end their lives at Dignitas (Purdy, Pretty). Why should there be inequality between technology-dependent people and other disabled people, or between non-disabled people and disabled people? This state of affairs appears unfair.

Furthermore, where people cannot carry out physical tasks, the principles of independent living suggests that they should be able to employ others to carry out those tasks, under the control of the disabled person themselves. Non-disabled people in an end-of-life situation are often capable of committing suicide. Disabled people with the same desire who are not medically dependent may be incapable of implementing that choice (as in the case of Dianne Pretty or Debbie Purdy). If applied consistently, the principle of equality and non-discrimination might suggest that disabled people should receive the assistance they need to end their own lives if they have capacity and this is their settled wish.

However, while there may be no morally relevant difference between the suffering and/or loss of autonomy that people whose death is ‘reasonably foreseen’ experience, versus that experienced by people with very significant illness or impairment, where death is not ‘reasonably foreseen’, there is a difference when it comes to risks[[134]](#footnote-134). There appears to be minimal risk in allowing people whose death is ‘reasonably foreseen’ to have a death that comes a few days or weeks earlier than their natural death. In opting for assisted dying, people in this category are deciding *how* they will die, not *when* they will die. But there is considerable risk in making death possible for people who would otherwise have lived for many more years or even decades, and who may have experienced a restoration of quality of life as they adapt to their restrictions or discover independent living supports in the community. The two situations are by no means equivalent. In the former case, a person gets a better death than they would otherwise have done; in the latter case, someone’s opportunity to lead a meaningful life is forever removed.

Disability rights advocates deploy the principle of individual autonomy in a different way. Their fear is that enabling some people with disabilities to end their lives (e.g. the first group listed above) will put the lives of other disabled people at risk (e.g. the second and third groups above). Self-evidently, different disabled people have different views and desires. The danger is that the desires or decisions of one disabled person will have negative implications for the desires or decisions of other disabled people.

If assisted dying is made available for all people with illness or impairment, then this could imply that it is better to be dead than to be disabled. A social assumption might follow that all disabled people should prefer death. Disability becomes equivalent to a life not worth living. A message is sent that being reliant on technologies or assistance equates to a worthless or dependent life. Such assumptions, implications and meanings undermine the autonomy or self-worth of people in the second and third groups. This message could also be damaging to people who develop MS, spinal cord injury or have strokes, because it could suggest that the resultant life would not be worth living. These negative assumptions will shape the decisions of other disabled people and undermine their autonomy.

In bioethics, this emphasis on messages sent by a social policy is the expressivist objection already mentioned, because it highlights how policies ‘express’ negative valuations and promote stereotypes which may be damaging. We do not consider the expressivist objection to have weight in all circumstances. For example, it would surely be wrong to restrict polio immunisation for fear of sending negative messages about people with polio. Prenatal diagnosis is more contentious, but few people consider the expressivist objection a strong argument it. In both these cases, the potential benefits of the medical procedure outweigh the rather indirect potential reinforcement of negative valuations of people with something like polio or Down syndrome. However, it is vital to break the strong cultural association between ‘having a significant impairment’ and ‘leading a miserable and useless life’, an association which may engender sympathy for the current litigation in some members of the public, but which would be challenged by most disabled people and indeed by empirical research.

The question then becomes an empirical one: does the risk to the many of permitting assisted dying outweigh the benefit to the few who may choose to resort to assisted death? On what grounds is it permitted to restrict autonomy? Following Mill[[135]](#footnote-135), bioethicists argue that autonomy can only be restricted where its exercise would do harm to others. The disability community have consistently feared that permitting all people with significant physical impairments or illnesses to have assistance to end their lives would constitute major harm to disabled individuals who may be isolated, unsupported or psychologically vulnerable.

One worry is that a person newly disabled may seek to end their life, when in the bottom of the J-curve subsequent to injury or diagnosis. Over successive months or years, it is highly likely that the individual would have come to terms, adapted and moved on, enabling them to regain their previous levels of well-being. But this positive prognosis is interrupted, if the individual ends their life believing everything to be hopeless and futile[[136]](#footnote-136). In particular, those new to impairment often blame themselves for their difficulties, rather than contextualising them in terms of wider social barriers and failures of services: they adopt the so-called ‘medical model’ understanding of disability, rather than the more liberating ‘social model’, in which difficulties are attributed to social and environmental factors.

A second fear is that a disabled person, particularly someone with a newly acquired impairment, may not have access to the services and situations that can render disability liveable. For example, a disabled person usually needs an accessible home; they need access to personal assistance services which can meet personal care needs without indignity; they need to be able to find affordable accessible transport to get them from A to B; they need meaningful things to do with their life, including personal relationships and probably productive occupational role. To access all these social goods can be a struggle for a disabled person, particularly in a society where austerity predominates, or in a rural context, or in a culture where these individual rights are seen only as needs, not entitlements. Without these provisions, life for disabled people can indeed be very limited, lonely and depressing. Thus lack of access to independent living can compound any psychological issues surrounding newly diagnosed illness or acquired impairment and result in reduced quality of life. Further, there are many things that can be done for disabled people to enhance the quality of their lives.

A third problem, which encompasses both the newly impaired and those with a condition of longstanding, is that a disabled person may be vulnerable to explicit or implicit pressures arising from their context. These pressures have been elaborated in much of the literature on assisted dying. For example, there may be expectations from family members, financial situations, cultural messages, or even something as dramatic as coercion in rare situations. Rather than living with a condition, coming to terms with it, and having every chance of a good and fulfilled life, the individual comes to believe that their best option is to end their life – whether to stop being a burden, to avoid using up limited family resources, because life as a disabled person is socially or personally unacceptable, or to avoid a lingering death that would be difficult for family members to cope with.

When the scope of assisted dying legislation is widened to all disabled people, this brings many more individuals into the purview of the law, and thus potentially makes many more people vulnerable to these pressures or to the temptation of ending their life. Whereas people who are in the end stage of a terminal disease, where death is ‘reasonably foreseen’, are inevitably going to die within months, those in the second or third categories have every chance of living for decades, and indeed of reaching their average life expectancy. Most people in the third group, and many people in the second group, will die from a health condition unrelated to their primary disability. Therefore, the availability of assisted dying could harm the life chances of people in the second and third groups, whereas to the people in the first group, it only brings forward an inevitable death by a matter of weeks or months. Obviously, people in the second group may eventually join the first group: rather than being at hypothetical risk of death from their degenerative illnesses, they may reach the stage of very advanced muscular dystrophy or spinal muscular atrophy or multiple sclerosis when death is reasonably foreseen. They may even bring that state of affairs nearer by their refusal of medical treatment and care, for example, ventilation, dialysis, feeding or hydration.

The danger is that making medical assistance in dying available to all disabled people, who are not otherwise dying, provides an option that may be much easier to access. Knowledge of the availability of medical assistance in dying brings comfort to people whose death is reasonably foreseen, who know they have a way out from the pains and indignities of dying. But the countervailing worry is that medical assistance in dying might appear tempting as a solution to everyday difficulties or distress for more individuals, who are already vulnerable due to their health condition and social and cultural situation, and possibly the pressures placed upon them. Death by suicide generally is not considered to be a positive option or a neutral choice. This applies equally to disabled people as it does to nondisabled people.

By analogy, if medical assistance in dying was available to all disabled people who are not otherwise dying, this would change the experience of life considerably, and arguably not for the better. People would be aware that if things became difficult for them, they could end it all. Someone who had lost their job, or their partner, or suffered a bereavement, when life felt no longer worth living, would know they had an easy way out. There is a considerable difference between this hypothetical situation, and the current situation where death by suicide is technically possible for anyone in one of these situations – and indeed is resorted to in certain tragic cases. The point is that availability and ease of access to dying changes one’s possibilities and increases the dangers for people who may find themselves in a vulnerable situation. Medically assisted dying should only ever be a last resort, not an easy option.

In the UK, the restriction to the condition of terminal illness has also been advocated by many, but not all, scholars[[137]](#footnote-137) [[138]](#footnote-138) who have discussed the matter. The various attempts to liberalise the law in the United Kingdom – for example the Private Members’ Bills introduced in the House of Lords by Lord Joffe, Lord Falconer and others - have all made the key distinction between end of life situations versus non-terminal stage situations of illness and impairment. The restriction to the condition of terminal illness was also the position of the UK Commission on Assisted Dying, which recommended that non-terminally ill persons with significant physical impairments should not be eligible. This distinction was made partly as a response to evidence submitted by many disabled people:

“The intention of the Commission is to… establish a clear delineation between the application of assisted suicide for people who are terminally ill and others with long-term conditions or impairments. The adoption of this distinction in any future legislation would send a clear message that disabled people’s lives are valued equally.”[[139]](#footnote-139)

Internationally, majority public opinion in countries as disparate as India, Togo and France has been found to support medical assistance in dying, sometimes depending on the circumstances of the situation[[140]](#footnote-140). Autonomy arguments predominate in developed countries, but are less relevant in developing countries. Physicians are generally opposed, which is understandable given that their vocation is to preserve life, not to end it. However, in UK physicians organisations are moving to a position of neutrality, rather than opposition, reflecting overall public opinion in favour of limited rights to assisted dying.

The perennial difficulty with medical assistance in dying legislation is to find a workable compromise. The only entirely clear and consistent positions are either to ban all medical assistance in dying, or to permit all medical assistance in dying. Most jurisdictions currently adopt the former position. There has been an anxiety that if medical assistance in dying was permitted for people in a narrow category of cases – terminal illness – it would inexorably be widened to cover more and more people, threatening long and deeply held principles of the sanctity of life and opening up the situation for potential abuses. The same, understandable, sympathy with those suffering pain or restrictions that led to the medical assistance in dying legislation leads legislators or judges subsequently to widen eligibility criteria.

Empirically, the USA states which have permitted medical assistance in dying – Oregon, Washington and several others – have not widened criteria. By contrast, Belgium and Netherlands have seen a widening of criteria over recent years, and indeed people who are weary of life, rather than suffering from any accepted physical or mental illness have on some occasions been assisted to die. Currently Canada has permitted medical assistance in dying where death is ‘reasonably foreseen’, but the law has been challenged by people with disabilities who claim that there is an injustice, in that they are suffering unbearably, but death in their case is not reasonably foreseen, and so they cannot access assistance. There is always a danger, in extending medical assistance in dying beyond those who are terminally ill – and will die anyway soon – to people who are unhappy or suffering, then there is more scope for abuse, pressure, or cultural messaging. If assisted dying legislation is permitted, there are strong arguments that it should be limited to people who are at the end of life, who are able to make their own choices free of outside pressure, and who are not suffering from depression or other illness that might cloud their judgement. However, libertarians, and some disability rights activists, might disagree on grounds of autonomy or of equality.

**6. Disability bioethics in a global context**

The bioethics of disability is played out in very different ways according to location, for two main reasons. Bioethics arose in response to new ethical issues posed by the development of high-tech medicine in the HIC of the global north. The bias towards engagement with this highly technologized type of ethical issue rather than more mundane, persistent problems of social and global injustice remains in all areas of bioethics, including disability bioethics. At several points this report has highlighted the enormous variation that exists across the world in health and social care provision, and research into disability and disabling conditions. This is affected by the wealth of the country but also by political decisions about provision of health and social care. The 2011 *World Report on Disability* produced by the World Health Organization and World Bank noted that people with disabilities across the world share generally poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than nondisabled people, but that these difficulties are exacerbated in less advantaged communities[[141]](#footnote-141). Disability is a complex multidimensional experience and poses several challenges for measurement. Particular types of disability are often defined using only one aspect, such as impairments – sensory, physical, mental, intellectual – and may conflate chronic health conditions with disability.

Furthermore, as a field bioethics has long had a strong bias towards high-technology interventions, and hence the health systems of HIC, rather than more mundane interventions and issues of relevance to low income settings. This discrepancy has not been a central area of concern, even though justice is one of the famous ‘four principles’ enunciated by Beauchamp and Childress in their influential *Principles of Biomedical Ethics*.

In a global context, data on all aspects of disability and contextual factors are important for constructing a complete picture of disability and functioning. As we have noted, people with the same impairment can experience very different types and degrees of disabling restriction, depending on the context. There are significant differences between countries and communities in terms of access to healthcare, social supports, and environmental and attitudinal barriers to participation. For example, many children drop out of school in Brazil because of a lack of reading glasses, widely available in most high-income countries. Cultural stigma attached to impairments also varies very widely. Exposure to poor sanitation, malnutrition, and a lack of access to health care (such as for immunization) are all highly variable around the world, often associated with other social problems such as poverty, which also represents a risk for disability. Major environmental changes, such as those caused by natural disasters or conflict situations, will also affect the prevalence of disability not only by generating new impairments but also by creating unprecedented barriers in the physical environment, while campaigns to change negative attitudes towards persons with disabilities and largescale changes to improve accessibility in public transport or other public infrastructure can dramatically affect barriers to activities and participation for many persons with disabilities.

**7. Disabled people as a vulnerable group**

Areas as diverse as bioethics, research ethics and public health policy have found it useful to consider people with disabilities as *a vulnerable group***.** The idea of a vulnerable group is meant to indicate that disabled people, by virtue of having an impairment, are disproportionately likely to experience possible harms. The nature of the harms varies from, for example, greater risk of becoming ill and of being more severely affected by infectious disease, to possible exploitation of people with disabilities in recruitment into research studies, and to increased likelihood of injury or death in situations of disaster and emergency. Research ethics approval procedures are frequently designed so that the involvement of disabled people triggers extra ethical scrutiny.

What tends to be forgotten is that the relationship between vulnerability and disability is bidirectional, since disability itself disproportionately affects populations that are *already* vulnerable for other reasons. There is a higher prevalence of disability in lower income countries than in higher income countries. People with low incomes, and other disadvantaged groups such as women, older people, or people with minimal education have a higher prevalence of disability. Data from several countries show that children from poorer households or from ethnic minority groups are at significantly higher risk of disability than other children.

How exactly does disability produce vulnerability? Vulnerabilities can develop for significantly different reasons even if the cause (disability) appears to be the same. Some vulnerabilities are inherent to the impairment itself and are health-related, such as long-term degenerative processes or fatigue. Genetic syndromes can entail multiple impairments, some of which may be health related. Other vulnerabilities may be inherent to the impairment but are not directly health related, such as a learning disability leading to poor reading skills and hence inability to access important information[[142]](#footnote-142).

Social-relational models suggest that the other vulnerabilities of people with disabilities are secondary to social or environmental factors. So the vulnerabilities of a learning disabled person could be reduced if essential information were made available in forms that do not demand such a high level of reading comprehension. The vulnerabilities that result from disabled people being disproportionately more likely to live in poverty or be unemployed, or to receive poor education and health care, are neither natural nor inevitable consequences of the impairment: they occur because of inequalities in the way that material, cultural and social resources are distributed. Although the presence of an impairment plays a role, the major harmful impact occurs through social relations and institutions.

*Disaster and humanitarian bioethics:*

How people with disability are categorised as vulnerable, and how vulnerability is understood, are particularly relevant in what has become known as ‘disaster bioethics’. These are the ethical issues that arise during humanitarian responses to situations of disaster, conflict and global health emergency (GHE). Over the last 20 years, the humanitarian response community has become more aware than before that disabled people are disproportionately affected by GHEs. There are disturbing statistics and individual horrifying stories:

“A quadriplegic woman in New Orleans …kept telling me she had been calling for a ride to the Superdome [after Hurricane Katrina] since Saturday, but despite promises, no one came…I was on the phone with her that afternoon when she told me, with panic in her voice, “the water is rushing in” …We learned five days later that she had been found in her apartment, dead, floating next to her wheelchair.”[[143]](#footnote-143)

People with disabilities are more exposed to harm during GHEs and are therefore often categorized within disaster preparation or response guidelines as a ‘vulnerable group’. However, these guidelines can lack specificity about the adjustments to the humanitarian response that should be made in view of this. There is also a general lack of awareness that this vulnerable may be directly connected to their impairment, but not always: societal and environmental factors are important too. People with disabilities are globally more likely to be poor, unemployed, socially excluded, and have little or no access to transport or communications -- all factors separate from the impairment, but that increase their vulnerability. In the course of a GHE disabled people may be unable to access information or warnings, or to reach shelters or camps. Assistive devices may be lost or damaged. The community or family networks, including assistive animals, that provide everyday support are likely to be disrupted. Furthermore, during a GHE the humanitarian response often focuses on acute impairments caused by new trauma or illness rather than less obvious, longstanding disabilities.

According to Article 11 of the 2006 United Nations Convention on the Rights of Persons with Disabilities, “State Parties shall take…all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.” Following this, humanitarian response guidance now generally emphasises rights-based approaches and acknowledges the particular needs of disabled people [[144]](#footnote-144). But there is less evidence that ideas about inclusion and accessibility have been incorporated into practice. Humanitarian actors still tend to be more familiar with medical and charitable models of disability than the social and rights-based model of the CRPD. Cultural prejudices about disability (including those held by humanitarian workers) are hard to shift and generate attitudinal barriers with severe practical consequences[[145]](#footnote-145). For example, GHEs and disasters commonly raise acute questions of prioritization and allocation of scarce resources, and underlying attitudes that disabled people are of less value or are burdensome to the community can lead to significant differences in distributive outcomes.

Discriminatory attitudes also lead to the injustice of people with disabilities being excluded from humanitarian planning, preparation and management. Although they are often best placed to identify both needs and solutions, disabled people “are more often seen as a problem than a resource.”[[146]](#footnote-146). The UN Office for Disaster Risk Reduction’s 2014 report *Living with Disability and Disasters* states that “The key reason why a disproportionate number of disabled persons suffer and die in disasters is because their needs are ignored and neglected by the official planning process in the majority of situations.” [[147]](#footnote-147)

**8. Law, policy and regulation**

As this background document has already noted, bioethics has concerned itself primarily with high-tech, innovative biomedical developments. In many parts of the world, these clinical and public health innovations are highly regulated for ethical as well as economic and political reasons. Regulation *within* national borders is essential to ensure that as far as possible, permitted practices reflect accepted cultural norms and mores. At the same time, many bioethical issues clearly have effects that extend beyond borders and have global repercussions. There is therefore a growing network of international or ‘universal’ guidelines, declarations and regulation relating to biomedical practices that attempt to reflect and shape shared values. One example is provided by the Council of Europe’s Convention on Human Rights and Biomedicine (Oviedo Convention), currently the only legally binding international instrument in this area [[148]](#footnote-148). Similarly, since it was founded in 1993 UNESCO’s Bioethics Programme has produced guiding international Declarations on the human genome and human rights, human genetic data, and bioethics and human rights. While efforts at harmonisation continue it is important to note that countries differ markedly in their approaches and capacity. As the background to the Universal Declaration on Bioethics and Human Rights notes, “States have a special responsibility not only with respect to bioethical reflection but also in the drafting of any legislation that may follow…[but] whilst many States have framed laws and regulations aimed at protecting human dignity and human rights and freedoms, many other countries wish to establish benchmarks and sometimes lack the means to do so.”[[149]](#footnote-149)

Current international bioethics declarations make little specific reference to disability, except in the context of people who lack capacity to consent to medical treatment or research (eg Article 6 of the Oviedo Convention). Article 24 (3) of the UNESCO Universal Declaration of Bioethics and Human Rights notes that states should have “special regard for those rendered vulnerable by disease or disability or other personal, societal or environmental conditions”. By contrast the UN Declaration on the Rights of Persons with Disabilities contains a number of stipulations that directly or indirectly relate to bioethical issues, including the right to life (Art 10), right not to be subjected to medical experimentation without consent (Art 15), respect for physical and mental integrity (Art 17), and respect for home and the family (Art 23). Moreover there is a general obligation of States to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes (Art 4).[[150]](#footnote-150)

It is beyond the scope of this background report to detail the role of the state or international bodies in upholding the bioethical rights of people with disabilities. However, it is clear that much more needs to be done to encourage the better integration both of disability issues into bioethical regulation and guidance, and of bioethics awareness into policy affecting disabled people. In addition, there is currently a lack of disabled people’s representation in the development of bioethics law, regulation and governance at both national and international levels.

**9. Conclusions, recommendations and questions for consideration**

In another context, the bioethicist Professor Jonathan Glover famously discussed an image of a house, where the people on the top floor were arguing about what wallpaper to hang, and the people on the bottom floor were drowning because of rising floodwaters. We think this image is resonant for the state of international bioethics, where the dominant voices are probably discussing concerns – non-invasive prenatal diagnosis, gene editing, assisted dying – which are currently most relevant for high income countries, or for the richest people in low and middle income settings.

In this report we have highlighted bioethics’ importance for people living with disability today. Bioethics helps societies decide which sorts of interventions into and supports for disability are morally good. But we also note that disability is important for bioethics, in that the diversity of human bodies that can exist is a central focus of biomedicine’s, and therefore bioethics’, attention. Moreover, over the last decades bioethical debate has become an integral part of public discourse about health and technology. The field of bioethics therefore not only reflects to a large extent the prevailing cultural beliefs about disability, but also has the power to shape attitudes towards people with disabilities. This is becoming increasingly important as advances in knowledge and technology increase the ways in which people with disabilities are affected by medical or technological interventions. *It is vital that bioethics acknowledges the limitations of its approach to disability, and that efforts are made to encourage more disability-inclusive bioethical work.*

We have identified the *key difficulties*in bioethics’ response to disability, and make some recommendations in response:

1. Acceptance of a *medicalised conceptualization of disability*, as a medical problem with only medical solutions*.* Bioethics should consider disability as a complex socio-medical phenomenon, an intrinsic part of the human condition, and recognise that it is possible to have a flourishing life with disability if the right social and medical supports are available.
2. Ignorance of the *realities of disabled experience*, leading to a vague, abstract and undifferentiated picture of ‘disability’ being used in bioethical debates*.* Bioethics needs to be better grounded in empirical knowledge of disability, and more open to diversity: the diversity of disability, of the contexts in which people with disabilities around the world live, and of the ways in which it is possible to lead good lives.
3. *Exclusion of disabled voices* from discussion of bioethics, regulation and governance. Bioethicists should be encouraged to remember that the field has its roots within mid-twentieth century patient rights movements. More direct engagement with the people with the health conditions that bioethics is considered with is in line with this history. The voices and experiences of disabled people should be essential parts of bioethical debates.
4. A focus on the *healthcare problems of the global North* at the expense of the different profile of issues of particular concern to the global South*.* In particular, there is scant literature on developing world bioethics and disability. Little is known of the ethical attitudes of developing country populations as a whole towards disability, let alone the views of persons with disabilities in those settings. Because of the great disparity between healthcare available to the poorest and the richest people in the world, there will be problems in ensuring disability equality is upheld in resource-constrained settings. Social media and the internationalisation of research make it even less excusable that scholars from the global North continue to ignore issues relevant in the South. Support should be given to scholars from the global South, in particular disabled scholars, to become published and funded bioethics researchers.
5. *A narrow focus* on the most technologically sophisticated responses to illness and impairment.The emphasis within bioethics on the more heroic, technologically sophisticated response to illness and impairment seems unbalanced, given that the majority of the world’s population subsist on $1/day healthcare, and will never access even ordinary pharmaceuticals, let alone high-tech innovations. Moreover, there is inequality and suffering within countries as well as between countries, as evidenced by the disability rights community argument about the impact of austerity policies on health outcomes within the UK. There needs to be more bioethical debate about these inequalities and how they affect the possibility of flourishing for persons with disabilities and their families. Such broad questions of social justice have traditionally been seen as falling outside bioethics’ key remit, but we argue that they should be made central to bioethical debates in the future.

As well as these points about bioethics as an intellectual activity, there is a set of considerations arising from the ethical dimensions of healthcare. We have not set these out as recommendations, but rather as *questions for consideration* that are more appropriate to the highly contextualized nature of disability worldwide.

First, there are questions about *voice and decision-making*, thinking about individual healthcare dilemmas as well as about collective governance.

* What provision is made for the inclusion of disabled people in decision-making and public debate – both at an individual and collective level?
* Are individuals with disabilities able to self-determine (as far as is appropriate given local cultural norms), or do others speak and decide for them? Medical ethicists translate this into the question of whether informed consent is respected in treatment and decision-making about screening, for example, such as whether people are supported to reject, as well as adopt, screening and selective termination (where relevant).
* Is informed consent of disabled people respected in participation in medical research?

Second, there is a set of questions about *justice and equality*. For example:

* Do people with disabilities get access to reproductive technologies on an equal basis to others?
* Is social justice evident in access to healthcare technologies?
* Where biomedical provision is regulated, do the regulations apply to everyone, or are people able to circumvent prohibitions? Does ability to pay always determine access to healthcare?
* Is palliative care available for everyone, including persons with disabilities? Do people with degenerative or terminal health conditions have access to analgesia? Where medical assistance in dying is provided for people at end of life, is disability perceived as a sufficient reason for offering assistance in dying?
* In humanitarian situations, do persons with disabilities receive fair consideration? Does disaster preparedness take into account particular healthcare and communication and access needs of people with disabilities, particularly chronic conditions?

Third, there is a set of questions about *inclusion and about the appropriate responses* to impairment and disability:

* Are efforts to prevent illness and impairment balanced with efforts to include individuals and families affected by illness and impairment within any particular society?
* Is there an assumption that ‘cure’ is the appropriate response to illness and impairment, rather than support and inclusion?
* Is there an appreciation of social and environmental factors in disability, or is disability reduced to genetic factors?
* Are children and adults with disabilities exposed to unproven or non-evidence-based medical interventions because of their impairments?

We are at a critical junction at the moment, for a number of reasons. Biomedical interventions that both support and potentially challenge people with disabilities are multiplying in high income settings, sometimes in tension with the growth of disability identity and disability politics. At the same time, the divide between high income and low/middle income countries in terms of medical and social care for disabled people is becoming more acute. The mechanisms of compliance with the UN Convention on the Rights of Persons with Disabilities challenge states to consider ethical as well as political and economic concerns. Moreover, in an internationalising world, with increasingly mobile populations, questions cannot be resolved within one state alone: people and problems can often cross borders, and information and communication connect communities and concerns across the world. We believe that bioethics, as a way of thinking and as a route to informing policy-making, can make an essential contribution to upholding the rights of and respect for disabled people globally; but to do this bioethicists must work more closely with disabled people and disabled people’s organizations.

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