

ADVANCES IN DISABILITY  
RESEARCH ETHICS

# ADVANCES IN RESEARCH ETHICS AND INTEGRITY

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ADVANCES IN RESEARCH ETHICS AND  
INTEGRITY VOLUME 11

# ADVANCES IN DISABILITY RESEARCH ETHICS

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INVESTOR IN PEOPLE

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In developing this book we have had the support and assistance of a good many people. Our thanks go in particular to those who provided helpful comments in the peer review process- their contributions added great value to each of the chapters.

We also wish to thank Sarah Fitzgerald who provided a great deal of early editorial support in shaping the writing.

Finally, we wish to note that this collection contains the last publication by Celia Brown who sadly passed away during the books production process.

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# INTRODUCTION

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## BACKGROUND

Advances in Disability Research Ethics builds on the reflections included in the *Handbook of Research Ethics and Scientific Integrity* edited by Ron Iphofen, which was published in 2020. The Handbook included a specific chapter on disability research ethics by [Anne Good \(2020\)](#). Good's chapter emphasised the crucial importance of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) for the development of disability research ethics across the globe.

Two broad-ranging implications of the UNCRPD for the field of disability research ethics were identified. First, Good pointed out that the Convention required a reliable and comprehensive global knowledge base, to act as a bedrock for designing and implementing the Convention's ambitious change programme. This means that ethical practice in research and data collection are crucial to the success of the new Convention. Second, Good argued that the UNCRPD research and data processes had launched the largest and most comprehensive global disability research programme ever undertaken. The UNCRPD praxis in research ethics was therefore destined to have a major impact on all future disability research ethics. These conclusions provided the starting point for this new volume.

Advances in Disability Research Ethics, was designed during 2020–2021 and aimed to cover developments in disability research ethics since the Chapter for the Handbook had been completed. It was designed to propose considerations for future developments in the field.

### UNCRPD Article 1 – Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

(UNCRPD, 2006)

According to the WHO (2023), there are over 1.3 billion disabled people worldwide, which equates to 16% of the global population. In 2006, the UNCRPD set out a comprehensive transformative programme to improve their lives. The Convention aims to empower disabled people to fulfil their potential, to live their lives in harmony with their aspirations and, to the best of their abilities, contribute to the societies in which they live. Its aim was to vindicate the rights of disabled people, who historically have experienced human rights abuses, inequality, exclusion, and injustice. Since 2006, a significant section of human society has looked to the Convention, hopeful that it will ensure their historical experience of discrimination will be replaced with equality, inclusion and respect across all aspects of society.

The Convention did not create new human rights. Rather, it interpreted existing economic, social, cultural, civil, and political human rights through the lens of disabled persons' lived experience around the world (Della Fina et al., 2017). Like all UN instruments, the CRPD considers both the universality and particularity of the rights of disabled people. It intends to have everyday relevance and meaning, through honouring the diversity and complexity of disability identity and experience in all geographical, social, economic, political, and cultural locations. The UNCRPD also acknowledges intersecting identities, and the specific rights and challenges of groups who experience risks to, and violations of, their rights. It does this through articles on equality and non-discrimination (Article 5), women (Article 6), and children (Article 7), and by having a focus on addressing those disabled people at risk of or in poverty. Furthermore, in line with its origin in a global social movement, the CRPD prioritises international solidarity through its article on international cooperation (Article 32).

As we embark upon this book focussing on research ethics, it is worth noting that the eight guiding principles of the CRPD (see Box 1) provide anchors for disability research ethics.

The guiding principles also highlight how the CRPD is a real-world, accessible human rights instrument, with a particular emphasis placed on its impact, thus supporting the ethical engagement of researchers in the advancement of all human rights. It anchors research ethics in a set of definitions (communication, languages, discrimination on the basis of disability, reasonable accommodation,

**Box 1.** Eight Guiding Principles of the CRPD.

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
2. Non-discrimination.
3. Full and effective participation and inclusion in society.
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
5. Equality of opportunity.
6. Accessibility.
7. Equality between men and women.
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities for the right of children with disabilities to preserve their identities.

and universal design) (Article 2); and requires cross-cutting practices such as participation (Article 4.3), equality and non-discrimination (Article 5), awareness raising (Article 8), and accessibility (Article 9); definitions – including ‘communication’ (Article 2) (languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader, and augmentative and alternative modes, means, and formats of communication, including accessible information and communication technology); ‘language’ (in all forms, verbal and non-verbal); and Principles (Article 3).

The CRPD also identifies cross-cutting principles and practices such as participation (Article 4.3), equality and non-discrimination (Article 5), awareness raising (Article 8), and accessibility (Article 9), as well as setting standards for Statistics and Data Collection (Article 31). Throughout the Convention, particular emphasis is placed on its impact in the real world. Reflecting this real-world character and impact focus, the Convention also recognises that definitions of disability, and disability rights, are evolving. All these issues are acknowledged in this book.

## CRPD'S UNIQUE CHARACTERISTICS

To date, 177 countries globally have signed up to the Convention (International Disability Alliance, [www.disabilityalliance.org](http://www.disabilityalliance.org), accessed 28 December 2023). The UNCRPD created obligations on States as a requirement in the countries which have ratified it, to ensure that they are human rights compliant for quality research and data collection. This is carried out at every level and communicated to rights holders. This gives the CRPD an authority over other international and regional instruments (such as global UN – SDGs and the Council of Europe) in uniquely representing both a global consensus, and one which has a focus both on participation and on data which monitors that participation.

As noted above, creating data that is reliable, comprehensive, and ethical in nature, is continually required to provide the knowledge base that is essential for implementing, monitoring, evaluating, and reporting on the various aspects of the Convention – from planning the necessary changes, to monitoring and evaluating the impact of those changes. The field of disability research, and of data collection more broadly, is thus an important component of this Convention, since it allows the change programme to be designed, monitored, and assessed. Moreover, it is notable that this requirement has implications, not only for disability-focused research, but also for any other research where a subset of the population being investigated is comprised of disabled people. This is challenging, as in such situations, ableism can impact on the methodological approach and interpretation of data.

## CHALLENGING ABLEISM ETHICALLY

The core of the change that is being monitored can be summarised as replacing ableism (from the profound to the vestigial) in the disability knowledge base, with a human rights-based bedrock of research, which more accurately reflects the lives and aspirations of disabled people (Good, 2020). Ableism has been defined as follows:

Ableism is the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that disabled people require ‘fixing’ and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as ‘less than’ and includes harmful stereotypes, misconceptions and generalisations of people with disabilities. (University of Cincinnati, 2023)

Much work remains to be done on how the required new ethical architecture for disability research might be best achieved. However, unless total transformation of the disability research field is ensured, resulting in the ending of ableist research and its replacement by research rooted in equality and human rights, the UNCRPD will be undermined at its heart.

The first systemic change that should be considered is how the declared principles, on which ethical guidance and practice must be based, should be applied in relation to research with disabled people. The most recognised generic research principles of Respect, Consent, and Beneficence (including non-Maleficence) were set out in the Helsinki Declaration of 1964 (WMA, 2013), and relate to human participants in medical research. Current changes to ethical processes are already in progress at the time of writing (Chapter 1). These changes can be recognised as efforts to make the long-standing, core generic ethical principles, such as the principle of Beneficence, a lived reality in the complex field of disability research. As the contributions to this book illustrate, this requires clarity, coherence, communication, and practical work to make those principles meaningful and impactful in all their various aspects, and at all levels of research. An ambitious cultural change in disability research is thus already underway. However, there is arguably

a need to add new ethical principles to the list of those recognised as crucial in research and data collection, respond to the complexities of research with those who have disabilities.

The UNCRPD adds to the original Helsinki principles with the further principles of Diversity and Privacy in Articles 3, 17, and 31. One measure that can be taken in developing non-ableist research ethics is to ensure these additional principles are overtly included in the planning and scrutiny of future research projects. A second is to examine how these principles are to be interpreted in the context of disability. Third, it is necessary to ensure that those interpretations are applied in real-world research and data collection through practical changes at every stage of the research process. The examples presented in this book each provide exemplar and discussion of how this might be achieved.

## **THE LIMITS OF THE GENERIC IN HUMAN RIGHTS**

Beyond the need to do additional work on research principles, there is also a need to query the dominant generic approach to changing ethical practice. UN work on formal global Human Rights laws and practices began with the UN Declaration on Human Rights of December 1948 (UNGA, 1948). This was a vital milestone in setting out the human rights of all people in the context of a post-World War II world, which plainly showed the human cost of terrible rights violations. While the UN Declaration was an important breakthrough at the time, in subsequent decades it was found to be insufficient and limited in its effects, leading to expectations around its impact, which were not met.

Over time, it has become clear that a key reason for the limited impact of The Declaration was its fundamentally individualistic and generic approach to rights, which did not sufficiently address embedded systemic and discriminatory social structures. A generic approach such as that set out in the Declaration assumes sameness rather than equivalence, in other words, adhering to pre-existing norms, and assuming universality of application. This works on the principle, that what has been done, or needs to be done, in one area of human rights law, policy, and research ethics, could be considered similar and transferable to that in another research field. However, this transference has not happened. For example, while the overarching principles, such as Beneficence may indeed be the same in name and intention, their significance, meaning and implementation vary across different legal and research fields.

A generic approach is inadequate and due care needs to be paid when applying the Declaration to the rights of disabled people. This complexity applies also to the research needed to underpin those laws and explore their impacts. Unproblematised genericism allowed vital structures in the field of research and data collection to remain permeated with discriminatory attitudes, assumptions, and practices such as sexism, ageism, racism, ableism, and heterosexism. Post-1948, it was increasingly recognised that in order to rectify stubborn and deep structural barriers which prevent the realisation of human rights in the

everyday lives of large swathes of people, the Declaration on Human Rights itself needed to be developed beyond the generic, into further specific explanations and refinements.

## **INTEGRATED AND INTERSECTIONAL ETHICS**

Although progress has been made, there is still a need to move towards the type of transformative social change required to improve the lives of disabled people. It is also clear that the general, if uneven and uncertain, movement towards universal respect for human rights in law and policy, also creates new imperatives in the fields of research and data collection, as there is a continued reliance on older, generic approaches. New, specific requirements must be effectively stitched into any future generic research ethical instruments. For example, New Human Rights laws must run alongside the development of specific new principles and practices regarding research and data collection. At a minimum, this must include disaggregation and analysis of population-level data (e.g. Census data) by age, gender, disability, race, and ethnicity. The ultimate goal is to learn from research ethics discoveries in disability research, in order not just to inspire specific ethical guidance and practices within these fields, but also to take these innovations into the generic ethical research field. The same applies to those from other research fields, such as those challenging sexism and racism in research, which in turn can inform research ethics in disability research. Diversity and voice are likely to be common components within this intersectional approach.

## **BEYOND THE GENERIC APPLICATION OF ETHICS**

In recent years, researchers working with disabled people have acknowledged the need to move beyond the generic application of existing research ethics, towards an approach which recognises the lives of disabled people and disability policy, service provision, and lived experiences. This transition towards a more effective and comprehensive focus on ethics in disability research can be traced back to the emergence of the Disability Rights Movement in the early 1970s. The DRM led to the rejection of persistent attitudes and behaviour which denied or undermined the humanity of disabled people.

This means that in parallel with, and providing a basis for the social change across all areas of life that are mapped out in the Convention, what is needed is deep transformative change within disability research ethics itself: moving from the generic to the nuanced, the specific, and the complex. In essence, what is required is a new ethical research culture based on human rights and equality, that can transform disability research from the status quo of remaining at least partially ableist, towards a truly inclusive approach. To assist in this change programme, the CRPD itself sets out a number of key principles which must be effectively honoured in disability research and data collection, as well as within the various

policy fields addressed by the Convention (such as education and transport). This confronts all involved with the UNCRPD with a challenging task.

Yet, fulfilling that task is essential if the implementation and monitoring of the UNCRPD are to be rooted in an evolving, high-quality ethical knowledge base, which itself adheres to the terms of the articles relating to data and research which are contained within it. Furthermore, this process of transforming research ethics needs to be built by honouring and placing the UNCRPD at the centre of all processes of ethical planning and scrutiny and of conducting disability research, which echoes the core assertion of the disability rights movement which says *Nothing about us without us*. The Voices of disabled people, as they are in this text, must be central at every level to the change process. The authors in this book provide methods for doing so, thus allowing for exploration beyond what can often be tokenistic consultation exercises.

## ADVANCES IN DISABILITY RESEARCH ETHICS

This book, *Advances in Disability Research Ethics* has been designed to contribute to the creation of that essential, high-quality knowledge base; to advance the implementation and monitoring of the CRPD based on ethical data and research; and to ensure that the Convention can achieve positive change in the lives of millions of disabled people. The goal of our text is to ensure such knowledge is rooted in ethical practice at every stage. It does so by presenting accounts from authors who detail the advances they have made towards this goal in relation to diverse types of impairments and disabling barriers. *Advances in Disability Research Ethics* also draws together national, international, and comparative perspectives, which acknowledge the historical context of research, research ethics with disabled people, disability evidence and data, while also critiquing the vulnerability discourse and concept of structural vulnerability.

The chapters provide reflections and living examples pointing towards more effective, non-ableist ethical practice in disability research and data collection, and in doing so highlight how such ethics must be built on a clear understanding of, and commitment to, the human rights and equality model rooted in the Convention. It includes accounts acknowledging intersectional histories, with the intention of advancing our understanding of the contextual factors associated with this research. These include (but are not limited to): the challenges to evidence and ethics; the consequences of the COVID-19 pandemic (the pandemic); weakness of data infrastructure; operation of vulnerability discourse; perpetuation of the medical model of disability; as well as the regression of rights and anti-rights discourses. However, it also identifies advances such as the UN Special Rapporteur comment (AI), policy, guidance (populations: Indigenous peoples, children; sectors: work and employment, education) and the opportunities offered by flexibility of working life for disabled researchers.

The book opens with Chapter 1, *Systemic Change in Research Ethics for the UNCRPD Knowledge Base: Mapping a Way Forward* in which authors Anne

Good and Gary Allen set the scene for this edited collection by exploring the systematic changes that are needed to ensure global disability research complies with the CRPD. They argue that developing a new approach to ethics is at the very heart of these changes, highlighting that the scale and complexity of what is needed in working towards and embedding a new ethics in disability research should not be underestimated. Nevertheless, they suggest these changes are essential so that the evidence base driving the implementation of the CRPD is no longer contaminated by ableist thinking and research practice. To facilitate planning for these changes, they provide a discussion of two recent generic research ethics programmes, the European Union PRO RES project and the revised Australian National Statement on Research Ethics and Integrity. These examples present models and ideas that can allow researchers to map out plans for moving their research practice towards a more equality and human rights-based approach. Most importantly Good and Allen argue for improved approaches to ensuring that the Voice of disabled people is listened to at all stages in the research process.

In Chapter 2, *Ethical and Legal Issues in the Collection, Use, and Dissemination of Data on Disability*, Dan Mont presents the ethical and legal issues around the use of data. Mont focuses on the context of international law and national implementation in monitoring. He stresses the importance of having an evolving approach to the definition of disability, as well as balancing this with data system requirements in relation to accuracy and time series. Mont further sets out the 'global consensus' of the CRPD, and highlights the resources and importance of reviewing current data collected that is in alignment with the CRPD. Mont also makes a case for the vigorous pursuit of improvements in data collection, which he argues should play an important role for Organisations of People with Disabilities (OPDs). This chapter provides practice examples and considers equality, discrimination as well as human rights and the historical issues affecting this area of practice. Throughout Mont argues for a rights-led, rather than data-led agenda, which starts from a position committed to advancing disability rights, suggesting that data should be reported on and analysed, while also being provided to disabled people for their independent analyses.

The significance of data is also stressed in Chapter 3, *The Importance of Definitions of Terms in Disability Research*, Jennifer H. Madans argues that definitions of disability need to be grounded in human rights frameworks, while also acknowledging State commitments – without this, she suggests, findings cannot be used. She also suggests that ethical research in this area requires the identification of varying points of disability for different research and data objectives, highlighting that this necessitates information about the level of functioning along a continuum. In this chapter, Madans goes on to argue that quality is enhanced by CRPD alignment of administrative data systems, and collections not originally created for research or statistical purposes. Such data can enhance CRPD reporting on implementation and the demonstration of rights enjoyed through disaggregation of outcomes of disabled versus non-disabled people.

In Chapter 4, *Ethical Inclusion and Participation of People with Disability in Research: Problematizing Vulnerability*, Mellifont et al. turn to explore the role played by researchers with disabilities, calling out the ableism that is inherent in the