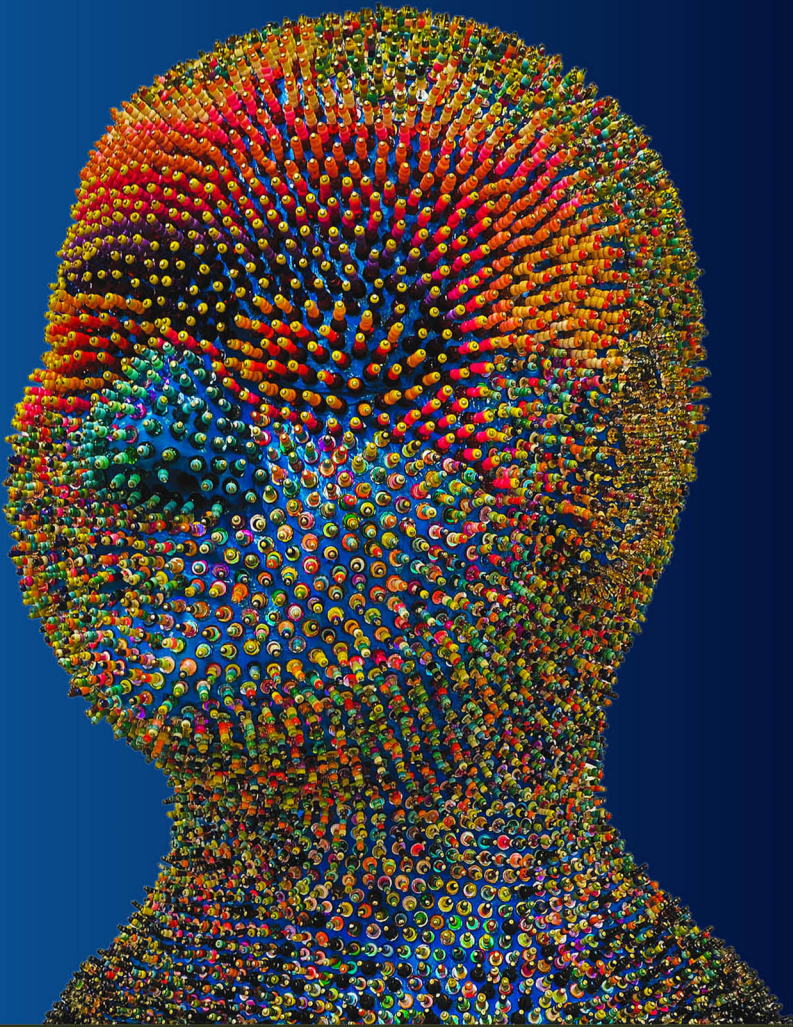


DISABILITY, SOCIETY AND CULTURE

Understanding Models of Disability



EDITED BY KATIE ELLIS, JENNIFER MCKELLAR,
GWYNETH PEATY AND MIKE KENT

DISABILITY, SOCIETY AND CULTURE

This book provides an accessible introduction to critical disability studies, which helps students question existing notions of disability and interrogate how these have become embedded in our social and cultural understanding of disability.

This interdisciplinary text, authored by a team of leading critical disability scholars, defines and explains the core foundational concepts and models referred to in disability studies literature: the medical model, the tragedy model of disability, the social model, the cultural model, the human rights model, the affirmation model and critical disability studies. These seven particular models have been selected due to the centrality of their influence on people with disability, wider society and culture and the academic study of disability. These models provide students with new ways of understanding how disability interfaces with society and offer students from a variety of disciplines an important foundation for any further formal study in this area. This text is also co-designed with students studying models of disability, so the authors fully understand the issues students experience when learning about these models, and this text actively addresses how to overcome them.

This book will be an essential resource for undergraduate and postgraduate students studying critical disability studies from various disciplines including media and cultural studies, communication studies, disability studies and sociology.

Katie Ellis is Professor in Internet Studies and Director of the Centre for Culture and Technology at Curtin University. Her research is located at

the intersection of media access and representation. She is the author or editor of 19 books on the topic of disability, the media and popular culture including most recently with Mike Kent and Tama Leaver, *Gaming Disability* (2023) and *Disability and Digital Television Cultures* (2019) and with Mick Broderick, *Trauma and Disability in Mad Max: Beyond the Road Warrior's Fury* (2019).

Jennifer McKellar is an academic and researcher whose work focuses on inclusivity. Her work supports health and aged care in multicultural communities, as well as the development and expansion of critical disability studies as an academic discipline. She contributed to the *Routledge International Handbook of Critical Disability Studies* (2025) and was the lead author on the paper 'Governance in Social Research: Advancing Inclusive Approaches for Marginalised Communities' (2025) in the *Australian Journal of Social Issues*.

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Understanding Models of Disability

*Edited by Katie Ellis, Jennifer McKellar,
Gwyneth Peaty and Mike Kent*

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*We dedicate this book to students studying
disability and exploring theoretical flexibility,
maybe for the first time.*

*Models matter because they shape how we think,
which in turn shapes how we act. By centring
disabled people's knowledge and leadership, you
can create a more inclusive future.*



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This textbook is the result of the convergence of our teaching and research at Curtin University at a critical moment in time. Through initiatives such as the Accessibility Challenge and our edX Massive Open Online Course, *Exploring Models of Disability*, we have explored different ways to introduce models of disability to students within and beyond our discipline. Through this teaching, we have experienced what happens when mindsets change and students begin to think about disability differently. Buoyed by these students and the members of the Curtin Critical Disability Working Group, we embarked on this collaborative project, in which students of disability directed how students could learn about models of disability via the textbook format. This is the book we wished we had.

Katie would like to thank her co-editors, Jen, Gwyneth and Mike, as well as her family – Chris, Stella and Connor – for being amazing sources of support. Her greatest thanks go, of course, to the members of the Curtin University Critical Disability Working Group, who contributed their ideas, wrote sections and chapters of this textbook and reviewed each other's work. Finalising this textbook is a testament to this group's willingness to participate at every stage of the process. I am deeply grateful for your insights, enthusiasm and willingness to reflect on your own experiences to progress a more inclusive future. I have learned so much from each of you.

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Kim Cousins is a disability researcher and media, public relations and communications professional. Her research looks at improving engagement and policy development between people with disability and government organisations. She has lived experience of chronic illness, with her life shaped by systemic precarity and underprivilege. Although she sees all models useful in understanding the different experiences of disability and disablement, she is drawn to the inclusive nature of the cultural model.

Achala K. Dissanayake is a Sri Lankan academic, reading for her PhD at Curtin University. She has a background in English studies. Her PhD research explores the lived experiences of epilepsy in Sri Lanka and Australia, and combines her love for writing with her lived experiences of epilepsy. She has particular interest in how disability intersects with social factors like gender, ethnicity and nationality, and how such intersections impact affirmation of disability.

Jordan Alice Fyfe is a disabled artist, academic and advocate. Her PhD uses co-design methodologies to foster a strong community and future for disabled artists. The Affirmation Model of Disability originated in the Disability Arts sector, challenging the tragedy narrative of disability and positioning disability as a valid and valuable experience. Jordan finds this model useful in her work but also believes each model has a place as tools that illuminate different dimensions of disability experience.

Divya Garg is Research Fellow in the Digital Disability research cluster in the Centre for Culture and Technology at Curtin University, Western Australia. Her monograph *Decolonizing Media Fandom: Disability, Race, and Marvel Superhero Fans* (University of Iowa Press) examines the experiences of minority fans in global fan spaces. When first encountering the social model, Divya found it quite powerful in its activist orientations, transforming her understanding of and attitudes towards disability.

Lauren Henley has more than 15 years of experience working in disability policy-related roles. Her work is informed by her real-world experience as a person who is blind. She has a strong interest in human rights and previously worked for the Australian Human Rights Commission. She has represented the interests of Australians with disability at the United Nations and has made a successful complaint under the Optional Protocol to the Convention on the Rights of Persons with Disabilities. Lauren has also designed and delivered training on disability rights and other related topics for a range of organisations.

Hersinta is an academic and researcher at LSPR Communication and Business Institute in Jakarta, Indonesia. Her current research and publications focus on disability and popular culture, augmentative and alternative communication and developmental disabilities in Southeast Asia. She finds the social model is impactful in driving disability activism and shaping policies as it emphasises the structural barriers, communication access and the lived experiences of disabled communities.

Maria Ionita has a background in both operational delivery and policy development within the National Disability Insurance space (NDIS). Her work has focused on improving systems and outcomes for people with disability. Maria's research explores the critical intersection between the NDIS and the criminal justice system, examining how policy and practice shape the experiences of Aboriginal and CALD people with cognitive disability in contact with the justice system.

Kai-Ti Kao is a PhD candidate at Curtin University, researching how power and privilege intersect with and within digital technologies and spaces. As a non-White, mixed-race, migrant-settler living in so-called Australia, she is particularly interested in the experiences of those who are intersectionally marginalised. She finds the cultural model helpful for recognising the ways that disability can be socially and culturally constructed, interpreted and experienced.

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Melissa Marsden is a researcher and journalist with a background in media, politics and history. Her research is focused on disability, the Paralympics and interspecies interdependence. She lives on the unceded lands of the Kaurua people and is legally blind and experiences some short-term memory loss. As a para-equestrian, she values the cultural model as it focuses on how disability gains discursive power in different cultural settings.

Michael Mioceovich is a practicing disabled artist. His body of work represents a journey of self-discovery and study, from representative figurative works to abstract impressionistic pieces. His works are a search for a new language in art that can represent disability, without the baggage of historically ableist representation.

Kelly Moes recently completed her PhD in Critical Disability Studies and Health Humanities at Curtin University. Her research focuses on experiential expertise, meaningful engagement and developing more inclusive and responsive approaches to chronic illness-disability research, management and support. Informed by her professional, academic and lived experiences with chronic illness-disability, Kelly recognises disability models as contextual tools, navigating between them based on environmental, relational and temporal contexts, acknowledging each offers different insights and complexities of the disability experience.

Tim Pitman is the Trials and Evaluation Program Director at the Australian Centre for Student Equity and Success (ACSES). He is a higher education policy researcher and his work focuses on equity, access and participation, particularly for students with disability. A 2020 NCSEHE Equity Fellow,

he completed his PhD at UWA and leads national efforts to evaluate and improve student equity initiatives.

Chloe T. Rattray (she/they) is a PhD student with a background in media and disability studies. Her research explores how children's animated television can challenge normativity and reimagine more inclusive futures. Chloe's work draws on critical disability studies as a tool for analysing subjects beyond disability itself, questioning broader cultural norms and revealing new ways of understanding identity, difference and belonging. She also draws on the affirmation model, which recognises disability as a source of pride and community. Beyond academia, Chloe works as a researcher and advisor on projects focused on disability inclusion, queer identity and mental health.

Meagan Shand is an experienced disability leader and social innovator. She values disability as a source of strength, identity and pride; appreciates the emerging nature of disability theory, and the complexity of social change. Meagan is passionate about disability leadership and is committed to empowering disabled people and communities to lead change.

PROLOGUE

‘Everything’ — An artist’s journey with disability

Front cover sculpture and words below by Michael Miocevich.

During the progress of my studies in Fine Art, I found recurring tropes centring around disability, many of which spoke only of the perception of ourselves by outsider others. I felt that our lives of complexity and differentiation were too easily bundled up, given a descriptor based on old notions of good and evil and disability being the punishment of transgressions or of us as poor, blighted souls who should be pitied, shunned or feared. In my studies I chose to take the path of complexity that our disabled lives cannot be so easily labelled, and neither should our art or creativity be. In doing so I want to push back against the ideas that our art, our creations, our very existence can be easily read, dismissed and then forgotten. We disabled people are not a collective of lost souls and cast-offs. We are a plurality of humanity, as equal as any other.

‘Everything’, the artwork seen on the cover of this book, is my representation of the inner life I live. My disabilities are, for the most part, completely invisible to others. The sculpture itself is neither sorrowful nor ecstatic. It is the meeting head-on of the challenges disability brings, fortifying the self against trying times and looking forward with anticipation to times of disabled joy. Each pin is coded in a specific combination to represent different aspects of my disabilities, and each has a meaning about my existence depending on its placement. The sculpture is the same size as my own head and neck, as I did not want to shrink down my experience just to fit someone else’s narrative. It has taken my life to conceptualise this story of myself, years to make the sculpture from start to finish and discipline to see it through despite setbacks and fatigue. It represents me the way I want to be represented. It is Everything.

1

AN INTRODUCTION TO LEARNING ABOUT MODELS OF DISABILITY

Katie Ellis and Gwyneth Peaty

Introduction

This textbook is about disability. It is about how we understand disability and the ways this understanding is shaped by certain influences. Approximately 16% of the global population lives with a disability, and individual experiences vary significantly (WHO, 2022). At the same time, people with disability are increasingly recognised as a group within society with common experiences, for example, inaccessible environments, prejudice and exclusion. When considering the friends and families of people with disability, disability is an issue with far-reaching effects throughout society. Nevertheless, disability is often still viewed as an anomaly or solely as a medical issue arising from an individual's physical condition. This functional lens emphasises individual deficits and can be described as a medical or individual model of disability. However, the medical model represents only one perspective on disability; there are numerous other recognised models of disability. Social model approaches shift the focus to societal barriers, while more recent hybrid frameworks – such as cultural and human rights models – combine these perspectives to capture disability's multifaceted nature. This textbook is designed to introduce students to this wide range of models, seven in total, all of which are foundational to how we understand disability.

Throughout the history of science and the humanities, models have been used to explain, predict and critique patterns and principles (Bod, 2018). Within academia, there is a strong link between theories and models. While theories are broad bodies of knowledge, models are “narrower in

scope and often more concrete, commonly applied to a particular aspect of a given theory, providing a more local description or understanding of a phenomenon” (Fried, 2020, p. 336). There is no universally accepted definition of a model (Bod, 2018). Models can be ideal depictions of reality or simplified explanations of complex concepts. The term has been used for likenesses, replicas, theories, templates, products and even people (Frigg, 2022).

For researchers and students in disability studies, models are especially important; these have been developed to explain experiences of people with disability in different contexts and shape understanding, policy and lived experience. These models provide new ways of understanding how disability interfaces with individuals, society and culture. They have become essential touchstones for understanding the history and progress of disability as a concept and as an experience. Models of disability serve as structured frameworks for understanding disability by integrating personal, environmental and societal dimensions.

However, there is no one text of which we are aware that defines and explains the foundational models of disability, nor how they compare to one another. Throughout this textbook, we discuss seven models in depth and point towards other more specialised models of disability. We consider each model presented in this book as a useful tool in addressing and explaining the complexity of disability. Models are not right or wrong; they are tools that highlight different aspects of complex phenomena and lead to different interventions. Some models, however, can be seen to encourage ableist thinking about disability, such as viewing disability as a ‘tragedy’ or moral ‘punishment’. As students and researchers, we need to be aware of how much ideology is built into the tools of our trade. Our choice of which model to use will shape our findings and the language we use to share them.

One way in which this is illustrated is in how media representations of disability are approached in research proceeding from different models of disability. Take, for example, the character Sheldon Cooper from *The Big Bang Theory*. Sheldon is often viewed as embodying autistic traits, although the show avoids explicitly labelling him (Ellis, 2015; Rajan, 2021; Tobia & Toma, 2015). Psychologists, educators, disability rights advocates and medical professionals have all analysed Sheldon’s behaviours from their own perspectives, often reaching differing conclusions. For example, studies have examined the intersection of autism and race in his portrayal (Matthews, 2019) and how viewers’ autism traits influence the perception of Sheldon (Rourke & McGloin, 2019). The show’s representation of higher education and academics as a ‘freak show’ has been critiqued (Harbour, 2015, p. 1), while Sheldon’s character has been analysed as part of a

broader shift in sitcom representations of autism (Kaklamanidou, 2023). Linguistic analyses have explored how Sheldon's dialogue constructs 'nerdiness' (Bednarek, 2012, p. 199). Critics have noted potential misrepresentations of Asperger's syndrome in the show (Rajan, 2021), while others have used Sheldon as a teaching tool for understanding DSM-5 diagnostic criteria (Tobia & Toma, 2015). The show's approach to autism representation has also been compared unfavourably to other sitcoms like *Community* (Gaeke-Franz, 2022).

This brief summary of the academic discourse critiquing the representation of Sheldon from a number of disciplines demonstrates the power of different theoretical models at work. Each interpretation is informed by different traditions and priorities and seeks to intervene in different debates. While a medical model of disability may be more relevant to understanding the DSM-5 diagnostic criteria, the analysis of academia as a freak show or the shifts in representations of autism across time and television programming invokes the cultural model of disability. The evolving findings presented in these studies indicate a change in the social status of individuals with autism.

These shifts can be located back to the activities of UK activists in the 1970s who sought to challenge the individualisation of disability and instead located disability in social and cultural practices. They developed a social model of disability, positioning disability as arising from societal barriers and discrimination rather than from intrinsic deficiencies within the individual (Söder, 2009). That is, rather than viewing disability as something that exists within an individual, the social model places disability within society, highlighting how societal norms often overlook those with bodies that differ from the imagined majority. This model makes a point of separating **impairment**, which refers to physical conditions, from disability, which is shaped by social factors. This perspective was foundational in launching the field of *disability studies*.

However, in the 1990s, critiques from feminists, cultural studies researchers and post-modernists challenged the binary perspectives found within both the medical and social models of disability. This shift led to the use of the term *critical disability studies* to move beyond simple oppositions such as the social versus the medical model, British versus American approaches or disability versus impairment (Meekosha & Shuttleworth, 2009). Around this time, humanities and cultural studies scholars in the United States expanded on this idea by recognising the importance of psychological, cultural, discursive and physical factors (Meekosha & Shuttleworth, 2009) in advancing social justice and diversity.

The importance of critical disability studies across a number of disciplines has grown dramatically in recent years. Critical disability studies

challenge traditional ideas about disability and examine how these ideas have influenced academic perspectives (Vehmas & Watson, 2014). Critical disability studies “start with disability but never end with it: disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all” (Goodley, 2013, p. 632). It is an active field of enquiry that examines the interrelationship of material, social, cultural, political and other contextual factors that shape contemporary conceptions of disability, rather than isolating any single aspect.

This book proceeds from this critical disability perspective to outline and define seven distinct models of disability. Following this introductory chapter, seven chapters each address a different model of disability – the medical, tragedy, social, cultural, human rights, critical disability and affirmation models of disability.

We begin with Jennifer McKellar’s chapter on the *medical model of disability*. Many of the disability models we encounter in critical disability studies are defined in opposition to or are critical of the medical model of disability. It is the dominant model of disability and is intuitively understood by most people. Yet, despite being so foundational to both academic and community understandings of disability, it is very rarely defined in depth. The medical model locates disability within the body, positioning it as a health issue to be cured or cared for. While this approach to disability is heavily criticised in the disability studies literature, **medicalisation** or the process of redefining non-medical problems as illnesses or disorders has also brought with it social benefits. For example, the medicalisation of endometriosis, postnatal depression and PTSD has resulted in social improvements for people experiencing these conditions.

The next chapter by Katie Ellis and Jennifer McKellar tracks the rise of the *tragedy model of disability*, considering influences such as medicalisation, **industrialisation** and **eugenics**, religion, the association of disability with dependency and a lack of understanding of human rights. The tragedy model does not recognise the role of societal and environmental factors in creating barriers and exclusion for people with disabilities. As such, it fails to acknowledge that disability is not solely an individual issue but is also influenced by the broader social context.

Then in the *social model of disability*, Hersinta and Kelly Moes outline the emergence of this model and address the ways it has been defined in opposition to the medical and tragedy models. It is often described as ‘the big idea’ of disability studies. Key to the social model is its separation of impairment and disability – impairment is located in the body; disability is society’s reaction to impairments.

In the *cultural model of disability*, Kim Cousins, Kai-Ti Kao and Katie Ellis explore this model as an expression of the diversity of human

experience in which disability forms a natural aspect of human life, shaped by elements like culture, time period and ethnicity. In recognising cultural influences, the cultural model helps address the critique of the social model that it does not give sufficient concern to the impact of impairment on people with disability. It also starts to explore the notion of **ableism** and assumptions that enforce disability. The cultural model aims to change societal values and attitudes by keeping disability in context.

Following this, Maria Ionita explores the *human rights model of disability*. This model is based on the idea that the enjoyment of human rights does not depend on the absence of impairment. This chapter tracks the rise of the human rights model of disability in the latter half of the 20th century as a response to the limitations and shortcomings of earlier models. Key factors include international human rights frameworks, disability rights activism, the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the scholarly contribution of academics and academic-activists in both disability studies and critical disability studies, legal advocacy and changing social attitudes.

Then, in *critical disability studies*, Kelly Moes and Chloe T. Rattray present this expansive theoretical framework as a model of disability that supports both interdisciplinary and transdisciplinary approaches. This model rigorously interrogates social, cultural, political and historical constructions of disability. It underscores the importance of **intersectionality**, emancipatory politics and **accessibility**, thereby broadening disability studies to engage with wider systems of oppression and power.

Following this, Achala K. Dissanayake, Kelly Moes and Jordan Alice Fyfe explore our final model, the *affirmation model of disability*. This model centres the voices and lived experiences of disabled people, promoting a positive and non-tragic view of disability and impairment. This model affirms disability as a valuable and fulfilling identity shaped by individual and collective experiences and activism such as the disability arts and disability pride movements. At the same time, it does not diminish the significance of impairment in the lives of individuals with disability and acknowledges that these experiences can yield valuable perspectives, framing them outside the tragic discourse that has dominated understandings of disability.

The concluding chapter brings together the various models discussed throughout the textbook, focusing on their merits, conflicts and overlaps. It briefly introduces other more specialised models of disability and considers where disability theory is headed in the future.

Finally, the epilogue authored by Kelly Moes reflects on a lifelong, evolving journey with disability, shaped by personal, professional and academic experiences. The narrative traces how early, unconscious encounters