The Palgrave Handbook of Disability and Citizenship in the Global South

Edited by
Brian Watermeyer
Judith McKenzie · Leslie Swartz

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ISBN 978-3-319-74674-6 ISBN 978-3-319-74675-3 (eBook)
https://doi.org/10.1007/978-3-319-74675-3

Library of Congress Control Number: 2018945898

This Palgrave Macmillan imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

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Notes on Contributors

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Roger Behrens is an associate professor in the University of Cape Town's (UCT) Department of Civil Engineering. He is director of the Centre for Transport Studies and of the African Centre of Excellence for Studies in Public and Non-motorised Transport. He graduated with a Master's degree in City and Regional Planning from UCT in 1991 and a PhD in 2002. His research activities relate to the integration and improvement of para-transit services, the dynamics and pace of changing travel behaviour, the use of transport systems by pedestrians, and the urban form prerequisites for viable public transport networks.

Charlotte Capri works as a clinical psychologist with many jobs at Alexandra Hospital (Western Cape Department of Health). She is affiliated to the UCT where she covers a large variety of academic duties for the Department of Psychiatry and Mental Health. She trained at Stellenbosch University and recently completed a PhD in Intellectual Disability with Professor Leslie Swartz. Capri is working on incorporating Ethics of Care into Intellectual Disability practice. She is a member of various underground networks aiming for integrative and medical de-specialised approaches to Intellectual Disability in South Africa. The mission is to re-socialise local responses toward the constitutional treatment of people with Intellectual Disability. This would include re-politicising Intellectual Disability into South African legislature, rights realisation, and policy discourses. Capri also holds a doctorate in Political Science.

L. Juliana Claassens is Professor of Old Testament with a focus on human dignity at the Faculty of Theology, Stellenbosch University. Her most recent book *Claiming Her Dignity: Female Resistance in the Old Testament* has recently been published (2016). She is also the author of *Mourner, Mother, Midwife: Reimagining God's Liberating Presence* (2012) and *The God who Provides: Biblical Images of Divine Nourishment* (2004). Other publications include *Searching for Dignity: Conversations on Theology, Disability and Human Dignity* (co-editor with Leslie Swartz and Len Hansen; 2013). She serves as the head of the Gender Unit at the Faculty of Theology, Stellenbosch University.

Peter Coleridge has worked in disability and development in developing countries for more than 30 years with the aim of making disability a mainstream development issue. For 13 years, he was Oxfam's Middle East Coordinator and made disability a central theme of Oxfam's programmes in Lebanon, Palestine, Jordan, Egypt and Yemen. From 1995 to 2001, he was the programme manager for a large national community-based rehabilitation programme in Afghanistan run by the UN and NGOs.

He now works as a consultant, writer and researcher on disability and development, which includes work for World Health Organization (WHO), the International Labour Organisation (ILO), and the European Union, as well as NGOs. He is the author of *Disability, Liberation and Development* (1993), an exploration of the empowerment model of disability in developing countries, and has written numerous articles and book chapters on disability and development. He was a lead author on the WHO *Community Based Rehabilitation Guidelines* (2011) and an adviser on the World Bank *World Report on Disability* (2011).

Beverley Dickman is a clinical psychologist who graduated with an MSc and holds a PhD from the UCT. Alongside a private practice in individual psychotherapy, Dickman worked from 1984 to 2014 at Cape Mental Health as a consultant psychologist. Dickman was involved in the establishment of a psycho-legal programme at Cape Mental Health, which facilitates access to justice for complainants with intellectual disabilities in sexual abuse cases. In addition to acting as an expert witness in these cases, Dickman was involved in training and liaison with police and prosecutors, as well as research evaluating the programme. Dickman is involved in teaching professional ethics, with a special interest in ethical issues with people who are disempowered.

Fatima Essop has been the head of De Heide Children's Special Care Centre (which is part of the Western Cape Cerebral Palsy Association) for 25 years and has worked there for 32 years. She is also chairperson of the Western Cape Forum for Intellectual Disability (WCFID) and a board member of the Network on Disability, and she serves on the Right to Education Task team.

She is an activist and lobbyist for mental healthcare and for the constitutional rights of children with severe to profound disabilities, as well as in issues involving disability, gender and racial discrimination. Her passion is children

with severe multiple disabilities and how these impact on their families, and her role includes community family intervention and support and assisting families to engage with the relevant role players.

She completed her MPhil in Disability Studies at the UCT in 2013 and is registered for her PhD. Essop wrote a chapter in the Vera Grover training manual *Learning to Think* (2016) and continues to be involved on various platforms with other NGOs, funders, stakeholders and government.

Steven Friedman is a research professor in the Humanities Faculty of the University of Johannesburg.

He is a political scientist who has specialised in the study of democracy. He researched and wrote widely on the South African transition to democracy both before and after the elections of 1994 and has, over the past decade, largely written on the relationship between democracy on the one hand and social inequality and economic growth on the other. In particular, he has stressed the role of citizen voice in strengthening democracy and promoting equality.

He is the author of *Building Tomorrow Today*, a study of the South African trade union movement and the implications of its growth for democracy, and the co-editor of *The Long Journey* and *The Small Miracle* (with Doreen Atkinson), which presented the outcome of two research projects on the South African transition. His work focuses on the theory and practice of democracy and his study of South African radical thought, *Race, Class and Power: Harold Wolpe and the Radical Critique of Apartheid*, was published in 2015. He writes a weekly column in *Business Day* on current political and economic developments.

Augusto Galery graduated with a degree in Psychology from the UFMG (1997), with a Masters in Administration from Fundação Getúlio Vargas in São Paulo (2005). He holds a PhD in Social Psychology from the University of São Paulo (USP) (2014). He is a postdoctoral fellow in Social Psychology at USP, an assistant professor at Fundação Escola de Comércio Álvares Pentead (FECAP), and a guest professor on the Master's course at Fundação Getúlio Vargas. For five years, he was coordinator of the DIVERSA Center of Studies for inclusive education at the Rodrigo Mendes Institute and has experience in the areas of social inclusion, social psychology, psycho-sociology and mental health and work. He has been studying and researching the inclusion of people with disabilities since 1997. In 2017, he produced *School for Each and Every One*, a book about inclusive education, published in Brazil.

Rosemarie Garland-Thomson is Professor of English and Bioethics and founding co-director of the Disability Studies Initiative at Emory University. She works in the fields of critical disability studies, bioethics, American literature and culture, health humanities and women's studies to bring forward disability access, equity and identity to communities and institutions across society. She is the author of *Staring: How We Look* and several other books. Her current book project is *Habitable Worlds: Disability, Technology, and Eugenics.*

Gerard Goggin is Professor of Media and Communications, University of Sydney, and an Australian Research Council (ARC) Future Fellow. He has a longstanding interest in disability, media and culture, stemming from his collaborations with disability activists and disabled persons organisations (DPOs) in the struggles for digital media access in the early 1990s. Goggin's key books include *Digital Disability* (2003) and *Disability in Australia* (2005) (both written with the late Christopher Newell), *Disability and the Media* (2015, with Katie Ellis), *Normality and Disability* (2018, with Linda Steele and Jessica Robyn Cadwallader), *Routledge Companion to Disability and Media* (2018, with Katie Ellis and Beth Haller) and *Listening to Disability: Voices of Democracy* (2018, with Cate Thill and Rosemary Kayess).

Dan Goodley is Professor of Disability Studies and Education at the University of Sheffield and co-director of iHuman: the Research Institute for the Study of the Human. Recent publications include *Disability Studies* (second edition, 2016) and *Dis/ability Studies* (2014).

Tristan Görgens is a policy analyst in the Policy and Strategy Unit of the Department of the Premier in the Western Cape (Görgens writes in his personal capacity and his views to not necessarily reflect the views of the Western Cape Government). He previously was the urban land researcher for Isandla Institute, a public interest think tank focused on improving the quality of developmental local government and democracy in South Africa, and lectured at UCT. In this role, he co-edited a book in 2016, *Upgrading Informal Settlements in South Africa: A Partnership-based Approach*. He has also been involved in a number of NGOs working on community development and disability rights. He is a Mandela Rhodes Scholar and a Steven Bantu Biko Leadership Fellow.

Ana Grein holds a Bachelor of Law from the UFMG, and a postgraduate degree in Legislative Power and Democracy in Brazil at the School of Parliament of the São Paulo City Hall. Her thesis addressed the democratic gender deficit in her country. She studies philosophy, politics, feminism and human rights. She is a feminist, and lesbian, gay, bisexual, transgender, queer, intersex, asexual (LGBTQIA) and social minorities rights activist, as well as an academic researcher on these issues. She worked for almost a decade as an assistant and adviser in the Court of Law at Minas Gerais and worked as a trainee in several public agencies (City Hall of Belo Horizonte, Military Police of the State of Minas Gerais, Judicial Assistance Division of UFMG, Institute of Social Security of the State of Minas Gerais).

Anna Horton studied social anthropology at undergraduate level at Edinburgh University and is enrolled in a graduate program in family medicine at McGill University, in Montreal. Her research interests are mainly concerned with conducting anthropological research in healthcare. Specifically, she is interested in the effects of privatisation on frontline healthcare practices, and her research is situated in the context of increasing privatisation of services, heavy cuts and changing accountability structures within the UK's National Healthcare Service.

P. David Howe is a reader in the social anthropology of sport in the School of Sport, Exercise and Health Sciences at Loughborough University, with research interests in disability sport and physical activity cultures. Howe's ethnographic research focuses on unpacking the embodied sociocultural milieu surrounding inclusive physical activity and disability sport. His publications on the co-constitution of disability and medicine in sport mark him out as the leader in the sociocultural investigation of disability sport with reference to the culture of disability, ethics of Paralympism, health and disability and medical discourse surrounding the Paralympic Games. Howe is concerned with his research highlighting ways and means of making sport and physical activity more empowering for marginalised populations. Howe is also editor of the Routledge Book Series, *Disability, Sport and Physical Activity Cultures* and holds a guest professorship at Katholieke Universiteit Leuven, Belgium, and adjunct professorships at Queen's University and Western University, both in Canada.

Xanthe Hunt is a PhD candidate and researcher at Stellenbosch University. She has a background in Psychology, Media Studies and Public Health and works in the fields of disability, sexual and reproductive health, maternal health and global health. Her PhD explores attitudes towards the sexuality of people with physical disabilities and the experiences of sexual and reproductive health services and sexuality of people with physical disabilities in South Africa.

Callista Kahonde completed a PhD in Disability Studies at the UCT in 2017, a Master's degree in Physiotherapy at the University of the Western Cape in 2010 and a BSc Honours Physiotherapy Degree at the University of Zimbabwe in 2004. Her research interests involve issues of community life and family living for people with disabilities, especially those with reduced capacity to self-advocate and identifying avenues through which research can influence policy and practice on programmes to support people with disabilities and their families. She is also a passionate disability activist and advocate and is involved with training workshops for service providers and families of persons with intellectual disabilities in the areas of sexuality and life skills. Kahonde is a postdoctoral fellow within the Centre for Rehabilitation Studies at Stellenbosch University.

Rebecca Lawthom is Professor of Community Psychology at the Manchester Metropolitan University. She leads the Centre for Social Change and Community Well-being. She is a community psychologist and feminist. Her research interests include disability, migrants, community and feminist psychology, utilising qualitative participative methods that embrace marginality and co-production. She is editor for the journal *Community Work and Family*.

Marlene le Roux is the CEO of Artscape Theatre in Cape Town, South Africa. She is the first person of colour and also the first woman to fill this position. Le Roux joined Artscape as Director of Audience Development and Education in 2001. Her work involves outreach and theatre-related capacity development in under-resourced areas. She is a motivational speaker and has done advocacy work for the rights of women, children and the disabled. Le

Roux conceptualized and edited a book of essays and photographs on women with disabilities called *Look at Me* published in 2008. Most recently, she compiled a book on the icons of Mitchells Plain, *Place in the Sun*, which strives to counter the negative stereotyping of people of colour. Le Roux has received numerous awards and won the Shoprite/Checkers Woman of the year Award in 1998 (Art category), the Desmond Tutu Legendary Award in 2001, the Chevalier des Ordres et des Lettres (French Knighthood in the performing Arts) in 2002 and the Western Cape Provincial Award for Arts & Culture in 2004. She also serves as an international expert on the London Olympic Committee 2012.

Kirsty Liddiard is a research fellow in the School of Education and the Institute for the Study of the Human (iHuman) at the University of Sheffield. Her research spans disability, gender, sexuality and intimacy and youth, with a particular interest in how disablism and ableism both inform and shape these experiences in the everyday lives of disabled people.

Theresa Lorenzo is Professor of Disability Studies and Occupational Therapy in the Faculty of Health Sciences at UCT. She has developed expertise in community-based disability and development programmes in the rural and urban communities in South Africa, which has involved the training of community rehabilitation workers. She joined UCT's occupational therapy department in 1996 and has worked with many non-government organisations in building students' capacity to engage with civil society organisations in addressing the needs of disabled people and their families. She initiated the Disability Studies Postgraduate Programmes at UCT in 2003 to bridge the gap between activism and scholarship. Her research experience has focused on addressing poverty, inequality and employment of disabled youth and women, including monitoring and evaluation of disability-inclusive development.

Roy McConkey is Emeritus Professor of Developmental Disabilities at Ulster University, Northern Ireland. A psychologist by training and a native of Belfast, he has previously held posts in England, Scotland and the Republic of Ireland. He is visiting professor at the UCT, South Africa and at Trinity College, Dublin.

He has worked in the field of intellectual disability for over 40 years and has authored, co-authored and edited over 15 books and published nearly 200 book chapters and research papers in learnt journals. His latest book is *Disability and Human Rights: Global Perspectives*, which was published by Palgrave Macmillan in 2016. He has acted as a consultant to various United Nations agencies and International NGOs. This work has taken him to some 25 countries in Eastern Europe, Africa, Asia and South America.

He is a consultant to Special Olympics International and is involved in the international evaluation of their Unified Sports and Healthy Communities programmes.

He is fellow of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. In 2010, the American Association of Intellectual and Development Disabilities selected him for their International Award. In 2015, he was awarded an Order of the British Empire (OBE) by Queen Elizabeth for services to intellectual and developmental disabilities.

Judith McKenzie is an associate professor and head of the Division of Disability studies at the UCT where she teaches and supervises postgraduate students. She has been involved in areas of inclusive education and intellectual disability for close to 30 years as both a parent, an advocate and, more recently, a researcher and academic. She is interested in the ways in which communities and systems can be reimagined in such a way as to become more inclusive and finds herself particularly challenged by those who are most marginalised in society, that is, people with severe to profound and multiple impairments.

Christine Peta is a public healthcare practitioner who holds a PhD in Disability Studies, a number of Master's degrees and a BSc degree. Her research interests are in the intersections of disability and sexuality, including disability and maternal and child healthcare. Peta has a number of publications to her name in scientific journals and has written a book entitled *Disability and Sexuality: Voices from the Periphery* published in 2017. She is based at the Centre for Rehabilitation Studies, Department of Global Health, Faculty of Medicine and Health Sciences, Stellenbosch University.

Alan Roulstone is retired professor of Applied Social Sciences (Disability Policy) at the University of Northumbria and honorary professor at the University of Swansea. He is an internationally leading researcher in disability policy and practice. He has been involved in numerous research projects around adult health and social care, disability, social exclusion, transitions to work and adulthood, chronic illness, new technologies and social futures, older people and disability law. Roulstone's research focuses on disability policy, disabled young people and social exclusion, the role and impact of new social movements, disability-led research, transitions to work and adulthood, chronic illness, new technologies and social futures, older people and disability law.

Katherine Runswick-Cole is Chair in Education in the School of Education at the University of Sheffield. She works in the field of critical disability studies. Recent publications include *The Palgrave Handbook of Disabled Children's Childhood Studies* (with Curran and Liddiard, 2016, Palgrave Macmillan) and *Re-thinking Autism: Disability, Identity and Diagnosis* (with Mallett and Timimi, 2016).

Sa'diyya Shaikh is an associate professor in the Department of Religious Studies at the UCT. Her research is situated at the intersection of Islamic Studies and Gender Studies, with a special interest in Sufism. Her areas of research include gender-sensitive readings of Hadith and Quran, theoretical debates on Islam and feminism, religion and gender-based violence and empirical work on South African Muslim Women. Her published books include *Sufi Narratives of Intimacy: Ibn Arabi, Gender and Sexuality* (2012 and 2013) and *Violence*

Against women in Contemporary World Religion (co-edited with Dan Maguire, 2007). She was a fellow of the *Wissenschaftskolleg Zu Berlin* (2016–2017) working on a research project entitled "Gender, Sufi Ethics and Social Justice".

Tom Shakespeare is Professor of Disability Research at the University of East Anglia, UK. A sociologist, he has conducted qualitative research with disabled people in the UK as well as in Africa. His books include *Disability Rights and Wrongs* (2006) and *The Sexual Politics of Disability* (1996). From 2008 to 2013, he worked at the WHO, where he was an editor and author of the *World Report on Disability* (2011).

Karen Soldatic holds a PhD (Distinction), is an ARC DECRA Fellow, at the Institute for Culture and Society, Western Sydney University. Karen's DECRA, entitled "Disability Income Reform and Regional Australia: The Indigenous Experience", draws upon two previous fellowships: British Academy International Visiting Fellowship (2012) and The Centre for Human Rights Education, Curtin University (2011–2012), where she remains an Adjunct Fellow. Soldatic's research on global welfare regimes builds upon her 20 years' experience as an international-, national- and state-based senior policy analyst and practitioner.

Leslie Swartz is a Distinguished Professor of Psychology at Stellenbosch University. He trained as a clinical psychologist at the UCT, where he completed his PhD. He has published widely on mental health and disability issues, with a particular emphasis on access issues in Southern Africa. He has served as lead research partner for the research programme of the Southern African Federation of the Disabled. He served as founding editor-in-chief of the *African Journal of Disability*. He has extensive experience in disability-related research in Africa, and he is interested in the politics of "capacity building" in disability in the Global South.

Willson Tarusarira holds a diploma in Education from the University of Zimbabwe in 2000. He worked as a primary and high school teacher in Zimbabwe. In 2004, he completed his Bachelor of Arts Degree from the University of Zimbabwe. In 2014, he completed his Postgraduate Diploma in Disability Studies and then enrolled for a Master's degree in Disability Studies at the UCT, where he graduated in June 2016. He joined the People Against Suffering, Oppression and Poverty (PASSOP) Team as the Disability Project Coordinator in 2016 and is now a PhD candidate in Health and Rehabilitation studies at Stellenbosch University. He has over five years of development and organisational experience.

Brian Watermeyer trained as a clinical psychologist (MA Clin. Psych.) at the UCT, before completing a doctorate in psychology (DPhil), focusing on disability studies, at Stellenbosch University. He was first editor of South Africa's first major text in disability studies, entitled *Disability and Social Change: A South African Agenda*, published in 2006. His second book, *Towards a Contextual Psychology of Disablism*, was published internationally in 2013.

Watermeyer has an extensive list of international journal publications, book chapters and media appearances as a disability scholar and disabled (severely visually impaired) activist. He teaches on postgraduate programmes in disability and clinical psychology, as well as guest lecturing in medicine and rehabilitation science.

Tessa Wood completed her Honours in Social Work at UCT (1985) and has been involved in developmental work for the past 30 years, 25 of which have been in the disability sector. She received a scholarship to attend the Council of International Programmes (CIP), USA, in 1989, an international programme in the human services. Entering into the mental health arena in 1992, she established a mental health branch in a rural setting in the Eastern Cape in 1994. In 1998, she took over the leadership of the WCFID, a support network for service providers of more than 190 organisations and individuals. The core business is training staff working in the sector and campaigning for the rights of people with intellectual disability. Wood is not new to the fight for justice, known to have taken on numerous government departments and authorities back in the 1980s.

Gina Ziervogel is an associate professor in the Department of Environmental and Geographical Science and research chair at the African Climate and Development Initiative at the UCT. Her work has focused on climate, development and resilience through the lens of water and governance. She is particularly interested in transdisciplinary projects that bring together civil society, government and academics to address problems collaboratively and creatively. Ziervogel has published widely and been involved in international and national initiatives related to climate change adaptation.

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CHAPTER 1

Introduction

Brian Watermeyer, Judith McKenzie, and Leslie Swartz

What does it take for a person to be considered one of those who are "full members of a community" (Marshall 1950, p. 28)? What does it take to be considered fully human? Questions such as these have been cause for contemplation in many fields of humanities for some time. Throughout history, full citizenship rights and recognition have been denied to people in various contexts on the basis of race, gender, and religion, to name only three identity markers amongst a host of others. Indigenous and colonised people have been denied citizenship rights, and it is on the basis of ideas of citizenship that innumerable political struggles have been waged. At the current time, during which migration and the status of refugees is a key global concern, many scholars are thinking and writing about what migration means for citizenship (Bloemraad and Sheares 2017; Ní Mhurchú 2014).

The question of who may and may not be considered a full member of a community is a pivotal one to disability scholars and activists. Historically, and to the present day in many parts of the world, disabled people are not only denied full membership of their communities, but their very humanness is called into question (Kittay et al. 2005). Disability struggles are not just about belonging, they are about personhood itself (McBryde Johnson 2005). Added to that, disability scholarship goes even further—with the turn to what has

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B. Watermeyer et al. (eds.), *The Palgrave Handbook of Disability and Citizenship in the Global South*,
https://doi.org/10.1007/978-3-319-74675-3_1

been termed "posthumanism" in social sciences (Braidotti 2013), some disability studies scholars are making the important point that the very categories of "person" or "human" are problematic in their exclusion of some disabled people. In this view, to aspire to personhood—to being considered a "fully qualifying" human—is to strive for inclusion in a typology which is set up to exclude disabled people and, indeed, has been used in systematic efforts to eliminate disabled people altogether (Goodley et al. 2017). There is clearly a lot at stake as we approach disability and citizenship.

Given the centrality of questions of citizenship for disability studies, it is not surprising that over the past 20 years, there has been a dramatic upward trend in writing about disability and citizenship (Sépulchre 2017). A recent review of work in the area showed clearly that the vast majority of scholarship dealt with disability and citizenship issues from the Global North and that even in cases of work concerned with the Global South, authorship was still heavily biased towards the North (Sépulchre 2017). Now, there can be little argument that at the very foundations of disability studies is the politics of voice. The question of who speaks for whom is the heart of struggles for self-representation and, indeed, for citizenship. A few years ago, one of the editors of this volume (Swartz) was fortunate to attend an excellent disability studies meeting in a wealthy country in Europe. One of the keynote speakers argued forcefully and cogently that if disability studies is to have any meaning for the vast majority of disabled people[1] in the world, far greater inclusion of scholarship from the Global South is simply essential. Though fully in support of the speaker's position, Swartz pointed out that what was being enacted at the meeting was exactly the problem the speaker wanted to address. Here was an expert from the Global North telling other people, overwhelmingly from the Global North, that they should be talking with people from the Global South. Once again, people from the Global South (and disabled people at that) were being spoken *for* and *about*—rather than speaking for themselves and being spoken with. They were not part of the conversation. With this issue in mind, this book makes an attempt to begin to bridge the immense gap bequeathed to us by both our colonial history and the global structural inequalities surrounding participation in scholarship.

But the book concerns itself not just with disability studies' knowledge lacuna regarding disability and citizenship in the Global South. As editors, we are also centrally concerned with the effacement of disability issues from citizenship debates in the broadest context. Just as it is no longer possible to discuss any aspect of citizenship without considering gender inequality as part of the equation, it should not be possible to address citizenship without thinking about disability. Scholars and activists should not have to demonstrate that certain forms of oppression or exclusion are widespread in order to justify these being attended to. In the case of disability, however, we often encounter surprise, including in progressive circles, at the fact that disabled people may well constitute the single largest minority on earth after women[2] (WHO and World Bank 2010). This occurs notwithstanding the fact that, when asked, most people "discover" that they have an experience of disability in their families or

close networks. Surprise at how prevalent disability is, is not a chance thing. On the contrary, part of the work of disablism and exclusion globally is to make disability invisible (Swartz and Bantjes 2016; Watermeyer 2013). As just one example of the pervasive drive to conceal, consider the fact that, until as late as the 1970s, parts of the US maintained "ugly laws" designed to keep disabled people, and other "unsightly" individuals, off the streets (Schweik 2009).

This book grew out of a programme of public engagement run by ourselves and some colleagues, with the generous funding support of the National Research Foundation, South Africa. As South Africans who have lived through the apartheid era and the transition to democracy, we were (and are) committed to contributing to the formation and maintenance of a more open and fair society. In 2006, ten years after the adoption of South Africa's Constitution—a Constitution which explicitly mentions disability rights[3]—the three of us contributed to a book which located disability inclusion in our country within broader struggles for securing citizenship rights (Watermeyer et al. 2006). Despite publicity around the book, including a launch event at South Africa's Constitutional Court, we were concerned that public events surrounding disability tended to attract the same audience—people already mobilised regarding disability issues, including disability activists. If the project of realising the citizenship rights of disabled people was to gain traction, we believed, it was important for us to get out of what amounted to an echo chamber of like-minded people. We had to begin engaging earnestly with civil society organisations in the broad sense, as well as with government directly. With this in mind, we arranged a series of public debates, each focussing on key issues of concern to all living in our young democracy. Representatives were invited from civil society organisations which were, and were not, explicitly concerned with disability, as well as delegates from local and national government and interested members of the community. Topic areas included transport, education, media access, sport and physical activity, health, and the legal system, along with many others. The twist to these engagements was that we asked speakers and participants to think through what these issues meant in the lives of disabled people and what disability could teach regarding these development challenges broadly. In keeping with MacLachlan, Mannan and McAuliffe (2011) in their work on disability as an indicator of equity in health systems, we believed that putting disability at the centre of discussions concerning equity in the lives of everyone would help people think not only about disability but about questions of inclusion in all areas of community and civic life. In a sense, we were taking a universal design (Hamraie 2017) approach in order to strategically infuse disability concerns into debates and activism regarding citizenship.

We received positive responses to the series of public meetings. In particular, we noted participants who commented that they had hardly thought about disability before but now saw its central relevance to broad democratic concerns and vice versa. Putting together a book based on the public engagement process was the logical next step, and some of the chapters in this volume began as talks in the initial series. As we developed the book, though, it morphed and expanded

into a work some way beyond where we started. Although many of our authors are South African, and many of the examples are from our own country, our concern became much broader. We have enlarged the scope of the book to the broader Global South, and these pages include contributions from many parts of the world.

Part I of this book engages with key cross-cutting concerns regarding disability and citizenship in the Global South. To begin, Soldatic introduces the notion of "surplusisity", thereby locating the discussion of citizenship within the global economy and the politics of labour and exploitation. She highlights the nebulous, if not precarious, position of disabled people within neoliberal discourses of economic participation, where the promise of inclusion brings with it interpellation. Next, through her discussion of Kazuo Ishiguro's novel *Never Let Me Go*, Garland-Thomson raises important questions about what it takes to create a world in which there is a place for all to live, a place where physical and social environments act as drivers of flourishing rather than as barriers. The novel's inversions of normate and disabled status bring into stark relief the contradictions inherent in normative ideas about citizenship, such as the "good life" being defined by health, vigour, and attractiveness. Picking up on this issue, Friedman locates disability struggles within broader concerns about how society and the economy is organised. As a political scientist who is new to the field of disability, Friedman provides a clear-eyed analysis of the obstacles to full citizenship faced by disabled people and ways in which these are held in common with other groups such as slum dwellers in India or shack dwellers in South Africa. Subsequent to this, Swartz places the concerns of the book within the context of a contemporary global challenge—the question of how to claim citizenship rights and entitlements in the "post-truth" era of Donald Trump. Developments in the most powerful country on Earth have profound ramifications for those living far away from it, in circumstances probably unimaginable to Trump and his allies. By contrast, Watermeyer uses his own local experience as a white disabled person in a highly racialised country, South Africa, to ask much broader questions about identity politics, paradoxical aspects of intersectionality, and claims to citizenship rights. At issue is the question of how to figure disability disadvantage in a society where colonial and post-colonial racial capitalism continues to structure the very foundations of exchange. Görgens and Ziervogel add to the changing perspectives by examining the use of resilience thinking in addressing complex development challenges emanating from urbanisation, displacement, and climate change, with special emphasis on vulnerable groups, and the idea of "no one left behind". Their analysis demonstrates both the potentials and weaknesses of global development discourses in attending to diverse local problems.

Part II is composed of contributions dealing with networks and contexts of disability in the Global South. First, Kahonde and McKenzie discuss the crucial, yet poorly understood, role of families in supporting people with intellectual disabilities. Their focus is on how family caregivers respond to the sexuality of

their intellectually disabled relative, in ways which may promote or limit flourishing. Then, Horton and Shakespeare invert the common stereotype of disability as abjection by exploring how disabled people in a number of very challenging African contexts find ways to access education and livelihoods. Their innovative study suggests questions regarding psychological aspects of resilience, as success occurs in very divergent ways in different contexts—what may be an overwhelming obstacle in one circumstance may appear as a spur to action in another. Wood, Essop, Watermeyer, and McKenzie provide a case study of how it is possible under very trying circumstances to make progress in realising the citizenship rights of vulnerable people in a young democracy. This narrative underlines how obtaining a judicial directive for service provision by the state can function as the beginning point of collaboration between government and civil society in building inclusive structures. Finally for this section, Claassens, Shaikh, and Swartz address an issue which is elemental to the experiences of millions of disabled people in the Global South but one which is commonly overlooked in policy documents and processes—the issue of faith and religion.

Part III imagines what an inclusive society should look like and explores potentials for change. Watermeyer and Goggin suggest that the optimism around the potential of new digital technologies to change lives of vulnerable populations may need to be tempered by a clearer understanding of the stubbornness of exclusion. Appropriate, inclusive training and product support for disabled users of digital devices must be shown specific, rigorous attention if the potential of digital connectivity for promoting citizenship is to be realised. Similarly, while Behrens and Görgens note the achievements in South Africa regarding accessible transport, they also show how much remains to be done in this regard in the Global South. The lack of accessible, affordable public transport in many Global South countries is often the backbone of physical exclusion, with international development policy failing to appreciate the challenges of urban settings where both formal and informal service providers are not only present but also essential. Howe tackles an issue of international interest—the question of the extent to which an event which presents itself as increasing inclusion for disabled people globally (the Paralympics) is in fact able to deliver on this aspirational promise. His analysis is incisive and sober, asking difficult questions about what inclusion and development are and are not. Following this, Goodley, Lawthom, Liddiard, and Runswick-Cole suggest that part of what drives exclusion, and keeps it entrenched, is the way in which we think of disability, challenging us to develop a new conceptual toolkit for disability-related work globally. Hunt, le Roux, and Watermeyer explore the potential of theatre and public performance to create a more inclusive society, noting that one of the key challenges for transforming representations and participation is that every attempt at change cannot help but draw on and, to an extent, reproduce old tropes. In a similar vein, Lorenzo and Coleridge explore the complexities of alliance-building to create networks of support for disabled people, using examples from a range of contexts.

Part IV explores ecologies of exclusion and suggests how we might disrupt, and drive change in, these ecologies. Peta and McKenzie show how for disabled women in Zimbabwe sexuality and sexual agency are denied and how this dehumanisation interacts with other forms of exclusion in an oppressive society. Their analysis brings important evidence of how uncritical application of human rights discourse can serve to embed patriarchal and racial discourses. Thereafter, Capri shows the many ways in which the personhood of people with intellectual disability is often not recognised in institutional contexts, exploring how those contexts "unmake" personhood. Using an ethics of care framework, she vividly demonstrates the immense power and ubiquity of forces of exclusion in the lives of intellectually disabled South Africans. Galery, Alves, Grein, and Watermeyer, taking Brazil as an example, examine by means of an historical account how vicissitudes in the national legal and political context relate to actual exclusion on the ground, tracking the benefits and false promises of political rhetoric. Dickman, by contrast, documents an example of how professionals with an emancipatory activist agenda can make inroads into what may appear an impenetrable legal system, as she explores the resource of citizenship rights in the lives of rape and sexual assault survivors with intellectual disability. McConkey continues the theme by exploring the global imperative for citizenship rights for intellectually disabled people. Next, Roulstone's contribution takes us from the question of exclusion to the even more troubling issue of overt violence against people on the basis of disability, reminding us that social prejudices and biases can have catastrophic embodied consequences. Tarusarira and McKenzie close the volume by exploring a key contemporary issue for the ecology of disability, mentioned earlier in this introduction—the issue of citizenship rights in the context of migration.

The book offers a diversity of stories, approaches, and perspectives, and we have seen our roles as editors as one of not imposing our own biases on our authors. We hope that readers are stimulated to grapple with this array of complex and challenging issues not just through reading the chapters, but also through considering the spaces, contradictions, and unevennesses between them. An important part of this book's contribution to considerations of disability and citizenship in the Global South comes from contestations and areas of disagreement with our authors and ourselves. We welcome this contestation for at least two reasons. First, as a general principle, we believe that debate and disagreement are essential in any discipline and in activist scholarship in particular. In disability studies, because of the importance of solidarity, there have on occasion been tendencies to disallow debate or to make the discussion of certain aspects of the disability phenomenon beyond the pale. We understand the activist roots of calls to academic and intellectual solidarity. But we also believe that the key and distinctive contribution that scholars can make to disability politics, the contribution which distinguishes them from some other activists, rests in their commitment to the role of debate and contestation in taking the field forward. Debate, contestation, and the vigorous exchange of

perspectives are more important than ever in a post-truth era, which though ostensibly ushering in an "anything-goes" approach to the truth actually embodies the reproduction of totalitarian ideas. This is no time to tell people what to say and how to think. It is a time when debate and disagreement must be enacted and celebrated. Our second reason for welcoming debate is rather more local to the intellectual history of this book. We are in the early days of discussions about disability and citizenship in the Global South. If, as the field develops, there are not better and more sophisticated analyses than those presented in this book, we have failed in our task.

As with any book of this nature, there are important gaps. Given where we are positioned, we are proud that all the editors and many of the contributors are in the Global South. This in itself represents a major inversion in the politics of knowledge. But also, because we are where we are, there is a bias in the book towards Southern African examples. While we believe the examples are of relevance, for example, to Asian and South American contexts, we do not want to make the same mistake made by many in the Global North—the belief that what is said in a particular context must be of universal import. We look forward to debate and discussion on this issue. We want to hear where our examples resonate and where they feel wrong or contextually inappropriate. Just as we have a geographical bias in the book, we also have chosen to focus on certain topic areas and not others. As anyone who has edited a book of this nature will know, securing contributions is a matter of activating networks and doing the best one can to cover a large field. We have tried to be comprehensive but, inevitably, there are important areas of concern which have fallen through the cracks. We acknowledge that there may be issues we have overlooked of which we are not aware, as well as those where we would have liked to have been more comprehensive. For example, we would have chosen to include more on climate issues, on disasters, on psychosocial disability and neurodiversity, on LGBTQI issues, on human trafficking and sex work, on employment, and on lifestyle and physical activity. In addition, we would have liked to showcase more theoretical work on the concepts of citizenship and disability, debates surrounding intersectionality, questions about what decolonisation is and is not, and the politics of language and the language of politics. This said, we are very grateful to our authors, each of whom worked hard to make this book a reality, and we hope the volume as a whole honours each individual contribution.

This book would not have been possible without the support of our families, colleagues, and friends, too numerous to mention but all deserving of thanks. We received wonderfully high quality technical support from Jacqueline Gamble, Xanthe Hunt, and Megan Moll. Each of these colleagues gave her considerable skills and talents, but perhaps more importantly, each displayed generous humour and patience with editors who were difficult, driven, capricious, and demanding.

We are honoured that this volume is part of the Palgrave Studies in Disability and International Development series, and we thank the series editors, Shaun

Grech, Nora Groce and Sophie Mitra, both for their faith in us and our work and for their ongoing support. We also thank Katelyn Zingg and everyone at Palgrave for their technical help.

Finally, we thank the readers of this volume for your attention and, we hope, for your contestation and debate.

Notes

1. As editors of this book, we choose to use the term "disabled people" in line with the view of the social model of disability that people with impairments are disabled by society. We recognise, however, the arguments in favour of the "people first" terminology "people with disabilities". We have allowed authors in this volume to follow their own preferred usage.
2. There are in fact more men than women on Earth; we use "minority" here in the sense of a group having less political power than the more powerful or "majority" group.
3. See https://www.gov.za/documents/constitution-republic-south-africa-1996

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PART I

Theorizing Citizenship and Diversity in the Global South

CHAPTER 2

Surplusisity: Neoliberalism and Disability and Precarity

Karen Soldatic

Thoughts on Neoliberalism: Personal Prologue

9/11. 11/9. Maybe 11 September? What about 11th of September? Year, do you know the year: 2001. No, that's not right. It was another year. Yes, I now remember, 1973. 11 September 1973. That's the 9/11 I'm searching for. Not 9/11 2001. It seems a long way in the distance now, some 45 years ago. A global event of mammoth proportions, yet I have amnesia to its meaning. It's significant, right? It changed everything – well, maybe lots of things? But when I think of 9/11 I now often think of 2001 – the day of the planes, the day that the towers fell, bodies and rubble scattering the surrounding earth. The 9/11 where we were told that our citizenship is under threat, our freedoms; freedoms that we must curtail to curtail further violence. Violence of a particular kind, that is… 9/11. A crisis of democracy.

Then there is 2007 and 2008. Remember those? According to the Guardian there are five dates: 9 August 2007. 15 September 2008. 2 April 2009. 9 May 2010. 5 August 2011. These are dates of that other kind of crisis – financial crisis. These are dates that offered legitimacy to ideas of retraction. Retract, contain, withdraw. But maybe this was already happening? Maybe it was just an extension of before? Maybe these dates gave only continued justification to keep going with a particular economic plan? For whom did these dates have meaning? Numbers, the quoting of numbers, with affect, statistics that drive panic, spur on action, propelling bodies, minds and souls to new surfaces, new practices. Experienced differentially, different spaces, different movement and mobilities. A financial crisis.

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B. Watermeyer et al. (eds.), *The Palgrave Handbook of Disability and Citizenship in the Global South*,
https://doi.org/10.1007/978-3-319-74675-3_2

2017. Oxfam says eight people own as much as the globe's poorest 3.6 billion. Isn't that half the world's people? Who are they? Where do they live? What are we doing to stop this, change this – do something, please. Is that really right? Where does that number come from? Too many people with not nearly enough and a select few with way too much. A crisis of people.

Numerical chatter. The chatter of numbers. Numbers that are markers of new forms of economic life, economic divides, lives of precarity. Numbers, appearing spurious – distant from our own numerical existence – embodied in everyday materialities. Materialities of lack, deprivation and distributional reordering with deep embodied effects.

The dates stated above are central to neoliberalism and its movement from a nascent political experiment to its normalisation as an authoritative ideological politics of global governing, a political economic doctrine with particular tendencies. By 2017, these nascent forms of disruption are publicly embedded through fiscal discourses of debt, crises and the necessity for budgetary surplus in everyday life, despite our own personal indebtedness via household debt. Neoliberalism exists as the ideational, ideological and financial murmurings of everyday life, increasingly ingrained via political consensus.

Neoliberalism: An Introduction

This chattering of numbers, posed as dates, when cluttered together tends to erase particular memories—memories of historical moments that have altered times, places and our very subjectivities. The numbers bring with them new forms of embodiment, coupled with nascent economic realities. 9/11 has multiple meanings, unevenly spaced, that are not mere temporal flows, rhythms and movements but represent global disparities of power—disparities of affect, stigmatisation and growing inequality, new forms of debility and disability. All are numbers that represent the core concern of this chapter, what is commonly known as neoliberalism. Neoliberalism is often described as a system of governance, a system of economic reordering that legitimises new forms of capitalist maldistribution from the poor to the rich, coupled with an ideological mapping that trumps the individual over collective concerns of the good, the just, inequality, poverty and deprivation.

11 September 1973, Harvey (2005) suggests, is the date that symbolises the emergence of neoliberalism as a global economic doctrine. In terms of tracking back to a key historical moment, that is, the beginnings of neoliberalism as a real, material and ideological political possibility, 11 September 1973 represents the moment of breaking with the old world order. It was an order established at the end of World War II (WWII) among Western powers, to impose new forms of global economic power under the tensions of Cold War (communist/capitalist) politics. The WWII political economic consensus, commonly referred to as the Bretton Woods consensus (1944), established Keynesian economic realities: strong state social investment and redistributive mechanisms via the welfare system; building of national economies through military spending and expansion and a global economic management system