STOP!

The Routledge Handbook of Disability Activism

Edited by Maria Berghs, Tsitsi Chataika,
Yahya El-Lahib and Kudakwashe Dube

THE ROUTLEDGE HANDBOOK
OF DISABILITY ACTIVISM

The onslaught of neoliberalism, austerity measures and cuts, impact of climate change, protracted conflicts and ongoing refugee crisis, rise of far right and populist movements have all negatively impacted on disability. Yet, disabled people and their allies are fighting back and we urgently need to understand how, where and what they are doing, what they feel their challenges are and what their future needs will be.

This comprehensive handbook emphasizes the importance of everyday disability activism and how activists across the world bring together a wide range of activism tactics and strategies. It also challenges the activist movements, transnational and emancipatory politics, as well as providing future directions for disability activism.

With contributions from senior and emerging disability activists, academics, students and practitioners from around the globe, this handbook covers the following broad themes:

- Contextualising disability activism in global activism
- Neoliberalism and austerity in the global North
- Rights, embodied resistance and disability activism
- Belonging, identity and values: how to create diverse coalitions for rights
- Reclaiming social positions, places and spaces
- Social media, support and activism
- Campus activism in higher education
- Inclusive pedagogies, evidence and activist practices
- Enabling human rights and policy
- Challenges facing disability activism

The Routledge Handbook of Disability Activism provides disability activists, students, academics, practitioners, development partners and policy makers with an authoritative framework for disability activism.

Maria Berghs is an anthropologist with a PhD in sociology and social policy. She works in the field of medical anthropology and sociology, specialising in disability studies. Her research interests include disability, global health (sickle cell), humanitarianism, ethics, gender and West Africa (Sierra Leone).

Tsitsi Chataika is the Chairperson and a Senior Lecturer in disability and inclusive education in the Department of Educational Foundations, University of Zimbabwe. Her recent publication is *The Routledge Handbook of Disability in Southern Africa*.

Yahya El-Lahib is a long-time disability activist and Assistant Professor at the Faculty of Social Work, University of Calgary. His research focuses on the intersection of disability and displacement as interlocking systems of oppression that continue to shape the marginalization experiences of people with disabilities within and outside state borders.

Kudakwashe Dube is the Chief Executive Officer (CEO) of the Africa Disability Alliance and has over 30 years of experience designing, managing, evaluating and monitoring development and disability programmes with international and grassroots movements. He is also Chair of Trustees of ADD International that fights for independence, equality and opportunities for disabled people living in poverty, alongside organisations of disabled people.

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This book is dedicated to the people who have gone before us; who set the foundations for disability rights, those who are fighting now to ensure continued justice, equality and equity; and to those who come after us who with more sharpened advocacy and lobbying skills will build a more inclusive world.

In memory of
Shamiso Michelle Dube (29.12.2000–28.03.2002)
'It's just a world where all things come and go,
It's just a world where all things come and go,
Don't you cry, don't despair;
I went – it was my time to go.'

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CONTRIBUTORS

Heather Allan identifies herself as a unique-abilities person with a love for life. Heather has spoken at many events about Williams Syndrome. Heather is a co-researcher with the *Partnering for Change Research Project*, a multi-city, multi-year research project in Ontario, Canada exploring the intersections and pathways through homelessness, education, and employment services for youth labelled with intellectual and developmental disabilities. She hopes to use her sympathetic nature to help other people.

Donavon O'Neil Allen is a former ward of the child welfare system. He is a founding member of the Voyager Project and thinks of himself as the 'glue' that bridges the different generations of Voyagers together. He is also a co-researcher with the *Partnering for Change Research Project*. He is interested in finding solutions to address the complex and multitude of problems facing homeless youth with learning, developmental or mental disabilities.

Christine Austin is an advocate for the intimate rights of disabled mothers. In 2002, she received the Cindy Niemi award for her work on disability issues and access to post-secondary education. Having been interviewed by the media, she has also made numerous presentations on women, disability and abuse. She brought this knowledge to her work as a co-researcher with the *Re-imagining Parenting Possibilities Project*. She is actively involved in sharing this work through conference and community presentations and forum theatre workshops.

Khairani Barokka is a writer, poet and artist, whose work has been presented extensively in 15 countries. She is Modern Poetry in Translation's Inaugural Poet-in-Residence. Among her honours, she was an NYU Tisch Departmental Fellow and Vermont Studio Center's first Indonesian writer-in-residence, and is a UNFPA Indonesian Young Leader Driving Social Change for arts practice and research. She is co-editor of *Stairs and Whispers: D/deaf and Disabled Poets Write Back* (Nine Arches), author-illustrator of *Indigenous Species* (Tilted Axis), and author of *Rope* (Nine Arches Press). Recent exhibitions were at SALTS Basel and the ICA in London. She is a PhD candidate in Goldsmiths' Visual Cultures Department.

Maria Berghs is a Lecturer at De Montfort University in the UK. She works in the field of medical anthropology and sociology, specialising in disability studies. Her current research projects are on sickle cell in Sierra Leone and the UK.

Pamela Block is a Professor of Disability Studies, focusing on health promotion, community-building and capacity-building for autistic and disabled people and groups. She teaches in the doctoral program in Health and Rehabilitation Sciences and is Director of the Graduate Certificate in Disability Studies. Her recent book Occupying Disability is a co-edited volume exploring concepts of 'occupying' and 'decolonizing' disability across the fields of disability studies, anthropology and applied health fields such as occupational therapy. She is a former President of the Society for Disability Studies (2009–2010), and a Fellow of the Society for Applied Anthropology.

Margaret Campbell's research examines intersections of disability, gender, and sexuality by exploring the varied ways that people with disabilities experience their gender and sexuality. As an individual who lives with a chronic illness, work and identity often collide as she pursues various research interests such as the sociology of the body, disability studies, and the sociology of gender and sexuality. Margaret has taught courses on the Sociology of Disability at Mount Allison University and the Sociology of Gender at Concordia University. Margaret is currently completing her PhD in Social and Cultural Analysis at Concordia University.

Tsitsi Chataika is the Chairperson of the Department of Educational Foundations and also a senior lecturer in disability and inclusive education at the University of Zimbabwe. Her research interests allow her to understand how disability intersects with education, work, gender, culture, religion, childhood studies, development and postcolonialism. Chataika has several publications and her most recent edited book is the '*The Routledge Handbook of Disability in Southern Africa'*. She was She has presented at various national and international platforms; and facilitates workshops on inclusive development and inclusive education in Africa; thus promoting inclusive sustainable development with implications for policy and practice.

Anna Chowaniec-Rylke is a PhD student of anthropology at the University of Warsaw. Her main areas of interests are rare and genetic disorders, which are the topic of her doctoral thesis. She was an assistant researcher in two projects financed by the Polish National Science Center and her articles were published in Polish anthropological journals. She also wrote a book chapter on children, health and childhood studies. She has presented her work at various international conferences.

Sam Cleasby is a writer, blogger and radio presenter from Sheffield and works for disability charity, Scope. She has a chronic illness and a permanent ileostomy and is passionate about raising awareness and supporting disabled people. She is a mum of three teenagers and can be found on her award-winning blog, So Bad Ass Me, breaking the taboos around poo and sharing her experiences of life with an ostomy bag.

Stephanie J. Cork received her PhD in Kinesiology (Physical Cultural Studies) from the School of Public Health at the University of Maryland, College Park. Prior to moving to the United States, Stephanie completed her Bachelor's (Honours) and Master's in Sociology at Queen's University in Kingston, Ontario. Her research focuses on diversity, inclusion, equity and justice with a special interest in supporting the disability community within higher education. Stephanie is extremely involved with service and teaching at her current institution and has worked with many campuses entities on large scale projects such as Disability Awareness Month, the Disability Studies Minor, The UMD Disability Summit, and the Student Facilities Fund: Lactation Room Improvement Project.

Liz Crow is a British disabled woman and long-time activist and artist. She is a doctoral candidate at University of West of England, undertaking practice-led research into methodologies of activism. Liz is also mother to a teenager who has recently become a disabled person.

Erin Davenport is a graduate student at UNC–Chapel Hill. She graduated from Davidson College with a B.A. in Political Science in May, where she was Editor-in-chief of the Davidson student newspaper, a Leadership Fellow, and a passionate advocate for minority rights on campus and beyond. Erin is interested in the intersections between academia, arts, and activism, which she explored through an installation art project, *Rainclamation*. The project allowed Erin to travel and present at many conferences, including two in Europe, and caused her to realize a passion for sociology, which she is now pursuing in graduate school.

Pragya Deora is a 2018 Batch Indian Information Service Officer currently undergoing training. She did Bachelor of Commerce from University of Delhi and M. A. and MPhil in Sociology from Jawaharlal Nehru University. She has worked and delivered talks on a range of issues confronting persons with disabilities. She has been a part of organising team of various conferences on disability. She was also the first woman convenor of JNU Visually Challenged Students' Forum. Pragya was a part of Anubhav Lecture Series organised by the Harris School of Public Policy at University of Chicago for capacity development of individuals working at grassroots in India. Social entrepreneurship is one of Pragya's key interests and she believes in finding sustainable solutions to social problems.

Beth Douthirt-Cohen is currently the Executive Director of Diversity, Equity and Inclusion at Frederick Community College, where she leads and supports efforts to strengthen inclusion throughout the College. Previously, she was the Deputy Chief Diversity Officer at the University of Maryland (UMD) where she directed various prejudice reduction efforts and educational initiatives to further social justice, including UMD's Intergroup Dialogue programme. A person with a disability, Beth is part of the Calico Hill Collective, a group of social justice educators seeking to further racial, disability, gender, LGBTQIA, class, religious, and immigrant justice, healing and processes of truth and reconciliation across all dimensions and intersections of oppression. Beth has her undergraduate degree in from Barnard College of Columbia University, her M.Ed. from Harvard University, and her PhD from UMD.

Kudakwashe Dube is the Chief Executive Officer (CEO) of the Africa Disability Alliance and has over 30 years of experience designing, managing, evaluating and monitoring development and disability programmes with international and grassroots movements. He is also chair of trustees of ADD International that fights for independence, equality and opportunities for disabled people living in poverty, alongside organisations of disabled people.

Nqobani Dube has a Master of Arts in development and human rights from Swansea University. His thesis focused on land reforms and livelihoods of people with disabilities in Africa. In the past 12 years, he has extensively worked in different roles around southern Africa for various disability organisations and the Government of Zimbabwe. This strengthened further his research and work, which revolves around the intersections of disability inclusion with development and humanitarian interventions. Nqobani remains interested in representations of disability rights activism in popular culture and radical pedagogy.

Kareem Elbard works in various capacities, promoting awareness about disability and intimacy issues and supporting others labelled/with intellectual disabilities. He presented at an international conference on Disability and Diversity in Rome (2008). His presentation highlighted how supports, societal and institutional discrimination, form his possibilities as a disabled man in relation to employment, intimacy and health. As a co-researcher with the *Re-imagining Parenting Possibilities Project,* he interviewed key informants and people with lived experience of parenting and intimacy stories to share across Ontario; and participated in the development of forum theatre scenes as a means of sharing lessons learnt.

Willem Elbers is senior research fellow at the African Studies Centre at Leiden University (Netherlands) since 2015, where he heads two research projects on advocacy in the global South. While one of these projects examines advocacy strategies targeting the rights of children with disabilities in Sierra Leone, Cameroon and Zambia, the other focuses on the role of international agencies in enabling and constraining local advocacy on the ground. Willen is also the coordinator of the Advanced Master in International Development, a post-graduate programme seeking to enable excellent MA-graduates to pursue a career in the field of international development.

Yahya El-Lahib is an assistant professor at Calgary University in Canada. As a disability activist, Yahya's research, practice and policy background is centred on working on disability issues at all levels of intervention; from frontline work with individuals and families, to community practice, policy development, and research on a variety of issues. These include education, employment, poverty, political and civic engagement, and the impact of war. Yahya is closely affiliated with the disability movement in Lebanon, working from a grassroots social justice approach, which has informed his community involvement, teaching and research in Canada, a critical transnational dimension to social work.

Emma Frobisher is a Junior Researcher and a doctoral fellow at the African Studies Centre at Leiden University. She holds a Master's degree in Development, with a major in Social Policy for Development, from the International Institute of Social Studies of Erasmus University Rotterdam, from where she graduated in December 2016. She has also worked in various NGO roles in the UK, Peru and Malaysia.

Ann Fudge Schormans is an Associate Professor in the School of Social Work at McMaster University (Ontario, Canada). She was a practicing social work for many years, working with people with intellectual disabilities in the Community Living and Child Welfare sectors. This practice background, combined with ongoing activist work and her experiences parenting her daughters with intellectual disabilities influence her teaching and research. She uses inclusive, co-researcher methodologies in her research work, along with arts-informed methods (such as forum theatre, documentary film-making, photography, and mapping). Much of this research has focused on issues that co-researchers with intellectual disabilities who have worked with her have identified as needing attention.

Marco Antonio Gavério is a social scientist, sociologist, and Ph.D. student at the Graduate Program in Sociology, at the Federal University of São Carlos in São Carlos, Brazil. Researcher of the SexEnt: Body, Sexuality and Entertainment, at UFSCar. Gaverio's studies was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES).

Rasa Geniene is a PhD Candidate of the Social Work and Social Welfare Department, Faculty of Philosophy, Vilnius University, focusing on the deinstitutionalisation of residential care and the development of community-based services for people with mental/intellectual disabilities. Before, she worked for a non-governmental organisation, which initiated piloting and development of good practices of community service models. Currently, Rasa is working in the Ministry of Social Security and Labor of the Republic of Lithuania, where she explores and operates the issues of transition from institutional care to family and community services for people with disabilities which has a direct link with her dissertation.

Violeta Gevorgieniene is Associate Professor in the Department of Social Work and Social Welfare, Faculty of Philosophy, Vilnius University since 2000. She has a background of educational sciences and social work and is an expert on disability issues. In 2009, she was elected as the member of the Executive Committee of the European Association of Schools of Social Work and served in this position up to 2017. She has authored over 20 scientific publications and learning materials for persons with disabilities. Her research interests also include competences of social work, social work education, socio-cultural identity and migration.

Melissa Graham is the founder and one of the key organizers for the Toronto Disability Pride March. Melissa is a social worker and community activist involved in disability issues throughout Ontario, including her position as Vice-President of Citizens with Disabilities Ontario. She is also a recipient of an Ontario Volunteer Service Award for 2018. She has previously written about disability issues in national publications such as *The Monitor* and *Our Times Magazine,* as well as on her blog, 'Sit Down, Fight Back'.

Nathan Gray is a member of the Voyager project, which aims to improve the educational attainment of crown wards by encouraging young people in care to pursue their educational aspiration. He was also involved in directing a peer mentoring video. He is a rhythm and blues (RnB) singer. He is a co-researcher with the *Partnering for Change Research Project.* He hopes the knowledge generated from this research on the systemic barriers faced by homeless young people with learning, developmental or mental disabilities will reach a wider audience and inform change in policy and practices that serve this population.

Maria Grazia Gargiulo is Ph.D. in Environmental Education and Sustainable Development and Expert in Disability Pedagogy and Social Model of Disability at the Suor Orsola Benincasa University of Naples in Italy.

Miro Griffiths has a PhD and teaches at the University of Leeds, he is active within disability rights and is a member of various local, national and international advisory boards, including In Control, British Council and the European Network on Independent Living. His particular interests are: the concept of Independent Living, community development and youth participation in decision-making processes.

Anahi Guedes de Mello is a social scientist, anthropologist, and Ph.D. student at the Graduate Program in Social Anthropology, at the Federal University of Santa Catarina (UFSC), in Florianópolis, Brazil. She is a researcher of the Nucleus of Gender Identities and Subjectivities, at the UFSC's Department of Anthropology, and of the Nucleus of Disability Studies, at the UFSC's Department of Psychology. She is also an associate researcher at Anis – Institute of Bioethics, in Brasília, Brazil.

Damian Haslett is a Doctoral Researcher at Durham University, UK. His research focuses on the intersection of disability rights and disability sport. Damian is a full member of the Division of Sport, Exercise and Performance Psychology in the Psychological Society of Ireland, and he serves on executive committee of Irish Wheelchair Association Sport.

Kevin John Head is a self-advocate who recognises the importance of educating non-disabled people in order to work towards change. As a co-researcher with the *My Life in the City Research Project,* an arts- and technology-informed qualitative study looking at of how people labelled/with intellectual disabilities use and give meaning to their experiences of public city space, Kevin is very involved in sharing information about the research with a variety of audiences, in many different ways. He is particularly proud of the documentary the co-researchers have made, and is now actively involved in the creation of the project website.

Tyler Henderson is a co-researcher with the *Partnering for Change Research Project*. He is an active member on many Hamilton (Canada) Councils. He actively engages in public speaking and workshops for youth audiences. Having faced adversity in his own life around issues of mental health and addiction, he is committed to supporting other youth in similar situations and give back to the community. To fulfill this commitment, he recently started in a Bachelor of Social Work programme.

Sylette Henry–Buckmire has a PhD in Health and Rehabilitation Sciences, Disability Studies track from Stony Brook University. Her study is a feminist, ethnographic practice that takes a historicised look at disability formation, and is committed to disability, mobility and occupational justice. It creates a space to discover a deeper, more textured understanding of how people move and occupy with physical disabilities. Sylette's research interests include disability studies, mobilities studies, occupational therapy, Caribbean studies, and feminist, postcolonial, and critical race theory.

Kelly M. Hoffman is a doctoral candidate at the College of Information Studies at the University of Maryland. She earned an M.L.S. from the University of Maryland in 2007 and worked as a systems librarian and knowledge manager before returning. Her research interests include algorithmic literacy information personalization. Kelly's thesis focuses on public librarians' awareness and perceptions of the role algorithms play in information access. She has helped coordinate several conferences that bring together researchers, practitioners, and communities around issues of common interest.

Karrissa Horan–LaRoche is a co-researcher with the *Partnering for Change Research Project*. She is currently on the Social Planning Research Council Street Youth Planning Collaborative Youth Leader's Committee (Hamilton, Canada) whose goal is to improve the system that supports homeless youth. She is also working with a team of individuals to identify barriers in access to services that help youth find employment and find solutions to break down those barriers. She enjoys helping people and wants to enable equal opportunities for all people. Her future goal is to become a Child and Youth Worker in residential housing.

Rainbow Hunt is recognised as a trans-activist and a person labeled/with an intellectual disability working to help bring awareness to the discrimination and isolation that trans and disabled people face. Rainbow is an experienced co-researcher with the *Re-imagining*

and disabled people face. Rainbow is an experienced co-researcher with the *Re-imagining Parenting Possibilities Project* presenting in conferences, academic settings and to community organizations. Rainbow draws on personal experiences of intimacy and intimacy rights in her work as a peer facilitator, delivering workshops across southern Ontario on sexuality and disability. She coordinates events for isolated youths to network and learn about community resources.

Paul T. Jaeger is Professor, Diversity & Inclusion Officer, and Director of the Master of Library and Information Science programme of the College of Information Studies, as well as Co-Director of the Information Policy and Access Center at the University of Maryland. He is the author of more than one hundred and eighty journal articles and book chapters, along with seventeen books. Paul's research has been funded by the Institute of Museum & Library Services, the National Science Foundation, the American Library Association, the Smithsonian Institute, and the Bill & Melinda Gates Foundation, among others.

Charlotte Jones is a Postdoctoral Research Fellow at the University of Exeter's Wellcome Centre for Cultures and Environments of Health. Her work responds to conversations within feminist theory, queer theory and critical disability studies. She was awarded her doctorate on intersex people's experiences of relationships, intimacy and prejudice by the Department of Sociological Studies, University of Sheffield in 2017. Charlotte previously worked on sexual violence and disclosure in Higher Education settings, community activism and advocacy for HIV pre-exposure prophylaxis, and as Research Fellow on Around the Toilet, a project about the public toilet as a location of exclusion and belonging for queer, trans and disabled people.

Gill Kemp's career has spanned education, law and the media. She has been involved with various charities and campaigns and is the founder of Public Toilets UK. She is also a co-founder of the Toilet Consortium UK. While giving evidence on the effects of public toilets closures to Government committees, Gill also worked with various official organisations to produce booklets on topics such as reducing vandalism in toilets and access to facilities for lorry drivers. She has also written handouts on health issues that affect UK lorry drivers. Gill has several publications she was a participant in the innovative Around the Toilet project based in Sheffield.

Rados Keravica is working for the United Nations Human Rights Team in Serbia as a human rights project associate, where he coordinates the joint United Nations project on the rights of persons with disabilities, autonomy, voice and participation of persons with disabilities in Serbia with the focus on legal capacity regime reform, empowerment of women and girls with disabilities and development of innovative models of employment of persons with disabilities. From 2011–2016, he worked for Disability Rights Promotion International as a Regional Officer for Europe. He is a Board Member of the European Network on Independent Living (ENIL) and the President of the ENIL Youth Network.

Brian LeBlanc grew up in New Orleans, LA and has lived in the Gulf Coast area since then. He found his niche in the professional world as a Marketing and Public Relations Executive. All that changed in October of 2014 when he was diagnosed with Early-Onset Alzheimer's Disease. He made a career by using his voice, he knew what he HAD to do… so he talked about it. He now spends his time as an International Alzheimer's advocate,

keynote speaker and session presenter at inter/national and local conferences, seminars and workshops. He is also a Crisis Intervention Team Trainer for Law Enforcement.

Lars Lindberg is an activist in the Swedish disability movement and an independent consultant. His work centres on human rights, disability policy and activism. Lars Lindberg is former Deputy Director at the Ministry of Health and Social Affairs in Sweden and worked with Disability Policy Coordination in the Government Office.

Eleanor Lisney is a campaigner, founder member, public speaker and director of Sisters of Frida, a disabled women's collective. She is an access advisor, an aspiring creative practitioner and co-founder/ director of Culture Access CIC, which is about supporting access (including to toilets and transport), bringing an inclusive edge intersectionally.

Fabrizio Loce–Mandes has a PhD in social anthropology. He has carried out long-term ethnographic fieldwork related to deafness in multiple social spaces, including associations, state institutions, and hospitals, as well as research related to cochlear implants. Currently, he is coordinator of the project *MUSAE – Musei, Uso Sociale e Accessibilità, per contrastare l'Emarginazione* (Museums, social use and accessibility, to contrast marginalization). The project is co-founded by *Fondazione Cassa di Risparmio di Perugia* (Dec 2018–Nov 2020), under the *Insieme per un Welfare di Comunità* grants.

Rex Marchi has a job which he enjoys. He will have a pension when he retires which he is very happy about. Rex has been an active co-researcher with the *My Life in the City Research Project*. The project is important to Rex because it has created opportunities for him to connect with other people and to make new friends. He contributed to the project by sharing his experiences, helping to create the project's artwork, and interviewing people during the making of the project documentary.

Alan Santinele Martino is a Ph.D. candidate in the Department of Sociology at McMaster University. Alan's main areas of interest include critical disability studies, gender, sexualities, contemporary social theory, and qualitative research methods. His dissertation examines the romantic and sexual experiences of adults with intellectual disabilities in Ontario and his 'relationship to disability' comes in the shape of being a loyal and loving brother of a young man with a developmental disability. Alan has been working closely with community organizations and self-advocacy groups for over a decade and is deeply committed to continuing these collaborations.

Abraham Mateta is a lawyer by training and a disability rights activist by calling. He holds among other qualifications, a Bachelor of Law from the University of Zimbabwe and a Masters in International and European Human Rights from the University of Leeds. Mateta has worked in government and the civic society and currently, he is into private practice. He works with various organisations engaging in disability. Mateta is currently the Secretary for the Lawyers with Disabilities Association Zimbabwe Trust, which seeks to advance the rights of disabled lawyers and the rights of all disabled people to get access to justice.

Donna McCormick has been a self-advocate for many years and actively involved in disability activism for people labeled intellectually disabled. She is a founding member of *The PhotoChangers,* a co-researcher group facilitated by Ann Fudge Schormans. As such, Donna has been involved in numerous presentations, exhibits and guest lectures of the group's two

projects: the first being a critical engagement with public photographic images of people labeled/with intellectual disabilities, the second a photo project exploring issues of importance to people labeled with intellectual disabilities, including intimate citizenship, parenting, belonging, and employment.

Hannah McGlade holds qualifications in law and human rights. She is the author of 'Our Greatest Challenge, Aboriginal children and Human Rights' and recipient of the Stanner award. In 2016, she was appointed the Senior Indigenous Fellow of the United Nations Office of the High Commissioner for Human Rights and the Senior Indigenous Research Fellow at Curtin University. A member of the Noongar community, she is a prominent Australian Indigenous human rights and social justice advocate.

Denise McKenna has used mental health services for over 25 years and has been a mental health campaigner for most of this time. She has been involved with Mad Pride, co-founded Mental Health Resistance Network (MHRN) and Four in Ten (an LGBT mental health project), is part of Disabled People Against Cuts (DPAC) and has taken part in direct actions with DPAC and MHRN. She instigated a judicial review against the DWP and has spoken at a wide range of events. She is an artist and art historian.

Wendy Merchant is a British mother-activist, researcher and nurse whose interests include parenting, disability and interactions with health, education and social care professionals. She has worked on various research projects including the 'Getting Things Changed' project at the Norah Fry Centre for Disability Studies at the University of Bristol and her own auto-ethnographic research 'Caring for disabled children in hospital: Mothers and nurses experiences' at the University of the West of England, Bristol. Wendy's experience of activism involves working alongside other mothers, actively contesting the othering of our 'disabled' children, whilst actively resisting those forces that seek to define children less as than human beings.

Peter Mittler was a clinical psychologist and Lecturer in Developmental and Abnormal Psychology, Birkbeck College, University of London (1963–1968); Founding Director Hester Adrian Research Centre for the Study of Learning Processes in the Mentally Handicapped University of Manchester (1968–1992); Professor of Education, Head of School of Education and Dean of the Faculty of Education, University of Manchester (1991–1995). Currently, he is Honorary Research Fellow Division of Nursing, Midwifery and Social Work in the Faculty of Sustainability, Education, Environment and Development, University of Manchester.

Rich Moth is a Senior Lecturer in Social Work in the School of Social Sciences, Liverpool Hope University, UK. Before moving into social work education he worked for 15 years in various roles in the social care sector including as a mental health social worker. He has worked alongside activists from the survivor and disabled people's movements as an ally in a number of mental health, welfare and anti-austerity campaigns. He is a longstanding member of the national steering committee of the Social Work Action Network and an active trade unionist.

Martin Musengi is Associate Professor of Deaf, Special Needs and Inclusive Education at Great Zimbabwe University (for the last 14 years), where he was Chairperson of the Jairos Jiri Centre for Special Needs Education from 2015 to 2018. He is currently the Director of Quality Assurance and Academic Planning. He taught in a special school for the deaf for 15

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Auma Okwany teaches Social Policy for Development at the International Institute of Social Studies of Erasmus University Rotterdam in the Netherlands (ISS-EUR). Her teaching and research interests centre on the relationship between policy, practice and theory for children, girlhood studies, youth and their families in contexts of risk and marginalisation. She is the Lead researcher for Tanzania on the Oak Foundation-funded two-year research project; 'Adolescent Perceptions on Healthy Relationships in Tanzania and Bulgaria.' She is also the Overall Director of the four-year Netherlands Government funded EUR-ISS project, 'Strengthening Education and Training capacity in Sexual and Reproductive Health and Rights in Uganda.'

Nagase Osamu is Eminent Research Professor at the Institute of Ars Vivendi, Ritsumeikan University, Kyoto, Japan, and is a disability studies scholar. His current activities include chair, membership committee and Officer of Inclusion International, of which he is a life member, vice-chair of the CRPD Committee of Japan Disability Forum, which is a national umbrella organization of/for person with disabilities in Japan, inaugural board member of Japan Association for Disability Law and an editor of 'Disability & Society'. Nagase was one of those who publicly appealed for an official apology and compensation of eugenic sterilisations in December 2002.

Carmela Pacelli graduated in Educational Sciences and Primary Education Sciences and is responsible for the University Service for the activities of students with disabilities (SAAD) at the University of Suor Orsola Benincasa in Naples Italy and a coordinator of the Naples in The Hands Network.

Paula Peters is a disability rights activist with Disabled People Against Cuts (DPAC) and member of Mental Health Resistance Network (MHRN) in the UK. She is also chair of Bromley and Croydon Unite Community trade union branch and a member of the Labour Party. Paula is a photographer who has extensively documented resistance against the Conservative government mounted by the mental health survivor and disability rights movement. She is also a poet and writer.

Romeo Dontae Tresean Biggz Pierre's passion is for the performing arts and trans-activism. He has co-presented and co-produced work in national and international contexts. He has written and performed his own music at Pride and numerous arts and music festivals. He uses his experiences of growing up with an intellectual disability and being a trans man to inform his activism. Romeo brought his storytelling skills to his work as a co-researcher with the *Re-imagining Parenting Possibilities Project,* an Ontario-wide project using a co-researcher model that explores the parenting experiences and aspirations of people labeled/with intellectual disabilities.

Paula Campos Pinto is an Associate Professor at the School for Social and Political Sciences/ University of Lisbon, and a researcher at the Center of Administration and Public Policies and the Interdisciplinary Center on Gender Research. Since 2013 she coordinates the *Observatory on Disability and Human Rights*, a platform that brings together academics, disability organizations and decision-makers to support disability research in Portugal.

Member of ANED, an academic network of experts who conduct analyses of public policies affecting persons with disabilities at EU level, and research associate with Disability Rights Promotion International, a worldwide initiative to monitor disability rights.

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John Rae was a board member of many human and disability rights organizations, including Co-chair of the Coalition on Human Rights for the Handicapped, which secured the first human rights coverage for persons with disabilities in Ontario. John is a Past President of the Alliance for Equality of Blind Canadians, the Canadian Legal, Advocacy, Information and Research Association of the Disabled and PAL Reading Service. He is currently a member of the Council of Canadians with Disabilities National Council, Chair of its Social Policy Committee, and a member of its Human Rights and National Accessibility and Inclusion Act Committees.

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PART I

Introduction – contextualising disability activism

INTRODUCING DISABILITY ACTIVISM

*Maria Berghs, Tsitsi Chataika, Kudakwashe Dube and
Yahya El-Lahib*

Introduction

The onslaught of neoliberalism, austerity measures and cuts, impact of climate change, protracted conflicts and ongoing refugee crisis, rise of far right and populist movements have all negatively impacted on disability. These circumstances have created more impairment and deaths in the global South and North. At the same time, we are witnessing the watering down of many rights, legal entitlements and policies that sustained disability lives. This includes the ability and willingness of academia, non–governmental organisations, multinationals and institutions to get involved in fighting back politically, economically, culturally and socially to ensure change. Yet, disabled people and their allies are fighting back and we urgently need to understand how, where and what they are doing, what they feel are their challenges and their future needs.

We are living through 'activist' times with differing formal and informal expressions of what activism looks like from individual actions, artistic movements, mass protest marches, hashtag activism (e.g. #ArabSpring, #BlackLivesMatter, #JeSuisCharlie, #MeToo movement, #ThisFlag), consumer activism, climate activism, peace activism; to ensure collective institutional, legislative or political change (Shirky, 2008). These campaigns are viewed as more inclusive, democratic, 'liquid' and horizontal in nature, in that anyone can join (Tufecki, 2017; Gerbuado, 2018). With the impact of social media, boundaries between public and private life collapse. The personal now can become political and part of public discourses, as well as imagery, and experienced as individually empowering. Public spaces become 'occupied' and appropriated for direct action, political slogans of resistance and mass protests (Gerbuado, 2018). Most activists now use technology, such as mobile phones and the Internet, as well as email, photographs, videos, podcasts, crowdfunding and blogs, making it accessible to a wider global audience.

Much of the physical and emotional labour of activism and advocacy, in terms of writing letters or calling, recruiting new members, ensuring funding, thinking of campaign slogans and planning innovative actions and tactics for attention, has thus profoundly altered with this new media landscape (Shirky, 2008; Tufecki, 2017). At the same time, there have been criticisms of this 'new activism', with some despairingly calling it mainly 'online', 'cyber' or 'digital' activism, 'clicktivism', or 'slacktivism' (Karpf, 2010; McCaughey & Ayers, 2013).

While the new activism seems to fit ideas of social movements in terms of collective message, vision and shared ideas for change, often popular appeal, quantitative impact or even on-line vitality of a campaign, has not always translated to effecting real change, especially in neoliberal times (Tufecki, 2017).

Despite mass appeals of transnational movements, software platforms (i.e. Facebook, Twitter, WhatsApp, Telegram, Instagram) and international non-profit organisations focusing on whistling blowing (i.e. WikiLeaks), this has led to very little structural political change, particularly in dictatorial countries (Tarrrow, 2005; Gerbuado, 2018). Moreover, overt individual direct political dissent in undemocratic countries, activism that threatens international economic powers or whistle-blowing globally, is fraught with dangers and often ensures that certain types of (hack)activism have to go underground (Lindgren & Lundström, 2011). A kind of hierarchy emerges in how the risks and rewards of legal and illegal, as well as overt and covert activism are understood. Increasingly, we are also seeing the rise of not only more politically conservative types of activism; but also openly violent, fascist, racist, homophobic and populist activism alongside neoliberal 'extractivist' activism for private economic gain or terror and conflict, which goes unregulated and unpunished. Much of the new activism, especially online, seems to be done from positions of technologi-cal comfort, digital, political and economic algorithmic power as well as language privilege, which is rarely acknowledged. Tufecki (2017, p. xi) argues that we are witnessing a shift in how social movements 'operate' and how they are opposed due to 'technological affor-dances'. These 'technological affordances' also come with real technological, physical and emotive risks, in terms of loss of privacy and need of new technological skillsets to protect oneself in the real and virtual world.

Criticisms have also been directed at much of the online policing in terms of language and terminology that is being used, noting that this is undemocratic, encourages censure and is counter to freedom of expression. It also entails that activism is not setting agendas; but one of disagreement, dissent and resistance as well as encouraging 'self-censure' for personal preservation in public spaces and the creation of 'echo-chambers'. In the United States of America (USA), critics argue that cyber activism through the use of online marketing and algorithms for the political right, has contributed to division, 'shock-politics' and 'post-truth' acceptance (see Klein, 2017). Concerns have been raised about the proliferation of 'big data' and how inequalities have gradually become automated in institutions. Conversely, they have real consequences for poor people in terms of employment, insurance, mortgages, justice and healthcare (O'Neil, 2017; Eubanks, 2018).

The trajectories of new activism have also been criticised as being neo-colonial, racist and mostly from North to South with very little cultural sensitivity and local expertise, as exem-plified by the Kony 2012 video campaign cited in Cole (2012). Furthermore, questions have been raised about links to consumerism, identity politics and lack of transparency about who really benefits from the work of activism and branding of oneself as a particular type of 'ac-tivist' (Chataika *et al.*, 2015). It almost seems as if it has become 'trendy' to proclaim oneself as an 'activist' in terms of neoliberal identity management, possible access to resources and moral branding or virtue signalling. Activism has become another commodity to buy into, in terms of neoliberalism, thus blurring the boundaries between consumerism, humanitari-anism and resistance (Mukherjee & Banet-Weiser, 2012; De Waal, 2015).

What is missing from many of the above criticisms and analysis of new forms and impetus of activism is 'disability' (Soldatic & Johnson, 2019). This is a grave concern, particularly when we are living in what some have defined as 'Crip Times' or neoliberal austerity that

particularly affects and creates disability (McRuer, 2018). Accordingly, this makes manifestos for disability justice and activism urgent (Ellis *et al.*, 2018). In the newer forms of disability activism, the focus on the everyday and people behind the hashtags or understanding the individual and collective motivations for participating in particular protests has been missing. While everyone is involved in new forms of activism – from local to global (this is inclusive of age, ethnicity, gender, socio-economic class and so on), disability theory, people with impairments, illness and chronic conditions, as well as different forms of new activisms, have been neglected. This could be because disability activism is often misunderstood or relegated to those disability rights activists with active social media profiles, academic careers, international contacts or involvement in Non-Governmental Organisations (NGOs) (Soldatic & Johnson, 2019). More so, the work of those who write profusely in the English language is easily accessed by large human rights organisations in the global North and South (Chataika *et al.*, 2015).

Disability activism is also incorrectly viewed as only about disability 'rights' or with inadequate cross-cultural or interdisciplinary reach. It is often erroneously seen as something 'special' or 'different', with limited political or human rights impact that only those with a 'disability' identity can do. However, there is often no nuanced understanding of what 'disability issues' involve. We have nonetheless seen a surge of disability advocacy, activism, campaigning and research on activism, from confrontational protests and symbolic direct action in Bolivia for pensions (Brégain, 2016; Vásquez Encalada, 2019), a mother advocating for justice for her disabled child in the United Kingdom (UK) (Ryan, 2017), the Sins Invalid[1] performance project on disability and sexuality, the African Network on Evidence to Action on Disability (AfriNEAD) (Mji *et al.*, 2011), to the start of a disability movement and advocacy on disability issues in China (Zhang, 2017) and its intersectionality to other movements like #MeToo (Lin & Yang, 2019). All these different forms of activism have been infused with a renewed sense of global urgency due to the political, social, cultural and economic times in which we live. They were also influenced by a shared history, theories and collective social movement, which is important to understand. We do not set any boundaries around the language and theories being used in this book, but we rather give a brief introductory overview.

Understanding models, language and movements

Over 15% of the world's population has a form of impairment, and this has come to the world's attention due to the disability movement (WHO & World Bank, 2011). In order to understand how the disability movement became a collective global movement, there is a need to comprehend the importance of models and theories of disability to ensure a collective consciousness. It may seem as if the disability rights movement began in the 1960s with the start of the civil rights, women's rights and other differing social movements in the UK and USA, but its origins lie earlier (Sabatello & Schulze, 2013). If we think models or theories influence language and effect social change, we note that the earliest models of disability were charity models, which is reflected in policy and legislation and early formation of organisations and institutions around specific forms of impairments.

A *charity model of disability* views disability as something to be 'pitied' and a disabled person as in need of charitable aid. Thus, it looks at disabled people as individuals who are unable to do things for themselves, who need to be protected and decisions made on their behalf (Chataika, 2019). Hence, we can locate this in advocacy, for example, in the 1600s, in the early laws for the poor, infirm, aging or even aid for soldiers who gain physical and mental injuries

through battle, as well as creation of the first 'mad' houses and charities in the 1800s. The charity model of disability is closely tied to a *medical model understanding of disability,* which views disability as a problem or biological pathology that can be medically cured, fixed by medical technology or rehabilitated. Thus, the medical model focuses on the impairment – on what is 'wrong' with the person (Oliver & Barnes, 2012). It looks at the ways in which the person deviates from the norm, and tries to narrow that gap. The assumption here is that 'normal' is automatically desirable and to be aspired to. The 'problem' lies with the individual, depending on what they can or cannot do (WHO & World Bank, 2011).

Early global disability advocacy and movements were linked to colonialism and imperialism; for example, the creation of impairment-specific organisations and institutions, such as for 'blind' people (Phillips, 2009; Rembis *et al.*, 2018). Yet, these organisations were mainly run by and controlled by non-disabled people in the global North, which were closely linked to Judeo-Christian understandings of disability. The British and Foreign Society for Improving Embossed Literature for the Blind, a forerunner of the UK's Royal National Institute for Blind People, was founded by a doctor who had issues with his eyesight; but this remained exceptional. The great depression after the First World War meant the formation of The League of the Physically Handicapped in the USA, which advocated for welfare issues (Longmore & Goldberger, 2000). The two world wars also entailed the start of specialised rehabilitative services, inclusive of sport for service men and women who became disabled during conflict (Albrecht, 1992; Brittain & Beacom, 2018).

In contrast, the *social model of disability* developed from the experiences of disabled people and their activism against the charity and medical models of disability, as well as the control that these professionals exerted over their lives. Thus, in the 1970s, a group called the Union of Physically Impaired Against Segregation (UPIAS) campaigned for the rights of people with impairments to participate fully in society, to live independently, to undertake productive work and to have full control over their lives. The social model of disability suggests that a person is disabled by society's inabilities to adapt to disabled people's needs. For example, the wheelchair is not the problem, the stairs are. UPIAS made a difference between physical, sensory or cognitive impairment and the experience of oppression created by barriers, discriminatory attitudes and exclusion, which they called disablement. According to UPIAS (1976, p. 14):

> It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.

The social model removes the focus and 'blame' from the disabled person to society in general. Since then, the social model has encompassed not just people with physical impairments, but also people with sensory impairments, intellectual and mental health conditions. This idea was foundational to understanding disablement and disability identity as imposed on top of impairment, meaning that there was nothing 'wrong' with a person who had impairment(s) but instead that society had to be fixed, cured or rehabilitated. This led to a more positive affirmation of a disability identity, as well as a very clear focus on removing barriers in society to ensure rights, welfare entitlements and citizenship (Shakespeare, 2017). The social model lay at the foundation of the independent living movement and anti-discrimination legislation in the UK, US, Europe and Canada (Barnes, 1991; Vanhala, 2010). What was mainly a grassroots movement became a global movement advocating the 'Nothing about us, without us' mantra and disability rights (Charlton, 1998).[2]

The social model also came under criticism in terms of being mainly advocated by white western men with physical impairments. Theoretically, it also came under criticism with disabled people arguing that it ignored significant experiences linked to impairment, such as pain, presupposed that disability identity should and could be ascribed to, and everyone that had an impairment was 'oppressed' (Dyson & Berghs, 2019). The concept of lived experience was also changing, resulting in more distinct but also fragmented identity politics and people who no longer identified as 'disabled' or 'person with a disability' but applied the social model to impairment (Woods, 2017). Other aspects of identity, as well as medical definitions, may carry more cogency for people and change along the life-course as impairment changes, yet there has been limited understanding of this.

Hybrids of the social model have also formed, such as more *social-relational models* (Thomas, 2004), also found in the Nordic countries focusing on normalising the environment for disabled people, *embodied models* (Shakespeare, 2004; Wiseman, 2014) or/and *minority models* found in North America, where disability is viewed as part of a minority culture, which has rights and whose cultures need protection (Sabatello & Schulze, 2013). Others have left the social model behind, arguing for a more *critical disability studies perspective* and noting that disability and impairment are social constructions (Goodley, 2014).

Foundational to the disability rights movement was also a *human rights model of disability* and the links that were institutionally made between disability and human development. The year 1975 marked the United Nations (UN) Declaration on the Rights of Disabled Persons. The 1980s marked global advocacy on disability, with 1981 declared the International Year of Disabled Persons and 1983, the beginning of the UN Decade of Disabled Persons. Such initiatives were tied to understandings of disability, poverty and development as correlated in terms of a global challenge (Ingstad & Eide, 2011). The 'fight' against poverty also became connected with ideas of research co-production and inclusion of people with disabilities in poverty reduction work (Yeo & Moore, 2003).

Poverty is multi-dimensional as a person is more likely to be disabled if poor; disability is connected to chronic poverty, lower employment rates, lower educational attainment and higher medical expenses, especially in the global South (Charlton, 1998; Mitra *et al.*, 2013; Mitra *et al.*, 2017). This was conceptualised as the 'poverty-disability and chronic poverty-disability cycle' (Yeo, 2001; Yeo & Moore, 2003). However, the latest evidence indicates that disabled people also 'face various forms of barriers and intersecting inequalities, which can result in multi-dimensional poverty, exclusion and marginalisation' (Mitra *et al.*, 2013; Chataika, 2019, p. 4). Thus, despite all development work taking place, particularly in the global South, there still exists a disability gap (Groce, 2018; Chataika, 2019) as disabled people are being left behind irrespective of their need of both disability-specific and inclusive policies (Berghs *et al.*, 2016; Groce, 2018). The disability gap can be explained by the way in which poverty is more of a multi-dimensional matrix than a cycle. There are situational factors linked to impairment that become 'embodied and potentially (but not necessarily) linked to disability discrimination' (Berghs *et al.*, 2016, p. 43) in that, chronic deprivation is correlated to entrenched inequalities affecting disabled people (Berghs *et al.*, 2016).

While national and international legislation changes have been made and litigation engaged in, what has been critical is the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). It gives expression to how poverty and development are linked to disability, which can however be addressed by changing attitudes, removing barriers and assurances of protection of rights in every aspect of life.

In the CRPD, disability is also described as an 'evolving concept' and defined in terms of person first language, such as persons with disabilities. The CRPD states:

> Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.
>
> *(United Nations, 2006)*

While the CRPD has been hugely influential, there have also been criticisms in the sense that real citizenship has not been achieved for many disabled people in the global South (Chataika *et al.*, 2015; Watermeyer *et al.*, 2018). In response, people have argued that while rights are important, so is understanding the way in which negative attitudes influence barriers. There is a difference between *ableism* and *disablism* in the sense that we live in a world that is created and ascribes positive meanings to an able-body (Campbell, 2009; Goodley, 2014). This is different from disablism, where negative meanings are associated with disability.

The history of disability and activism has also been viewed mainly from the global North and in response, newer models have started to evolve: Latin, African and Asian. For instance, indigenous models inspired by southern African theory and ethics, such as an *Ubuntu model of disability* (Chataika *et al.*, 2015). Others have argued for a *cultural model of disability,* arguing for a disABILITY MUNDUS or more transnational materialist view on disability (Devlieger *et al.*, 2016). Despite this, a unifying model from the global South has not evolved yet and calls for decolonising disability and development studies remain cogent (Kolářová, 2016). In response to the rolling back of much of the welfare and entitlements that the disability community gained in the global North and South, there have also been calls for stronger models to protect rights such as the *social model of human rights* (Berghs *et al.*, 2017; 2019) or a more *radical model of disability* (Berghs, 2015), which would focus on structural causes of disablement and political changes for disability justice. Others view a new impetus in the *emancipatory models of disability* (Barnes, 2014). However, if we look at the work of activism, it is a message of resistance and hope that is mainly being carried out by disabled people rather than the charities or NGOs (Wong, 2018). Williams–Findlay (2018) argues that any research done about disabled people's lives has to focus on resistance, rights and reclamation. In this respect, we see a more activist or *active model of disability* (Levitt, 2017) that could be emerging in terms of newer theories and *models of disability resistance, hope and reclamation*.

It is against the above background that we present the book outline. The handbook is divided into the ten broad sections, navigating into conceptual, practice, personal experiences and cross-cutting within the disability activism agenda. This introductory chapter provides the background and the book overview. The virtual roundtable captures disability activism dynamics from emerging disability activists from the global South. Chapters 1 to 34 are distinctive chapters, which when read together, inform the disability activism journey travelled so far and future directions. Finally, Chapter 35 brings the handbook to a conclusion by drawing lessons, best practices, challenges and opportunities for future disability activism. The handbook is therefore divided into ten parts that we introduce in turn.

Part I: Introduction – contextualising disability activism

This book starts with two introductory chapters. The **first introduction** by Maria Berghs, Tsitsi Chataika, Kudakwashe Dube and Yahya El-Lahib provides the background of the book and how it is structured. The second introductory chapter is a **virtual roundtable** with activists from the global South, which sets the scene of the book. Tsitsi Chataika coordinated

the virtual roundtable and gave a platform, not to the 'usual suspects' in disability studies, famous academics or well-known disability activists, who are acknowledged throughout this book in terms of their foundational work. She deliberately invited emerging disability activists, Abraham Mateta, Samantha Sibanda (Zimbabwe) and Krishna Bahadur Sunar (Nepal), to the virtual roundtable so that their voices can be heard at a global level. The focus shifts to those people working on the front lines of everyday activist practices. The purpose of the virtual roundtable was to understand what the 'everyday' consists of, in terms of new disability activism; as well as the challenges that activists now face within their contexts. It is through engaging with this chapter that readers establish what the activists think works best – confrontational or non-confrontational activism. Thinking about decolonial practices and engaging in dialogical activism means giving the floor to emerging disability activists from the global South so that the world can 'listen and learn' from them.

Part II: Neoliberalism and austerity in the global North

Part II sets the tone of the times and justifies why activism has become so important. It is about the problems of the disability vanguard having to change with the challenges of an increasingly neoliberal world (Oliver & Barnes, 2012; Shakespeare, 2013; Goodley, 2014; McRuer, 2018). In many ways, this section is about the limitations of humanitarianism (Gill & Schlund-Vials, 2016) and inclusion when the laws begin to change around welfare and entitlements to health and social care, education, employment, housing and leisure. We move to the global North where there are two interlinked issues that disability activism is now fighting: 1) neoliberal economic policies and 2) the impact of austerity in rolling back many of the rights and entitlements that people have fought so hard for.

We thought it was important to begin with Mo Stewart's **Chapter 1**, where she discusses what the impact of neoliberalism and linked welfare reform has been in terms of realities of disabled people's lives. She begins by explaining what is at stake in the move of liberalisation of services and institutions in the United Kingdom (UK), including the loss of dignity, human rights and people's lives. Understanding the impact of neoliberalism entails a close reading of transnational disability politics and where to situate newer and younger members who will take over the disability movement. Hence the question: Is the disability movement equipped to deal with these future challenges?

In **Chapter 2**, Miro Griffiths explains that the vanguard does not always include younger members in the UK's Disabled People's Movement (DPM) and that they might be politically more neoliberal than past generations. He found that the social model was acting as a barrier towards young people's involvement, in that it was functioning as ideology, instead of democratic tool. He also examines how the philosophical foundations of DPM are changing which means both challenges and opportunities in term of 'futurology'.

Joanne Sansome's **Chapter 3** turns to what she thinks are the greatest successes of the disability movement in the UK, in terms of legislative changes, links with global movement and also the harnessing of social media. She gives several examples of successful campaigns that have brought people together around protests against austerity and welfare cuts. Yet, ultimately, she wonders if trans-disability solidarity for activism is possible without new paradigms focusing on employment and changed political structure in the UK and USA. She ascribes to human rights models, but notes that disability has become a reactive political movement instead of one that is proactively activist in nature.

In **Chapter 4**, Liz Crow expresses how disabled people have been using art to resist, protest and ensure solidarity and how disabled people have become forgotten

'figures' in austerity. She writes and illustrates *Figures*, which was a mass sculptural pro-test on the banks of the river Thames, in front of the House of Parliament, to protest against the human costs of austerity.

Last in Part II is **Chapter 5**, where John Rae notes how the hopes and promises of technology for disabled people have not held true, in terms of employment and greater political and social involvement in daily life. Despite all the promises and opportunities of technology making things possible, it is now bound with neoliberal norms and values, and can pose as threat. John explains how technology is linked to unemployment and how important unions and legislation are in terms of activism and rights.

Part III: Rights, embodied resistance and disability activism

Part III examines embodied activism in touching upon some of the intimate complexities that are linked to intersectional identities. In differing ways, new coalitions have been formed around ensuring 'embodied citizenship' in making the private and personal, now public so that rights can be accessed (Russell, 2011; Wiseman, 2014) or protected in sex-trafficking (Sherry, 2019). While there are risks and rewards in making the personal so public, Alan Santinele Martino and Margaret Campbell argue in **Chapter 6** that this is necessary by giving an overview of 'intimate citizenship' and activist work to ensure sexual rights. They suggest that by guaranteeing a better intersectional understanding of the experiences of people with disabilities regarding sexuality, questions of sexual identities and practices can be highlighted, thus, dismantling barriers to sexual expression that disabled people face.

Embodiment is also a concern for Fabrizio Loce-Mandes, who through his fieldwork in Italy, friendship and shared artistic endeavours illustrates how anthropologists also embody activist practices as ally in **Chapter 7**. Through visual materials and performances used by people in the D/deaf social movement, he and Marco analyse the ways in which the experience of the body and the notion of 'health' are understood, constructed and continuously negotiated in D/deaf cultural repertoires. He touches on how and why the personal becomes public in that, notions of 'cure' and a medical model of deafness have to be negotiated, resisted or accepted.

More and more, diverse activist identities become negotiated around medical or psychiatric resistance and the 'disability' identity weakens as embodied resistance becomes more specified as correlated to specific type of impairment, psychiatric survivor experience, cultural or minority identity affirmation and identity politics in general. It is people with 'lived experience' that are at the forefront of such movements and it is this lived experience that should be affirmed as expertise (McWade *et al.*, 2015). We have seen this in terms of the 'neurodiversity' movement (Ortega, 2009) that argues for a neurodiverse identity and 'neurodiverse politics' (Runswick-Cole, 2014). The work of activist-scholars who are open about their identities and their moral positioning in debates around language, identity and research practices has been foundational (see Milton, 2017). There has also been a similar movement in 'mad studies' (LeFrançois *et al.*, 2013), which builds on mental health 'survivor research' in reclaiming experiences and language from professional control (Faulkner, 2017).

Mad-studies, while seemingly broad, has also drawn lines around inclusion and exclusion within the movement, in terms of only insiders having access (Beresford & Russo, 2016), noting issues of colonisation from sanism (Russo & Beresford, 2015). There are strengths and pitfalls in such a stance. For example, in terms of 'neurodiverse' politics and the 'us and them' outlook in neoliberal times (Runswick-Cole, 2014), where identity and control are important, so is wider political and social support. McWade *et al.* (2015) argue that bridges

between movements in terms of affirming and creation of impairment; for example, in terms of psycho-emotional disablism and creation of mental distress (see Graby, 2015), need to be made. Overall the (bio)medical model, linked to various conceptions of cure, has become increasingly diffuse and now seeped into all facets of life, including welfare reform entailing embodied activist resistance, also becomes a mental resistance.

In **Chapter 8**, Denise McKenna, Paula Peters and Rich Moth give an account of the emerging mental health survivor-led social movement against 'psychocompulsion' to the 'work-cure'. They elucidate welfare 'reforms' and shifts in mental health policy and practice in the UK. They also describe activists' collective responses and interventions to challenge these policy agendas, noting developing alliances and strategies of resistance. Their focus is on how they can work together to ensure active policy change through direct action, protest and formation of new participatory community, inclusive of allies. The affirmation of identity, creation of new networks and movements is critical to activism; so is ensuring that activism is not controlled or co-opted by elites in terms of ensuring participatory approaches. This has led to the creation of, for example, the Participatory Autism Research Collective[3], which is trying to relinquish control and power of the research process to communities of people involved. In such stances, we see a more active model of disability emerging that focuses on the 'actions' of disabled people (Levitt, 2017); but can we call it a model of disability if that identity is not affirmed? Are these active models of impairment affirmation or counter affirmations of a biomedical model? That is why we wanted to end Part III with **Chapter 9**, where Tafadzwa Rugoho in Zimbabwe reminds us of how powerful the affirmative model of disability (Swain & French, 2000) is when one acquires impairment and becomes disabled. While he notes medical and charitable models of disability, he explains how a rehabilitative model is found within affirmation of disability and why he uses the disability identity as embodied ammunition in being able to advocate for himself. The chapter reminds us that for all the work on identity politics, it is the disability rights frameworks and legislation that people can fall back on to advocate for themselves and ensure their rights.

Part IV: Belonging, identity and values: diverse coalitions for rights

In Part IV, we examine the needed expansions of the disability rights frameworks and what the work of activism looks like when rights are missing in terms of self-advocacy. We begin with Liz Crow and Wendy Merchant in **Chapter 10**, who write about their experiences of motherhood as disabled women with disabled children. One found her way to activism through advocating for her child; the other found the onset of impairment in her child disrupted and changed her activism. In their chapter, they note the relationship between activism and impairment and share what they have learnt about 'holding' activism. They note that their moral authority is linked to motherhood and how impairment constantly calls that authority, their roles as mothers and even activism for their children, into question.

In **Chapter 11**, Kate Swaffer, Brian LeBlanc and Peter Mittler share their personal experiences of dementia and why a large part of their activism revolves around combating the questioning of the dementia diagnosis. In many ways, they are using a human rights model to combat charity and pity models linked to dementia, as well as fighting against ideas of segregation and enforced helplessness. They share their global advocacy and activism; how they think that a disability framework and particularly the CRPD (United Nations, 2006) is needed by people with dementia to progress beyond what is currently poor care, poor diagnosis rates and the continued medicalisation of dementia. They advocate for an understanding of dementia in terms of a disAbility.

In **Chapter 12**, we are presented with how a disability legislative framework is also needed for claims of reparations against a state history of eugenics (Bashford & Levine, 2010; Steele, 2016). Disability histories, gender, ethnicity, impairment and intersectionality to violence are examined through the voices of male and female survivors of forced sterilisations of Japan's Eugenics Protection Law 1948–1996 by Nagase Osamu. He notes how survivors and their families are speaking out against state-sanctioned medical violence through the courts, and how they found a new legislative process to demand reparations. After twenty years, the Japanese state is finally compensating people who were forcibly sterilised because of learning disabilities, mental health and genetic conditions. Through survivors' accounts, we note how violence against disability is often linked to incarceration and structural violence in society, in how disability is viewed as dishuman (see also Goodley & Runswick-Cole, 2016; Steele, 2018). Through families of survivors, we are also introduced to how disablement affects families and violence is intergenerational and acts as an environmental contagion, which reparations seeks to heal. Such an understanding of rights and advocacy reveals how disability is intertwined with the social and environmental.

In **Chapter 13**, Khairani Barokka extends our understanding of disability through *Indigenous Species* and artistic description of how climate change is linked to histories of neoliberal violence and colonialism that disables. The chapter illustrates how disablement is ongoing in killing ecosystems in the global South and creating more violence in both the human and non-human.

Part V: Reclaiming social positions, places and spaces

Part V is about how activism for social positions, places and spaces in society are 'mobilised' by disability, challenging societal norms and arguing for more encompassing ideas of citizenship. Throughout this section, we note how disability challenges ideas of place and space in terms of mobility and occupation (Block *et al.*, 2015). **Chapter 14** by Damian Haslett and Brett Smith is on disability sport as a context for disability activism. In particular, they discuss the potential of elite Paralympic sport to understand new forms of disability activism and differences to the disability movement.

In **Chapter 15**, Ciro Pizzo, Carmela Pacelli and Maria Grazia Gargiulo explain how a university got involved in ensuring accessibility of museums, art and cultural heritage through their exploration of the 'Naples in the Hands' network. They examine how legislation becomes linked to universal design but also complexities in how total accessibility for everyone is not possible.

Concerns with accessibility drive the 'Around the Toilet' project in **Chapter 16** by Charlotte Jones, Jen Slater, Sam Cleasby, Gill Kemp, Eleanor Lisney and Sarah Rennie. Reflecting on the contemporary context of toilet activism and issues of accessibility in the UK, they situate the toilet within a wider disability justice movement which speaks to issues of austerity, categorisation, in/visibility, and both social and physical marginalisation.

In **Chapter 17**, we are introduced to the idea of 'mobility' and how that continues to be shaped in the Caribbean nation of Trinidad and Tobago in a history of colonialism and post-colonial neoliberalism. Sylette Henry-Buckmire introduces the idea of 'mobility-as-occupation' and activists who use a variety of (non)confrontation types of activism.

Part VI: Social media, support and activism

Part VI focuses on social media and what kind of role the 'new medias' are playing in disability politics and activism. In times of political turmoil, social media has meant the

creation of online communities where disability activism takes place (Trevisan, 2018). In **Chapter 18**, Nqobani Dube argues that the use of social media in the global South has been neglected and marginalised by research examining the experiences of disability activists in the global North and priorities of neoliberalism. He interviewed disability activists in Zimbabwe and South Africa to establish their experiences of online activism. He makes connections to understanding online disability activism in terms of a social movement, but notes limitations of such activism. He also touches on activism in times of political repression.

Chapter 19 moves to Brazil, where Marco Antonio Gavério, Anahi Guedes de Mello and Pamela Block give a virtual ethnography of a cyber-activist campaign linked to the International Day of Disabled People, celebrated on the 3rd of December. They describe how the activists collectively met on Facebook and started to fight ableism through the hashtag #ÉCapacitismoQuando (#It'sAbleismWhen). In their chapter, they note the importance of timing of campaigns, embodied history of political repression, which may prevent older activists from involvement, and context of digital activism that ensures a new generation gains a platform.

Chapter 20 illuminates how disability history and disablement is embodied and linked to past and present political movements in how journalists, lawyers and academics use social media. Hannah McGlade examines how disabled indigenous people are caught up in the prison industrial complex in Western Australia and explains connections to the Black Lives Matter movement in the USA. She highlights how the neglected experiences of Indigenous prisoners (women, men, children) are found online in family protests, news stories, legal documents, academic websites and reports to demonstrate that racism is not just institutionalised, but also part of the social fabric of creation of more disablement; making human-rights based reforms imperative.

In **Chapter 21**, Anna Chowaniec-Rylke examines how, despite criticisms about lack of digital privacy, Facebook is an important element of health movement activism, especially for parents of children with a rare genetic condition in Poland. She notes how the Internet is a means of advocacy, for not only the value of their children and ensuring they are part of family life, but also in terms of dealing with bureaucracy to secure their human rights.

Part VII: Campus activism in higher education

In Part VII, we move towards understanding campus activism in higher education and what the academy includes, excludes and avoids (see Bolt & Penketh, 2017), as well as how resistance is politically constructed in the face of academic ableism (Wolbring, 2008; Dolmage, 2017). **Chapter 22** illustrates how the ableist infrastructure of post-secondary education in the USA is not genuinely inclusive of disability as a full part of the university community, focusing instead on bureaucratic, medical or teaching 'compliance' to the Americans with Disabilities Act. Stephanie Cork, Beth Douthirt-Cohen, Kelly M. Hoffman, Paul T. Jaeger and Amanda Strausser illustrate how a university can actively include disability culture, activism and advocacy as foundational to its work. They note how in the USA, popular culture has become disablist and disinformed (Cork *et al.*, 2017), including on campuses, and ask us to become not allies but accomplices, which is a more radical political stance. In the USA, disability is viewed as part of a greater diversity, in line with a minority model of disability, and the authors argue that disability policies and practices in higher education should not be 'random', but part of politics of inclusion.

In **Chapter 23**, Armineh Soorenian illustrates how intersectionality and diversity in impairment is not reflected in academia. She shares a moving account of her trajectory to PhD as a disabled woman and the violence of the academy in disableism, sexism and racism, as well as her resistance to this through her work. Soorenian was unemployed for several years after her PhD, even though publishing, attending conferences and teaching at the highest levels in the academy. She describes considerable personal and academic 'unpaid labour' outside the academy and how there were never any 'reasonable adjustments' made for her (Inckle, 2018).

Chapter 24 examines how the creation of cultures of inclusion through greater sensitisation should not just focus on nondisabled people, but also on disabled people. Pragya Deora gives examples from a campus in India, noting how intersectionality needs to be mainstreamed in student activism around disability.

Chapter 25 gives an example of what undergraduate activism looks like on campus in the USA. Erin Davenport describes how an art installation project was started with her non-disabled friend and ally, focusing on experiences of disabled students using elevators. It illustrates how resistance begins with the feeling of indignation at an injustice and then protest to educate, re-tell and ensure change. Davenport also examines archival material to reclaim a kinship and history with other disabled students who faced discrimination and oppression.

Part VIII: Inclusive pedagogies, evidence and activist practices

Part VIII focuses on the increasing correlations between inclusive pedagogies, evidence and activist practices, especially in terms of greater need to illustrate qualitative and quantitative impact in terms of social change. We turn to how academics, higher education and activism are working together against ableism and disablism to ensure this change. **In Chapter 26**, Martin Musengi shares his 'DeafCrit' activism as an academic against 'audism' in higher education. He explains how he became an academic activist in ensuring Zimbabwean Sign Language was recognised as an official language in Zimbabwean schools and discusses issues such as reverse inclusion. In many ways, this draws on DisCrit or an intersectional framework, together with disability studies and critical race theory, in examining connections between disability, education and ethnicity to explain life trajectories of marginalisation, segregation and incarceration (Ervelles, 2011; Annamma *et al.*, 2013; Annamma, 2016).

As illustrated in Chapter 10, one of the most marginalised and segregated groups that have been disproportionately globally affected by cuts to services and austerity are people with learning disabilities (Bates *et al.*, 2017; Carpenter, 2018; Power & Bartlett, 2018). As a group they have been hit in all aspects of their lives, from health, education, employment, welfare, reproduction, and justice to incarceration. For example, in the UK, a confidential inquiry found that people with learning disabilities or difficulties face multiple forms of discrimination, while men died on average thirteen years earlier than the general population; and for women, it was twenty years (Heslop *et al.*, 2014). This makes **Chapter 27** so critical, as Ann Fudge Schormans, Heather Allan, Donavon O'Neil Allen, Christine Austin, Kareem Elbard, Kevin John Head, Tyler Henderson, Karrissa Horan-LaRoche, Rainbow Hunt, Nathan Gray, Rex Marchi, Donna McCormick, Romeo Dontae Tresean Biggz Pierre and Sean Rowley explain why inclusive co-produced research and knowledge with people who are labelled with intellectual disabilities, is a political and rights-based practice. Building on the slogan of the disability movement 'Nothing about us without us' (Charlton, 1998), they explain how ensuring societal respect and value begins with a sharing of control over research processes to challenge wider societal attitudes and discrimination. The chapter

is aligned to emancipatory models of disability research (Barnes, 2014) and action research (Bradbury, 2015), which prioritise citizen co-production (Beresford & Croft, 2016). It also advocates for inclusion in all forms of research and collection of research evidence (Berghs *et al.*, 2016).

Chapter 28 examines how participation and the statistical collection of evidence for disability rights is understood in the Disability Rights Promotion International (DRPI) system globally**.** Marcia Rioux, Paula Campos Pinto, Dagnachew Wakene, Rados Keravica and Jose Viera explain how evidence-based participatory indicators can be used to provide a strong account of what poverty, exclusion and the denial of rights mean to disabled people. They note how it is important to monitor progress for disability rights to understand what enables or disables activism, arguing that participatory and emancipatory monitoring strategies are urgently needed to ensure social change.

Part IX: Enabling human rights and policy: international politics

Part IX scrutinises what enables disability rights, justice and policy in terms of international political perspectives on activism. **Chapter 29** explains how transitions to human rights frameworks are structurally implemented in Eastern European post-Soviet states and why there is a struggle between imitating what has been done before, required by international politics, and national authenticity in developing rights. Egle Sumskiene, Violeta Gevorgieniene and Rasa Geniene illustrate this through the implementation of the CRPD (United Nations, 2006) and how it functions in terms of bureaucracy on paper or in legal frameworks, but not always practically in changing lives and ensuring the rights of disabled people.

In **Chapter 30**, Marie Sépulchre and Lars Lindberg give an overview of the history of the disability movement in Sweden and highlight different strategies activists have used to ensure welfare reforms. They argue that there has to be a shared vision or mission statement between a national and the international disability movement. They also examine newer tactics of disability activism such as litigation and the use of social media, and examine their effectiveness.

Chapter 31 examines how disability rights intersects with other rights and how they are politically implemented in terms of gender mainstreaming in the global South. Emma Frobisher, Willem Elbers and Auma Okwany argue that gender and disability mainstreaming is often the work of national and international NGOs. They illustrate implementation policies of one such NGO in the West African country of Sierra Leone. They argue that such programmes for female empowerment, despite their criticisms in terms of neoliberal consumerism and ignoring structural causes of female disempowerment (Switzer, 2013; Hickel, 2014), were found to be positive for girls with disabilities. Drawing on Crenshaw (1989; 1991), they argue for more research on intersectionality to understand why rights become implemented in terms of interplay between age, gender, disability and other inequalities.

In **Chapter 32**, the intersections between new activist movements and the disability movement is highlighted to illustrate how they can give impetus and innovate intersectional identities and spaces. Melissa Graham describes the formation of the Toronto Disability Pride March (TDPM) in Canada in 2011, the year of the Occupy protests in which disabled people played a pivotal role. She notes that what was a one-person event grew out of intersections of ableism, sanism and other forms of oppression and was influenced by the Occupy movement's successes and failures. The creation of such newer intersectional spaces for Lesbian, Gay, Bisexual, Transgender/sexual, Queer/Questioning (LGBTQ+) are critiques of a disability movement in which some may not feel comfortable, as they are

typically controlled by white heteronormative men from the global North. Graham terms this a form of disability justice and notes the limitations of the social model, having links to institutions that also oppress, arguing that it is not necessary to remake the past but challenges us to rethink it.

Part X: Conclusion – the coming challenges and future directions

Finally, in Part X we turn to challenges of the disability movement and what a transnational and emancipatory politics would look like. In this section, we also provide the final chapter, which brings together the book to a sound conclusion. In **Chapter 33**, A.K. Dube engages in an analysis of disability mainstreaming in terms of a supply and demand perspective of disability rights holders. He notes all the political successes of the disability movement in getting their agendas for change in different types of legislative and political frameworks by examining the relationship between disability and development. He addresses key questions that many activists struggle with, where are the resources going and how can we get them to ensure disability programmes and policy implementation?

Chapter 34 turns to the migration and disability nexus and argues for more interdisciplinary analysis, bringing together different ways of knowing to ensure more theoretical and practical innovation (El-Lahib, 2017). Natalie Spagnuolo and Yahya El-Lahib argue that we need to allow different ways of knowing in terms of translocalism. They argue that by reconceptualising displacement through a consideration of translocal, disability realities entail a broadening of analytical lenses to account for disabled people who have not crossed geographic boarders. In this way, it becomes possible to view people with intellectual disabilities as sharing similar support needs as many migrants and refugees. Both groups have experienced considerable stigma, questioning in terms of citizenship and loss of rights in neoliberal times (Goodley, 2014; Tyler, 2013; 2018) and can be viewed as 'abject' or lying outside of the rights of citizenship. In terms of globalisation and neoliberalism, disability activism is about defining how and why disability matters or does not. In this way, new activisms need to be built to illustrate what it means to be human, why that is under threat and what we can do about it.

Chapter 35 brings to the book to a conclusion by drawing lessons, best practices, challenges, and opportunities for more strengthened disability activism. Maria Berghs, Tsitsi Chataika, Yahya El-Lahib and Kudakwashe Dube reflect on how each chapter feeds into each other and the conclusions can inform future directions for sustainable disability activism that has positive implications on the livelihoods of disabled people all over the world.

Conclusion

Disability activism, while inclusive of new activism and technological developments, is about more than just disability. It is also about how values of equality, inclusion, respect and dignity become translated in our everyday lives. We hope that we lift the veil of what disability activism is about and illustrate how and why people are engaged in new forms of resistance. We wanted to work in a participatory way that would ensure that people's frustrations, challenges and rewards of activism are highlighted, to ensure a greater understanding of how to support such advocacy and why disability activism is crucial. Throughout this book, we have also focused on the importance of why an interdisciplinary perspective is important, welcoming allies, accomplices or coalitions (Fearon *et al.*, 2018) for disability hopes and futures.

Notes

1 See https://www.sinsinvalid.org/.
2 This has also entailed that we were questioned about our links to disability and identification as 'disabled' in this book project.
3 See https://participatoryautismresearch.wordpress.com/.

References

Albrecht, G. L. (1992). *The Disability Business: Rehabilitation in America*. Newbury Park, CA: Sage.
Annamma, S. A., Connor, D., & Ferri, B. (2013). Dis/ability critical race studies (DisCrit): theorizing at the intersections of race and dis/ability. *Race, Ethnicity and Education* **16**(1), 1–31.
Annamma, S. A. (2016). *DisCrit: Disability Studies and Critical Race Theory in Education*. New York and London: Teachers College Press.
Barnartt, S. N., & Scotch, R. K. (2001). *Disability Protests: Contentious Politics 1970–1999*. Washington D.C: Gallaudet University Press.
Barnes, C. (2014). What a difference a decade makes: reflections on doing 'emancipatory' disability research. In M. Nind, J. Rix, K. Sheehy, & K. Simmons (eds), *Ethics and Research in Inclusive Education* (pp. 55–70). London: Routledge.
Barnes, C. (1991). *Disabled People in Britain and Discrimination: A Case for Anti-discrimination Legislation*. London: C. Hurst & Co. Publishers.
Bashford, A., & Levine, P. (eds). (2010). *The Oxford Handbook of the History of Eugenics*. Oxford: Oxford University Press.
Bates, K., Goodley, D., & Runswick-Cole, K. (2017). Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity. *Disability & Society* **32**(2), 160–175.
Beresford, P., & Croft, S. (2016). *Citizen Involvement: A Practical Guide for Change*. London: Macmillan International Higher Education.
Beresford, P., & Russo, J. (2016). Supporting the sustainability of Mad Studies and preventing its co-option. *Disability & Society* **31**(2), 270–274.
Berghs, M., Atkin, K., Hatton, C., & Thomas, C. (2019). Do disabled people need a stronger social model – a social model of human rights? *Disability & Society*, (forthcoming).
Berghs, M., Atkin, K., Graham, H., Hatton, C., & Thomas, C. (2017). Public health, research and rights: the perspectives of deliberation panels with politically and socially active disabled people. *Disability & Society* **32**(7), 945–965.
Berghs, M. J., Atkin, K. M., Graham, H. M., Hatton, C., and Thomas, C. (2016). Implications for public health research of models and theories of disability: a scoping study and evidence synthesis. *Public Health Research* **4**(8), 1–4.
Berghs, M. (2015). Radicalising 'disability' in conflict and post-conflict situations. *Disability & Society* **30**(5), 743–758.
Block, P., Kasnitz, D., Nishida, A., & Pollard, N. (eds). (2015). *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability*. Cham: Springer.
Bolt, D., & Penketh, C. (eds). (2017). *Disability, Avoidance and the Academy: Challenging Resistance*. London: Routledge.
Bradbury, H. (ed). (2015). *The Sage Handbook of Action Research*. London: Sage.
Brégain, G. (2016). Comparative study of two protest marches for disabled people's rights (Spain 1933–Bolivia 2011). *Moving: The Social Journal of Social History and the History of Social Movements* **56**, 115–140.
Brittain, I., & Beacom, A. (eds). (2018). *The Palgrave Handbook of Paralympic Studies*. London: Palgrave Macmillan.
Campbell, F. (2009). *Contours of Ableism: The Production of Disability and Abledness*. Cham: Springer.
Carpenter, N. (2018). *Austerity's Victims: Adults with a Learning Disability*. London: CreateSpace Independent Publishing Platform.
Charlton, J. I. (1998). *Nothing About Us Without Us: Disability, Oppression and Empowerment*. Berkeley, CA: University of California Press.
Chataika, T. (2019). Introduction: critical connections and gaps in disability and development. In T. Chataika (ed), *The Routledge Handbook of Disability in Southern Africa* (pp. 3–13). London: Routledge.

Chataika, T. (ed). (2019). *The Routledge Handbook of Disability in Southern Africa*. London: Routledge.

Chataika, T., Berghs, M., Mateta, A., & Shava, K. (2015). From whose perspective anyway? The quest for African disability rights activism. In A. De Waal (ed) *Advocacy in Conflict: Critical Perspectives on Transnational Activism* (pp. 187–211). London: Zed Books.

Cole, T. (2012). The white-savior industrial complex. *The Atlantic*, 21 March.

Cork, S. J., Jaeger, P. T., Jette, S., & Ebrahimoff, S. (2017). The Politics of (dis) information: crippled America, the 25th anniversary of the Americans with Disabilities Act (ADA), and the 2016 US Presidential campaign. *The International Journal of Information, Diversity, & Inclusion* **1**(1), 1–15.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics, *University of Chicago Legal Forum* **1**, 139–167.

Crenshaw, K. (1991). Mapping the margins: intersectionality, identity politics, and violence against women of color. *Stanford Law Review* **43**(6), 1241–1299.

De Waal, A. (ed). (2015). *Advocacy in Conflict: Critical Perspectives on Transnational Activism*. London: Zed Books.

Devlieger, P., Miranda-Galarza, B., Brown, S. E., & Strickfaden, M. (eds). (2016). *Rethinking Disability: World Perspectives in Culture and Society*. Antwerp and Apeldorn: Garant.

Dolmage, J. T. (2017). *Academic Ableism: Disability and Higher Education*. Ann Arbor: University of Michigan Press.

Dyson, S., & Berghs, M. (2019). Ethnicity, disability and chronic illness. In S. Chattoo, K. Atkin, G. Graig, & R. Flynn (eds), *Understanding 'Race' and Ethnicity in Social Welfare* (pp. 27–44). Bristol: Polity Press.

El-Lahib, Y. (2017). Theoretical dimensions for interrogating the intersection of disability, immigration and social work. *International Social Work* **60**(3), 640–653.

Ellis, K., Garland-Thomson, R., Kent, M., & Robertson, R. (eds). (2018). *Manifestos for the Future of Critical Disability Studies*. London: Routledge.

Erevelles, N. (2011). *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. New York: Palgrave.

Eubanks, V. (2018). *Automating Inequality: How High-tech Tools Profile, Police, and Punish the Poor*. New York: St. Martin's Press.

Faulkner, A. (2017). Survivor research and Mad Studies: the role and value of experiential knowledge in mental health research. *Disability & Society* **32**(4), 500–520.

Fearon, K., Papaloukas, P., Rivzi, S., Berghs, M., The People's Forum, Bright Sparks & Arts in Mental Health – Leicestershire NHS Trust. (2018). *Creating diverse coalitions for equality in neoliberal times?*: Presented at the *Locating the emancipatory city* Conference, 4th July 2018, British Sociological Association (BSA) and the Centre for Urban Research on Austerity (CURA) at De Montfort University.

Gerbaudo, P. (2018). *Tweets and the Streets: Social Media and Contemporary Activism*. London: Pluto Press.

Gill, M., & Schlund-Vials, C. J. (2016). *Disability, Human Rights and the Limits of Humanitarianism*. London: Routledge.

Goodley, D. (2014). *Dis/ability Studies: Theorising Disablism and Ableism*. London: Routledge.

Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education* **37**(1), 1–15.

Graby, S. (2015). Neurodiversity: bridging the gap between the disabled people's movement and the mental health system survivors' movement? In H. Spandler, J. Anderson, & B. Sapey (eds), *Madness, Distress and the Politics of Disablement* (pp. 13–25). Bristol: Policy Press.

Groce, N. E. (2018). Global disability: an emerging issue. *The Lancet Global Health*, 6(7), e724–e725.

Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet* **383**(9920), 889–895.

Hickel, J. (2014). The 'girl effect': liberalism, empowerment and the contradictions of development. *Third World Quarterly* **35**(8), 1355–1373.

Inckle, K. (2018). Unreasonable adjustments: the additional unpaid labour of academics with disabilities. *Disability & Society* **31**(9), 1–5.

Ingstad, B., & Eide, A. (eds). (2011). *Disability and Poverty: A Global Challenge*. Bristol: Policy Press.

Karpf, D. (2010). Online political mobilization from the advocacy group's perspective: looking beyond clicktivism. *Policy & Internet* **2**(4), 7–41.

Klein, N. (2017). *No is not Enough: Defeating the New Shock Politics*. London: Allen Lane.

Kolářová, K. (ed). (2016). 'What kind of development are we talking about?': a virtual roundtable with Tsitsi Chataika, Nilika Mehrotra, Karen Soldatic and Kateřina Kolářová. *Somatechnics* **6**(2), 142–158.

LeFrançois, B. A., Menzies, R., & Reaume, G. (eds). (2013). *Mad Matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholars' Press.

Levitt, J. M. (2017). Developing a model of disability that focuses on the actions of disabled people. *Disability & Society* **32**(5), 735–747.

Lin, Z., & Yang, L. (2019). 'Me too!': individual empowerment of disabled women in the #MeToo movement in China. *Disability & Society* **34**(5): 842–847.

Lindgren, S., & Lundström, R. (2011). Pirate culture and hacktivist mobilization: the cultural and social protocols of WikiLeaks on Twitter. *New Media & Society* **13**(6), 999–1018.

Longmore, P. K., & Goldberger, D. (2000). The league of the physically handicapped and the great depression: a case study in the new disability history. *The Journal of American History* **87**(3), 888–922.

McCaughey, M., & Ayers, M. D. (eds). (2013). *Cyberactivism: Online Activism in Theory and Practice*. London: Routledge.

McRuer, R. (2018). *Crip Times: Disability, Globalization and Resistance*. New York: NYU Press.

McWade, B., Milton, D., & Beresford, P. (2015). Mad studies and neurodiversity: a dialogue. *Disability & Society* **30**(2), 305–309.

Milton, D. (2017). *Said the autistic endorsed autistic informed academic: neurodiversity, academia and activism*. Presented at the 9th Lancaster Disability Studies Conference, 11–13 September 2018, Lancaster, UK.

Mji, G., Gcaza, S., Swartz, L., MacLachlan, M., & Hutton, B. (2011). An African way of networking around disability. *Disability & Society*, *26*(3), 365–368.

Mitra, S., Palmer, M., Kim, H., Mont, D., & Groce, N. (2017). Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal*, **10**(4), 475–484.

Mitra, S., Posarac, A., & Vick, B. (2013). Disability and poverty in developing countries: a multidimensional study. *World Development* **41**, 1–18.

Mukherjee, R., & Banet-Weiser, S. (eds). (2012). *Commodity Activism: Cultural Resistance in Neoliberal Times*. New York: NYU Press.

Oliver, M., & Barnes, C. (2012). *The New Politics of Disablement*. Basingstoke and New York: Palgrave Macmillan.

O'Neil, C. (2017). *Weapons of Math Destruction: How Big Data Increases Inequality and Threatens Democracy*. New York: Broadway Books.

Ortega, F. (2009). The cerebral subject and the challenge of neurodiversity. *BioSocieties* **4**(4), 425–445.

Phillips, S. D. (2009). "There are no invalids in the USSR!" A missing Soviet chapter in the new disability history. *Disability Studies Quarterly* **10**(4), 475–500.

Power, A., & Bartlett, R. (2018). 'I shouldn't be living there because I am a sponger': negotiating everyday geographies by people with learning disabilities. *Disability & Society* **33**(4), 562–578.

Rembis, M., Kudlick, C. J., & Nielsen, K. E. (eds). (2018). *The Oxford Handbook of Disability History*. Oxford: Oxford University Press.

Runswick-Cole, K. (2014). 'Us' and 'them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability & Society* **29**(7), 1117–1129.

Russell, E. (2011). *Reading Embodied Citizenship: Disability, Narrative, and the Body Politic*. London: Rutgers University Press.

Russo, J., & Beresford, P. (2015). Between exclusion and colonisation: seeking a place for mad people's knowledge in academia. *Disability & Society* **30**(1), 153–157.

Ryan, S. (2017). *Justice for Laughing Boy: Connor Sparrowhawk – a Death by Indifference*. London: Jessica Kingsley Publishers.

Sabatello, M., & Schulze, M. (eds). (2013). *Human Rights and Disability Advocacy*. Philadelphia: University of Pennsylvania Press.

Shakespeare, T. (2017). Critiquing the Social Model. In E. F. Emens (ed), *Disability and Equality Law* (pp. 67–94). London and New York: Routledge.

Shakespeare, T. (2013). *Disability Rights and Wrongs Revisited*. London: Routledge.

Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian Journal of Disability Research* **6**(1), 8–21.

Sherry, M. (2019). Sex trafficking, activism and disability. In K. Soldatic & K. Johnson (eds), *Global Perspectives on Disability and Activism: Our Way*. London: Routledge. (forthcoming).

Shirky, C. (2008). *Here Comes Everybody: The Power of Organizing without Organizations*. New York: Penguin.

Soldatic, K., & Johnson, K. (2019). *Global Perspectives on Disability and Activism: Our Way*. London: Routledge.

Steele, L. (2018). Restrictive practice in education settings: institutional violence, disability and law. In K. Trimmer, R. Dixon, & Y. S. Findlay (eds), *The Palgrave Handbook of Education Law for Schools* (pp. 533–552). Cham: Palgrave Macmillan.

Steele, L. (2016). Court authorised sterilisation and human rights: inequality, discrimination and violence against women and girls with disability. *UNSWLJ*, *39*, 1002.

Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & Society* **15**, 569–582.

Switzer, H. (2013). (Post) Feminist development fables: the girl effect and the production of sexual subjects. *Feminist Theory*, **14**(3), 345–360.

Tarrow, S. (2005). *The New Transnational Activism*. Cambridge: Cambridge University Press.

Thomas, C. (2004). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research* **6**(1), 22–36.

Trevisan, F. (2018). Connective action mechanisms in a time of political turmoil: virtual disability rights protest at Donald Trump's inauguration. *Australian Journal of Political Science* **53**(1), 103–115.

Tufekci, Z. (2017). *Twitter and Tear Gas: The Power and Fragility of Networked Protest*. New Haven: Yale University Press.

Tyler, D. I. (2013). *Revolting Subjects: Social Abjection and Resistance in Neoliberal Britain*. London: Zed Books.

Tyler, I. (2018). The hieroglyphics of the border: racial stigma in neoliberal Europe. *Ethnic and Racial Studies* **41**(10), 1783–1801.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. New York: UN.

Union of the Physically Impaired Against Segregation (UPIAS). (1976). *Fundamental Principles of Disability*. London: UPIAS.

Vanhala, L. (2010). *Making Rights a Reality?: Disability Rights Activists and Legal Mobilization*. Cambridge: Cambridge University Press.

Vásquez Encalada, A. (2019). The fight to be steadfast: Bolivian disability activists. In K. Soldatic, & K. Johnson (eds), *Global Perspectives on Disability and Activism: Our Way*. London: Routledge.

Watermeyer, B., McKenzie, J., & Swartz, L. (eds). (2018). *The Palgrave Handbook of Disability and Citizenship in the Global South*. Cham: Springer.

World Health Organisation and World Bank (2006). World Report on Disability. Geneva: WHO.

Williams-Findlay, B. (2018). Researching disabled lives in the age of austerity engaging with the 4 Rs: research, rights, resistance, and reclamation. *Creating diverse coalitions for equality in neoliberal times?*: *Locating the emancipatory city* [Conference, 4th July 2018, British Sociological Association (BSA) and the Centre for Urban Research on Austerity (CURA) at De Montfort University.]

Wiseman, P. (2014). *Reconciling the 'private' and 'public': disabled young people's experiences of everyday embodied citizenship*. PhD thesis, University of Glasgow.

Wolbring, G. (2008). The politics of ableism. *Development* **51**(2), 252–258.

Wong, A. (ed). (2018). *Resistance and Hope – Essays by Disabled People: Crip Wisdom for the People*. San Francisco: Disability Living Project.

Woods, R. (2017). Exploring how the social model of disability can be re-invigorated for autism: in response to Jonathan Levitt. *Disability & Society* **32**(7), 1090–1095.

Yeo, R., & Moore, K. (2003). Including disabled people in poverty reduction work: "Nothing about us, without us". *World Development* **31**(3), 571–590.

Yeo, R. (2001). Chronic poverty and disability. *Chronic Poverty Research Centre Working Paper*, (4).

Zhang, C. (2017). 'Nothing about us without us': the emerging disability movement and advocacy in China. *Disability & Society* **32**(7), 1096–1101.

A VIRTUAL ROUNDTABLE

Re/defining disability activism with emerging global South disability activists

Tsitsi Chataika (ed), Samantha Sibanda, Abraham Mateta and Krishna Bahadur Sunar

Introduction

Tsitsi Chataika

The justification for this virtual roundtable book chapter is to interrogate disability activism in the global South from the perspective of emerging disability activists. We understand that a disability rights movement is a global social movement aiming to secure equal opportunities and equal rights for all disabled people (United Nations, 2006). The intention of any disability activism is to break attitudinal, environmental (physical and communication) and institutional (policy and programming) barriers, which prevent disabled people from realising human rights, just like other citizens (Chataika, 2019). Activists and critical disability scholars are aware that the disability community tends to be fragmentary and politically inactive as they are often socially and physically isolated (Haagaard, 2017). This is due to disabled people being usually enculturated by ableism beliefs and disabling models of disability such as the medical and charity models of disability (WHO Health Organization [WHO] & World Bank, 2011; Wapling & Downie, 2012). Thus, disability rights concerns become fragmented as a result of their practical implementation at more localised levels of government. Hence, the need for disability activism, or rather advocacy, which is focused on operational aspects of services rather than the broad systemic issues that underpin issues of inequity and access for marginalised groups (Haagaard, 2017). This is because small-scale interventions are easier to conceptualise and implement, with immediate tangible results to politicians or corporate patrons who tend to sponsor impairment-specific interest groups. That is why top-down charities tend to dominate advocacy work in fragmentary contexts. Regrettably, this disfranchises disabled people making disability rights activism challenging.

It is beyond the scope of this chapter to discuss about the history and status of disability rights activism and related policy-making. Rather, the chapter focuses on re/defining disability activism with emerging global South grassroots disability activists. I am also interested in the emerging disability activists' reflections on the ways in which the notion of disability activism interacts with and influences the way disability is being conceptualised in their cultural locations.

Speaking from the geo-political location of Zimbabwe, I am thinking about the role of emerging grassroots disability activists whose voices are usually overshadowed by the established disability activists. Could we perhaps re-imagine the notions of stuckedness, retrogressiveness, non-development for critical work towards disability activism (Haagaard, 2017), which practically improves the lives of disabled people? Thus, this thematic virtual roundtable as indicated earlier, provides a space for discussion around the issues re/defining disability activism with emerging grassroots disability activists, but also around the questions of productive disability activism. Also, how can there be possibilities for alliances between the global South and the global North in promoting progressive disability activism without undermining each other? I seem to have more questions than answers. To address these and many other questions, this virtual roundtable discussion is structured into three parts. Authors sequentially contribute to the critical questions raised, while basing their arguments with the nature of their grassroots activism work in their countries, at the same time, drawing lessons from other contexts.

Post one

Tsitsi Chataika

To open our conversation, I want to discuss the ways in which our work reflects the geopolitical investments in disability activism. This thematic roundtable is thought to provide a space for discussion around the issues re/defining disability activism with emerging grassroots disability activists, but also around the questions of productive disability activism. Chataika, Berghs, Mateta and Shava (2015) argue that disabled people have always been involved in several of forms of activism. The authors also argue that 'the sites of disability resistance dislocate spaces of activism from global to local and challenge our perceptions of what it means from global to local' (Chataika *et al.*, 2015, p. 188). It also further challenges what it means to have a voice and to be heard. Hence, my initial questions are: Are we witnessing the rise of a new disability activism or is there a need for a new disability activism? Is disability activism just becoming reactionary than social agenda setting? Are identities politics still at stake or are activists moving towards safeguarding disability rights?

Samantha Sibanda

I totally agree with the need to redefine disability activism and engage more into productive disability activism. It is indeed overdue to challenge the current disability activism trend and allow emerging disability activists to have a more pronounced voice within the disability discourse. The new disability activism should channel its energy more on the rights-based approach. As an emerging disability activist, I have observed a sort of competition among disabled people's organisations (DPOs) and disability activists themselves. In Zimbabwe for instance, there seems to have no common disability agenda as each organisation and individuals have their own motives, resulting in having disjointed voices. If a new activism would arise, one that would allow productive discussion forums so that we have a common understanding with regards to disability rights, then a new dispensation would have emerged. This kind of having unified goals will go a long way in influencing policy, with implications for inclusive intervention programmes that can improve the lives of disabled people in Zimbabwe. I also believe that as disability activists, we need the type of activism that enables us to represent all disabled people. For instance, we should be able to have a person with

albinism who is able to articulate issues to do with the hearing impaired or visually impaired people. This is the nature of disability activism I believe would change the status of disabled people in Zimbabwe.

I am convinced that the current type of disability activism in Zimbabwe somehow discriminates nondisabled activists. As a psychiatry survivor, I am concerned about how the United Nations Convention on the Rights of Persons with Disabilities (CRPD) defines a disabled person. Its definition includes those who have long-term physical, mental, intellectual or sensory impairments (United Nations, 2006). Hence, it seems to sideline people like me. So I conform to nondisabled people, together with others who have undergone various rehabilitation interventions. The current activism also sidelines academics, which I find very unfortunate as they research issues from various countries and are informed of what has failed or succeeded. Thus, academics and nondisabled people sometimes do not have a seat at the table, despite the efforts they make in their day-to-day lives. This makes activism challenging for people like me, who cannot always explain their experience as I seem to be a citizen of two worlds (Sithole, 2019). Being a psychiatric survivor and also a seemingly nondisabled person, has given me the privilege to look at the world through the lens of both disabled and nondisabled people.

I am also an ardent supporter of self-representation. However, I feel that that there is need to build the capacity of the crop of emerging disability activists so that they become the catalysts of change that promotes disability inclusion in development processes. I agree with Forber-Pratt and Aragon (2013) who observed that the voice of disabled people is being silenced in discussions about disability. In most cases, it is because most of them are not well-informed about the topical disability issues and the general national debates. That is why I am in support of Charlton (1998) who argue that disabled people need to take control of their own lives. However, without capacity development, the level of disability activism is comprised to petty talks and confrontational disability activism, which unfortunately widens the gap between disabled and non-disabled people (Chataika, *et al.*, 2015). Hence, the need for both disabled and non-disabled people joining hands in creating a more inclusive platform, at the same time, giving disabled people a voice since they are the ones who have the firsthand experience of having impairments.

People with disabilities live in a society and not a vacuum. Therefore, they should engage other people who will also help propel their struggles. In the past, I thought that an activist should be experiencing a situation or speaking on behalf of others. However, I now strongly believe that this should be redefined as I have realised that most activists support and believe in the agenda they are pushing for.

Abraham Mateta

I start my response to this discussion by indicating that Zimbabwe, from where I write, presents a very interesting situation because although belonging to the global South, it produced globally renowned disability rights activists. Obviously, it follows that any discussion of the need for transformation of disability activism in such a situation demands a lucid justification. Secondly, fragmentation to the disability movement as aptly captured by Tsitsi in the introductory part of the chapter and reiterated by Sibanda, is a potent challenge. As activists therefore, we must strive to bring unity of purpose and clarity of thought into the current disability activism at local level. I therefore contend that while the need for change in disability activism cannot be overemphasised, there are some fundamental issues that should be borrowed from the old activism. As emerging activists, while well-grounded in the needs of our locality, we must be able to understand international trends in disability.