



**Theatre and Performing Arts, Disability
Citizenship and Community Development**
- Perspectives from the Global South and North

Vibeke Glørstad, Tone Pernille Østern, Tony McCaffrey,
Kelvin Chikonzo and Nehemiah Chivandikwa (Eds.)

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Introduction: Community Participation through Arts and Cultural Disruptive Citizen Practices

Vibeke Glørstad VID Specialized University, Norway

Tone Pernille Østern NTNU Norwegian University of Technology and Science, Norway

Tony McCaffrey National Academy of Singing and Dramatic Art, Ara Institute, New Zealand

Kelvin Chikonzo University of Zimbabwe, Zimbabwe

Nehemiah Chivandikwa University of Zimbabwe, Zimbabwe

“States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society,” states paragraph 2 of the Convention on the Rights of Persons with Disabilities, Article 30 – Participation in cultural life, recreation, leisure and sport (CRPD) (UN General Assembly, 2006).

In this book, disabled persons’ opportunities and challenges for developing creative, artistic, and intellectual potential are highlighted. Furthermore, both individual and societal enrichment, and barriers to this enrichment, are made visible.

How might inclusive arts practices strengthen active citizenship and community participation? This is the main question that inspired us to engage with glocal collegial networks which led to this book project.

In this introduction we will share the history of the book project. First, we lay out some of the premises and theoretical background for the project. We then present (our always limited) perspectives on: the concepts of community work; disability citizenship; critical disability studies; disability in the fields of arts and culture in the Global South and North; and arts, culture, and disability. We also give short introductions to the 18 peer reviewed

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articles and practical encounters that comprise the chapters in this book. Finally, we offer a few words on what we hope to achieve.

The history of this book project

We invited practitioners and scholars, who want to contribute to developing knowledge of how inclusive arts and cultural practices, combined with critical disability theories, might strengthen active citizenship and community participation for people with limited access to the arts and social communication. Discrimination leading to exclusion from the arts and from active participation in society tend to walk hand in hand (Benjamin, 2002, 2022; Chivandikwa, 2020; Falola & Hamel, 2021; Watermeyer et al., 2019). We, the editors, envision a community of participation and well-being for everyone, in which barriers to inclusion and participation are non-existent. We understand arts and cultural practices as rich and empowering ways of activating partnership, participation, and deconstructing oppressive discourses through the possibilities offered through the arts.

Societal inequality is a persistent and growing challenge, in societies both in the Global South (or the Global Majority) and North (or the Global Minority) (UN News, 2020). Democracy and civil society are under constant pressure, and must be nourished and developed (International Institute for Democracy and Electoral Assistance, 2017, 2023). Democracy needs unruly citizens to avoid the shrinking of civic space (Haerpfer et al., 2009). Arts and cultural practices are a peaceful and powerful way of being unruly and practicing resistance. Cultural forms of expression, such as theater and other performance practices, bring the struggles of those who are marginalized into a public sphere – out into the public space – thus creating places for visibility and dialogue through a diversity perspective (Balme, 2018; Visser-Rotgans & Marques, 2014). The editors foresee theater performances and other arts practices as having the potential to provide disabled participants with opportunities for embodied disruptive citizenship, thus challenging and subverting misrecognition (Fraser, 1992) and political-economic injustices, within and beyond performance and arts communities. This is because citizenship and community belonging are actualized in active participation. A sustained critique of existing ableist practices and discourses is thus achievable to engender alternative modes of theater performance and other artistic participation for communities of

disabled people. Those of us who experience a disability and see disability as a valuable general characteristic of humanity, often feel that agency is complex, contextualized, and challenged.

The authors included in this edited book subscribe to an affirmative and human rights understanding of the experience of being disabled. An affirmative model promotes the experience of differences as positive identities, celebrating people's diversity and multitude, and challenging the value-laden presumption that living with a disability always entails a loss (Swain & French, 2000). The human rights model (Degener, 2016) assumes that experiencing disabilities is rooted in a lack of realization of human rights, as expressed in the Convention on the Rights of Persons with Disabilities (UN General Assembly, 2006). Hence the editors are focused on apparently persisting ableist language, theatrical and artistic forms celebrated in broad theater and arts practice, and the clearly limited visibility of disabled communities in theater and performing arts productions. This limited visibility is really striking, because mainstream theater and other progressive performances emphasize social justice, liberation, and the eradication of dehumanizing elements, such as poverty, apathy, ignorance, and oppression.

Community work

A community refers to a group of people who, although diverse, live in and share a specific geographical space within a common level of infrastructure development (Larsen et al., 2014, p. 3, with reference to Sewpaul, 2008). Community is also defined as a group of people who share a common interest, but may be spatially separate, and indeed may never physically meet (Ife, 2016; Larsen et al., 2014, p. 3, with reference to Sewpaul, 2008, p. 98). Community *work*, then, refers to a method of working with groups of people, including a range of community organizations, for the purpose of enhancing human well-being and fundamental freedoms, and optimizing opportunities and human capabilities (Kenny et al. 2018, Kleibl et al., 2020; Larsen et al., 2014, p. 4). Community work can be either an aim or a process for change. As an aim it is used by marginalized groups to achieve something. In community work as a process, and a bottom-up approach, sustainable changes are achieved when people participate in an active way, bringing to the development process their knowledge, skills, and experience. Several factors may make participation difficult. One could be self-exclusion through lack of self-confidence or that their opinions will

be met with laughter. Self-exclusion may also be an outcome of previous participation without results, so participation is perceived to be worthless (Chataika, 2019; Cornwall, 2008; Larsen et al., 2014; McCaffrey, 2023).

In this book, we advocate community work through the principles of participation and citizen involvement. In each chapter, the authors explore how they, community workers, or artists they have studied with, adopt radical and emancipatory approaches to community work, pursuing “acts of citizenship” (Isin & Nielsen, 2008).

«Acts of citizenship»

As a social science discipline and theoretical analytical framework, citizenship studies have as a starting point, among others, the English sociologist T. H. Marshall who, in the 1950s, tried to describe how the individual’s rights have developed over the centuries. The development is thus summarized: civil rights in the 19th century, political rights in the 20th century, and social rights in the 21st century (Sepulchre, 2021, pp. 2–3). Marshall has been criticized for not looking at marginalized groups in terms of the rights of the population. Not everyone has easy access to the opportunities that might secure rights. Since then, more inclusive citizenship theories have been developed (Donaldson & Kymlicka, 2017; Isin, 2009; Turner, 2016). The emphasis on legal rights has been expanded, focusing on practices that develop citizenship.

One example of developing analytical tools is Engin Isin’s later works, where he sees citizenship as performative, with a basis in language philosophy and performance studies. A performative perspective means understanding people as acting beings, in their objective and subjective situations, focusing on how they enact their subjectivity (Isin, 2017, p. 500). Performativity involves the moment in which a subject – a person or a collective – asserts the right to a livable life, when no such prior authorization (claim) exists. Performing acts of citizenship often invokes a break with convention. To Isin, analyzing citizenship from a performative perspective means recognizing that the extent of our claims both refers to and reiterates social conventions, yet has force and effects that exceed them (2017, p. 501).

Isin further argues that we must focus on *acts of citizenship* to understand how citizenship is developed as a critical and performative methodology. The aim of acts of citizenship, as a conceptual tool, can be understood as shifting from a focus on habits/conduct (behavior) to situations where

claims are made – the act itself (the notion of becoming). The word “act” as a verb means putting something into motion, and being directed towards something. Isin (2009, p. 379) emphasizes that to act is to actualize a rupture (Ames et al., 2019; Glørstad, 2022, 2023). In their book *Performing Citizenship*, Paula Hildebrandt and Sibylle Peters (2019) discuss how cultural co-creation takes place, and what role art may have in developing new citizenship positions in struggles for participation and inclusion: “We see artistic experiments which critically highlight long-hidden aspects of citizenship, promote new emerging agencies, create new choreographies and scores of movements in public space or invent and test nascent institutions” (Hildebrandt & Peters, 2019, p. 2). This book project can be understood as creating space for acts of citizenship through radical and disruptive arts and cultural practices, where critical and performative methodology is put to work. The authors claim, or support claiming, visibility and citizenship, as they explore and articulate the glocal practices in focus. Used as a critical methodology, attention is paid to how subjects constitute themselves as citizens (Andrijasevic, 2013, p. 49) in this book through innovative arts and cultural practices.

Disability citizenship and critical disability studies

Disability is unique as an identity category, because “anyone can enter [it] at any time, and we will all join it if we live long enough” (Garland-Thomson, 2002, p. 20). The aim of the Convention on the Rights of Persons with Disabilities (CRPD) (UN General Assembly, 2006) is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity,” as described in Article 30 – Participation in cultural life, recreation, leisure and sport, paragraphs 1–4.

The authors of this book subscribe, directly or indirectly, to the interdisciplinary and diverse theoretical tradition of critical disability studies as introduced by Melinda Hall (2019) in the *Stanford Encyclopedia of Philosophy*. Theorists and practitioners within this theoretical tradition see experiences of disability as a material and “real,” yet historical, relative, cultural, social, and political phenomenon. Critical disability theory is described as an emancipatory discourse that examines the socio-political constructions of disability, and follows the impact of these constructions

on those who experience disability (Goodley et al., 2018, p. 206; Hall, 2019; Meekosha & Shuttleworth, 2009, p. 48). The starting point is the lived experience of disability. The goal is to change the conditions that oppress individuals' experiences. A fundamental theme in critical disability theory is to visualize and analyze ableism, discrimination based on ability (Campbell, 2009, p. 5; Hall, 2019). Authors of critical disability studies have challenged ableism through deconstructing and criticizing the binary logic of disability versus ability. Dan Goodley (2018) makes a distinction between disablism (the direct discrimination of people with disabilities) and ableism (societal structures and practices that favor non-disabled people). Postcolonial scholars seek to decolonize disability by centering the Global South, challenging neo-colonialism in capitalism, culture, and discourse, and revisiting questions of disability through a diversity of cultural perspectives (Hall, 2019, referring to Meekosha & Shuttleworth, 2009, p. 54). Hall refers to how critical disability theory engages in dialogue among cultures, emphasized by Helen Meekosha and Russell Shuttleworth (2009, p. 54), who "call for an explicit dialogue with human rights and emancipatory thinking from the diversity of cultures," and hope to avoid "projecting an international ideal" from Western to non-Western cultures (2009, p. 54).

Disability in the arts and cultural fields of the Global South and North

The authors of this edited book are based in different parts of the Global South and North. Historically, community work has suffered when it has been shaped – as a colonial and postcolonial construct – and associated with a secondary political agenda of the funding government (Conradie, 2011, p. 312; Sewpaul & Larsen, 2014, p. 233; Watermeyer et al., 2019). In view of dominant discourses and North-South power dynamics, knowledge that emerges within Western contexts becomes valorized and universalized (Hovde et al., 2021). The voices of the "other" have often been silenced, and indigenous knowledge remains marginalized. Assumptions about what constitutes valid knowledge and good practice have contributed to professional imperialism (Sewpaul & Larsen, 2014, referring to Midgley, 1981).

Researchers from the Global South note that the impact of colonialism on disability practices and discourses is still being felt long after independence. Values, beliefs, and practices engendered by the advent of colonialism are still present (Grech, 2015; Ndi, 2012; Shava, 2008; Soldatic, 2015).

Kudzai Shava (2008), for example, posits that disability has long been considered a welfare and charity issue rather than a human rights issue, because of the pervasive influence of Western-based individual charity and medical models of disability, imposed by missionaries and colonial administrators. Even after independence, non-governmental organizations perpetuated colonial practices. For this reason, the policy of institutionalizing disabled people remained unchallenged, even after such practices had been abandoned in their countries of origin (Chataika, 2007). In this sense, Global South scholarship notes that globalization has promoted development discourses, which undermine efforts to politicize disability. An equally crucial argument from the Global South is the apparent ambivalence of Western disability discourse on the increasing incidence of impairments, occasioned by globalizing neo-liberal capitalism (Grech, 2015; Ndi, 2012; Soldatic, 2015). It is noted that this social model generally ignores impairments that are especially prevalent in the Global South. The reality of socially constructed impairments as legitimate human experiences deserves to be recognized, contextualized, and problematized in theatrical performances, which seek disruptive national and global citizenship, and inclusive community participation (Chivandikwa, 2020; Connell, 2011; Ndi, 2012; Soldatic, 2014). The editors envision theatrical performances and arts practices that are sensitive to these geopolitical dynamics.

The disability art movement started in the 1960s, and is now a broad global movement, partly institutionalized in national cultural policies and by global networks (Crossing the Line, 2020; Czymoch et al., 2021; Disability Arts International, 2024). Disability art, culture, and media studies engage with the socially constructed stories that drama, theater, dance, film, television, literature, art, media, and entertainment talk about, as well as what it means to be disabled (Hadley & McDonald, 2018, p. 2). Disability studies and disability arts, culture, and media studies have worked in parallel, and in productive conversation, as mutually committed contributors to the disability rights movement. Bree Hadley and Donna McDonald (2018) elaborate on these issues in their introduction to the *Routledge handbook of disability arts, culture and media*. A range of scholarly literature attempts to identify, document, and describe art, culture, and media practice about, with, or by disabled and deaf people (Hadley & McDonald, 2018, p. 3). Their handbook accounts of professional, experimental, and political arts and media practices by disabled people run parallel with accounts of arts, health, well-being, and therapy projects and practices for disabled people.

The authors argue for more accessible, collaborative, creative research methods that can assist in making different voices heard. Collaboration between scholars in creative fields and the education, social services, science, health, and medicine fields that also research disability issues may create the possibility for relations of interdependency, engagement, conflict, and negotiation (Hadley & McDonald, 2018, p. 17).

This book – negotiating a public sphere

The authors of this book present theater, performance, arts and/or other cultural practices, innovations and strategies that imply practical, social, economic, educational, political, and theoretical actions. These actions help break down specific and general barriers to participation – for artists themselves, but also for community members – in the larger community and society. The authors critically present and discuss methods and models for inclusive and innovative arts and cultural citizenship practices, which leverage off of disability as the special positive driving force and game changer for a more open society (Fraser, 1992, 2009; Hadley & Mc Donald, 2018; Mead & Shawn, 2021; Østern et al., 2023). In this way, cultural citizenship is made visible (van Hensbroek, 2010).

The authors of the 18 chapters in this book engage with theater, performance, arts and/or other cultural practices in different ways, from different critical perspectives, such as dance, performance, theater, and visual arts in local contexts in the Global South and North. These practices might exist in the margins of dominant arts scenes and mainstream society, but they do, we argue, have great expressive power (Anttila & Suominen, 2019). The artists and community members who are the authors themselves, or with whom the authors of this book engage, are people with physical, cognitive or sensorial disabilities, and are thus part of disabled minorities experiencing discrimination in ableist societies at large. In various ways, the chapters are statements in a common public sphere. The statements highlight various forms of criticism of oppressive structures that marginalize experiences of disabilities, at the same time as they highlight inclusive art practices. The chapters document the gap between disabled/abled, at the same time as they go beyond this binarism and highlight structures of opportunity that create equality and inclusion. The contributions in this book inscribe themselves in one way or another onto a radical form of community work, either as critique or support, which the following short presentation of each

chapter reveals. Of the 18 chapters, 12 are peer-reviewed research articles from different, in most cases marginalized, contexts in the world. Further, six practical encounters are included. These are written by practitioners that we wanted to give space to within the mission of this book – to enable opportunities for developing creative, artistic, and intellectual potential among diverse voices.

Peer-reviewed chapters

After the editorial introduction chapter, we allow the book to start with Tony McCaffrey’s chapter “‘We are on the political spectrum’: How is learning disabled theatre political?” The chapter takes us straight into the core of what this book is about: The creation and development of theater as art, and how this artistic endeavor connects with creating space for disability citizenship and community development. McCaffrey is the artistic director of Different Light Theatre located in Christchurch, New Zealand, and in this chapter, he explores the political potential and significance of learning disabled theater. The author concludes that we are all located somewhere on a spectrum.

In “Vulnerable agencies: A performative research assemblage on dis/ability” Liisa Jaakonaho describes an artistic research process stemming from her work as a dance pedagogue in disability services. Her aim is to develop a nuanced and ethically sensitive understanding of diverse and vulnerable agencies in the boundary areas between arts, research, and social care. With her performance installation at the New Performance Turku Festival in Finland in 2018 as a pivoting point, Jaakonaho considers the complexity of participation, power relations, and decoloniality in artistic research, based on methodological experiments and theoretical discussion, including the ethics of care, vulnerability, dis/ability, and ableism.

“Breaking barriers through theatre: The case of King George VI Centre in Bulawayo” by Cletus Moyo, Nkululeko Sibanda, Courage Chipatiso, and Inez Hussey explores the way that King George VI (KGVI) Centre in Bulawayo, Zimbabwe sets out to break barriers that limit people’s agency and participation in social and public spheres of life. King George VI is a purpose-built center for physically and hearing-impaired young people ages 3 to 20. The authors scrutinize the theatrical works entitled *I Am Disabled, So What?* and *Dancing Queen*, created with young disabled people at the center, and how they are agentic, transformative, and barrier-breaking.

In “We do not need pity. We need opportunities. Consideration of a performer with differentiated body” Felipe Henrique Monteiro Oliveira and Andrea Pagnes advocate a politics of care as they analyze Oliveira’s artistic experience of having lived in a region of northeastern Brazil, which is still permeated by a culture of intolerance and indifference. Taking the readers through the historical emergence of performance art as a place where the artist’s body is the main material used to challenge social norms, the authors identify performance art as a practice that does not discriminate against *differentiated bodies*, a concept coined by Oliveria.

In “Performance of protest – people with learning disabilities marching in the streets of Trondheim, Norway, 2019” Vibeke Glørstad analyzes an event where a group of people – people with learning disabilities, their families, and social and health workers – marched in protest through the streets of Trondheim, Norway. They had had enough of budget cuts, and delivered signatures to the deputy mayor, asking for a dialogue with politicians. The author approaches this performance of protest through the lens of performativity, and the civil right of freedom of assembly, arguing that the performative power of assembly strengthens citizen status and practice for people with learning disabilities.

The next chapter is written by Aleksandra Dunaeva, a Russian project maker in socially engaged arts, currently living in Finland. “The Meeting – The Apartment – Conversations. The Right to Be Present: An inclusive project in search of its own place in Russia’s theatrical art of the 2010s and early 2020s” questions the place of inclusive theater in the sphere of Russian culture given the country’s growing autocracy. With Russia’s full-scale invasion of Ukraine happening during the period this book was written, the editors acknowledge that the author is taking a risk in contributing this critical chapter.

Ciane Fernandes takes on the perspective of a Brazilian mother and caregiver of a severely autistic young adult in her chapter “Towards an intermodal merger: Somatics, disability, and Brazilian collaborative performance”. She discusses an educational system that perpetuates neurotypical models; an academic context that excludes disability from social justice debates, events, and actions; and a society that insists on erasing the perspective, experience, and unique contributions of people with disabilities. Exploring the affinity between somatics, performance, and neurodivergent perception, she offers somatics and intermodal performance as neurodiverse modes of integrating and creating new possibilities for a more egalitarian and participative world.

In “The potential of visual arts in the reinforcement of citizenship for individuals with intellectual disabilities in Norway” Daniela Musli explores outsider art as a person-centered form of visual art, created by self-taught artists who work outside the established visual arts systems. She scrutinizes the work of Arnstein Aano, an artist with disabilities living in a Norwegian residential care facility. As a result, Musli advocates the use of visual arts as an everyday tool to enhance citizenship for individuals with intellectual disabilities, guided by ethical principles from Norwegian social educators, the Convention on the Rights of Persons with Disabilities, and the human rights model.

With his chapter “Representation of disability identity in Sinhala Theatre” Nimal Wijesiri addresses issues related to disability identity representation in Sinhala Theatre, in a Sri Lankan context. Wijesiri conducted a case study in connection with the Samanalayaya (Butterfly Plane) Theatre Festival, organized by the Sunera Foundation in Sri Lanka. His study reveals that the Buddhist concept of *karma* is the most influential phenomenon with respect to a religious/charity model of disability in the Sri Lankan context. Dialoguing with critical disability theory, combined with identity theory and intersectionality, the author argues that this religious influence challenges the critical thinking capacity of Sinhala Theatre practitioners.

Through an analysis of the hip-hop dance production, *Broken Pavement*, Gugwelihle Ngwenya, Courage Chinokwetu, Kelvin Chikonzo, and Nehemiah Chivandikwa examine how Blessing Fire, a physically impaired dancer, resists and dismantles stereotypical constructions and representations of people living with disabilities, resulting in their chapter “Celebrating embodied agency in disability performances in Zimbabwe: The case of Blessing Fire’s *Broken Pavement*”. In tandem with critical disability theory, especially the affirmative model, the authors demonstrate how Blessing Fire transforms performance space into a site for celebrating and communicating disability corporeal politics, using dance as a vehicle of liberation and resistance against imposed forms of oppression of disabled people.

Hilde Guddingsmo has explored the working methods of Teater non-Stop, an ensemble of 15 professional actors with learning disabilities and six social educator students, owned by Namsos municipality in northern Norway. The research material analyzed in the chapter “Promoting ownership through joint improvisation on ephemeral ideas. Lessons for the field of social work from exploring the methods of Teater nonStop, a professional

ensemble of artists with intellectual disabilities” consists of a conversation between the artistic director, Line Strøm, and the author. This discussion reveals how the creative work succeeds by offering empowering levels of openness and recognition.

Tone Pernille Østern, Terje Olsen, Elen Øyen, Lise Lien, Lene Christin Holum, Anne Ogundipe, and Kaja Tvedten Jorem explore structural barriers for co-designed research in their own collaborative process between disabled and non-disabled researchers, and commissioners, in the chapter “Towards a crippling of research practices – peeling off ableist structures in an arts, culture and disability researcher and commissioner collaboration in Norway”. In dialogue with critical disability theory, the authors scrutinize their own process, arguing that *cripping* research structures must be part of research projects trying to crip society, arts, and culture. Otherwise, the ableist system might repeat itself within the research.

Practical encounters

“Adaptive dance and physical theatre at Dissimilis” presents the methods developed in Dissimilis’ national competence center in Norway, a center for people with developmental disabilities. Adaptive dance and physical theater mean that the lessons are designed for people with a developmental disability, and that through adaptation participants can feel accomplishment, joy, and get to move in their own ways. The author, Caroline Marie Sprott, has, since 2017, been responsible for the adaptive dance and theater lessons at Dissimilis, as well as for their productions’ choreography. In this practical encounter, she explores and articulates her own teaching practice.

The practical encounter “Theatre of the deaf: An Amakhosi Theatre experience” is written by Cont Mdladla Mhlanga, and mildly revised by the editors after his passing. The chapter documents and tributes the work of Mhlanga, as the Zimbabwean *Amakhosi Theatre’s* executive artistic director, and the theater’s actress and theater director, the late Gogo Thembi Ngwabi, for the deaf community in Bulawayo, Zimbabwe. Amakhosi Theatre was founded in 1980 and staged its first play *The Book of Lies* in Bulawayo in 1982. The chapter describes how their collaboration with Rosemary Zhira pushed Amakhosi to work with deaf members in play writing, acting, production and performance.

“AMANZI: An inclusive theatre project between three institutions in Zimbabwe and Switzerland” is a practical encounter written by Fortune

Ruzungunde from Bulawayo, Zimbabwe. In the project focused on in the chapter, Ruzungunde worked with artists from King George VI, an institution that caters to people with disabilities, and also hosts arts programs in Bulawayo, Zimbabwe and Theatre Hora in Zurich, Switzerland, a theater company of artists with mental disabilities. The collaboration started in 2003, and ended with the musical folk drama entitled *AMANZI – grosse und kleine Tiere* [AMANZI – big and small animals] that toured Switzerland in 2005.

Josadaque Albuquerque da Silva Pires, Nara Salles, Felipe Henrique Monteiro Oliveira, and Andrea Pagnes explore an artistic residency that culminated in “(Lou)Cure-se!!! An Artaudian approach to existence in scenic instaurations at the Psychiatric Hospital Dr. João Machado”. This is a series of scenic instaurations displayed in a hospital pavilion in the psychiatric hospital, Dr. John Machado, in Natal, Brazil in 2016. The project *Literacy in contemporary art and creative processes: Investigations about madness* was conducted by students from the art department of the Federal University of Rio Grande do Sul, to benefit mental health patients, their corporeity, and daily intersubjective interactions.

“Including Irina: A personal retrospective and sideways glance from a theater critic on being an artist with a disability in the 1980s and 1990s” by Sara Granath is a reflection on the road taken by the disabled from being audience, to being represented in various media, to being the creators and artists themselves. Examples are given from the 60’s onwards, with the main focus on the accomplishments of a writer/actress from Finland with Down’s syndrome. The text also touches on the benevolent reactions from people wanting to protect these artists from exposure.

Tine Skjold has, since 2020, been the Director of NUK – Ny ung kunst (New Young Art), an annual, inclusive art festival for young people (14–20 years), established in 1992 as part of the larger festival, Festspillene i Nord-Norge (The Festival of Northern Norway). In the practical encounter “Exploring inclusive art practices in the context of CRPD” Skjold critically and self-reflectively looks at how she could use the CRPD to further develop inclusive art practices in her capacity as the director of an inclusive arts festival for youth.

As a final word and “push” into the reading of the chapters of *Theatre and performing arts, disability citizenship and community development – perspectives from the Global South and North*, we wish to emphasize that community participation and (the work for) active citizenship are about

values, attitudes, and an orientation towards active participation of all stakeholders in arts and performance culture: writers, directors, producers, disabled participants, and the audience. The editors realize that this entails combining the intellectual, social, aesthetic, and socio-political resources of the broader community with the corporeal, cognitive, and social skills or competencies of disabled theater and other arts participants and audiences to create communities, stories, and images, which recognize and assert the much-maligned disabled body for disruptive citizenship. Hence the need for sustained focus on the participation of disabled theater, performance, and arts participants/audiences as thinkers, organizers, creators, and performers, is premised on the recognition that their participation in theater and arts (particularly as creators and performers), and related processes, is not automatic, given the years of artistic marginalization and the apparent ableist nature of theater and arts. There is, therefore, an urgent need to foster the participation of disabled communities in theater and arts processes, in ways that might stimulate radically new emotions, physical states, and social attitudes that legitimize disabled bodies within and beyond performance spaces.

Author biographies

Vibeke Glørstad, is a senior lecturer at VID Specialized University, Faculty of Health Science, Stavanger, Norway, a BA in social education and Licentiate Degree in Sociology and Cultural studies from the University of Oslo. Her teaching expertise includes social education/social work at BA level and at the Master's degree in citizenship and co-operation within the health, social, cultural and educational field. Her research interest is related to how vulnerable groups as people with disabilities access and practice their citizenship rights, based in critical disability perspectives. She publishes on political and cultural inclusive citizenship practices by people with disabilities and marginalized groups. Glørstad is a member of the *Performance and disability working group in IFTR* (International Federation of Theatre Research), with a rich international network.

Tone Pernille Østern Tone Pernille Østern has a Dr. of Arts in Dance with a focus on dance and disability from the Theatre Academy, now part of the University of the Arts Helsinki. She is Professor in Arts Education with a focus on Dance at the Department for Teacher Education, NTNU

Norwegian University for Science and Technology, and Visiting Professor in Dance Education at Stockholm University of the Arts. She is active as artist/researcher/teacher with a special interest in participatory arts, choreographic processes, inclusive and critical pedagogies, bodily learning, and the performativity of research, learning and teaching. She co-authored *Artist – an available profession? A research project about artists with disabilities in Norway* (2023) commissioned by Arts and Culture Norway and co-leads the research group *How to do things with disabilities*. She is Editor-in-Chief of the peer-reviewed journal *Dance Articulated*.

Tony McCaffrey, BA(Hons), PhD, Senior Lecturer, National Academy of Singing and Dramatic Art, Ara Institute, Christchurch New Zealand. Artistic Director, Different Light Theatre, an ensemble of learning-disabled performers, Co-convenor, Performance and disability working group, International Federation for Theatre Research. He has contributed articles to Theatre Research International, Global Performance Studies and Performance Philosophy. He is the author of *Incapacity and theatricality* (Routledge, 2019) *Giving and taking voice in learning disabled theatre* (Routledge, 2023) and is currently working with the Different Light artists on *The ends of theatre: Learning disabled performance and research* (Routledge, forthcoming).

Kelvin Chikonzo is an Associate professor in Theatre/ Performance and Film at the University of Zimbabwe. He is interested in identity driven models of empowering and recuperating marginalised/ subaltern voices. He deploys applied media with clear strategies of structure and form that not only unveil instances of subtle oppression but possible means of resistive agency imbedded in stories told from below. As a direct outcome of his doctoral studies, he developed a transformative media model which is being piloted in the making of documentaries, docu-dramas and verbatim performances on disability, gender based violence and substance abuse.

Nehemiah Chivandikwa is a Professor at the University of Zimbabwe and holds a PhD in applied theatre and development communication from the same university. His major research projects focus on applied media development communication with a particular emphasis on disability, gender and rural development in theatre, television, participatory video and community radio. He has a particular interest in audience studies /

reception of political theatre and radio/television programs on politics in Africa. He researches on how structural factors impact on the production and reception of media and theatre productions. In the past three years, professor Chivandikwa has convened Media against Phobias conferences and Media and Crisis Communication Workshops.

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CHAPTER 1

'We are on the Political Spectrum': How is Learning Disabled Theatre Political?

Tony McCaffrey University of Canterbury/ Te Whare Wānanga o Waitaha, New Zealand

Abstract: In this chapter the author, the artistic director of Different Light Theatre located in Christchurch, New Zealand, explores the political potential and significance of learning disabled theatre. To do so, the author elucidates how various meanings of 'political' inform the emergence, the creation and work practices, and the representational politics of the theatre. He draws on 20 years of experience creating theatre, and of working and being together with the learning disabled artists of Different Light Theatre. The company's work has emerged in the context of the specific political context of learning disability in Aotearoa/New Zealand, expressed on the educational, juridical and social level. The company was formed in 2004 as A Different Light: to align with the notion of perceiving learning disabled people 'in a different light'. In the chapter, the concept of a 'political spectrum' is used as a multi-faceted framework to explore the complexity of political representation for learning disabled people, who often have limited or marginalised access to personhood. Building on a rich variety of practices, which are scrutinised in the chapter, the author presents the idea that 'a spectrum' suggests gradation but also connection, and even inclusion. We are all somewhere on a spectrum.

Keywords: learning disability, disability culture, performance studies, theatre studies, aesthetics and politics

Introduction: The political spectrum of Different Light

In 2019, the New Zealand learning disabled theatre company, Different Light, acknowledged 15 years of working together to create performances with *The History of Different Light* (McCaffrey, 2019), a production presented in the Christchurch Arts Festival. In a sequence in which the eight learning disabled performers introduced themselves and the company to the audience, performer Isaac Tait made a statement that he had contributed to the creation process: 'We are on the political spectrum.' In the immediate context of the performance, the audience laughed at Tait's self-presentation and description of the company. A young man, whom many in the audience would describe as 'on the autistic spectrum', flipped the script on the discourse of (self-) diagnosis and identity. Rather than communicating disability, he affirmed the possibility of his and the group's participation in political engagement. Most importantly, though, he did so with irony and self-deprecating humour. The utterance was performative in a number of ways: a refusal to disclose diagnosis; an act of affirmation; and an acknowledgement of the 'fugitivity' (Moten, 2018) of social and aesthetic representation, and, by implication, of the group's own sense of itself.

I would like to consider how that humorous statement is deeply resonant in terms of the political potential and significance of learning disabled theatre. In order to do so, I will try to elucidate how various meanings of 'political' inform the emergence, the creation and work practices, and the representational politics of this form of theatre. I will make use of the concept of a 'political spectrum' as a multifaceted framework, within which to account for the complexity of political representation for learning disabled people, who often have limited or marginalised access to personhood, to being considered political subjects. The idea of a spectrum suggests gradation but also connection, and even inclusion: we are all somewhere on a spectrum. In effect, though, many learning disabled people might be described as being on the outer edges of any social spectrum. There is, however, much to be gained by conceptualising the inclusiveness of a wide-ranging spectrum. In a negative sense, as history teaches us, the oppression or denial of rights happening today to those on the margins of the social network is likely to happen tomorrow to those who now feel more secure within the norm. In a more positive sense, the

accommodations we need to make to promote inclusion of those in the margins will be the accommodations most, if not all, of us will need in the future, if we are fortunate enough to continue our life journey through the later stages of ageing.

Learning disabled theatre as a spectrum of meanings and implications

The spectrum of light of the rainbow is the generally recognised symbol for inclusion: in the Bible, this spectrum of light is a covenant of hope after disaster. In taking up Tait's formulation of a 'political spectrum', I wish to consider the hope of inclusion that underlies this phrase, but to temper this with a consideration of the etymology of 'spectrum' that connects it, according to the Oxford English Dictionary, through the Latin 'specere' meaning to see, to 'spectre' or phantasm. The promise of inclusion is often belied by a lack of meaningful or effective action, and remains just a promise or, in effect, an unachievable phantasm of inclusion for those excluded. In addition, the question needs to be asked as to what promise there is in the promise of inclusion. In simple terms, into what kind of inclusion are learning disabled people being invited – into what kind of political situation – into what norms of behaviour? Does inclusion mean inclusion as economic units, as entitled selves, or autonomous personhoods of neoliberalism, which ignores the urgent need for collaboration and attention to and attunement to the cries of the planet? Or are there other possibilities that recognise the need for mutual cooperation and recognition of the needs of diverse humans and the non-human? Our current moment has been characterised by Fred Moten and Stefano Harney in *All Incomplete* (2021) as 'the socio-ecological Disaster' (p. 1). How can making learning disabled theatre have any impact on, or make any contribution to, this current complex, global political situation? Answering this question involves considering the various ways in which learning disabled theatre is political. Learning disabled theatre is situated within a spectrum of different meanings and implications of the political. Like the colours of the rainbow these different meanings of politics gradually and almost imperceptibly blend and gradate into each other, and like the colours of the rainbow they are capable of combining amongst themselves into new, unexpected, and beautiful variations and possibilities.

The 'inherent politics' of learning disability

To cite Kenneth A. Kavale and Steven R. Forness (2016, unpaginated), '[t]he field of learning disabilities is inherently political'. The core political truth of this statement is that the field of learning disabilities has not been constructed by learning disabled people. 'The field' is a field of study and practice far too often enacted upon, around, and about learning disabled people, without meaningfully involving or engaging them as subjects. Even using the term 'field' of learning disability, or referring to 'someone who works in the field', exposes the epistemic injustice (Fricker, 2017) to which learning disabled people are subjected. This field is generally not a level playing field.

The political construction of learning disability is apparent from the very moment of diagnosis, or, as Althusser would term it, interpellation. In the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013, p. 33), autism spectrum disorders are listed as including the following:

Asperger's syndrome (which term has recently become mired in political controversy in Sheffer's (2018) revelation of Hans Asperger's ties to the Nazi Party and the euthanasia of disabled people), Rett syndrome, childhood integrative disorder, Kanner's syndrome and pervasive development disorder.

This particular process of diagnosis is already clearly implicated with a history and continuing impulse towards eugenics, and the threat or actuality of erasure of disabled people. This threat is on an existential or ontological level. To be diagnosed is to be disabled. To be diagnosed with autism spectrum disorder, an individual must have 'deficits in social communication and social interaction' (DSM, 2013, p. 50), and show restrictive and repetitive behaviours. What the DSM does not say is how being subjected to such a diagnosis itself might bring about the very educational and social marginalisation and stigmatisation that determines and exacerbates such 'deficits'. A diagnosis of learning or intellectual disability is in many instances actually performatively disabling. The complexity of the situation is, however, that in many countries funding and support is dependent upon such diagnosis.

The operational politics of Different Light Theatre

I wish to give a specific example of working within the complex politics of learning disability by drawing on my 20 years of experience creating

theatre, and of working and being together with the learning disabled artists of Different Light Theatre. The company's work has emerged in the context of the specific political context of learning disability in Aotearoa/New Zealand, expressed on the educational, juridical and social level. The company was formed in 2004 as A Different Light, to align with the notion of perceiving learning disabled people 'in a different light'. A charitable trust was formed in this name, but over the years the indefinite article was dropped – and at times the word 'theatre' – as the activities of the company have become more diverse, and moved away from the designated buildings and practices of theatre, into performance and forms of activism. The company has had a precarious relationship with money throughout its existence, sometimes receiving local and national government funding, and a box office that has sometimes allowed the remuneration of the participants, sometimes not.

The company emerged from a city council initiative to include learning disabled people in theatre, which funded my leading an 8-week series of workshops within Hohepa Canterbury, Christchurch, a residential institution for learning disabled people. At the conclusion of the workshops, I did not wish to walk away. With the help of drama students from the National Academy of Singing and Dramatic Art (NASDA), where I work as a tutor, I established a performance company. The company has included between ten and twenty learning disabled performers, some with Down's syndrome, some diagnosed with autism, some with cerebral palsy, some with additional physical disabilities. It has also included a small team of never more than three or four non-disabled participants. We have operated in a variety of roles, which have been effectively analysed and developed through Yvonne Schmidt's engagement with practice in her article, "Towards a new directional turn? Directors with cognitive disabilities" (2017). These roles include: organiser (organising transport, schedules, and spaces and times for the learning disabled artists); coach (providing ongoing training in basic aspects of theatre); framer (providing a creative structure within which the learning disabled artists are free to create); filter or curator and editor of artistic ideas; artistic collaborator; and the more nebulous role of creative enabler, seeking to accommodate access, support, and the artistic process at the same time.

During the 20 years of Different Light Theatre's existence, I, as a theatre practitioner, founder and director of the company, and recently researcher, have attempted to engage the learning disabled performers in different modes of theatre and performance: naïve community theatre,

conventional dramatic theatre, postdramatic theatre, immersive, interactive, intermedial theatre, ecological theatre, and performance as research. These descriptors might appear abstract and academic, but the theatrical practices they describe need to be eminently understandable, practicable, and crucially, enjoyable, in order for actors to participate. The learning disabled actors of *Different Light* have had no problem engaging in these different modes of performance. They have proven more than capable of creating naturalistic characters; slipping in and out of ‘character’; collaborating in site-specific theatre; engaging audience members in immersive environments; incorporating pre-recorded and live-feed video, voiceovers and voice manipulation; participating in non-conventional performance in the streets of quake-damaged Christchurch (Kuppers, 2015); and collaborating with disability artist and scholar Petra Kuppers in gentle, environmentally conscious performances at Waikuku Beach (Kuppers, 2017). With each successive development, however, the performers themselves changed the goalposts in myriad practical, technical, material, unimagined and imaginative ways, shifting the paradigms and sending us, the non-disabled facilitators, back to the drawing board to reconfigure what we collectively understand as theatre, and the political and aesthetic assemblage that constitutes the group.

Transition

To give one example of how the local political conditions in which the group operates intersect with the creation and performance practices of the group, I will refer to the 2016 production, *Three Ecologies of Different Light* (McCaffrey, 2016), created by the company and presented at the Performance Studies International Conference at the University of Melbourne in Australia. The piece opened with what appeared to be a simple question about theatrical performance: How do they remember all those lines? This is a prevalent cliché of an audience’s response to theatrical performance. It is, however, quite a nuanced question, since it at once acknowledges the virtuosity of actors, whilst at the same time reducing the complex processes of theatrical performance to a feat of remembrance. The question was intended to capture this ambiguity in the performer/audience relationship, whilst at the same time resonating differently in the context of a learning disabled theatre performance. It was intended to challenge

audience assumptions about the cognitive (dis)abilities of the performers, implying an underlying question: How do learning disabled performers remember lines at all? The question was implicitly answered performatively, given that the performer had remembered this line, as had all the other performers all the other lines. The sequence that followed also presented a parody of the conventional disciplinary process of line learning. Performer Peter Rees, in the persona of an educator-cum-sergeant major, drilled the rest of the ensemble in learning a text taken from the *New Zealand Ministry of Education National Transition Guidelines* (Guidelines for transitioning students with additional learning needs from school to adult life). The text was as follows:

A transition is a process, not a one-off event. During transition an individual student receives support, through planning, to identify and achieve – or move closer to – their career and lifestyle aspirations.

(National Transition Guidelines, New Zealand Ministry of Education, unpaginated)

In New Zealand most learning disabled people attend high school, normally for non-disabled pupils between the ages of 13 to 19, until they are in their 20s. 'Transition' is a process with which all the Different Light performers are familiar, and within which they largely still remain. It consists of a continuing cycle of supported activities: sports, hobby courses, and forms of occupational therapy. There is nothing wrong with these activities in themselves, but the problem with this situation lies in the phrase that is positioned in apposition in the Ministry of Education guidelines – '*or move closer to – their career and lifestyle aspirations* (my emphasis added).' For many learning disabled people in New Zealand, transition is a bridge to nowhere. They do *not* move any closer to a career or lifestyle aspirations. Transition offers a circuit of well-intended 'activities', without the possibility of any staircasing into meaningful and paid employment or meaningful social inclusion. In the theatre production something of the frustration of the performers, and of the repetitive nature of these activities, was suggested by the sequence in which Peter Rees drilled the performers in the rote repetition of the lines about transition. Rees employed a number of strategies of his own choosing, which included word by word repetition, peremptory instructions to deliver the lines 'louder, faster, and funnier', and dramatically increasing the pace and intensity of his instructions. He joyfully acknowledged that he modelled these strategies on some of my

cruder attempts to ‘direct’ the performers. By good humouredly doing this he caused us to consider in what ways making and performing learning disabled theatre was like or unlike the circular activities and hobbyist pastimes of ‘transition.’ If Different Light eschewed the path of conventional, ‘professional’ theatre in favour of performance research and presentations at academic conferences, were we foreclosing options for the performers to gain meaningful paid employment as working actors? This is a dilemma we continue to address. The contributing factors remain financial, and include the infrequency of paid employment opportunities for learning disabled actors in the very small ‘industries’ of theatre and film in New Zealand. In addition, in New Zealand as in other countries, paid work as performers often jeopardises government benefits that people need to meet their daily needs. To highlight this financial quandary, when the Different Light performers returned from performing *Three Ecologies of Different Light* in Melbourne, they had received letters from the Ministry of Social Development informing them that, as they had not informed the ministry of their departure from New Zealand before they left, their disability benefit payments for that period had been stopped.

The politics of representation: Intersectionality and identity

Learning disabled theatre covers a variety of different practices in different parts of the world – mainly, it must be admitted, in the Global North (or the Global Minority). However, it is my contention that, at its heart, learning disabled theatre contributes to social and artistic ecologies, which has implications for the division between the Global North (or Global Minority) and the Global South (or Global Majority). These practices range from community or institutionally based theatre, which prioritises participation over the theatrical innovation or virtuosity of the professional companies that regularly tour the international festival circuit: Australia’s Back to Back, Switzerland’s Theater HORA, and the UK’s Mind the Gap, to name some of the most prominent. The performances of these companies have generated responses and critical discourse that open up and challenge what is meant by theatrical performance, as well as what is meant by ‘learning disability’. One of the key areas of this investigation is what might be termed representation and identity. The slogan ‘representation matters’ has almost reached the level of cliché at present, to signify the desire to include

various manifestations of what might be termed the spectrum of identity: the particular diversities of ethnicity, religion, gender and gender identity, and dis/ability. The phrase 'identity politics' has either highly pejorative or positive connotations, depending on the positionality of the speaker. Fred Moten offers a salutary warning not to ignore the *politics* in identity politics, which offers a critique of 'non-male, non-straight, non-white' identity, while courteously leaving politics to its own uncriticised devices (Moten, 2016, unpaginated).

The identity of learning disabled artists is complex and implicated with the tensions that Erin Manning refers to in the following:

How to problematize identity while remaining sensitive to the fact that for some the loss of a sense of identity may feel like the very same gesture as the colonial act of exclusion from the category of the human. (Manning, 2020, p. 354)

At the same time, recent developments within the field of disability studies have acknowledged the substantial lack of intersectionality, to use the term coined by Kimberlé Crenshaw (1989), in the field. This revelation is exemplified in Christopher Bell's intervention in the *Disability Studies Reader*. In his chapter "Introducing White Disability Studies: A Modest Proposal", he characterises White Disability Studies' tendency to:

...whitewash disability history, ontology, and phenomenology. White Disability Studies while not wholeheartedly excluding people of color from its critique, by and large focuses on the work of white individuals and is itself largely produced by a corps of white scholars and activists. (Bell, 2006, p. 275)

The post-colonial politics of Different Light

Different Light Theatre has emerged in the post-colonial environment of Christchurch in Aotearoa/New Zealand. In all honesty, the make-up of the group over 19 years has been largely white – albeit with significant contributions and participation by Māori, Filipino, and Black South African performers and creatives. The changing core ensemble of performers themselves has been keen to incorporate Te Ao Māori (the Māori way) in the activities of the group, because such elements are part of New Zealand schooling, and a part of asserting their own sense of identity in the face of the challenges and stigmatisation concomitant with the diagnosis of learning disability. In the group's early productions, which included two

Māori performers, we incorporated sections of text in Te Reo Māori. And in *Ship of Fools* (2007), which toured to the Awakenings Festival in Australia, we included a scene in which learning disabled actors playing Captain Cook and his crew ‘discovered’ a New Zealand that was already there and already inhabited, but by present day urban Māori, bemused by the arrival of Europeans from the eighteenth century.

The group as a whole is also aware of the dangers of tokenism in aesthetic and political representation, and what has become known as ‘performative’ activism. The group presented a mock PowerPoint presentation on the recovery from the Christchurch earthquakes presented at the Arts Access conference at the Concourse, Chatswood, in Sydney in 2012. In this presentation, a feature was made of the participation of Kim TePaiari Garrett, as assistant director and stage manager for the group. In introducing themselves, the group parodied the tokenism of biculturalism and ‘inclusive’ strategies, such as acknowledgement of the ‘ownership’ of the land:

ANDREW: We live in Christchurch in the South Island of New Zealand
 JOSIE: New Zealand is sometimes called Aotearoa
 BEN: Because we are sometimes a bicultural country
 KIM APPEARS
 ALL: Hi Kim
 KIM: Kia ora
 ALL: Kia ora
 BEN: See? We’re bicultural
 ANDREW: Christchurch was designed and built by the Anglicans in 1840
 BEN: But the Ngai Tahu iwi (South Island tribe) was already there
 KIM ENTERS AGAIN
 ALL: Hi Kim
 KIM: Kia ora
 ALL: Kia ora

In subsequent performances, the group has continued to draw on the difficulties of occupying the position of Tangata Tiriti, a Te Reo Māori term for non-Māori, meaning people of Te Tiriti O Waitangi/the Treaty of Waitangi (1840). Signed in 1840, this is the foundational document of Aotearoa/New Zealand, which established the basic principles of recognition and protection of *tino rangatiratanga*: Māori autonomy and self-determination, equity, active protection, and partnership. These principles, establishing the relationship between Māori and the Crown, stand in interesting apposition with the United Nations Convention on the Rights of People with

Disabilities (United Nations, 2006), to which New Zealand is a signatory. There is no ADA (Americans with Disabilities Act) or DDA (the Australian Disability Discrimination Act) in New Zealand, but there is now a Minister for Disability and a New Zealand Disability Strategy (2016–2026). Recently the intersection of the rights of Tangata Whenua (people of the land or Māori) and disabled people has seen the development of new words in Te Reo Māori for disability, which expand the possibilities for an indigenously-led vision of disability. The word chosen for 'disability' was *whaikaha*. *Whai* means to be equipped with, to have, to possess or acquire, and *kaha* means to be strong, able, courageous, intense, energetic, as in the common expression *kia kaha*: be strong, stay strong. The Māori word for disabled could thus be translated as being equipped with intensity and energy – as anybody with a disability surely needs to be in a world not designed for them. The word chosen for autism was *takiwatanga*. *Taki* means one by one, each and all, *wa* means time, and *tanga* means space. *Takiwatanga*: to each and every one, their own time and space.

Different Light has stood its ground in Ōtautahi, Christchurch through the earthquakes of 2010 and 2011, the mosque massacres of 2019, and the lockdowns and isolation of the COVID-19 pandemic of 2020 onwards. The company claims the city and the theatrical space as its *turangawaewae*, or place on which it stands and from which it speaks, whilst recognising that its claims to both spaces are precarious and contingent. *Three Ecologies of Different Light* opened with a version in English of a Māori *pepeha*, or formal greeting, in which each performer came on stage and spoke of their attachments to family or tribe, their river, and their mountain. When all were assembled, they then spoke of the *whakapapa* or genealogy of Different Light, an unscripted account of names of people, places, and performances that defined the group standing on stage at that moment. It was an attempt to invoke the strength and support of all who had contributed to the group up until then.

In 2021–2022, in preparation for a group presentation at the Performance Philosophy Problems conference at the University of the Arts in Helsinki in Finland, the group explored the journeyings of Māui, the cultural hero and trickster of Māori and Polynesian mythology, and how these stories related to their own experience. Māui had a difficult birth. Born well before his time with a frail body, nobody thought he could survive, and because of this his mother decided to throw her child into the ocean. In many accounts his mother threw her premature infant into the sea wrapped in a tress

of hair from her topknot or *tikitiki*. For some Māori scholars this represents the journey of research. This is not a journey to be taken lightly nor undertaken alone, as an autonomous individual, but one which requires the support of family and *whanau* extended family, both living and ancestral. The journey of learning disabled theatre requires similar support. In the presentation and performance at the Helsinki conference, I delivered via Zoom a *pepeha* on behalf of the group in Te Reo Māori, and performer Peter Rees gave his own version in English acknowledging his own network of support and family, as well as his dead grandparents, thus expanding the notion of *whanau* in alignment with Te Ao Māori.

Crossing the road is political

The company's first post COVID-19 live performance in three years was *The Journeyings of Different Light*, presented at the ADSA (Australasian Association for Drama, Theatre, and Performance Studies) conference, Travelling Together, at the University of Auckland in New Zealand in December 2022. In this performance, the group was influenced by the establishment that year of the first national holiday of indigenous origin in Aotearoa/New Zealand, to mark Matariki or the Māori New Year. The group also drew on their experience of the supposedly simple everyday action of crossing the road. The road in question was a 6-lane motorway on the way from the rehearsal room to a café for breaks from rehearsals. Each Sunday, ten of us walked and wheeled our way down the pavements of Ōtautahi/Christchurch, which are still buckled and highly uneven, the vestiges of the 2010–11 earthquakes. In fact, much of the city, partly rebuilt, partly under construction, and partly damaged is still very difficult to access for a person in a wheelchair. When we reached the two sets of traffic lights there is a button to press, supposedly to allow people sufficient time to cross the road. The *kairos* or good timing of this system does not, however, allow sufficient time for two people in motorised wheelchairs, and eight others, to navigate this simple journey safely across six lanes of impatient traffic. With reference to this, the Different Light performers devised lines of dialogue, making a play on the joke/cliché of: Why did the chicken cross the road?

PETER: ...Why did the person in a motorised wheelchair cross the road?

MATTHEW: HOW can the person in a motorised wheelchair cross the road?

...

PETER: Why did the person in a motorised wheelchair cross the road?
 MATTHEW: Why would a person in a motorised wheelchair cross the road?

They also referred to the pavements and road as uncertain forms of *turan-gawaewae* or place to occupy and traverse as disabled people:

JOSIE: We walk and wheel down the pavements of Ōtautahi/Christchurch...
 BIDDY: Below us Papatuanuku, the earth mother, for the moment, is still...

Their reference to *matauranga Māori* (Māori knowledge, myths and worldview) was then developed in the following sequence:

PETER: Above us, the light of the sky.
 DAMIAN: Beyond that the light of the stars.
 ...
 MATTHEW: Mahutonga, Matariki, Purapurawhetu.

Performer Matthew Phelan drew on his familiarity with *matauranga Māori* (which could be translated as Māori knowledge) from school and from recent media information on the new public holiday – about the stars:

Mahutonga: the constellation of the Southern Cross that is on the New Zealand flag
 Matariki: known in the West as the Pleiades or Seven Sisters
 Purapurawhetu: meaning literally star seeds or star dust, and referring to the cross-stitch pattern of woven flax that is often present on the walls of *marae* or Māori meeting places.

In the context of Different Light and disability performances in Aotearoa/New Zealand, Matariki has a deeper meaning that the leading disability dance group Touch Compass (Hau Tipua Toi) highlighted in their annual performance and parade, InMotion Matariki. The company interestingly claims a disability provenance for the constellation of stars that gives the Matariki Festival its name. Matariki is an abbreviation for 'Ngā Mata o te Ariki Tāwhirimātea' – the eyes of the god Tāwhirimātea.

According to Māori tradition, Tāwhirimātea, the god of the wind was so angry when his siblings separated their parents, Ranginui, the sky father, and Papatuanuku, the earth mother, that he tore out his eyes and threw them into the heavens. (Meredith, 2011)

With regard to Purapurawhetu, this connects to the play of the same name by Māori playwright Briar Grace-Smith, which refers to Matariki not just as the Māori New Year, but to the acknowledgement at this time of year to the continuing presence in the sky of the dead. “When someone special dies, their spirit joins the others in a wild tango in the night sky” (Grace-Smith, 1999, p. 41).

The Journeyings of Different Light was again drawing on the *whakapapa* (or genealogy) of the company, including the input of two of the company’s performers who had died in 2015, but the memory and spirit of whom the company still carries in each subsequent performance, as they constitute *whanau* (extended family) or ancestors. Different Light as a company – composed of learning disabled artists and my supposedly non-disabled input – thus attempts to find ways of attuning itself to indigenous knowledge, and the valuable perspective it can offer to heeding the cries of the planet in the current socio-ecological crisis.

The politics of communication

Because Different Light, as a learning disabled theatre company, is an amalgam of learning disabled and non-disabled input, there is always need for a great deal of care and consideration in the idea of the expression, presentation, and problematisation of the ‘voices’ of the performers. The latest book on the company’s work is entitled *Giving and taking voice in learning disabled theatre* (McCaffrey, 2023). It contains 20,000 words supplied by the performers themselves via interviews, video documentation, and from other archival sources. For full disclosure, these 20,000 words are then framed by 70,000 words from me as a practitioner/researcher: the book is a work in progress. The group has participated in a number of academic conferences, both as performers and participants in academic papers. This is in many ways an awkward fit. The Different Light performers are present at conferences at academic institutions, to which they would never currently be admitted as students. This awkward fit was referred to in the Performance Philosophy Problems conference at the University of the Arts in Helsinki in 2022. Eight Different Light performers participated by making a 20-minute video of a performance addressing the conference theme, filmed in an empty theatre. This was due to the fact that the performers themselves, many of whom have compromised immune systems, could not risk travelling all the way to Helsinki and back during the pandemic,

even if we could somehow have raised the funds for them to do so. In addition, two of the performers participated 'live' via Zoom in the 90-minute KeyGroup presentation, entitled "Collaboration, Care, and Conviviality" with colleagues Dave Calvert, Janet Gibson, and Kate Maguire-Rosier.

During the question and answer session following the presentation, Laura Cull Ó Maoilearca raised the interesting and crucial question of how it was possible to hold, in the same conceptual and social space, an academic conference with the participation of the learning disabled artists of Different Light. This is fundamentally a political question about inclusion, the meaningful inclusion of persons or speakers subjected to epistemic injustice, who are most often subjected to academic and philosophical analysis and discourse, rather than accepted as subjects themselves. It is a question that is constituted at the level of language and communication itself. Joshua Saint Pierre in *Cheap talk: Disability and the politics of communication* supports listening to very different 'voices':

A vast range of "voices": from the non-linguistic voices of those severely cognitively disabled or autistic, to the dysfluent speech of stutterers and those with cleft palate, the vocal tics induced by Tourette's, or the opaque speech present in some forms of cerebral palsy. (Saint Pierre, 2022, p. 13)

A voice with a speech impediment or stutter or using an assistive device requires taking time and care on the part of the listener. The process of listening to such voices becomes a kind of micropolitical act, in that it disrupts the expected free flow of free speech that contemporary capitalism demands, to cite Saint Pierre:

... crip voices that are unclear and produce uncomfortable aporia and silence, that stretch and break temporal norms and perceptible worlds point towards not simply an ethic but a politic. (Saint Pierre, 2022, p. 77)

Giving and taking voice are also political in that they subvert the neoliberal autonomy of the subject, as Eva Feder Kittay (2002) has articulated:

Liberalism invokes a notion of political participation in which one makes one's voice heard. It depends on a conception of the person as independent, rational, and capable of self-sufficiency. And it holds to a conception of society as an association of such independent equals. (Feder Kittay, 2002, p. 258)

The ‘disabled’ voice is a spanner in the works of not only the legal and economic fiction of autonomous personhood, but also of society as a collection of autonomous beings engaged in the free exchange of communication, testifying to Mladen Dolar’s astute understatement that ‘the voice and hearing are at the core of politics’ (Dolar, 2006, p. 189).

My own lived experience of studying alongside learning disabled artists, tells me that ‘voice’ is not a clear, untroubled process of the transmission of some pre-linguistic lived experience into verbal or even theatrical expression. There is, however, an expectation of self-devised learning disabled theatre, as with other forms of theatre, seeking to give voice to marginalised sectors of the population, that just ‘giving voice’ will somehow solve everything and include the excluded. This ignores epistemic injustice, the reality of exclusion from, or marginalised access to, the language and symbolic systems of those who are expected to give voice to their experience. It also ignores the fact that experience is mediated through language, and that a speaker’s voice is never entirely authentic. It is always already determined by language and may well be channelling the voices of others. In the case of a marginalised speaker, these may include the voices of authority or the voice of ‘common sense’, adopted as a coping strategy or way of passing as belonging to a community that excludes them. The marginalised speaker may be attempting to assimilate to the tone, register, or discourse of their interlocutor, particularly if that interlocutor appears to have more power or social capital than the speaker themselves.

The political potential of ‘listening others to speech’

The emergence of voice in learning disabled theatre resonates with an emphasis in contemporary theory and politics that might be termed a turn to listening that includes Krista Ratcliffe (2005), Nick Couldry (2010), Kate Lacey (2013), Andrew Dobson (2014), Jill Stauffer (2015), and Leah Bassel (2017). This turn has been taken up in performance and theatre studies by, amongst others, Kantar Kochar-Lindgren (2006), George Home-Cook (2015), Peter Eckersall et al. (2017), Lynne Kendrick (2017), Salome Voegelin (2018), and Susan Bennett (2019). Within this turn to listening I am drawing specifically on the work of Lisbeth Lipari (2014), and how it might be applied to learning disabled theatre, in particular, her notion of ‘listening others to speech’, an arresting phrase taken from her essay ‘Ethics, Kairos, and

Akroasis', and one of the characteristics of which she defines as "a listening others to speech that can reverse authoritative normative social arrangements that either silence others and refuse to listen" (Lipari, 2014 p. 95).

For the voices of learning disabled theatre to emerge, it takes a great deal of time, attention, and attunement on the part of non-disabled allies, collaborators, or co-researchers. Lipari develops this formulation from Nelle Morton's feminist ethics, "We empower one another by hearing the other to speech. We empower the disinherited, the outsider" (Lipari, 2014, p. 60). She categorises this listening to speech as "the empowerment of kairos as akroasis" defining these terms as follows:

Kairos—most superficially understood as right timing or the opportune moment—and akroasis—translated as listening and invoking the idea of secret, esoteric teachings. (Lipari, 2014, p. 95)

Kairos is a concept that is likewise utilised and reconfigured in M. Remi Yergeau's consideration of autistic rhetoric (2017), and in Margaret Price's use of 'kairotic space' (2014). I find their reconfiguration of kairos useful in terms of how good or right timing is reconfigured in a kind of 'crip time' in learning disabled theatre. Lisbeth Lipari's formulation of kairos as akroasis generates a way of thinking that enables the potential

to relinquish linear spatial and mechanical models of communicative interaction in favor of nonlinear, musical, and embodied models wherein temporality and communication ethics are enacted and perhaps even accomplished by speakers and listeners in concert. (Lipari, 2017, pp. 87–88)

This reconfiguration of the relationship of what is active and passive in listening and speaking allows the possibility for interdependence in the process of making learning disabled theatre. Rather than a model in which knowledge, skills, and techniques are transmitted from non-disabled creative enablers to disabled artists, this offers a more reflexive model in which participants co-create, and in which non-disabled participants learn from learning disabled artists, and *listen others to speech*. This also has implications for the interrelationship between performers and audience in the performance event. The event becomes an expression of a mutual musical engagement (akroasis), which is not the linear model of the transmission of performance, in which disabled performers perform for or, at, or to an audience assumed to be non-disabled. Such an event becomes more an

experience of being together, or being-with in the performance event, or of conviviality, and offers a glimpse of future collective politics.

Just as learning disabled theatre requires ‘thinking beyond’ the binaries and conventions of ideas and practices in and around ‘theatre’ and ‘learning disability’, so too does a consideration of the politics of this highly socially engaged and socially challenging art form. The political spectrum of learning disabled theatre may involve acts as mundane as crossing the road; getting learning disabled performers to the venues where they perform; dealing with the economic dependence and marginalisation of these performers; as well as the more conceptual issues of listening the voices of such performers into speech. Learning disabled theatre is an object lesson or case study of the need for cooperation and collaboration. The art form itself often deliberately exposes the hidden labour and support that underlies the politics of the communication event that is theatre. Such theatre adjusts the expectations of the temporality of theatre as communication, confronting audiences with normative expectations of listening, attention, and attunement, which are acts of collaboration and collusion that constitute theatre. The political spectrum of learning disabled theatre encompasses both the wider implications of what it means to be human, and the lives that matter as human, with the everyday considerations of how ‘we’ treat ‘others’. The category of others also includes the non-human environment and the planet. Is politics anything more complicated than how we treat others, and how we recognise and accept the other in ourselves? The spectrum of the rainbow is seen by those who have the faculty of sight, conceptualised in a kind of inner vision by those who do not. The spectacle of theatre is seen by an audience in the dark, and leaves its ephemeral impression after the lights come up and we leave the theatrical space. Relaxed performance, theatre for the blind, the integration of access and aesthetics in theatre for the D/deaf alert us to the fact that we need to keep rethinking and reconfiguring the sensorium of what constitutes theatre as one form of public access amongst many. Learning disabled theatre artists make extraordinary contributions to how we hold ourselves in actual, conceptual, and political spaces. Alongside them we can learn that we are always part of a spectrum of which we are certainly not the origin, but through which we can see and feel gradation, blurring, intersection, and overlapping. The spectrum is a spectre is a mirage – *all that is solid melts into air* – that yet helps us to find our interrelationships, our interactions, our intra-actions, and locates us as our responses and responsibilities for others.

Author biography

Tony McCaffrey, BA(Hons), PhD, Senior Lecturer, National Academy of Singing and Dramatic Art, Ara Institute, Christchurch New Zealand. Artistic Director, Different Light Theatre, an ensemble of learning-disabled performers, Co-convenor, Performance and disability working group, International Federation for Theatre Research. He has contributed articles to Theatre Research International, Global Performance Studies and Performance Philosophy. He is the author of *Incapacity and theatricality* (Routledge, 2019) *Giving and taking voice in learning disabled theatre* (Routledge, 2023) and is currently working with the Different Light artists on *The ends of theatre: Learning disabled performance and research* (Routledge, forthcoming).

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CHAPTER 2

Vulnerable Agencies: A Performative Research Assemblage on Dis/Ability

Liisa Jaakonaho University of Arts Helsinki, Finland

Abstract: In this article, I describe an artistic research process stemming from my work as a dance pedagogue in disability services. Describing and reflecting on the process that led to the artistic part of my research, a performance installation at the New Performance Turku festival in Finland in 2018, I aim to develop a nuanced and ethically sensitive understanding of diverse and vulnerable agencies in the boundary areas between arts, research and social care. The ethical dilemma I address in this article concerns the paradoxical nature of situated and shared vulnerability. I reflect on how the different vulnerable agencies have been negotiated in my research project, and what ethical insights this negotiation brings forth. Methodologically, my research is situated at the intersections of artistic and performative research, post-qualitative inquiry, and feminist ethnography. Based on methodological experiments and theoretical discussion, including the ethics of care, vulnerability, dis/ability and ableism, I consider the complexity of participation, power relations and decoloniality in artistic research. Through the example of my research project, I describe how frictions between different contexts in the arts, academia, and social care become tangible in light of the social-material-discursive phenomenon of dis/ability. In the conclusion I suggest that we should continue to reflect on the complexity of the possibilities of participation, problematising artistic and academic practices, in which disabled people's agency is determined and mediated by abled people.

Keywords: vulnerability, dis/ability, performative research, artistic research, agency

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You feel supported when you wake up
You feel restricted when it rains
You feel supported when you walk in the mountains
You feel restricted when you are in a hurry
You feel supported when you get your salary
You feel restricted when you don't understand
You feel supported when the sun shines
You feel restricted when it is nighttime
You feel supported when someone calls you
You feel restricted when you are cold
You feel supported when someone holds you tight
You feel restricted when someone holds you tight
You feel restricted when you are unable to do what you want to do
You feel supported when there are animals around you
You feel restricted when you have too many obligations

The above piece of text is an extract from a performative writing experiment co-written with the participants of a workshop that I and my colleague, artist-researcher Kristina Junttila¹ facilitated in a day centre for people with intellectual disabilities in Northern Norway in 2018. The workshop was part of a collaboration that resulted in the artistic outcome of my doctoral research: a performance installation presented at the international performance art festival New Performance Turku in Finland in 2018² (see figures 3 and 4; detailed description on pp. 79–81). Building on our professional experiences and research interests, the aim of our collaboration was to destabilise disability/abledness as fixed identity categories and to reflect on dis/ability as a theme that concerns everyone, informing how we experience and understand people's diverse, relational, and vulnerable agencies.

Theatre Academy of the University of the Arts Helsinki, the institution where I am based, conducts predominantly artistic research (e.g., Borgdorff, 2012; Hannula et al., 2014; Varto, 2018), which means that research involves artistic methods, often resulting in artistic outcomes. The artistic outcomes are formally examined as key products of the research. The written doctoral thesis, known as the 'commentary', can take diverse, sometimes experimental and 'expositional' (see Schwab & Borgdorff, 2014), forms to describe, comment on and/or complement the artistic outcomes. This article will be part of the commentary of my artistic doctorate.

1 <http://kristinajunttila.com/>

2 www.newperformance.fi/en/archive/2018

The ethical dilemma I want to address in this chapter concerns the paradoxical nature of vulnerability. I discuss the way vulnerability can on one hand be understood as a universal condition that we all share, and on the other hand is situated in specific circumstances and conditions, which highlights inequalities between individuals and social groups (Gilson, 2014). I reflect on how the different vulnerable agencies have been negotiated in my research project and aim to articulate the ethical insights that this negotiation brings forth.

After describing and contextualising my research process and its methodological influences, I introduce theoretical discussions on care ethics, vulnerability and dis/ability. Then, I describe the process that led to the artistic outcome and reflect on my choices concerning participants' agency. Finally, I conclude by discussing ethical insights that arose from the project.

A brief mapping of the research journey

I started my doctoral studies at The Performing Arts Research Centre, Theatre Academy of the University of the Arts Helsinki in 2015. Previously, I had worked in diverse contexts and settings in Finland and the UK in the boundary areas between the arts, health, and social care. At the start of my doctoral research project, I had been facilitating weekly creative movement sessions for three years at a day centre belonging to a Finnish private organisation in Helsinki that provides care services and activities for people with intellectual and developmental disabilities. This work was my practical starting point and the site of 'fieldwork' in the first stage of my research.

Between 2016 and 2021, I was also involved in the ArtsEqual research initiative.³ ArtsEqual was a large-scale research project coordinated by Uniarts Helsinki and funded by the Strategic Research Council of the Academy of Finland. The project examined how art as a public service can advance equality and well-being in society. According to ArtsEqual's final report, people who do not match the ableist ideal are often excluded from the arts and arts education services. ArtsEqual reinforced the rights of marginalised groups, including people with disabilities, and their opportunities to participate in artistic activities and arts education (Ilmola-Sheppard et al., 2021). Together with other ArtsEqual researchers, my aim has been

3 www.artsequal.fi

to develop a more nuanced and inclusive understanding of the power relations that impact people's possibilities of attaining artistic agency in different settings and life situations (Laukkanen et al., 2021).

Alongside my pedagogic work and collaborative research in ArtsEqual, I worked towards the artistic outcome of my doctoral research. I wanted to fully utilise the means of art in exploring ethical questions of dis/abled agency, whilst also making these questions visible in the contexts of art and artistic research. In summer 2017, I started a collaboration with artist-researcher Kristina Junttila. We set up a two-day workshop installation at the Research Pavilion during the Venice Biennale⁴, openly inviting people with professional and/or personal interests in dis/ability (Jaakonaho & Junttila, 2019). In 2018, we developed our piece *Post-Sense Room* for the New Performance Turku festival and asked scenographer and costume designer Ingvil Fossheim⁵ to join the collaboration. Her role was to help us in planning and implementing the visual and material elements of our piece. In the process of developing our piece, we organised a one-day workshop in a day centre of disability services in Northern Norway to develop and experiment with ideas and materials and to reflect on our questions together with people who have personal, lived experiences of disability. The final piece at the festival was open to the audience for three days. In the same space, I also presented my video installation entitled *Pako/Escape* based on data from the earlier stages of my research.

Mapping (and treading paths on) the methodological field

In the initial stages of my research, I had a sense that my work as a dance pedagogue at the day centre for people with intellectual and developmental disabilities would be a fruitful starting point for research. As I had been working in this context for three years, I developed my relationship and practice with participants to the point of becoming curious about starting to articulate and explore the tacit knowledge of the pedagogical practice through artistic research.

In the beginning of our weekly sessions, we always sat in a circle, discussing how everyone was, and how the week had been. Then we moved

4 <https://sites.uniarts.fi/web/research-pavilion-2017>

5 <https://www.ingvillfossheim.no/>

together. The movement was usually initiated by me first, suggesting something simple – such as stretching and rhythmic steps. Soon after this, the participants initiated their own movements – sometimes spontaneously, sometimes after I invited them to do so – which I mirrored with my movements and encouraged vocally. The participants responded in their diverse and unique ways, some more enthusiastically and vocally, some in more quiet and subtle ways. At the end of each session, we sat down again for a moment to reflect on our experiences. When I started the research project, the participants had all been coming to the group for at least one year, and they were all able to verbalise that they understood that I was going to document and reflect on our sessions for the purposes of my research.

After undergoing the formal process of getting a research permit and informed consent (see the ethical statement at the end of the chapter) from all the participants, I had to consider many practical questions: How should I approach documentation? How will I write about my experiences? How can I get information about the participants' experiences? As I was interested in the ethical questions concerning agency, every methodological choice felt meaningful. I needed to reflect on and explore different options before making every choice, as the choices often directly or indirectly concerned the agency and self-determination of the participants. I started taking notes and experimenting with documentation. I also became interested in the materiality of the space in which I ran the group: the fascinating combination of clinical whiteness, technological devices, brightly coloured soft materials, and handmade objects (see Jaakonaho, 2024). I photographed the environment to capture interesting details (see figures 1 and 2).

In my methodological choices, I found the intersections between artistic, qualitative, and ethnographic research practices particularly inspiring. Artistic research is a methodological paradigm in which knowledge emerges from and is articulated through artistic, embodied, experimental, and performative practices, usually conducted by artists and arts educators (Borgdorff, 2012; Hannula et al., 2014; Varto, 2018). I see artistic research not as a clearly defined, static framework but as something that is being constantly developed and redefined through different approaches and artistic practices, often in relation to other research traditions (e.g. Borgdorff, 2012). As an arts pedagogue and interdisciplinary practitioner working in the boundary areas between arts, education, and social care, I am interested in a broad and inclusive conception of art that acknowledges that art has diverse meanings and purposes in different contexts. As Borgdorff



Figures 1 and 2. From the day centre of disability services where I worked during the first stage of my research. Photographs by L. Jaakonaho.

(2012) points out, it is characteristic of art to escape essentialist definitions, meaning that the boundaries between the art world and other domains of life are subject to constant debate.

Ben Spatz (2015) advocates a 'research culture' in performing arts and other embodied practices that emphasises continuous creation and transmission of knowledge rather than individual ability. Building on Foucault's writings on technique, knowledge and power, Spatz argues that embodied practices are structured by knowledge in the form of technique, and therefore "technique is knowledge that structures practice" (Spatz, 2015, p. 1). Spatz (2015) divides the singular notion of 'art' into plural 'arts' defined as fields of craft, technique and knowledge characterised by embodied encounters of bodies rather than audiences' encounters with representations and spectacles in the public sphere. For me, this conception of art is interesting in the context of artistic research, particularly in relation to the agency of the researcher. As an artist-researcher I produce knowledge through embodied and ephemeral encounters in pedagogic and participatory situations; I articulate, make visible and build on the tacit knowledge that is embedded in the techniques of moving, interacting, and being.

My other field of methodological inspiration, *post-qualitative research* rejects conventional, predetermined research methods and practices. Ontologically, it is inspired by the Deleuzian philosophy of immanence that places life, thought, being and nature on a single surface of existence (St. Pierre, 2021). Both artistic research and post-qualitative inquiry have emerged from a friction with established qualitative methods (Østern et al., 2023). The two methodological fields share a postpositivist understanding of knowledge as relational, porous and indeterminate, supporting creative, polyphonic inquiry that combines different voices, social domains and discourses. However, according to David Rousell (2019), the relationship between art and post-qualitative inquiry is ambivalent. Rousell develops Deleuze and Guattari's (1994) argument that art, philosophy and science operate on 'different planes of material-semiotic production', suggesting that if art is treated as the solution to the post-qualitative methodological 'crisis', then the knowledge-producing potential of art may be diminished to serve the purposes of theory. Rousell (2019) proposes that art should be taken up as vigorously as any theoretical part of research, without reducing one element of the research assemblage to another. My choice to work in the direction of participatory artwork at a performance festival, was inspired by a similar logic: I wanted to take the artistry of the research seriously and present it in a context in which it would be viewed as artwork.

At the beginning of my research, during my interactions with the participants of the groups that I was facilitating, I was fully immersed and engaged in the embodied situations and encounters that I was studying. As a researcher, it was clear that I could neither be a neutral observer nor an equal member of the group. Consequently, I started thinking about the pedagogic situation, as well as my methodological experiments, as *performative*. Performative research started with Brad Haseman's 'A Manifesto for Performative Research' in 2006 and was further developed in artistic research and the social sciences (Arlander, 2018; Bolt, 2008, 2016; Haseman, 2010; Østern et al., 2023). In performative research the researcher is entangled with the researched phenomena through her embodied, sensuous being and by means of a performative approach towards languaging; "(...) not only using existing concepts and modes of creation, but actively languaging research phenomena in new ways." (Østern et al., 2023, p. 2). The research process emerges through constant negotiations and entanglements across the material, social and discursive planes. Knowledge is seen as a fluid and complex process of creation, involving also more-than-human agents (Østern et al., 2023). This resonates with the ways in which I was entangled with embodied encounters and material elements in my research, whilst experimenting with ways of languaging the situations of inquiry.

In my research, ethical questions were pivotal, and methodological considerations were always closely tied to questions of agency and power. This position resonates with the discourses of *feminist ethnography*. According to Beverly Skeggs (2007), feminist ethnography is a plural term, as are both words separately: 'feminism' and 'ethnography'. Feminist ethnographers adopt a reflexive approach to problematising the objectification of the Other.

My aim was to develop alternative ways of acquiring and articulating knowledge through bodily encounters, material negotiations and affective utterances. This kind of knowledge production can be seen as a *decolonial* project. Spatz (2019) makes an important distinction between decolonisation and decoloniality: decolonisation is, and should be, about the transfer of political power and sovereignty from a colonising society to an indigenous one, whereas decoloniality refers to a more thorough and complex transformation of knowledge. Emerging modes of artistic research, practice research and embodied research are grappling with decoloniality at a methodological level (Spatz, 2019). This distinction resonates with my experience of grappling with questions that are close to the discourse of decolonization, whilst being aware that I am a White, abled and

privileged researcher who has not experienced personal struggles caused by possessing a racialised or disabled identity. I would not say that my research is decolonizing – however, the notion of decoloniality, as Spatz (2019) describes it, supports the way I see that on a methodological level my research contributes to a broader transformation in institutions of academia, aiming to challenge legacies of colonialism.

On agency, care and vulnerability

My understanding of agency is in essence informed by a sociological definition, which sees individual agency and social structures as reciprocally constituting; individual agency is shaped by social structures, whilst social structures are also shaped by individuals and their actions (e.g. Giddens, 1984). Drawing from contemporary feminist and new materialist theories (e.g. Barad, 2003; Butler, 2016; Gamble et al., 2019), I take this idea of reciprocity further by acknowledging the relationality and interdependency between different agents, and between individual human agents and the non-human agency of the socio-material environments in which they act (see Jaakonaho, 2024).

In addition to my methodological experiments and artistic-pedagogic explorations, I have aimed to facilitate reciprocal and affirmative embodied interactions with dis/abled participants. In this practice, I have been informed by practices and questions of *care*, and found inspiration in *care ethics*. Care ethics is a feminist philosophical approach to moral theory that sees ethical concerns as relational, situated and embodied. Building on the works of Carol Gilligan, Joan Tronto and other key scholars of care ethics, Selma Sevenhuijsen (1998, p. 56) proposes a shift from the search for rules, principles, and duties to situated questions concerning responsibility, such as ‘How can I best deal with vulnerability, suffering and dependency?’

Erinn Gilson (2014) has further developed the feminist ethical standpoint on the basis of a multifaceted and critical reflection on the notion of *vulnerability*. Drawing on Butler, Deleuze, Cixous, Merleau-Ponty and other influential thinkers who touch on questions of vulnerability, she develops an *ethics of vulnerability*. As Gilson points out, how we perceive and understand vulnerability is ethically significant. If we consider vulnerability to be something inherently negative or a weakness, denying our own vulnerability and valuing invulnerability, we fail to respond ethically to others’ vulnerabilities. This can have stigmatising and controlling effects, making

the whole concept of vulnerability problematic. Instead, if we acknowledge vulnerability as an ‘ontological condition’ and a complex, ambiguous and multifaceted ‘condition of potential’ that can also have positive effects, such as connection, transformation, empathy, and compassion, we can accept vulnerabilities in ourselves and others and face them with ethical awareness and sensitivity (Gilson, 2014, pp. 10–11). However, we should still remember that although at one level vulnerability is a universal condition that we all share, there are also ‘situational vulnerabilities’ that are determined by people’s social positions and circumstances (Gilson, 2014, p. 37).

These views on ethics and vulnerability resonate with the ways in which I approached ethical questions and situations of embodied vulnerability in my research. I was more interested in searching for ways of making ethical questions visible and embodied and articulating them through artistic means than in finding answers or moral rules. I reflected on vulnerability as a shared and situated experience – something that concerned not only the disabled participants but was also embodied in me, although in a different way.

On dis/abled agencies

During my work of facilitating the movement groups in the disability services context, I became interested in how experiences of dis/ability are mediated by society and social-care institutions. I aimed to shift the focus from a marginalised group of others to asking how questions of dis/ability concern everyone, as we are all vulnerable and most of us struggle with society’s ableist structures and practices at some point in our lives.

Authors in critical disability studies have challenged the binary logic of disability versus ability, investigating how disability is produced and conditioned through socio-political structures and historically constructed ideologies that also affect non-disabled people (see, e.g., Davis, 2016). Dan Goodley (2018) makes a useful distinction between disablism (the direct discrimination of people with disabilities) and ableism (societal structures and practices that favour non-disabled people), claiming that disablism and ableism can only be understood in relation to each other. In other words, the normative category of ability concerns everyone in contemporary society. As citizens, we are expected to be self-sufficient, autonomous and independent. If we fail, we may be rendered disabled.

Using the notion of ‘compulsory able-bodiedness’, Robert McRuer (2002) shows that the norms attached to able-bodiedness are intrinsically

impossible to fully achieve and that, in fact, everyone is only ‘temporarily able-bodied’ – that is, everyone will eventually experience disability if they live long enough. This line of thought shifts the focus from disability to the patterns and effects of *ableism*. According to Bradley Lewis (2013, p. 129), ableism refers to the ‘social stigma and oppression against the physically different’. Fiona Kumari Campbell (2009, p. 44) defines ableism as ‘a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as perfect, species-typical, and therefore essential and fully human)’.

In my encounters with disabled participants, it was evident that they had many more meaningful things in their lives than their disabilities. One person was a mother and grandmother and enjoyed talking about that part of her life. Another person sometimes dressed up in women’s clothes and sometimes in men’s and enjoyed taking part in disability community events. There was also diversity in how much support the individuals needed – some were very independent, whilst others needed more support and assistance. This diversity resonates with an *intersectional* understanding of individuals’ social positioning, which acknowledges the complex and multiple dimensions of intersecting identity categories and their effects on individuals’ social positions, opportunities, and experiences (Crenshaw, 1991).

Whilst learning about dis/ability, I also became aware of the common, problematic assumption that disabled people suffer from their disabilities. Contrary to this assumption, I often witnessed a sense of joy and affirmation that the participants brought to the space, and I was uplifted by the many positive stories and experiences that they shared during our encounters. These observations resonate with the *affirmative model* of disability, which is connected to the development of the Disability Arts Movement (Swain & French, 2000). As John Swain and Sally French (2000) describe, the affirmative model challenges the value-laden presumption that disability always entails personal tragedy, repudiating the dominant value of normality, promoting positive identities and experiences, and celebrating people’s differences.

Supported and restricted agencies

The process that led to the performative outcome of my research developed from my observations and methodological experiments in the pedagogic practice, as discussed earlier, and from my collaboration with

artist-researcher Kristina Junttila. Informed by our embodied experiences of working with dis/abled people, Kristina and I chose the theme of *support and restriction* as a starting point that we thought many people could relate to, regardless of their abilities or disabilities. We believed that everyone has experiences of being supported and restricted by the environment, and the theme functioned as a means of approaching questions of dis/ability without focusing on a specific group of others. This thinking was based on our understanding that dis/ability experiences are mediated by ableist structures and practices (see, e.g., Campbell, 2009; Goodley, 2014, 2018).

Whilst developing the piece, Kristina and I wanted to involve people who had personal knowledge and understanding of disability as experts who knew more about disabled experiences than we did. A few weeks before the festival, we organised a workshop in a day centre of disability services in Northern Norway. To address our ethical concerns, we considered what the experience was going to be like for the participants and tried to be as transparent, clear and as fair as possible. It is important to acknowledge that our strategies were not 'neutral' in relation to the problem of colonising practices in participatory research (see Seppälä et al., 2021; Tuhiwai Smith, 2021). As researchers, artists, and educators, we must be particularly aware of our privileged positions in such cultural contexts as Northern Norway, where, similarly to other Nordic countries, the indigenous Sami people have been subjected to abuses, violations, and racism by the settler governments.

The aim of the workshop in the day centre was to try out some embodied experiments related to the theme of support and restriction, along with collective performative writing, to produce material for our performance installation. Before the workshop, we contacted the staff of the day centre to discuss the details of our visit. We also visited the site the day before the workshop and spent time getting to know the people and the environment, taking part in their daily activities, and expressing our interest in and wish for mutual dialogue. In the workshop, we used our professional skills and knowledge to create a reciprocal situation in which the participants were involved as active agents. We explained, in an accessible and appropriate way, what we were there for (to produce material and gain insights for our artwork) and made sure that we had everyone's informed consent and that the participants understood that they had a right to withdraw at any point if they chose to do so. The participants responded positively and were willing to take part in what we offered.

In the workshop, we conducted a writing experiment in which we gave the participants pages of sentences that we had started and asked them to finish these sentences in their own words, expressing their experiences of being supported and restricted (see the extract at the beginning of this article). We also facilitated some physical exercises with music and material elements (cloths and stretchy ropes), aiming to create a holistically engaging and playful atmosphere, whilst exploring the theme of support and restriction in an embodied way. Afterwards, we gathered all the texts that were produced in the workshop into one document, which we also sent to the participants. We translated, edited and recorded the text and presented it as one of the five audio tapes that audiences were invited to listen to as part of the final piece in Turku.

Post-Sense Room and Pako/Escape: Welcoming different agencies into a performative space

The following description depicts *Post-Sense Room* and *Pako/Escape*; the collaborative artistic outcome of my research, presented at the New Performance Turku Festival in September 2018.

As you enter the space, the first thing you notice is a clothing rack with different colourful and modified pieces of clothing, some with objects, such as balloons and sandbags sewn inside the fabric. On the floor next to the clothing rack, there is a note: 'Please choose a piece of clothing. Wear it whilst you are in the space. When you leave, please put the piece of clothing back.' One of the artists is sitting on a bench, crocheting a thick rope out of colourful strips of Lycra fabric. The rope travels through the space, around hammock chairs, large beanbags and three TV screens with pillows in front of them on the floor. Another artist is performing simple repetitive exercises. Next to her, she has diagrams showing instructions for movements and a bowl of pens, which she uses to trace her movements on the floor every now and then. The hammock chairs and beanbags have MP3 players and headphones attached to them. As you sit down on a beanbag and put on the headphones, you hear a voice asking you to pay attention to different body parts, pointing out that you may or may not have these body parts, and you can always choose another one. When you sit on a hammock chair, you hear a text that at first sounds like a list of facts about the body, but some sentences are fictive, such as 'we have brain cells in the soles of our feet'. When you sit on another hammock chair, you hear a list of different things that can support and restrict people. The voices in all these recordings are slightly altered and carry metallic echoes or glitches. One audio



Figures 3 and 4. from *Post-Sense Room*, a performance installation at the New Performance Turku festival in September 2018. Photographs by Jussi Virkkumaa (Image 3) and Julius Töyrylä (Image 4).

option includes only music with mellow and rhythmic ambience. Sitting on the bean bag in the back corner, you hear excerpts from theoretical texts about disability and agency, read by computer voices with different dialects of English. On one of three TV screens, you see the artist with a fur coat sitting on a rocking chair, and then tidying up a room in a care facility. A muffled voice on the soundtrack of this video talks about the

event of a disabled participant going missing after a movement group, and later being found in another part of the city. Another video shows a room full of people dancing, with all their faces pixelated. One video depicts landscapes – mountains, lakes, dwarf birches – filmed from a car window, followed by close-ups and still images of colourful soft materials, furniture, assistive technology, everyday items, and decorative objects in a care facility.

The concept for *Post-Sense Room* came from our interest in *sensory rooms* (also known as multi-sensory rooms), spaces in care homes and educational institutions meant for sensory stimulation and relaxation for neurodivergent people (e.g. Fowler, 2008). We wanted to develop a space that functioned as *a space of care*, both for ourselves and the audience, whilst also problematising questions of dis/ability and agency. The space, with its material elements, verbal instructions, and thematic contents, was designed to engage everyone that entered the room to reflect on their vulnerable and diverse agencies by engaging with materials that slightly changed (by supporting and restricting) their embodied experiences, such as clothes, hammock chairs and bean bags. The performative texts that were presented as audio tapes also suggested different perspectives on embodied agency. My performative action was crocheting; an activity that I found meditative and grounding whilst creating a visual element that connected the different parts of the space. The action that Kristina chose to do was to repeat physical exercises and trace the movements on the floor. The exercises were individually selected and given to her by a physiotherapist. Audience members were also welcome to try out our actions if they wanted to. My role also involved acting as a kind of ‘gallery guard’ by answering audience members’ questions or offering assistance if someone asked for it. The performance installation was open to the public for three days.

The three videos displayed in the space had their own title in the festival programme, *Pako/Escape*, and were produced by me alone. In the videos, I used documentation from various stages of my research. Filming transitions and material details between and within the different contexts of my research, including footage from the journey from Helsinki to Northern Norway, was a way of highlighting the fact that relations, transitions, and material elements were significant in the research process.

The audio in one of the videos was a text about the participant going missing, and later being found in another part of the city. This was a true story from the initial stages of my research. After one of the movement sessions I facilitated, one participant went on a walk on her own, rather

than taking the taxi to the supported housing that was waiting for her at the day centre. Afterwards, we reflected on this incident together with the staff of the day centre, to clarify roles and responsibilities. As I was not formally a member of staff at the day centre (I received arts funding to facilitate the sessions and therefore did not have a formal work contract), my duties did not include assisting participants in their everyday activities outside our sessions. Also, I did not have adequate access to information about the participants to always be aware of what kind of support they needed. However, I felt responsible and concerned when I heard that the participant had gone wandering around on their own. I included this incident in the video installation because I saw it as ethically significant. The incident brings forth interesting questions of responsibility, institutionalisation and agency: How much agency and free choice does a disabled person have in their daily life? How much can their freedom be restricted, by whom, and on what grounds? How is their agency mediated and controlled by the institutions that provide support?

The choices I made in anonymising and framing the videos were ways of addressing the problematic questions to do with the objectification of vulnerable people in research. Rather than aiming to resolve or hide the problematic relationship between my agency and the agency of the participants, I wanted to make these problematics tangible in the artwork. I saw the choices of anonymising and framing as both aesthetic and ethical: for example, pixelating people's faces is a way of ensuring that I comply with formal research ethics, but it is also an aesthetic choice.

There were many practical questions that we needed to address when developing *Post-Sense Room*, including questions of accessibility: Who was invited into the space? Whom was it for? Who heard and knew about the space? What kind of agency did the audience and the participants have in the piece? We wanted to ensure that the space was as accessible as possible – that the audience could choose how long they wanted to stay and how they wanted to engage with the objects and elements of the space. All audio with language had both Finnish and English options, and there was also a non-verbal option (the music). We were also prepared to physically adjust the space according to the needs of visitors, moving things around if needed.

We were happy that our piece was attended and enriched by a diverse audience, including families with young children and people of different cultural, professional, and personal backgrounds. At the end, we held an open discussion in the space to conclude the experience and reflect on

it together with audience members, supervisors, and examiners of my research. Although it was obvious that the people who took part in this discussion were either already familiar with my research or otherwise interested in the work, in the recording of this discussion it is evident that the piece facilitated some meaningful and affective moments and reflections.

On the paradoxes of vulnerability and participation

During the research project, I consciously chose to distance myself from the original context of my research (the day centre) and translate my questions into an artistic collaboration in another context (the performance festival). I am aware that the question of participant involvement in relation to the final products of my research is ethically significant, and one in which the paradoxical nature of situated and shared vulnerability (Gilson, 2014) is tangible. When I reflect on my choices now, I think it may have also been possible to carry out the artistic outcome of my research in closer collaboration with the disabled participants of the research. However, at the time I felt that inviting the participants to think about the complex questions of artistic research with me did not seem feasible, and offering them limited agency – for example to physically perform roles that I had given – did not seem ethically justified either. In the end, my doctoral research project was going to be in my name. The asymmetry of the relationship – the paradox – could not be easily resolved, and participation was not a simple answer for me.

The ethical insight that I gained from reflecting on these choices pertains to the possibilities and limits of participation. Whilst it is important and meaningful to offer arts activities in social care contexts and include disabled participants in artistic research, all the while remaining open, vulnerable, and ethically sensitive when facilitating such activities, we should problematise artistic and academic practices that exclude people with disabilities or only offer them marginalised, limited roles and agencies. We should also problematise participatory projects, in which disabled people's agency is determined and mediated by abled people. The complexity of the possibilities and limitations of participation is something that we should continue to reflect on, rather than trying to find quick fixes or ostensibly ethical solutions.

In the process that led to the artistic outcome, my agency as a researcher was formed in ethically charged negotiations with the agency of the participants, collaborators, and audience members. I aimed to create inclusive situations and ways of thinking, taking into account diverse and vulnerable others and welcoming them to interact within the elements of the research assemblage. The questions concerning the participants' vulnerable agencies touched on complex debates on care, disability, and ableism. Frictions between different contexts became tangible in light of the complexity of the social-material-discursive phenomenon of dis/ability.

In line with Rousell's (2019) problematisation of the relationship between art and post-qualitative research, I would like to think that the way in which the artistic outcome tackled the questions of my research cannot be reduced to a theoretical reflection. The multiplicity of voices, experiences, choices, and encounters created an assemblage in which the meanings and knowledge were moving and emerging beyond anything that can be theoretically framed or pinpointed.

Throughout the research process, including the process of writing this article, I aimed to integrate and develop a theoretical discussion that would both support and problematise my choices. I brought practical insights into dialogue with theoretical discussions to produce knowledge that hopefully contributes towards a more nuanced and ethically sensitive understanding of diverse and vulnerable agencies in the boundary between arts, research, and social care. I am not going to claim that, in my research, I managed to completely avoid colonising and ableist patterns, despite my efforts to address ethical concerns throughout the process. I followed through a learning process in which I was constantly becoming more aware of problematic patterns, trying to articulate and challenge them and re-think my own practices. By discussing and problematising my methodological, artistic, and pedagogic choices, my aim was to shed light on complexities and ethical tensions related to the potential of art and artistic research in the context of dis/ability and care.

Statement on formal research ethics

The research project presented in this article has received an ethical statement from The Ethics Committee of the Helsinki and Uusimaa Hospital District. All the disabled participants of the research, or their legal trustees,

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Author biography

Liisa Jaakonaho, MA, is a Lecturer in Dance Pedagogy and Doctoral Researcher at University of the Arts Helsinki. Previously she has worked in different roles across the fields of performing arts, mental health, education, and social care. In her artistic, performative and post-qualitative research she investigates questions of ethics and agency in the boundary areas between the arts, social care, academia and education. Her theoretical interests include critical disability studies, care ethics, feminist theory, posthumanism, new materialism, and affect studies. Through her research and pedagogical work, she aims to foster inclusion, diversity and anti-discrimination, and challenge ableist practices and discourses.

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CHAPTER 3

Breaking Barriers Through Theatre: The Case of King George VI Centre in Bulawayo

Cletus Moyo Lupane State University, Zimbabwe

Nkululeko Sibanda Rhodes University, South Africa

Courage Chipatiso King George VI Centre, Bulawayo, Zimbabwe

Inez Hussey King George VI Centre, Bulawayo, Zimbabwe

Abstract: Theatre is one of the ways of participating in the world as it provides alternative spaces for creating and sustaining narratives for people who find themselves on the margins of society. In this chapter, we present and examine the various artistic ways adopted by Bulawayo's King George VI (KGVl) Centre that endeavour to break barriers that limit people's agency and participation in social and public spheres of life. King George VI is a Centre for a purpose-built place for physically and hearing-impaired young people ages 3 to 20. Within the Centre, there is a purpose-built primary and secondary school. Students from the KGVl Centre have been featured in many drama activities and competitions, including the Plan International High Schools Drama Competitions, Music Crossroads and Zwakala Arts Festival. In this chapter, we examine how theatrical works and the acts of participating in them function as ways of breaking societally constructed barriers for young people living with disabilities.

Keywords: theatre and disability, King George VI Centre, *I Am Disabled, So What?*, *Dancing Queen*

Introduction

King George VI (KGVI) is located in Bulawayo, the second largest city in Zimbabwe, a country in Southern Africa. While the Zimbabwean constitution does not discriminate against people living with disabilities, some sections of society and its members do discriminate against and stigmatise these people either consciously or unconsciously. The KGVI Centre (which houses both a primary and secondary school) is one of the few in the country that caters to young people with disabilities. It has been active in theatre and music performances, performing live shows in Bulawayo and rural areas. These early performances were generally variety shows featuring music, song, dance, drama, poetry and modelling. Later, the group performed plays with a specific theme. When choosing what show to focus on, the guiding principle is utilising the available talents at KGVI at each particular time. For example, if deaf dancers are present, the show focuses on dancing (Hussey & Chipatiso, 2022).

The KGVI performances are directed mainly at schools and the general public. Audiences have received them well. Firstly, we examine this bold act of participating in these competitions as agentive and transformative to both the community and KGVI students. Secondly, we examine their productions as frameworks of integration and barrier-breaking, especially considering that children living with disabilities are isolated in the Centre. Using the core values of KGVI, such as determination, ability, courage, joy, confidence and independence, as a conceptual framework, we explore how these values manifest in its performances.

This chapter focuses on selected performances in particular; and also draws from the broader general repertoire of KGVI's performances. We focus on the play entitled, *I Am Disabled, So What?*, which revolves around the story of a mother (MaMoyo) who has a disabled daughter (Angeline) and has consequently been rejected by her community. Braving the societal challenges of exclusion and rejection, the daughter grows up to become a talented singer. Sadly, the mother dies of AIDS towards the end of the play. Another selected play is entitled *Dancing Queen*, which chronicles the experiences of a young deaf girl with a desire to become a professional dancer. Her father and rural community, however, are opposed to this idea. Her chance to follow her dreams comes when she enrolls at a school where she is encouraged to dance. Through this encouragement, she develops her dancing talent and becomes a star. She returns to her community to deliver

a show that proves her ability. All the characters in this play are nameless. We also selected the short dramas produced for the Zwakala interregional competitions with themes covering rural life, individual ability and xenophobia. We also refer to the dance show done during the KGVI Centre's 60th anniversary. In this chapter, we use the term *theatre* in its broad sense to refer to drama, dance and poetry.

Theory and methodological approach

This qualitative research uses a case study approach (Creswell, 2013). The KGVI School was selected as our case study because it is one of the few schools in the country that caters to people living with disabilities. Its prominent Drama Club has made a footprint in High Schools Drama competitions, which also cemented our choice. The school was, therefore, purposively sampled after it was seen to be information-rich in the context of this research (Etikan et al., 2016).

Qualitative researchers are interested in people's experiences to understand what is important to them. Cognisant of this fact, we adopted an approach that incorporates Knowledge Holders so that they can participate in telling their stories from their own perspectives (Lenette, 2019). We decided to do the research *with* the Knowledge Holders instead of merely researching them (Van der Vaart et al., 2018). So, when the data-gathering process started, the first and second authors, Cletus Moyo and Nkululeko Sibanda, performed this task. The third and fourth authors, Inez Hussey and Courage Chipatiso, were respondents or informants. However, during the research process, the first and second authors realised that the two informants' perspectives were critical for telling the KGVI Drama Club's story. The first and second authors, therefore, invited the informants to contribute to this chapter as co-authors. We believe that this has enabled the Knowledge Holders, as insiders to the KGVI School, to participate in the shaping of the narrative that has emerged from this research. We believe that through adopting this approach insiders have not been marginalised. Indeed, the Knowledge Holders have not been pushed to the periphery through being "spoken for." Therefore, the agency that this research desires has been cultivated.

Data was gathered through a focus group discussion conducted by the first and second authors with three staff members at KGVI School who have been involved with the KGVI Drama Club – Inez Hussey, who

has been spearheading drama activities at the school and directing the club; Courage Chipatiso, who is a drama teacher and the club's director; and Farai Mabhande from the Information Technology (IT) Department. During the focus group discussion, the KGVI staff members shared their experiences, observations and comments concerning the work of the KGVI Drama Club. After the focus group discussion, Inez Hussey and Courage Chipatiso made written submissions in response to the questions that the first and second authors had crafted. We also used observations drawn from the authors' recollections of the performances. While Courage Chipatiso and Inez Hussey provided most of these recollections, Cletus Moyo and Nkululeko Sibanda also attended some of the KGVI Drama Club's performances while adjudicating during the Plan High Schools Drama Competitions in Bulawayo. Data from the abovementioned sources was then subjected to thematic analysis in line with the focus of this research.

We deploy critical disability theory to problematise how the KGVI Drama Club performances explore and engage with the themes of liberty, ability, belonging, agency and cultural identity production within the context of the exclusionary Zimbabwean landscape. Nehemiah Chivandikwa (2019, p. 43) states that critical disability theory challenges notions of "normalcy and deviancy," and "the taken-for-granted power-laden discourse," operating as "forms of praxis." David L. Hosking (2008) views critical disability theory as a broad framework that challenges the constructions and discourses of impaired bodies. This study makes use of key critical disability theory concepts such as the "social model of disability, multidimensionality, valuing diversity, rights, voices of disability, language, and transformative politics" (Hosking, 2008, p. 5). Key to our study is the social model of disability, which challenges notions of ableism by creating a cartography that redefines disability using a multi-plural approach. This approach, according to Hosking (2008, p. 7) proposes that:

- (1) disability is a social construct, not the inevitable consequence of impairment, (2) disability is best characterised as a complex interrelationship between impairment, individual response to impairment, and the social environment, and (3) the social disadvantage experienced by disabled people is caused by the physical, institutional and attitudinal (together with, the 'social') environment which fails to meet the needs of people who do not match the social expectation of 'normalcy'.

This approach allows us to engage with KGVI's performances that adopt role reversals as a strategy for engaging with the stigma associated with disability. It also allows us to engage with the ideological, socio-cultural and physical discourses that impede/ enable KGVI to produce performances that engage and explore disability. Because critical disability theory radically seeks to remove exclusionary oppressive regimes that impede the full participation of disabled persons in the socio-cultural, economic and political affairs of society (Hosking, 2008), it allows us to read agentic intentions in the performances given by KGVI Drama Club.

Disability, theatre and liveness in performance

Notions of disability within the context of African cultures have for a long time been defined by challenges of social acceptance due to sociocultural, historical and economic factors (Folola & Hamel, 2021). Judith Mackenzie and Tsitsi Chataika (2018, p. 318) write that disabled people in Africa are often associated with malign spirits and family transgression that include “witchcraft, a curse or punishment from God, the anger of ancestral spirits, bad omens, reincarnation, heredity, incestuous relationships and the misdemeanour of the mother.” Consequently, within traditional societies, the voices of disabled people who contest mainstream conceptions of disability and the potential role of disabled people have been suppressed and marginalised (Hosking, 2008).

Addressing these multiple forms of disablement that Africans face requires confronting a variety of challenges related to the social acceptance of differently-abled people in society (Folola & Hamel, 2021). For this to happen, Collette Conroy (2009, p. 2) points to a need to re-conceptualise the way disability is viewed and engaged with: “For disability to be political, there must be a conceptual shifting of the world, a persistent re-imagining of the way that humans relate to each other across differences of corporeal form and function.” This would inspire models of disability that deconstruct Western-inspired and indigenous African exclusionary conceptions of disability as “otherness” and “normality.”

Deployment of “disability politics” locates disability as a “political identity rather than a bodily description” (Conroy, 2009, p. 8). Disability, as expressed through the bodily presence in performing arts, not only becomes “intrinsically political” but also “aesthetically challenging” where aesthetics

“is founded upon the assumption that we all experience the world through the senses – and the body acts as a conceptual glue here – broadly the same way” (Conroy, 2009, p. 11). In this context and from a performance perspective, the understanding of the body goes beyond the performer’s physical appearance (from the perspective of both the performer and spectator) by examining how (positive) power (social, political and cultural) plays out on stage. To this end, disability performances thus explore and problematise the positionality of the performer and spectator and question the meanings that arise at the point where the practitioner meets work (Conroy, 2009).

This point of intersection and convergence creates a liminal space from which the KGVI Drama Club performances were created. The liminal space is a “transactional phase, occupying a position on or on both sides of, a boundary or threshold” (Shain, 2006, p. 84) that transforms theatre performance into a site for political struggle. This site of liminality reframes the subject-object/ normal-disabled relationship. Our case study performances are thus framed as liminal performances as they set aside constructions of normality and disability, challenge marginalisation and force the spectators (including us – as readers of the performance) to develop new interpretations and meanings with regard to these performances.

Performing agency

KGVI students’ participation in theatrical events under review is agentive and transformative to both the community and KGVI students. Through art, they are actively participating in the world and seeking to transform it (Boal, 2006; Wolterstorff, 1980). In the backdrop of a society that pushes issues of disability to the margin (Chataika, 2019) and often chooses silence instead of discussing these issues, there is a need for amplifying voices that bring these issues up. Speaking out is important for any liberation to occur (Freire, 1970). The KGVI students therefore use art to raise issues that affect both people living with disabilities and society in general.

The KGVI Drama Club does not specifically engage with issues that affect differently-abled people in their creative works; rather, it engages with issues that affect humanity in general. This finds relevance in Conroy (2009, p. 11) who observes the following:

...the notion of inclusion in the form of opening the door to a room that exists already, to grant access to the excluded is one of the most misleading elements of disability

discourse, and it has found a form in disability theatre in the model of partnerships between disabled participants and established mainstream artists.

By opening this door, the KGVI students resist the temptation to only focus on disability issues, which in a way could be considered self-marginalisation as it would exclude them from taking part in debates that affect humanity as a whole. In the face of challenges, the KGVI students have mastered the courage, determination, ability and confidence needed to assert their agency in raising issues that affect people in their societies. For example, at the Zwakala Festival competitions in South Africa, they presented a production centred on the theme of xenophobia. KGVI has also given performances that explore other themes like HIV and AIDS, poverty and cultural issues. Chipatiso, their director, points out:

The recurring theme is disability of various forms and how a person with talent is overlooked because of discrimination. However, we also explore topical issues like HIV and AIDS, culture and tradition, and poverty. Our children do not always want to 'talk' about disability so they like to choose other social issues like poverty... There is always some message for society in our shows. (Chipatiso, 2022)

The KGVI Drama Club approaches the idea of disability *via negativa*. By approaching social and political issues and participating in competitions and festivals that are not exclusively for differently-abled groups, KGVI challenged notions of exclusionary ableism and spaces. Thus, KGVI approached disability arts from Thomas G. Couser's (2008) perspective, which asserts that disability needs to be viewed and acknowledged as an aspect of human diversity as race, ethnicity, gender and sexuality. In as much as the KGVI Drama Club could be setting itself up for inspection and interrogation, the content of their productions would in most instances challenge this negative interpretation and violation of privacy from an ableist perspective. For example, the KGVI Drama Club usually centres its positionality and agency within the "real" and not the mediated one. In the Plan High Schools Competitions at Intwasa Arts Festival koB-ulawayo, the KGVI Drama Club competed with mainstream schools and was graded as full competitors because the competition grading scale was inclusive.¹ In participating in these competitions with and against their

1 Nkululeko Sibanda worked with Intwasa Arts Festival in running and/or adjudicating the Plan High School Competition.

“mainstream” colleagues, the politics associated with how different their bodies are from their counterparts is altered, and exclusionary practices are transformed into sites (practices) of inclusion (Ames, 2019). Such transformative acts offer an “alternative view of disability, where embodiments can be explored without being seen through an ableist lens” (Shain, 2006, p. 140). Competitions such as the Plan High Schools Drama Competition are arguably exclusionary because KGVI had to be granted special approval for them to participate as they are not considered a mainstream educational facility by the Ministry of Primary and Secondary Education. Yet, the desire and purposefulness of the Drama Group present their agentive stance to challenge exclusionary practices within their demographic group and environment.

The sailing has not been smooth for the KGVI Drama Club. Notably, besides the Jairos Jiri Band of the 1990s, the KGVI Drama Club has been the main creators of disability theatre/ arts/ performances since the turn of the millennium. Disability theatre/arts seeks to address and redress the very idea of disability in the modern arts and, by extension, society in general through undermining stereotypes and stigma on the one hand and pressing the boundaries of aesthetic convention on the other (Johnston, 2016). Disability theatre is thus activist in orientation (Johnston, 2016). One of the greatest challenges to this practice of the KGVI Drama Club’s artistic activism is the performance spaces available for use or used by the group, particularly those who use wheelchairs. Places like the Bulawayo City Hall, where the group has often performed, have no ramp for wheelchair access, making getting wheelchairs on and offstage difficult.

A case in point is musical shows where most of the time, if not all of the time, a marimba band provides acoustic support for the KGVI Drama Club. Challenges arise because marimbas have to be transferred from the truck to the performance space, and fitting these instruments onto the stage together with wheelchairs is usually challenging and time-consuming. And for the group’s performers with hearing difficulties, there is always the issue of having to turn the volume up to high levels so that they can feel the beat, and this may be uncomfortable for some members of the audience. In traditional dancing competitions, KGVI usually performs dances without the expected clapping and singing accompaniment, which can be confusing to an audience accustomed to a particular way of experiencing these kinds of performances. When faced with these kinds of challenges, some groups might include non-disabled

performers to provide cues and guide their differently-abled counterparts, KGVI Drama Club encourages collaboration between and among its own students. For instance, performers with hearing difficulties are paired with singers or speakers who do not have challenges with their sight (often in wheelchairs). This affirmation that disabled roles are performed by differently-abled persons finds resonance with Victoria Ann Lewis (2000) in Alan Mark Shain's (2006) questioning of the use of non-disabled actors to play disabled roles. By extension, it asks very critical questions relating to the politics of representation and performance within the context of Zimbabwe's culture.

This kind of agency displayed and lived by KGVI Drama Club in its performances provides "ways to control the viewer's gaze to speak beyond the visual text of [their] identity" (Whatley, 2010, p. 45). It is this identity and the reframing of the gaze at bodily differences that KGVI Drama Club has long sought to challenge through participating in competitions and performing in spaces that are modelled on exclusionary practices.

Participating in theatre competitions that do not provide special categorisation or treatment comes with its own challenges in a setting that marginalises disability. While engaged in these efforts to shake off the stigmatising and marginalising tendencies the KGVI Drama Club gets exposed to every day, other students from mainstream schools have always grumbled about the KGVI drama group's winning competitions. These grumblings emerge from their ableist view that the KGVI Drama Club wins competitions because the adjudicators feel pity and empathy for them because of their varied disabilities. We agree with Davis Lennard (2013, p. 1) who states that in situations like these, the "'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person." Within this context, the "norm" is to treat the differently-abled persons as "sub-citizens" that need favours and a head-start from the "normal" so that they can become competitive. However, Ms Chipatiso refuted such claims and pointed out that the Drama Club wins competitions on merit – because of their ability and not disability. Yet, the ableist attitudes that seem to permeate society through the perspectives of high school children remain a challenge in the fight against exclusionary practices that promote "normality" and body presence at the expense of humanity, talent and content. From this view, theatre offers a platform to practise agency that makes pushing back possible.

***I Am Disabled, So What? and Dancing Queen* – destabilising integration and barrier-breaking**

Differently-abled communities in Zimbabwe and the world over face the challenge of having an integrationist approach anchored in ableist perspectives. These perspectives find roots and articulation in multiple approaches to disability, including the colonial, medical and cultural approaches (See Folola & Hamel, 2021; McKenzie & Chataika, 2018; Ngue, 2012). The colonialist approach positioned and associated disability with “malevolence rather than blessing, or as a result of divine retribution for transgressions against societal moves” (Shain, 2006, p. 74), invoking a Christian-Judaic morality that formed the basis of colonialism and perpetuation of neo-colonialism. Beyond this Christian-couched characterisation of disability, Ngue (2012, p. 145) proposes that, from the onset of colonialism, the colonised subject was considered “uncivilised,” “unclothed,” “uncultured” and defined by “inherent cultural and intellectual deficiencies.” Therefore, from a colonialist perspective, Africans were implicitly disabled by their inferior culture, and as such, the integration approach sought to attend to these deficiencies through education, religion and violence.

McKenzie and Chataika (2018) submit that in Africa, differently-abled people are often associated with malign spirits and/or family transgression that include witchcraft, curses, God’s punishment and/or ancestral spirit anger and punishment. The cultural perspective, founded on a eugenic logic that individual variations accumulate into a composite national identity (Davis, 2013, p. 6) was used to group together all “allegedly undesirable traits,” for instance, criminals and people with disabilities. This logic permeated through the traditional African societies and “criminalised” disability as in some ethnic groups such as the Zulu, where disabled children were killed at birth as a result of this “false idea of the body politic – that a hunchbacked citizenry will make a hunchbacked nation” (Davis, 2013, p. 6). These approaches to disability gave rise to an exclusionary mindset and placed the differently-abled body in a position of abjection and objectification (Shain, 2006, p. 112). How do we, therefore, re-frame and challenge this mindset using the performing arts in a postcolonial, Christian-centred environment?

We analyse two plays by KGV Drama Club entitled *I Am Disabled, So What?* and *Dancing Queen* as a starting point for responding to the

above question. We view these works in particular – and other theatrical works of KGVI in general – as frameworks destabilising the conventional integrationist approach and breaking barriers of empathetic feelings towards the differently-abled. Phillip Taylor’s (2003) positive overview of the role of applied theatre within the context of marginalised communities provides a departure point for our engagement with the works of KGVI. Taylor (2003) asserts that theatre can teach community members to teach others, assisting communities to deal with issues that affect them in their day-to-day lives; moreover, it can raise awareness or intensify it, present available possibilities or alternatives, heal psychological wounds or barriers, challenge current discourses and assist in voicing the voices of the silent and marginal. Within the context of disability studies, Shain (2006, p. 77) writes, as we read it within the context of Taylor’s observation, that the “only recourse is to see the difference as the inverse of all that is wholesome and good, placing disability outside the realm of ‘normal life.’” The choice of the themes, content and material used by KGVI Drama Club is key in using theatre to provide an inverse view of bodily difference as articulated by Hussey and Chipatiso:

We, the organisers, like to choose subjects that will make the audience aware of the ability of our performers. For us, it is also about advocacy and [we] truly believe that our performances have helped with disability awareness in Bulawayo. A compelling performance does more for advocacy than any amount of talking. If an audience can enjoy a performance by an artist with a disability, they will rethink their misconceptions about disability. (Hussay & Chipatiso, 2022)

Critical to the choice of the material is a positional challenge to the conventional understanding of disability as an abnormality, reversing and reframing the mirror back to mainstream society. As can be seen in Hussey and Chipatiso’s submissions, the material that the KGVI Drama Club presents to its audience explores their world as a “normal” world that needs no frames of integration into the mainstream but co-existence and collaboration.

I Am Disabled, So What? and *Dancing Queen* are both centred on the lives of two girls living with disabilities who have to deal with family and community rejection because of their bodily differences. Angeline in *I Am Disabled, So What?* is a talented singer who is physically disabled and rejected by her community, as a result turning to her artistic creativity to express her frustrations and stake out her position in the community. The nameless main character in *Dancing Queen* is a dancer with hearing

difficulties. In both plays, the young girls living with disabilities focus on their budding artistic careers; in the end, doing so makes them succeed against the public rejection by their family and communities. Angeline becomes an internationally acclaimed singer and musician while the nameless girl becomes a successful dancer.

Etymologically, the titles of the plays form a critical exercise of questioning the status quo and affirming the status of the lead dancer in *Dancing Queen*. The title *I Am Disabled, So What?* is an affirmation of the disability of the nameless character and other cast members and an invocation of the normality of disability as positive imagery. The positive affirmation finds relevance in Chataika's (2019, p. 3) observation that the struggle from a disability perspective is about "challenging oppression, voicelessness, stereotyping, undermining [...]". The declaration that the nameless girl is indeed disabled and therefore not different from anyone else in the community grants agency and voice not only to her but also to the differently-abled community. The title *Dancing Queen* positions the differently-abled dancers as queens – a title reserved for the prestigious and most important woman in a monarchy. Some of the synonyms of the title queen include – diva, princess, goddess, priestess, high priestess and prima donna – terms that challenge the negative framing of differently-abled persons characterised by stigma, dehumanisation and evil. The namelessness of the main character attaches a universality to the trials and tribulations as well as victories experienced by this character, portraying the challenges that this character faces as ordinary everyday trials that any other person might face. This takes away the focus and emphasis from the bodily difference of the nameless character in a way that rejects the valorisation of the disabled body as a site of deviancy, failure and inefficiency.

We view these plays as maps of experiences that capture and document the struggles of people living with disabilities and their commitment to breaking marginalising barriers. Our view is located in Karin Barber's (1997, p. 5) observation and engagement with African popular culture, specifically songs created by workers from the Mozambican plantations which, as she observes, were "generated by people's suffering, giving collective voice to memories of pain to make them serve as a 'map of experience'". Barber further observes that such popular artistic works represent the part of the mind that refuses to capitulate. With regards to the KGV Drama Club, Hussey and Chipatiso attest that these productions demonstrate the courage of KGV Drama Club members to resist being silenced. Faced

with opposition and discrimination from the community, and sometimes even their own family members, people living with disabilities are showing through theatre the determination and resilience that make them thrive in unfavourable conditions. As Hussey and Chipatiso point out:

It takes enormous courage for a young person with a disability to get up on a stage and perform and yet year after year we see these young people do just that. These same youngsters have suffered discrimination and jeering at home or in the streets and yet they dare to stand in front of the audience and perform. Those who come to coach our students are always blown away by their ability and determination to succeed. (2022, written submissions)

The determination to succeed demonstrated by Angeline in *I Am Disabled, So What?* and the deaf girl in *Dancing Queen* reflects the determination that is found in the KGVI Centre's learners to live their lives to the fullest. It is also meant to act as a stimulus to cultivate such a positive outlook and approach to life among the same learners. This is why the plays reflect the experiences of the learners to a certain extent while at the same time seek to inspire them through carefully selected and designed plots and themes. Judging from the way the learners are participating in these creative works, the plays and other works of art being done by KGVI Centre are making a positive impact. According to Hussey and Chipatiso:

In the end, very little allowance is made for any disability. You want to perform, you perform no matter what problems there may be for you to do this. Our deaf students love dancing, they love the order and visual impact of putting on a performance. Our singers in wheelchairs sometimes struggle with breath control but this does not stop them from giving their best. (Hussay & Chipatiso, 2022)

The two plays also portray the struggles that people living with disabilities face. In *I Am Disabled, So What?* Angeline enrolls in a school for people living with disabilities; it is there that she is encouraged to sing. Though the school is not named, it resembles the KGVI Centre. By making this school play a major role in nurturing Angeline's talent, the play is suggesting to members of the community that it is important to take their loved ones who are living with disabilities to these schools so that they can benefit from specialists such as the sign language teachers that are found in these institutions. Similarly, the deaf girl in *Dancing Queen* goes to town and attends a similar (if not the same) school. In rural areas, there is a problem

with parents of children living with disabilities hiding their children at home and not taking them to school. The plays seek to break the barrier that excludes children with disabilities from schooling and advance the idea that attending school is empowering to them. After having attended school, both main characters come back to their communities equipped with skills that can make their lives more fulfilling and fruitful. For KGVI, participation in theatre boosts the confidence of the learners and empowers them to navigate past their challenges. As Hussey and Chipatiso point out:

Most definitely! This [using art to break barriers] has been our goal throughout our arts programme, from day one. Seeing how audiences respond to a deaf dancer, a singer with a disability, a poet with a speech impediment, a model on crutches – this is the true success of our arts programme. So many of our children face terrible discrimination in their home areas but when they can perform in public and be applauded for a professional performance, this gives them the confidence needed to deal with discrimination. If we can get the man on the street to watch a performance they will be blown away and will have to revise their initial prejudice. (2022, written submissions)

In assisting in navigating past the everyday challenges of living in a society that discriminates against those living with disabilities, the KGVI plays adopt an endogenous approach to representation. This “inside-outside” model grants agency to the process, approach and work of the KGVI Drama Club because it allows them to position their experiences, modes of articulation and mediation. To this end, the notion of inclusion comes from the perspective of the differently-abled and their view of the world rather than the dominant mainstream ableist approach, making the fully able-bodied the “other” and the differently-abled the “centre.” For instance, in *Dancing Queen* and *I Am Disabled, So What?* the able-bodied performer is presented as an adjunct of the differently-abled performers, casting them in the freak role that more or less objectifies them in the manner mainstream communities do with differently-abled persons. This kind of reframing of the centre-margin characterisation of disability excavates deeply seated patterns of reality to disability, which the mainstream community usually takes for granted or uses to marginalise differently-abled persons further. Borrowing from Augusto Boal’s (1995) characterisation of art as a mirror of society, the KGVI Drama Club case study plays affirm, on the one hand, that differently-abled persons are complete and “normal” and therefore agentic; on the other hand, it exposes the audience members to the kind

of discrimination differently-abled persons go through because of their objectification and marginalisation as a result of ableist notions.

Lewis (2000) in Shain (2006, p. 139) observes that one of the challenges facing disability arts, especially film, is that non-disabled actors perform disabled roles, placing the representation of disability within the realm of fantasy where there is a role to be played rather than an acknowledgement of the valid presence of the differently-abled person in the world. This “acting” of disability becomes a site of objectification, marginalisation and exclusion of disabled persons because their presence is not acknowledged but rather “acted” out. However, in the play, *I Am Disabled, So What?* Angeline, who has a physical disability, takes centre stage and evolves with the story, which narrates the challenges of a physically challenged character in the mainstream world. Similarly, in *Dancing Queen* the narrative is centred on the nameless girl who has hearing difficulties; it culminates in the pivotal scene where she returns to the village to stage her show. During the live performance, the nameless character is always positioned in the centre of the stage, arguably the most powerful location. Of interest is that the KGVI Drama Club does not take the lived presence of the non-disabled for granted in their performances, as all non-disabled roles and characters were performed by able-bodied actors. These performances thus award privilege to the performers’ bodily presence and provide the audience and KGVI Drama Club with collaborative ways “to control the viewers’ gaze to speak beyond the visual text” (Whatley 2010, p. 45) of disability, which offers an alternative viewing lens.

Hussey and Chipatiso observe:

These public performances give our students the self-esteem to succeed in other aspects of their lives. A child who knows they can dance or sing on a stage will then have the confidence to do well in school or take on the daily living skills that are required in our Independent Living units. This pride in your special ability can be one of the greatest achievements for our students and if they can persuade family members to come and watch then that is even better. (2022, written submissions)

This observation speaks to the impact of positive bodily presence on the psyche and identity of differently-abled persons. Drawing from Boal’s (2006) submission and perception of performance as a rehearsal of life, the live performances of *Dancing Queen* and *I Am Disabled, So What?* offered not only the performers but also the audience an opportunity to challenge and question stereotypical perceptions of disability. In taking

lead roles that dictate the tempo and growth of the story in these live theatrical performances, these two productions transposed the bodies of the performances beyond the cultural text and broke the reception models and boundaries wide open. Specifically, within the Zimbabwean performing arts, differently-abled performers were associated with music due to the exploits of the Jairos Jiri Band and Paul Matavire. The emergence of the KGVI Drama Club within the theatre sector, which for all intents is physically demanding from the performer, calls for a re-calibration of the reception models.

The public theatre, dance and musical performances by KGVI exhibit a potential to act as ways that are practised by the learners, who spend a lot of time “isolated” at the centre, to be active in communal spaces. This is a way of integrating so that there is no binary between the learners at the centre and the rest of the community. These public performances therefore serve the purpose of breaking boundaries or barriers that seek to confine people living with disabilities to certain spaces instead of accepting them and their participation in communal and public spaces.

Conclusion

Participation in the plays and other artistic works created and showcased by the KGVI Drama Club, and by extension KGVI learners, exhibits a potential for breaking barriers that marginalise the arts. Participation in the performances as performers and audience members may have a transformative impact. The KGVI Drama Club has used theatre to break barriers that marginalise people living with disabilities as well as encourage and cultivate in the learners the values of the centre such as determination, ability, joy, confidence and independence.

Working with differently-abled young people in Africa, and specifically in Zimbabwe, is a difficult exercise because of the framing, understanding and appreciation of the conceptualisation of disability. As we have argued in this chapter, in line with Folola and Hamel (2021), there remains a gap for future studies where colonial global inspired conceptions of disability, disability arts and disability studies are de-linked for an African-inspired approach that combines actual experiences and knowledges located and emerging from the continent. The case studies we have engaged with in this chapter express a suppressed desire for a decolonisation and re-conceptualisation of (normal) being, (disability) knowledges

and (hierarchies of) power within society. The informed and articulate challenging of the norms, manifestations of social barriers, stigma and dehumanisation through participating in competitions that were crafted without consideration of the differently-abled is testament to this call. Secondly, the intentional inversion of the “normal” world and articulation of “normalcy” from the perspective of the differently-abled young people forcing the mainstream normal to be the differently-abled in the world of *Dancing Queen* is further testament for the need to delink the conceptualisation of disability and disability studies. In essence, the question that we need to continue being entangled with remains: When we define and conceptualise disability studies, whose perspective is fundamental and foundational?

Author biographies

Cletus Moyo is a senior drama lecturer at Lupane State University in Lupane, Zimbabwe. He holds a PhD in drama and performance studies from the University of KwaZulu-Natal in South Africa. He also has a Master of Arts in dramatic art from the University of the Witwatersrand in Johannesburg, South Africa. His research interests are in applied theatre.

Nkululeko Sibanda is a Y2-rated researcher based at Rhodes University, with over 30 peer-reviewed articles and ten book chapters. Nkululeko is an editor for *Cogent Arts and Humanities Journal* (Visual and Performing Arts) and editorial board member of *Research in Drama Education: The Journal of Applied Theatre and Performance*. Nkululeko’s research is pivoted at the intersection of society, people and live performing arts from the vantage point of African visuality, aesthetics and experiences. The need to develop a formidable, relevant and practical performance theory and practice model within African performance practice (from an African paradigm) sits at the base of his research.

Inez Hussey has worked at the KGVI Centre for Children with Disabilities in Bulawayo, Zimbabwe, for over 30 years. During that time, she nurtured and encouraged the performing arts programme, believing every child has a talent. She believes that demonstrating that children with disabilities can perform professionally and entertaining is the best form of advocacy.

She has been vital in launching an international band and disabled and deaf performers who have shone in Zimbabwe and regionally.

Courage Chipatiso is a drama teacher and sign language tutor at King George VI Centre in Bulawayo, Zimbabwe. Her passion for the performing arts and work with the differently abled community was re-awakened when she worked for a local welfare organisation that advocated for the rights of a disabling condition called muscular dystrophy. From then on, she has worked with learners, touring locally, nationally and regionally. Ms Chipatiso has held several board positions, including the local Paralympics SRC and the Regional Advocacy Committee for NASCOH. She is the founding member of the Disability in Development and Services, a trust that advocates for disability issues in Zimbabwe and Southern Africa.

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CHAPTER 4

We Do Not Need Pity. We Need Opportunities: Considerations of a Performer with Differentiated Body

Felipe Henrique Monteiro Oliveira Centro Internacional de Pesquisas Artísticas e Acadêmicas sobre Antonin Artaud, Federal University of Uberlândia, Brazil

Andrea Pagnes (VestAndPage), ArtEZ University of the Arts, the Netherlands

Abstract: The text is about the significance of performers with differentiated bodies in performance art, specifically in the Brazilian art context. The core question is if the presence of such bodies is insubordinate and insurgent enough to overcome the medical gaze and the pity-filled gaze with which people often look at the disabled. Advocating a politics of care in this respect, the analysis stems from Felipe Henrique Monteiro Oliveira's own artistic experience after having lived in a region of northeastern Brazil that is still permeated by a culture of intolerance and indifference. He provides the first person voice in the text.

Keywords: differentiated bodies, disability culture, performing arts, protest, Brazilian art context

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Introduction

Originating at the beginning of the 20th century after having been modeled on famous European avant-garde movements (Futurism, Dadaism, Constructivism, Surrealism, the Bauhaus), the genre of performance art developed during the 1960s-1970s (Goldberg, 1988).

Since John Cage's first experiments, performance art has continued to shake traditional art ideas at their foundation, often aiming to provocatively violate norms and tacit rules of social interaction.

In 1952, *Untitled Event* was performed by Cage along with dancer Merce Cunningham, pianist David Tudor, artist Robert Rauschenberg, poets M.C. Richards and Charles Olson and others. Orchestrated by Cage, they all created what could be called the first "happening," an untitled event (also known as *Theatre Piece no.1*) in the Black Mountain College dining hall. While several performances took place within a choreographed time frame, they did so without any narrative or causal relation to one another.

The echo of *Untitled Event* played out in the following decades through avant-garde performance: discipline boundaries and distinctions between different art practices were challenged, making artistic paradigms converge and collide (Kirby & Schechner, 1965).

The *18 Happenings in 6 Parts* by American artist Allan Kaprow took place at the Reuben Gallery in New York over six days in October, 1959. Kaprow sourced theatrical elements of Dada and Surrealism. His happenings were the forerunners of performance art in the US; they also paved the way for the Fluxus movement.

However, the development of performance art is not a phenomenon confined to Europe and North America alone. In 1954, in Japan, Gutai avant-garde group's radical ideas and approaches to making art deployed the artist's body in deconstructing conventional art forms, such as painting and sculpture.

With the dematerialization of the art object in the 1960s and 1970s, performance art began to focus on the body, reflecting the political ferment of the time, e.g. the surge of feminism, which encouraged thought about the connections between personal experience and larger social and political structures.

With the rise of body art, the artist's presence translated into an artist's physicality— the flesh becoming a key feature of the work of art. This

was a mode pioneered by the Viennese Actionism radical, an explicit form of performance art developed during the 1960s. To break bourgeois taboos and express violent criticism against post-World War II Austrian society, the Viennese actionists often resorted to using blood and animal carcasses to lambaste a society that had been suppressing memories of the unspeakable atrocities committed by the Nazis. These activists were attempting to force people to face these traumas head-on through their extreme art-inspired activities.

During this same time period, the evolution of performance art in Eastern Europe and Latin and Indigenous America responded to dramatically different art-historical and socio-political factors – a form of rebellion against the authoritarian power regimes then in force in those countries (Gómez-Peña & Salgado, 2012).

In nations governed by post-war state socialism or dictatorial regimes, performance art has become a politicized mechanism of insurgence against the oppression of civil liberties and democratic ideals – a form of activism/artivism aimed at reclaiming the rights of the citizen: personal expression on the one hand and cultural autonomy on the other.

In this context, one of the most exemplary actions took place during the 1970 military dictatorship in Brazil. At the opening of the 19th National Salon of Modern Art at MAM in Rio de Janeiro, Brazilian artist Antonio Manuel¹ removed his clothing, then clandestinely climbed the staircase of the museum, eventually posing naked on the balustrade above the numerous audience members and shouting: “*O corpo é a obra*” [The Body Is the Work] as a statement criticizing the repression of ideas in art and society. Two years before, in fact, the Brazilian military government had established the Institutional Act No. 5 (AI-5) curtailing artistic expression (Canejo, 2020). A black woman joined Antonio Manuel in his action before they were both forced to flee the museum. Despite the restrictions imposed by the dictatorial regime, the Brazilian media paid a lot of attention to Manuel’s action, which later was named an “Experimental Exercise of Freedom.” (Enciclopédia Itaú Cultural, 2021)

1 Antonio Manuel, artist website: <https://antoniomanuel.net/>



Figure 1. Antonio Manuel. Exhibition view of *O Corpo é a Obra* (1970). III Venice International Performance Art Week 2016. Image © VestAndPage and the artist.



Figures 2 and 3. Antonio Manuel. Exhibition view of *O Corpo é a Obra* (1970)- *Revisão de Imprensa*. III Venice International Performance Art Week 2016. Image © VestAndPage and the artist.

Any type of body is a work (of art)

Indeed, in performance art, the artist's body is the *prima materia* used to challenge powerful regimes and social norms. "Placing the body front and center in artistic practice – no longer the object depicted in paintings, or sculpture, or film, or photography but the living flesh and breath of the act itself" (Taylor, 2016, p. 1) often creates a sense of unease in the audience. However, what is essential to consider is that through this type of operation – the exposure of the artist's body as the main tool of artistic creation and political uprising – performance art is a practice which does not discriminate against human bodies because of their physical characteristics, race or gender. Conversely, free from rigid narrative structures, perfectionism and virtuosity at any cost, it emphasizes bodies' uniqueness and diversity as sources of creativity with a clear focus on inclusion and openness.

Welcoming as it does all body types, performance art also highlights disability in every way. In doing so, it questions Otherness as "the result of a discursive process by which a dominant in-group constructs one or many dominated out-groups by stigmatizing a difference – real or imagined – presented as a negation of identity and thus a motive for potential discrimination" (Staszak, 2009, p. 4).

Valuing differences and promoting inclusion should not be considered acts of benevolence. In the performance space, performers endowed with a *differentiated body*, a term used to designate people with some type of disability (Monteiro, 2013), are driven by the urgency of being recognized as equal to all other human beings, thus disrupting the medical gaze with which they are often regarded.

Disability stigmas are the existential traits that people endowed with differentiated bodies carry with them throughout their lives. As a performance artist affected by a severe progressive spinal amyotrophy that does not allow me autonomy of movement and living in a region of northeastern Brazil, an area still permeated by a culture of intolerance and indifference, I approach performance art as a tool to deconstruct the limitations imposed by that same culture.

As a performer, I expose my vulnerable, defenseless body and organize performative situations to make life and art converge. I share my experiences with my audience about the difficulties I encounter in everyday life.

Through performance art, I can express my concerns about the hypocritical social environment where I live, which regards the disabled as an unwelcome problem to be relegated to a marginal place in society. For these reasons, I consider my performances as insubordinate, insurgent acts of aesthetic invasion into the folds of a reactionary system that ghettoizes all of the disabled people who live in precarious clinical conditions similar to my own, lacking as we do adequate financial resources.

I view my performances as insurgent acts of aesthetic invasion because I occupy the performance space to oppose a discriminatory society that categorizes individuals by their physical characteristics and cognitive traits, all of which are expected to conform to standards of perfection, beauty, productivity and efficiency. I make explicit the need to resist and dismantle dominant schemes that often exclude the differently-abled from the performing arts scene and public life. I advocate for an emancipatory, egalitarian and libertarian humanism that embraces differences and proposes alternatives to support marginalized people's rights.

I exercise the aesthetic of invasion and resistance in performance to draw upon my experience and shape the conversation about being different but still seen as equal by others. When performing, I can exercise my personal agency to express such concerns because of the visibility I acquire in the performance space (Phelan, 1993).

I did so in the performance *(DES)VITRUVIANDO* at the IV Performance Exhibition at Galeria Cañizares of the Federal University of Bahia (2014). I exposed my differentiated body, in all its fragility and vulnerability, to deconstruct the ancient classical and Renaissance ideal of human physical perfection still rooted in society today.

During the performance, I lie face up on a large white canvas. I then invite the audience to interact with me: talking or writing and/or drawing near my body, thus creating a poetic proximity that is almost intimate with my motionless body.

I conceived *(DES)VITRUVIANDO* to stimulate able bodied people's reflection on the process of stigmatization, which disabled people often suffer from because they are deemed to deviate from standardized norms of physical perfection. I thereby interfered with my differentiated body in a public art institution. I provoked a reaction of a social and aesthetic nature in my audience by opposing traditional, homologated scenic canons to value diversity with my presence in the performance space.



Figure 4. Felipe Monteiro with Ciane Fernandes and Susanne Ohmann. *(DES)VITRUVI- ANDO*. 2014. Photo: Luis Carneiro Leão.

The Artaudian plague

The presence of a performer with a differentiated body in the performance space may be unsettling to some people, for it has a clear visual and symbolic impact from which the audience cannot subtract. Yet, although creating a certain unease because of their physical impairments, performers with differentiated bodies often perform to value otherness, committed connectivity, interconnectedness, respect and union. For example, consider Italian Nicola Feroni,² affected by a severe form of scleroderma, and French-Algerian Kamil Guenatri,³ affected by a progressive genetic disease that reduces his mobility, express in their performances.

In his performances, Feroni approaches his body as an organic poetic device which allows him to discover a new way of being and perceiving himself; at the same time, he is capable of stimulating the spectator to reflect upon a broader dimension of existence for the actions he proposes.

Guenatri describes his art as mainly focused on exploring his differentiated body and thus total physical dependence on performing basic daily activities.

² Nicola Feroni, artist website: <https://www.nicolaferoni.com/>

³ Kamil Guenatri, artist website: <https://kamilguenatri-blog.tumblr.com/>

For him, his body is a tool of dialogue and interaction with the other; it is “a manufacturing plant of poetry and actions” (Guenatri, 2023, p. 3).

As a performance artist with a differentiated body, I do not need pity; rather, I need opportunities to showcase my artwork, just as all other artists do. I perform to express rupture and resistance against dominant cultural trends that discriminate, segregate or exclude the differentiated body from society and art. I counteract assistentialist, protectionist and pseudo-inclusive processes that threaten to subjugate and subordinate performers with differentiated bodies.

My refusal is based on the notion that performance produces a type of aesthetic agency linked to an emancipatory, egalitarian and libertarian humanism that welcomes particularities and alternatives. It guarantees human and artistic rights to the marginalized, thus opening a space for everyone to responsibly exercise their ethos and express their concerns through performance.

In this respect, my stance is that differentiated bodies in performance exemplify Antonin Artaud’s intuitions in his *Theatre of Cruelty*. For the French poet and essayist, theatre can disrupt spectators’ biases by triggering the most elementary anxieties: “From the human point of view, the action of theater, like that of plague, is beneficial, for, impelling men to see themselves as they are, it causes the mask to fall, reveals the lie, the slackness, baseness, and hypocrisy of our world” (Artaud, 1958, p. 32).

Thus, the presence of differentiated bodies onstage evokes the Artaudian plague, provoking the spectator to ponder on human fragility. A performer’s body is no longer a tool to accomplish feats like staging virtuoso movements. Instead, it holds the space for a confrontation with ideas of imperfection, failure, inadequacy and deficiency.

In performance, the body’s presence is central, and its vulnerability is highlighted through acts where the distinction between art and reality blurs (Butler et al., 2016).

When the audience is infected (in the Artaudian sense) by the presence of performers with differentiated bodies, a disturbance may arise; this is because differentiation takes place and generates some identification. In the performance space, when a human body manifests itself as it is and is recognized as such, it transforms into an aesthetic device producing accretive meanings. As Kristine Stiles writes of the collaboration between Nam Jun Paik and Charlotte Moorman, there are performance actions which “are extraordinary demonstrations of the role the body plays in structuring not only the meaning and presence of objects, but the juridical and institutional

practices that control, manage, and litigate that body” (Stiles, 1993, p. 84). This provokes people to reflect on human frailty.

In the encounter between the spectator and the performer with a differential body, the spectators are inevitably confronted with disability. They are therefore pushed to consider living in a shared world with the vulnerable, hopefully orienting their thoughts toward a more socially inclusive future (Kuppers, 2021).

There is no concealment of the physical limitations of artists with differentiated bodies. Spectators cannot escape their voyeuristic gaze and personal preconceptions of the body. In that, Artaud compares theatre to the plague: while theatre can reveal individual and collective cruelty, it can also disrupt spectators’ biases by triggering their most elementary anxieties. Artaud recounts secular rituals because they allow a community to recognize and restore its desires, memories and identities. In such transitory events, artists and the public are no longer separated into spatial dichotomies or specific theatre functions. In these experiences, life and art merge and erase any distinction between them (Artaud, 1958).

Comparing and even assimilating the theatre to plague, Artaud undertook the philosophical concept of *catharsis* in a transgressive manner. “The theater like the plague is a crisis which is resolved by death or cure. (...); it shakes off the asphyxiating inertia of matter which invades even the clearest testimony of the senses” (Artaud, 1958, pp. 31–32).

The urge to impact and jolt the spectator’s senses will later merge into contemporary performance and body art. When this happens, the staging of differentiated bodies in performance brings to light certain overlooked medical truths. It is an operation that can be regarded as a therapeutic healing ritual. Still, it mainly activates a process of transformation in the body (of both the performer and spectator) by exchanging information about different living conditions through seeking interconnectedness. To expose the differentiated body in the performance space means putting viewers in front of a reality of which they know little, providing them with the keys needed to access and understand it better and empathize with it, thereby changing their gaze on disability as a clinical condition due to misfortune, or, worse, to keep away from it because of their inability to relate to it, which often turns into indifference.

In body art, this exchange of information that allows us to acquire certain truths, this transformation that takes place between bodies in proximity that connect them to each other, is to be understood as a liberating act

that shakes the depths of the self – and which for these reasons can also be painful, shocking and frightening.

To expand knowledge, recognize differences, value stigma and accept diversity

Disquiet permeates my academic research and performance-based practice. How can a society guarantee socioeconomic and cultural opportunities for everyone? My worries arise precisely from the fact that I am faced with an inverse action every day based on the logic of exclusion. The social environment in which I live marginalizes, rejects difference and considers the individual with a differentiated body a problem.

Social models of a given society link disability to misfortune and other societal perceptions that create barriers and lead to social exclusion and stigmatization of those with bodies deemed unfit for the norm (Goffman, 1963).

The logic of exclusion is a consequence of socioeconomic and cultural inequalities: the more the distance between groups of power and people increases, the more likely that discrimination will occur.

In recent years, notwithstanding a period of growth that has made Brazil the first economy in Latin America and the seventh in the world, its societal system's multiple structural criticalities and contradictions are still present. The country suffers from a significant gap in wealth distribution, corruption rooted in the political fabric and severe problems with security and public order. In addition, it suffers from a chronic lack of infrastructure and a weak welfare system.

Brazilian people are demanding more rights, equality and reforms capable of improving their quality of life, counteracting the malfeasance and degradation of public institutions and improving a faltering health system that does not provide adequate support to the lower social classes who live in poverty, thus setting them apart from the more privileged who have easier access to medical care.

Inaccessibility weakens society's democratic character. When everything is subjected to capital metrics – including the human body – social justice, equity and solidarity become empty words.

Nowadays, the body is manipulated to respond to fictitious ideals of beauty, bodily perfection, youth and vigour as disseminated by the cultural industry via mass media. This perpetuates a discourse about the

homogenization of the human body as a constructed object of desire. The proliferation of images of toned, surgically sculpted bodies strengthens the cult of the normalized body – healthy, athletic and seductive, which most of the population does not have.

The differentiated body is excluded because it does not fit capitalist metric criteria. Considered inadequate for social life, individuals with differentiated bodies suffer prejudices and encounter daily difficulties in their social interactions since their body prevents others from physically identifying with them.

Anti-dialogue: A mechanism for social exclusion

In his *Pedagogy of the oppressed*, Paul Freire states that a powerful mechanism for social exclusion is anti-dialogue and that “to substitute monologue, slogans, and communiques for dialogue is to attempt to liberate the oppressed with the instruments of domestication” (Freire, 2005, p. 65).

The purpose of anti-dialogue is to confine and alienate human beings from decision-making about ways of living, being, organizing and participating in social life. It is a strategy of dominance that hinders them from exercising freedom of speech, and this hinders them from expressing their thoughts, criticizing society and problematizing reality.

Isolation and manipulation of feelings are strategies to annihilate and objectify the individual. These methods are often used by authoritarian regimes to maintain their power and coerce their people. When excluded from society, the subject becomes like a puppet, easy to control.

In art, an example of such a procedure is the experience of hardship that the late Brazilian outsider artist Arthur Bispo do Rosario⁴ (1909–1989) had to suffer. Similar to Artaud, he spent most of his life secluded in a psychiatric hospital.

Bispo has gained extensive recognition in recent years, being one of the central figures of the São Paulo Art Biennial (2012). He was also honoured with a retrospective at the Victoria and Albert Museum in London (2012) and acclaimed at the 53rd Venice Biennale (2013).

During his life, Bispo was segregated in a mental health facility for almost fifty years. I impute the cause of this segregation to a social system

4 Museum Arthur Bispo do Rosario: <https://museubispodorosario.com/>

with no prospects for change regarding the acceptance of the differentiated body.

Recognition and acceptance of diversity often collide with the desire to ensure homogeneity in the most diverse contexts, including art. From my perspective, the problem resides in people's aversion to difference, which makes the ideal of social inclusion generally challenging to apply in society and, thus, also in the arts.

Inclusion implies acknowledging dissimilarities. Saying "we are all equal" risks mischaracterizing differences and misinterpreting stigmas as signs of inadequacy, erasing their intrinsic value. If so, inclusion paradoxically becomes a one-sided hierarchical process ranking individuals for their skills and appearance.



Figure 5. Arthur Bispo do Rosario wearing one of his "Annunciation Garments" in 1943. Photo: Jean Manzon. Via ArtReview. Encyclopedia Itaú Cultural, courtesy Cepar Cultural.

Exploiting and misconceiving disability: Is it because I am lucid?

In the Brazilian art context, my experience as a performance artist endowed with a differentiated body led me to question the exploitation and misconception of disability in the performing arts field.

To expose my physical deficiencies in front of an audience is to arouse their empathy; or is it an operation aiming to reveal something more profound? Are my performances or limitations what allow me to achieve artist status?

Sometimes, the exploitation I suffered as a performance artist resulted from my ingenuity. The organizers who offered me the opportunity to participate in performance art events did not fully understand my urgency. Was I invited to perform because of my physical differences, thereby creating sensationalism?

I have never considered myself a performance artist that just exhibits his disability on stage. Nor do I assume that my differentiated body in the performance space is a pretext to overcome people's biases and prejudices that stigmatize disability as a condition of inferiority. My performances do not simply reproduce or denounce the exclusion conditions I live under, and I do not just show off the stigma I carry. If anything, I perform to act out the stigma.

Human beings have performing potential; therefore, it is erroneous to think that performers with differentiated bodies are passive on stage. Also, recruiting them for tokenism, to obtain funding or to give the appearance of equality in a workforce does not help them free themselves from the stigmatizing situation in which they constantly live. On the contrary, it detrimentally preserves that situation.

Poverty (also a scarcity of financial resources to make art) frames most Brazilian society, especially regarding disability. Additionally, disabled people are not facilitated by architectural accessibility, and it is complicated to move autonomously from one place to another.

The case of Brazilian dancer Mickaella Dantas, who sadly passed away on the 10th of February 2024, is noteworthy in this regard. At age eleven, she was diagnosed with cancer in her leg, and she had two years of chemotherapy until amputation was offered. The healthcare system she endured affected how she experienced disability in our country.

In 2011, Mickaella Dantas left first for Portugal and then the UK, where she found extensive support for prosthetics and general health, both of which she would not have received in Brazil (Dann, 2020).

She danced for choreographers Henrique Amoedo (Companhia Dançando com a Diferença [Dancing with the Difference Dance Company]), Paulo Ribeiro, and Clara Andermatt. From 2017 through to 2021, she joined the prestigious Candoco Dance Company⁵, whose mission is to expand what dance can be by employing disabled and nondisabled artists who find innovative ways to collaborate. As a full-time company dancer with Candoco, Dantas performed nationally and internationally in more than 10 different productions.



Figure 6. Mickaella Dantas for Hetain Patel – *Let’s Talk About Dis* by Candoco Dance Company. Photographed by Camilla Greenwell at Aspire National Training Centre, Stanmore (2018). Courtesy Camilla Greenwell and Candoco Dance Company.

5 Candoco Dance Company website: <https://candoco.co.uk/>

I have attempted to offset the exploitation and misconception of disability in art and society with the performance *O problema é porque sou lúcido?! [The problem is because I am lucid?!]*, (2018). I exposed my differentiated body, which had been atrophied by progressive spinal amyotrophy. I decided to wear onstage only a tailored vest that I received as a gift from British stylist Vivienne Westwood and a pair of underwear.

Progressive spinal amyotrophy is a neurodegenerative disease of genetic origin and autosomal recessive inheritance. It invades the lower motor neuron body in the anterior horn of the spinal cord. This disease causes progressive degeneration of motor neurons but does not affect the sensory system, at least in my case. The performance title is therefore a question and an affirmation simultaneously.

I chose this title because sometimes I disagree with the care I receive from the professionals attending to me at home. They want me to be docile (Rabinow, 1984), and I do not deny it. Years ago, during a meeting, a social worker said: “The problem is because [he is] lucid.” Though I have a body deprived of locomotion, I still have a voice to speak out about my concerns, which are often overlooked.

I am lucky to be attended to by a multidisciplinary team that offers me as much independence as possible at home and in a professional environment. This is to minimize complications in my musculoskeletal and respiratory systems.

I depend on others to help me perform my daily tasks and take part in professional activities. My muscles are atrophied, my hands and feet have malformations, and I lack the strength to perform movements (*tetraparesis*). I use a device intermittently which helps keep my lungs open and my breathing muscles less overloaded.

During the performance, I lay on a hospital stretcher breathing through a non-invasive ventilation device. The sound of my heartbeat recorded from an echocardiogram accompanied a projection of photographs of meaningful moments in my life. The theatre’s foyer doors were left open, and spectators could stay as long as they wished. Some sat on benches and watched the photographs, while others watched me closely and asked if they could touch me. As time passed, it became evident that spectators had more sensory reactions than rational responses. They were partaking in a performance ritual, co-creators of an artistic event in the present moment.

In exposing my body as such and asking for physical contact with audience members, my intention was not to provoke reactions related to

feelings of compassion, pity or embarrassment. I aimed to reveal my desire to realize myself as a human being.

I attempted to demonstrate that the simple act of sharing brings forth a valuable, collective experience for everyone involved. I offered spectators the freedom to come, stay and leave the performance space as they pleased, approaching and touching my body gently when they wished, thus becoming co-creators of a togetherness that, in ordinary life, people hardly ever find.



Figure 7. Felipe Monteiro and Ciane Fernandes. *O problema é porque sou lúcido?!* 2018. Photo: Audience member.

Conclusion

In the context of the performing arts, with the emergence of performance art in the 1960s, the presence of artists with differentiated bodies is based on the assumption that it is neither a democratic scene giving voice to the marginalized nor a practice of tolerance, but rather a contrary movement that affirms the belief that what is considered socially unproductive becomes a matter of creation and aesthetic experience.

Disability arts and culture movements were raised in the 1980s in the United States and the United Kingdom, and they became increasingly

international in reach and orientation in the following decades (Kuppers, 2017). There were, however, a few disability-focused theatre companies pre-dating the disability arts and culture movement, for example, the National Theatre of the Deaf,⁶ founded in the US in 1967. Notable disability theatre companies established in the 1980s and early 1990s include the Compagnie de l'Oiseau-Mouche⁷ (1978, which became professional in 1981, consisting of twenty-three permanent actors with mental disabilities); Graeae Theatre Company⁸ (1980, UK); Theatre Terrific⁹ (1985, Canada); Back to Back Theatre¹⁰ (1988, Australia); RambaZamba¹¹ (1990, Germany); Theatre HORA¹² (1993, Switzerland), and Isole Comprese Teatro¹³ (1998, Italy).

However, disability theatre is still a niche in many countries, including Brazil. Often, performers with differentiated bodies remain on the fringes of the Brazilian performing arts scene. Other times, they are exploited to fulfil show-business purposes.

Conversely, performance art allows the differentiated body to directly evoke human fragility and the need for love, its live image dwelling into the spectator's heart and mind. Physical deficiencies are transformed into poetry to speak to viewers on a profound level, reopening their eyes to reality.

Performance art should not ask for permission to exist because it is an art form that implodes the artistic paradigm itself. Although there are undoubtedly performances that are representations on some level, for example, those characterized by the presence of the performer playing the role of a *persona* or interpreting an imaginary character, performance artists mainly present themselves as they are. They do not do "as if" like in a stage play. Rather, they perform to express their concerns while time expires. They are often outsiders to mainstream art, uncaring of artistic trends that strive to rank what functions in the contemporary art world and what does not.

My performances portray my life experience, and I scan the tissues of everyone's symbolic roles in my everyday life. I poetically emphasize what alienates me: the lack of freedom my differentiated body has in the social

6 National Theatre of the Deaf website: <https://ntd.org/>

7 Compagnie de l'Oiseau-Mouche website: <https://www.oiseau-mouche.org/>

8 Graeae Theatre Company website: <https://graeae.org/>

9 Theatre Terrific website: <https://www.theatreterrific.ca/>

10 Back to Back Theatre website: <https://backtobacktheatre.com/>

11 RambaZamba website: <https://rambazamba-theater.de/de>

12 Theatre HORA website: <https://hora.ch/>

13 Isole Comprese Teatro website: <https://www.isolecompreseteatro.it/>

context. I confront myself with my imperfections – the *prima materia* of my performance art practice. In my work, I blur the line between art and reality to portray the body's vulnerability. I do not adhere to modes of theatrical representation. I do not take action under a character's circumstances and entrust that a form will follow. Instead, I bring into play my subjective experience of a performer with a differentiated body.

I do not perform as if a fourth wall was present. I transfer my real life and disability into the performance space to create a sharing situation. I deploy my emotional memory, state of mind and fragile, differentiated body as devices to engage with the audience and stimulate in them a reflection on life itself and an understanding of disability through care in a non-stigmatizing way. There is nothing fictional in my performances or acts of histrionic delivery.

In doing so, I do not treat the audience as voyeurs or remain absorbed in my life drama. I directly acknowledge the audience's presence by addressing my clinical condition poetically for reciprocity and mutual dialogue: "I am here, with you." Therefore, I do not recur to apologetic or composed, artificial forms of performer-audience persuasion in what I do. I do not devise metadramatic and metatheatrical functions to bring attention to my status as a performer with a differentiated body. My body simply speaks of its reality. Eventually, the immediacy of the audience's response in front of it (be it astonishment, embarrassment or loving-kindness) is the primary source of strength I need to continue performing.

In the performance space, therefore, my differentiated body is not a tool for virtuosity; I position it to infect spectators in the Artaudian sense. In fact, I have often observed something disturbing in their reactions while in proximity to my differentiated body. Some move away, others remain close, and an empathic exchange begins to take place in this proximity – something that rarely happens in everyday life.

Do my differentiated body and physical condition generate identification? Are spectators faced with the fact that the human body is imperfect? Are they then brought to reflect on human finitude? Do they still believe in their obstinate procedures to distance themselves elusively from inescapable death?

The differentiated body stigmatized and routinely relegated to social and artistic ostracism destabilizes the deceitful ideal of bodily perfection. Eventually, by bringing inside the performance space the derogatory situations in which I live through revealing my vulnerability and apparent

weakness, I have the opportunity to operate as an artist. I can be recognized for my creative potential and objective to discuss and acknowledge diversity, otherness and alterity for societal change.

Author biographies

Felipe Henrique Oliveira Monteiro is the founder and director of the International Center of Artistic and Academic Research on Antonin Artaud. Monteiro is also a performer and a postdoctoral fellow at the Postgraduate Program in Performing Arts at the Universidade de São Paulo. Monteiro holds PhD in performing arts from the Universidade Federal da Bahia. His research interests include: theater studies, performance studies, differentiated bodies, performance art, activism, post-dramatic scenes, Antonin Artaud and Frida Kahlo.

Andrea Pagnes (he/him) works with Verena Stenke (she/they) as VestAndPage. They explore performance art and performance-based filmmaking as “thin places” phenomena through their collaborative practice, artistic research and curatorial projects. Their psycho-geographical works move between the unseen and unforeseen, the oppressed and unspoken, the forgotten and the repressed. They are the founders and curators of the Venice International Performance Art Week, recipients of Best Film Awards at the Berlin Independent Film Festival (2018) and lecturers at ArtEZ University of the Arts (NL) and Unidee Academy (IT).

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CHAPTER 5

Performance of Protest: People with Learning Disabilities March in the Streets of Trondheim, Norway, 2019

Vibeke Glørstad VID Specialized University, Norway

Abstract: This chapter addresses how people with learning disabilities in the city of Trondheim, Norway, spoke up regarding the precarity of their living conditions through the demonstration, *Life Matters*, in 2019. I approach this performance of protest through the lens of performativity and the civil right of freedom of assembly. The research question is: *How may the power of assembly strengthen citizen practice and citizen status for people with learning disabilities?* Through an illustrative case methodology, I argue that the embodied character of the demonstration created a plural form of agency. The power people have, when coming together, is itself an important political prerequisite, which may also strengthen the position of people with learning disabilities as political subjects and citizens.

Keyword: protest-performance, learning disability, freedom of assembly, counter-conduct, resistance

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Joe B. Turner, a social scientist researching citizenship from marginal spaces (2016), argues that there is a general absence of analyses of the emergence of political events, moments or acts of resistance, in the literature on exclusion. Marginality may provide conditions for forms of political becoming and the emergence of alternatives. Engin F. Isin (2017, 2019), researching citizenship studies, has pointed out “acts of citizenship” as practical acts that cause ruptures, and asserts that they are the necessary condition for increasing citizenship status for marginalized people. In this chapter the demonstration Life Matters, in itself could be seen as an act of disruptive citizenship practice. I explore the demonstration from a sociological and cultural studies framework, through freedom of assembly and performance study perspectives, and ask: *How may the power of assembly strengthen citizen practice and citizen status for people with learning disabilities?*

In the following I first introduce the context of post-institutionalism and disability activism. Then I outline the theoretical framework of resistance as counter-conduct through the power of assembly, and disability culture activism. I then describe the demonstration, Life Matters, in more detail. In the discussion section, I use the above-mentioned theoretical perspectives to describe how the power of assembly strengthens citizen practice and citizen status for people with learning disabilities in the demonstration Life Matters.

The politics of post-institutionalization and disability activism

In the early spring of 2019, a group of people walked with placards through the streets of Trondheim, a coastal city in the middle of Norway. They were people with learning disabilities, their families, and social and health workers. The protesters in the campaign Life Matters, had had enough of budget cuts, and handed the deputy mayor signatures from people supporting their struggle, asking for a dialogue with the politicians. The initiative came from one social worker, Stener Skogmo, a leader in the services, and one of his friends, Roar Berg Buan, who was receiving services from the municipality.

It is over 30 years since the deinstitutionalization of people with learning disabilities began, whose intention was integration and fuller citizenship. Still, the ideal of citizenship falls short given ongoing stories of human

rights violations and isolated lives in poverty, also in a Norwegian context. Living conditions are marked by violations of human rights according to the CRPD (Convention on the Rights of Persons with Disabilities) (United Nations (UN), 2006). Many lack access to healthcare, housing, work, education, self-governance, and participation in organizational, cultural and political life (Meld St. 8, 2022–2023 (Norwegian Policy Paper)).

Several welfare professions support people with learning disabilities, as social workers and social educators, specializing in disabilities. Although one is obligated to work from a holistic perspective, the rights of people with learning disabilities often do not extend to support for being able to participate in political life (CRPD, art. 29, UN, 2006).

Niklas Altermark, a Swedish researcher, describes this in his book on intellectual disabilities and biopolitics (2018) as a “production of citizens,” through shaping behavior and teaching skills that the staff think are important, parallel with an “undoing of citizenship” (p. 4) through restrictions, coercion, and paternalism. “It is way of governing that relies on both crafting citizens and continually monitoring and correcting their conduct, sometimes by brute force, in case an appropriate citizen fails to materialize” (Altermark, 2018, p. 4). Rikke Gurgens Gjørum (2017) describes this situation as regimes of care in danger of serious human devaluation. Both authors’ solution to resisting this regime of government emphasizes the necessity to address intellectual disability, and the human condition generally, as being marked by precariousness – “that is we need to get rid of the idea that the defining characteristics of humanity are independence and autonomy fulfilled by capacities of reason and rationality” (Altermark, 2018, p. 5). Licia Carlson (2009) constructs the history of intellectual disability with a Foucauldian genealogy and demonstrates that intellectual disability is contingent and constructed. Intellectual disability is an expression of human vulnerability, relating to how our bodies interact with the world, and how these interactions are culturally and socially constituted to become knowledge, classification, and thus subjectivity (Altermark, 2018, p. 5).

Despite little attention being paid to political activism among people with learning disabilities, we also see exceptions in the Norwegian context. Marthe Wexelsen Goksøyr, a woman with Down’s Syndrome, demonstrated in the Norwegian Parliament wearing a T-shirt with ENDANGERED on her back as a protest against abortion regulations. There was also a collective mobilization at a workplace where the municipality, due to budget

problems, had decided to turn it into a day center (Sæther, 2022). The Norwegian Association for Persons with Intellectual Disabilities (NFU) have used torchlight processions to protest against budget cuts in day centers. People with learning disabilities have also participated in cross-disability protests through umbrella organizations, for example in front of the parliament (FFO, SAFO, ULOBA, FFO Funksjonshemmedes fell-organisasjon – The Norwegian Federation of Organisations of Persons with Disabilities, SAFO – Samarbeidsforumet Av Funksjonshemmedes Organisasjoner, Norwegian Forum of Disabled Peoples’ Organizations, ULOBA independent living).

Internationally, the organization, Inclusion International, promotes activism (Inclusion International, 2024). Self-advocacy groups, such as People First (England) and Grunden (Sweden), and theater groups (Disability Arts Online, 2024) include political activism as part of their work. In Poland parents and their disabled children and adults occupied the Sejm, the Polish Parliament, for 40 days in 2018, between 18 April and 27 May, arguing for just welfare policies (Greniuk & Salkowska, 2022; Zdrodowska, 2023). Magdalena Zdrodowska argues that this sit-in had a significant effect in terms of visibility, and in the longer run, economic policies. As the author describes:

The image of disabled persons shouting their discontent in the public space or occupying a parliament building reshapes the mental framework, in which the broader public tends to think about and assess people with disabilities. Such images encourage a view of these citizens outside the model of a submissive and eternally grateful object of care and assistance. (Zdrodowska, 2023, p. 1)

Six months after, Teatr 21, a professional Warsaw theater employing actors with trisomy and various forms of autism, created a play titled “The Revolution That Wasn’t.” Actors with disabilities played the roles of public figures, who speak with contempt, hostility, or a humiliating concern for people with disabilities. These utterances, originally made with a sneer, and then repeated by the acting team of Teatr 21, had a subversive and liberating power, argues Zdrodowska (2023, p. 8).

In Poland, they were inspired by international cross-disability activism, such as the Capitol Crawl for the America for Disability Act, where some of the demonstrators cast aside their wheelchairs and crawled up the Capitol steps. Disability marches, occupying public space, and blockades have,

since the start of the disability rights movement in the 60s, been a central part of protest activism. Protests may be didactic, providing a new interpretation of a known problem. They may produce new meaning or they may unveil injustice (Cadena-Roa & Puga, 2021, p. 3). Most often, protests are one-off events, lasting over time they become campaigns and social movements. The protests have been analyzed historically and in relation to their effects (Pettinicchio, 2024), sociologically as social movements (Barnartt, 2010, 2014; Mann 2018), and through disability culture and art (Jackson, 2011; Koppers, 2011).

How does this activism challenge power relations?

Biopower, resistance and re-subjectivation

The French philosopher, Michel Foucault, has described the history of how repressive power develops and how resistance is possible (2003). Prior to the 17th century, power was expressed through the sovereign, who exercised negative power through coercion. In the 18th and 19th centuries, new forms of power developed, which are described as productive. Regulatory power focuses on the population as a whole, on phenomena such as birth rates, disease, and predictability (Foucault, 2003, p. 249). Threats are internal rather than external. Disciplinary power “deals with bodies individually – the body as the object of control” (Foucault, 1979, p. 181), through institutions, such as the prison, schools, and hospitals. It is achieved through monitoring and training, attention to detail, and repeated in multiple social locations including timetables, movement, diet, and behavior in daily life. Disciplinary power produces docile bodies (Foucault, 1979, p. 182).

The two technologies, regulatory and disciplinary, are linked through the norm and produce a normalizing society governed by biopower with the body at the center (Foucault, 2003, p. 253, my emphasis). The individual also self-regulates: “He who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself . . . he becomes the principle of his own subjection” (Foucault, 1979, p. 203). Foucault later calls this method of internalizing what is wanted from us, pastoral power.

Foucault uses “government” as his term for power, and “governmentality” as a theoretical tool for analyzing its rationality and procedures.

Power relations must be analyzed from the bottom up, and not from the top down. One should study the myriad ways in which the subjects themselves are constituted in these diverse but intersecting networks (Foucault, 1978; Gutting, 2022, p. 9). The concept of counter-conduct was developed to give the notion of resistance a “positive,” “productive” meaning, and not simply a “negative” or “reactive” one. Foucault writes:

Where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power. ... [The] existence [of power relationships] depends on a multiplicity of points of resistance: these play the role of adversary, target, support, or handle in power relations. These points of resistance are present everywhere in the power network. (Foucault, 1978, p. 95)

Foucault, as emphasized in Lorenzini (2016), argues that forms of counter-conduct may “restructure the relationship of oneself to oneself, since the attempt to be conducted (or to conduct oneself) necessarily entails the refusal of the specific form of subjectivity that, generally, pastoral government constitutes and imposes on individuals” (Lorenzini, 2016, p. 12). Subjects are not simply constructed by power. They are not just docile bodies, but actively refuse, adopt, and alter the forms of being a subject.

Disability rights activism challenges how disabled people are imagined in the context of biopower (Hall, 2017), and they produce new identities through different counter-conducts. The power of assembly is the central force.

The power of assembly and performance activism

The civil right of freedom of assembly (United Nations, 1948) creates opportunities for bodies to meet, it implies the right to appear. The power that peoples have to gather is itself an important political prerequisite for democracy, quite distinct from the right to say whatever they have to say once people have gathered. In *Notes towards a performative theory of assembly* (2015), philosopher Judith Butler outlines how political performance through assembly may produce progressive possibilities for formerly marginalized groups. She argues that access to public space is one precondition for persons to act in concert. Demonstrations have an embodied character, and acting in concert is *embodied* practice (Butler, 2015, p. 9).

For persons who are citizens and also service users, access to public space and acting in concert may be dependent upon the service providers' co-operation, as they are a necessary condition for assembly. Butler stresses that such acting in concert, when one body arrives with other bodies in a zone visible to media coverage, has an indexical, performative force (Butler, 2015, p. 9). This is highly concrete. It is *this body* and *these bodies* that require something, for example decent services, access to equal citizenship, and a sense of a future.

From a performance activism perspective Dan Friedman and Lois Holzman (2014) argue that a performance has the potential to be socially and culturally revolutionary "because performance, consciously practiced in daily life, is, by its nature, a creative social activity, which allows human beings *to break out of old roles and old rules*" (Friedman & Holzman, 2014, p. 1, my emphasis).

People's ability to perform – to pretend, to play, to improvise, *to be who we are and 'other' than who we are* – as simultaneously cognitive and emotive (...) allows human beings to develop beyond instinctual and socially patterned behaviour. This (...) changes the very nature of social change activism. (Friedman & Holzman, 2014, p. 9, my emphasis)

A protest performance may reconstruct social reality (Friedman, 2021, pp. 1–2). The performative aspect of protest is understood as the enacting of a symbolic social process, whose importance depends on how it is staged by the protesters and interpreted by the audience (Cadena-Roa & Puga, 2021). Performance requires a "script" and an audience. Important elements are charisma, choreography, imagination, use of songs, and slogans. Protest is designed to be photographed, which enhances its communicative power through the internet, as a new public sphere (Cadena-Roa & Puga, 2021, p. 104).

Protest performance is art. Defined broadly, including all creative expression – music, movement, visualization, art is the foundation of cultural resistance. Thus argues Stephen Duncombe in an interview (Bettel & Zobl, 2013, p. 3): The popular arts, or the appropriation of commercial culturelike advertising, speak in a language that people already understand. Duncombe argues that "The first rule of guerrilla warfare is to know your terrain and use it to your advantage. The political topography of today is one of signs and symbols, stories and spectacles. In order to be an effective

activist you have had to learn how to operate on this aesthetic terrain” (Bettel & Zobl, 2013, p. 3; Duncombe, 2016).

Disability culture as the origin

Disability culture is the source of disability activism, and this activism generates the culture, using all the creative means within performance activism. Petra Kuppers (2011, p. 109) defines disability culture as

a trajectory, a movement, a path, rather than a destination: Disability culture is the difference between being alone, isolated, and individuated with a physical, cognitive, emotional or sensory difference that in our society invites discrimination and reinforces that isolation – the difference between all that and being in community. Naming oneself part of a larger group, a social movement or a subject position in modernity can help to focus energy, and to understand that solidarity can be found – precariously, in improvisation, always on the verge of collapse.

Disability culture is also the steppingstone to more specific disability art, and also what Shannon Jackson (2011) terms social art. Performative art and culture have the possibility to reveal the social structures that support us.

It can be tricky to expose systemic contingency precisely because enabling systems often go unregistered in the moment we use them. ... The social world is in fact a large systemic prosthesis for the normative bodies its structures support. If, however, this social prosthesis is “subordinate to our focus and goals,” then it requires a break or deviation for us to remember that it is there. (Jackson, 2011, pp. 5–6)

For the “differently abled,” writes Jackson, it means realizing “whether suddenly or routinely that the world is not your dance floor. When the pace slows, when everyday objects are not in reach ..., we register the contingency of the ground that supports our everyday acts of self-figuration” (Jackson, 2011, p. 5). Jackson wants to place social systems in the foreground. “From a disability perspective, such traversals expose the formal and systemic contingencies of environments that take certain embodiments for granted. Disability comes forward not only as a factor through which identities are “othered,” but more radically as an impulse to reckon with human contingency in “the systemic whole” (Jackson, 2011, p. 5).

Methods and the case of the demonstration

In this chapter, a case study approach is applied, where documentation in form of public, published news clips from the demonstration are used as research material (Yin, 2018, p. 115). The news clips are limited to two documents: One newspaper article published 13 April 2019 by journalist Gøril Huse in the newspaper *Klar Tale (Speaking Out)*, a weekly, national Norwegian easy read newspaper; and one webpage report from The Norwegian Association for People with Intellectual Disabilities (NFU), published 25 May 2019. Further, I use the protesters' own open Facebook group.

Using texts and photos as empirical resources may make it possible to create new knowledge through already existing empirical material. My approach is to look for specific actions and utterances in the texts, which may be indicators of the possibilities of assembly. As an overall approach, I write within a critical sociology tradition (Gergens & Gergens, 2018). In being transparent with my reading strategies, I attempt to focus on the validity of my analysis (Bratberg, 2014, p. 12).

I have received consent from the authors of the news clips, and contacted the persons mentioned by name in the news clips I use, to acquire their consent for reusing their stories and pictures in the context of this research study. They have had the opportunity to read parts of the draft for this chapter if they wanted, encouraged as a research ethics quality standard by The Norwegian National Committee for Research Ethics (2023).

The case: What happened in Trondheim?

The campaign, Life Matters, was reported by journalist, Gøril Huse, in the newspaper, *Klar Tale*:

A group of people walked through the streets of Trondheim last week. The group consisted of people with learning disabilities, their families, social and health workers, and supporters. The march ended at the stairs leading up to City Hall. There, they met with the deputy mayor of Trondheim, and delivered to him 2,500 signatures demanding attention to their living conditions. They named their protest Life Matters. (Huse, 2019, p. 3, my translation to English).



Figure 1–3. Life Matters first protest the 25th of March 2019. Fig 1 The placards say Equity also for people with learning disabilities. Life matters. In fig 2 from left Stener Skogmo, vice major Ola Lund Renolden and Roar Berg Buan. Fig 3 Stener Skogmo and Roar Berg Buan. Photo Ove Engvik / private.

Journalist Gøril Huse interviewed several of the participants. They described the event as follows:

The municipality had cut as much as possible in services for people with learning disabilities. Many of them are now alone in their apartments. Although they live in group homes, they are not able to contact the staff. In addition, they are not offered leisure time activities. They are lonely. “We can’t watch this anymore,” says health worker Solveig Trolie. Solveig refers to how she has worked with people with learning disabilities for 25 years, and has spoken up several times previously, but there has been no change. “The service receivers use all their social security benefits for housing, help, and food. Many want to do more during the day, but do not have enough money.” (Huse, 2019, p. 3, my translation to English)

One of the parents, NFU (Norwegian Association for People with Intellectual Disabilities) member Håvard Ravn Ottesen said:

Many of the adult people with severe learning disabilities need as much care as when they were younger, but now they must stay in their flat alone between 5 p.m. and 10 p.m. This is indefensible, and unworthy. Being lonely is detrimental to their mental health; many are not able to describe how they feel. We want services that support their dignity as fellow human beings. (Huse, 2019, p. 3, my translation to English)

Roar Berg Buan, (service user, activist, started the campaign together with Stener Skogmo) was also reported in the newspaper article when he gave a speech to the deputy mayor. Buan has a visual impairment, and tells the deputy mayor and the protesters how he experienced receiving insufficient help:

Now we are in a situation where, for many, it is no longer about living but about surviving ... It’s important that we have something to do during the day. Do not cut our day activity services. (Huse, 2019, p. 3, my translation to English)

Journalist Huse continues: “The advisor for the deputy mayor, Asbjørn Strømme, admits that they must save money. Due to underbudgeting, the staff are not allowed to call for replacements when someone is ill. New staff are not employed when others quit.” (Huse, 2019, p. 3, my translation to English)

In the next news clip, the website for NFU (Norwegian Association for People with Intellectual Disabilities), 25 May 2019, the leader of NFU in Trondheim, Nina Braadland, tells what happened after the first demonstration:

The trade unions demanded a risk analysis. The results set off alarm bells. Several employees and people with learning disabilities were at risk of losing their lives. Politicians were shocked and blamed the deputy mayor. The deputy mayor pointed to the politicians who decide the framework for the budget. In May, the campaign had their first dialogue conference with the politicians. ... The health and welfare committee invited all the relevant organizations to present their views on the situation. Further, on 9 April, the politicians decided to cover the deficits. ... and on 22 May, they had another large demonstration, where several hundred people participated. (Norwegian Association for People with Intellectual Disabilities webpage, 2019, my translation to English)



Figure 4. *Equality also for people with learning disabilities – it’s a matter of life.* Photo by NFU, The Norwegian Association for Persons with Intellectual Disabilities.



Figure 5. *The placards say, “Enough is enough,” “We are many,” “Equality.”* Photo by NFU.

The protest Life Matters Facebook group

A central part of the campaign was also parallel activity online, through the Facebook group “Det gjelder livet (Life Matters).



The first posts started 2 March 2019 counting down to the first march on the 25th. More than 400 people participated. Stener Skogmo says, “It felt good to be noticed, to be seen in the cityscape, for both the participants and the organizers. We are forgotten” (Personal communication with Skogmo, 5 May 2024). The use of yellow vests was inspired by the “Yellow Vests Protests” in France, where angry farmers and others protested a lack of democracy, social and economic injustice. The Facebook group post presents news coverage of the protest in national and local newspapers and television, reports from dialogue meetings with the parties, and campaign messages at polling stations in connection with parliamentary elections in the current year. The voices of the service recipients emerge, such as Roar Berg Buan’s voice when he is interviewed by national and local TV and tell about the lack of opportunities for participating in activities. The Facebook group also created a happening during World Day for the Disabled where they were allowed to use a central lightboard in the city center in front of the Rock History Museum. With flames in the background it said, “Burn Crippled, Mong, User, Disabled” – words that refer to a derogatory view of people with learning disabilities.

Discussion

In this chapter I asked: *How may the power of assembly strengthen citizen status and citizen practice for people with learning disabilities?* The demonstration Life Matters, as counter-conduct, made people with learning disabilities more visible in several ways. I will highlight the following analytical points: Exploring political identities – to be other than you are; Addressing spatial injustice and representational isolation; Ethics in

practice – addressing our shared vulnerability; and Acknowledging disobedience and anger.

Exploring political identities: To be other than you are

The right to appear is connected to freedom of assembly as a fundamental human right. Access to public space is one precondition for persons to act in concert. Several enactments constitute how the participants in the demonstration participate as people in the streets. Firstly, an embodied form of action and mobility appears when the participants *marched*. These movements signify in excess of whatever is said. Butler (2015) describes this mode of signification as a concerted bodily enactment, a plural form of performativity. Bodily performativity only operates through forms of coordinated actions “whose condition and aim are the reconstitution of plural forms of agency and social practices of resistance” (Butler, 2015, pp. 8–9). In the march towards the city hall, the demonstrators walked, but also stood still.

So this movement or stillness, this parking of my body in the middle of another’s action, is neither my act nor yours, but something that happens by virtue of the relation between us, arising from that relation, equivocating between the I and the we, seeking at once to preserve and disseminate the generative value of that equivocation, an active and deliberative sustained relation, a collaboration. (Butler, 2015, p. 9)

Secondly, such plural embodiment may escape the way modern power works through internalization (Foucault, 1982, p. 783). Management of “proper” behavior in a population no longer requires a sovereign, who explicitly decodes and enforces proper behavior. Instead, we internalize and individualize what is wanted from us, a subjectivation that makes us fit into existing hegemonic relations. An example would be, people with learning disabilities are not supposed to take to the streets.

Through the demonstration, Life Matters, as counter-conduct (Lorenzini, 2016), the protesters may have experienced the ability to restructure “the relation of oneself to oneself” refusing the subjectivity that pastoral government constitutes and imposes on them (Foucault, 1978). People with learning disabilities may have been able to modify themselves through these practices of self in the campaign, artful reconstructing social reality (Friedman 2021, Duncombe 2016). They appeared no longer as docile bodies, but may perhaps actively refuse the process

of “production of citizenship and undoing of citizenship” (Altermark, 2018, p. 5).

Addressing spatial injustice and representational isolation

The campaign Life Matters, also addressed spatial injustices – territorial divisions that assign specific spaces to people, and separate them according to differences. Marginalization is maintained through mechanisms of territorialization. In the way the groups in the Life Matters campaign moved: out of the institutions; into the streets with placards; up the stairs to the city hall; on TV and radio; in newspapers and at conferences; on Facebook, they occupied new places and spaces where most people with learning disabilities do not participate on a regular basis. Their movements could be described as asking for spatial justice.

Liminal or marginal spaces may provide conditions for forms of political becoming and the emergence of alternatives. Practices, experiences, legacies of marginality (en)gender different sites, as counter-conduct of political struggle, which in turn shape, contest, and disrupt citizenship, as it is both practised and conceptualized (Turner, 2016). The lives of people with learning disabilities may be conceived of as marginal spaces, although through Life Matters the demonstrators addressed their own living conditions, and in this way were engendered (as) new political subjects.

The campaign invited a lot of actors: people with learning disabilities, health and social workers, politicians, deputy mayors, trade unions, disability organizations, newspapers, and Facebook groups dedicated to the campaign. All these actors and agencies generated meeting places, zones of contact between people who formerly were not in contact (Butler, 2015).

Ethics in practice: Addressing our shared vulnerability

The demonstrations started when service users, social educators, social and health workers had “had enough.” This could be described as a response to an individualized sense of anxiety and failure. This feeling of failure was produced by new public governance and the politics of individual

responsibilization. Butler describes demonstrations as producing a new form of insight:

The conditions of loneliness and poverty for people [with learning disabilities, my addition] are now social conditions both shared and described as unjust, and that assembly enacts a provisional and plural form of coexistence that constitutes a distinct ethical and social alternative to ‘responsibilization.’ (Butler, 2015, p. 16)

The march, as an assembly, raised the connected bodies both physically, psychologically, and socially. Bringing the relationships between service user and professional out into this open space – into the public sphere – may make the relationships transparent and accountable. And in this way, perhaps, it is “acknowledging how the persistent neglect of our shared vulnerabilities has been an underlying rationale in the constitution and government of the group with learning disabilities” (Altermark, 2018, p.5).

The boys and girls, women, and men with some sort of disability are also suddenly not disabled but *re-abled*. And the policies they produce through the march and the following events delegitimized the local budgetary politics by holding politicians accountable. “It may not be a triumph over all forms of precarity, though it articulates, through its enactments, an opposition to induced precarity” (Butler, 2015, p. 16).

None of us acts without the conditions to act, argues Butler (2015, p. 16), even if we sometimes must act to install and preserve those very conditions. The leaders of the campaign, Roar Berg Buan and Stener Skogmo, through creative means acted to establish the conditions for the assembly. This may be seen as the first steps, arranging for bodies to march in lines and crowds, exhibiting their value and their freedom, enacting – by the embodied form of gathering – a claim to the political (Butler, 2015, p. 18).

Asserting that a group of people is still existing, taking up space and obdurately living, is already an expressive action, a politically significant event, and that can happen wordlessly in the course of an unpredictable and transitory gathering. (Butler, 2015, p. 18)

The action group established the conditions for making political claims, as stated in ethical guidelines for social workers (FO 2019; IFSW 2018). Life Matters’ plural enactments make manifest the understanding of a situation as being shared, as Butler argues, and as contesting the individualizing morality, which makes a moral norm of self-sufficiency – or being thankful for “what one has” – unrealizable.

Showing up, standing, breathing, moving, standing still, speech, and silence are all aspects of sudden assembly, an unforeseen form of political performativity that puts liveable life at the forefront of politics. (Butler, 2015, p. 18)

Acknowledging disobedience and anger

Broad coalitions of service users themselves, staff, parents, politicians, trade unions, and associations represent a civil society network that builds bridges. Civil society may be seen as a battlefield. In *Life Matters* I see a battle: for grabbing a stage, being understood, and in how politicians and the deputy mayor blame each other. I see anger in the photos and in the Facebook group. People with learning disabilities' anger is often monitored closely. Here they were able to "escape from the institutions," and be angry together with their helpers and families. At the same time, they experienced establishing a common space in the dialogue conferences. The emancipatory potential could be seen as being released when the dialogue meetings were felt to be a success.

In this way a type of civility was confirmed: civility as a mindset in a society that brings out the best skill for solidarity, trust, and justice. Civility is not politeness. It is about responsibility, therefore disobedience as resistance can be civil. The march may be experienced as disobedience, because it is so unusual to see these acts in the public space by people with learning disabilities. Disobedience is necessary for developing new citizenship practices.

Conclusion: Engaging with the art of protest

The stories of how people with learning disabilities felt lonely and unable to get in touch with service providers when needed, indicate that they were not able to verbalize their needs. Also, the health and social workers had earlier tried to change the scenery, using formal political and administrative channels, but were not able to accomplish anything. Even as a unified municipal service organization, with associated quality control routines, they were not able to express the need for justice as well as the campaign, *Life Matters*, expressed it.

Taking place outside of political and administrative channels, the provisional assembly makes a call for justice. It is necessary "to rethink the speech act, in order to understand what is made and what is done

by certain kinds of bodily enactments: the bodies assembled “say” *we are not disposable*, even if they stand silently” (Butler, 2015, p. 18, my emphasis).

There is a beauty in this. The photos from Life Matters are a manifestation of the creativity of the campaign (Bettel & Zobl, 2013). We see placards with messages like “equality.” We see the march – people walking down the street on a cold day. We also see their different positions: people with learning disabilities, parents, and family, NFU representatives, spokespersons, all blending into a whole, creating a new space. Everyone is similar, in yellow vests of symbolic power. We hear the slogans and voices of the protesters, and there is joy in the representations. We also see the mayor’s representative on the grey stone stairs up to City Hall, who also represents the conditions for the assembly. It is the connection of these bodies, standing silent as an assembly and at the same time addressing injustice, which produces a demand, as Butler writes:

The sound of what they speak, or the graphic sign of what is spoken, is as important to the activity of self-constitution in the public sphere – and the constitution of the public sphere as a condition of appearance – as any other means. If the people are constituted [i.e. their plural agency] through a complex interplay of performance, image, acoustics, and all the various technologies engaged in those productions, then “media” is not just reporting who the people claim to be, but media has entered into the very definition of the people. (Butler, 2015, p. 20)

When people with learning disabilities, professionals, and relatives gathered creatively in the streets, everyone was more visible. This is the act of self-constitution, the place and space of the hegemonic struggle over who we are, argues Butler (2015).

Creating solidarity

In this chapter I have asked how the power of assembly may strengthen citizen status and citizen practice for people with learning disabilities. I have suggested that it is related to the way political agency was actualized, shared vulnerability demonstrated, and a celebration of diversity.

The demonstration directed attention to what Foucault (1978) describes as a diverse network of power points and positions, and turned these points into productive points of resistance. Thus, the demonstration was not just

a protest against something – instead it was an argument for something new, a new visibility. It was the long duration of the campaign, the inclusion of various actors, the media, and the dialogue conferences that also turned the protest march into social art (Jackson, 2011). The march made the contingencies of our welfare visible to all actors who produce, or not, living conditions – in a unifying way – for a while.

At the same time, the march was also an expression of disability culture, as Kupperts describes it: “being in a community, naming oneself part of a larger group, a social movement or a subject position in modernity can help to focus energy, and to understand that solidarity can be found, precariously, in improvisation” (Kupperts, 2011, p. 109). The assembly in Trondheim addressed the frames of injustice and broke them, for a moment. However, as Butler optimistically remarks (2015, p. 20), “It can happen again.”

Citizenship for people with learning disabilities will be further strengthened if they are allowed to participate in an ongoing process of political critique – with a strong link to the disability rights movement and disability culture, and possibly co-operating with local theatre groups or other cultural workers with learning disabilities, and others.

In this text I have tried to analyze the possibilities of the campaign Life Matters. A more empirical approach is necessary to explore the possible effects. It is necessary to encourage future research on the effects of demonstrations and activism, and how people with learning disabilities contribute to and experience these demonstrations. It is also important to make visible the various inequalities among the actors in different positions of power, and to give people with learning disabilities the opportunity to control the process even more. It is also about strengthening self-advocacy organizations. Further research topics might include the ways in which demonstrations interact with and impact individuals, as well as how they educate, reignite creativity, create conversations, and build communities.

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Author biography

Vibeke Glørstad, is a senior lecturer at VID Specialized University, Faculty of Health Science, Stavanger, Norway, holds a BA in social education and Licentiate Degree in Sociology and Cultural studies from the University of Oslo. Her teaching expertise includes social education/social work at BA level and at the Master's degree in citizenship and co-operation within the health, social, cultural and educational field. Her research interest is related to how vulnerable groups as people with disabilities access and practice their citizenship rights, based in critical disability perspectives. She publishes on political and cultural inclusive citizenship practices by people with disabilities and marginalized groups. Glørstad is a member of the Performance and disability working group in IFTR (International Federation of Theatre Research), with a rich international network.

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CHAPTER 6

The Meeting – The Apartment – Conversations. The Right to Be Present: An Inclusive Project in Search of Its Own Place in Russia’s Theatrical Art of the 2010s and Early 2020s

Aleksandra Dunaeva Freelance, Helsinki, Finland

Abstract: The article questions the place of inclusive theatre in the space of Russian culture in the country’s growing autocracy (2010–2020). Through the optics of the spatial turn formulated by Erika Fischer-Lichte and Benjamin Wihstutz, the article explores the work of one of Russia’s most important inclusive collectives of this period, a neurodiverse group united by the projects 1) *The Meeting* 2) *The Apartment* and 3) *Conversations*. Having originated in a state theatre during a short period of institutional interest in inclusion, the project soon had to settle in a non-theatrical space (The Apartment). Forced to leave this space, too, the group maintained its unity and returned to the theatre in 2019. Using Michel Foucault’s metaphor of the mirror and heterotopia, the article characterizes the group’s spaces as a reflection of the utopia of equality, solidarity and dialogue under external pressure. The group’s latest pre-war projects, the diptych *Chelovek. Effekty* politicise the presence of a non-diverse group in the public cultural space, giving hope for the emancipation (Jacques Rancière) of the whole inclusive movement. With the onset of Russia’s full-scale invasion of Ukraine, the group continues as an inclusive space of “weak” resistance. Research material has been provided by the author’s personal archive, performances, and interviews with the artists.

Keywords: inclusive theatre, socially engaged arts, social theatre, heterotopia, neurodiversity, spatial turn

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I started collecting materials for this article before the active phase of Russia's invasion of the territory of Ukraine began on February 24, 2022. Do we even care about theatre now? Why do I think it is necessary to talk about inclusive theatre when the Russian state's brutal and senseless war with Ukraine and its own citizens continues? Russia's leading contemporary political scientists, Ekaterina Shulman and Greg Yudin (Shulman, 2019, 2023; Yudin, 2022a, 2022b), cite "atomization" (disunity in society) as one of the key terms needed for understanding the autocracy regime created by Vladimir Putin. Despite justified accusations of apoliticality against Russian society, in the 2010s it managed to do a lot to promote social ties between communities and build up civil institutions "in parallel," as Shulman put it, with the state (Shulman, 2016). In this process, culture, including the democratic forms of amateur theatre played an important role.

In this chapter, my aim is to explore the history of the inclusive theater group, variously named, in terms of the spaces where its activities have been and are being carried out: 1) *The Meeting* 2014–2016, 2) *The Apartment* 2017–2019¹ and 3) *Conversations* 2019–present. I am interested in the connection between the group's spatial movements with respect to inclusiveness and how it was integrated into the work of different institutions. It is also important for me to show what opportunities the group's experiences that took place before February 2022 provide us in light of the war and repression now taking place in Russia, where the state seeks to control not only the dominant discourse, which is characteristic of authoritarianism, but also individual physicality and way of thinking.

The appearance of projects involving people with disabilities at the venues of professional repertory theatres in 2010–2020 in Russia has become part of the overall process of transforming the theatrical field. It was caused by the general rise of civic consciousness in Russia at the time (Lipman & Petrov, 2010; Paneyakh, 2015; RANEPА (Research Center for Sociological Research), 2016). However, when I talk about the presence of amateur artists, including artists with disabilities, on the repertoire stage, I do not mean that this presence was massive. Rather, I would call this process "a struggle for the stage."

1 Project page on the website of the Alma Mater Foundation, including the list of performers: https://amfoundation.ru/en/portfolio/___trashed/ Project pages in social networks: <https://www.facebook.com/apartment.talks>; <https://vk.com/apartment.talks>

Turning points for “special theatre” in a Russian context

The turning point for the “special” theatre with “special” people, as it was called in Russian context, came in 2014, when the play *Remote Proximity*, performed at the integrative theatre studio Krug-2, was awarded the Golden Mask National Theater Award in the category Experimental Theatre. Before this time, theatrical projects involving people with disabilities, including intellectual ones, already existed. However, according to the famous producer of social art Elena Kovalskaya, “until recently, a special theater was considered to be an activity of good-natured amateurs” (Kovalskaya, 2015). The national award legitimized the “special theatre” in professional culture.

Since 2010, I have observed and tracked the emergence of theatre groups and, more often, individual theatre projects in Russia in which professional theatre artists, together with amateur artists, created performances. I first became acquainted with the play *The Language of Birds*² in 2013 while I was working at the Bolshoi Drama Theatre which was named after Georgii Tovstonogov (BDT). The play had been written by students of the Anton Tut Ryadom Foundation³ (the first fund in Russia to support adults with autism). They joined actors, trainees and teachers of the BDT, and Boris Pavlovich’s social projects. This performance marked the beginning of *The Meeting* project – the unofficial name for all theatre projects involving Anton Tut Ryadom Foundation students. Then, in 2017, I came to the *Apartment* space as a researcher in a self-started research group, which, in addition to myself, included art critic Marina Israilova, anthropologist Vita Zelenska, psychologist Ksenia Linkevich and theatre expert and programmer Alena Palatchenko. What was the rationale for choosing this particular project? Why did this group’s experience seem important? In addition to the situational coincidence (my colleagues and I wanted to explore new form of theatre and the openness of this theatre - laboratory), this was the first theatre in St. Petersburg where professionals worked alongside people with autism and Down’s syndrome. People with autism were visible on the stage yet were otherwise invisible in the urban space. It was their immersion in laboratory work, showing the seriousness of their and my BDT colleagues’ intentions, and, finally, a completely new aesthetic shown in *The Language of Birds*, that pushed me to go to *The Apartment*.

2 Performance page on the website of Bolshoi Drama Theatre: <https://bdt.spb.ru/spektakli/yazyk-ptits/>

3 The Foundation’s website: <https://antontut.ru/>

According to public surveys, researchers working in the field of disability sociology are unanimous in their opinion that there is still a great social distance between people with intellectual and learning disabilities in Russia and the general public; in addition, this distance is being narrowed extremely slowly (Belyaeva, 2018; Iarskaia-Smirnova, 2020; Naberushkina, 2012; Rasell & Iarskaia-Smirnova, 2014). According to Elena Iarskaya-Smirnova, a leading expert on inclusion and disability in Russia, the stigmatization of people with disabilities is exceptionally strong in the country, especially against those with intellectual disabilities (Iarskaia-Smirnova, 2020). Thus, when speaking about the context of inclusive projects' existence in the public space, it is important to understand this widely held disparagement. Regarding dominance of a medical discourse in society as concerns disability, inclusive theatre was initially seen as a rehabilitation project. The theatre company, which I will explore further on, initially thought of itself as professional. This project's visibility in the space of "big art" shook the very boundaries of the privileged art field, changing the discourse on inclusion and disability. It was in the fullest sense the struggle of inclusive theatre for the right to be seen as art.

Methodology: Spatial optics

This chapter uses visits to theatre rehearsals and performances as well as interviews with performers as research material; the theoretical perspective has been taken from the *Performance and the politics of space* collection (Fischer-Lichte & Wihstutz, 2013). In my view, the collection states the problem of the "spatial turn" in relation to theatre. Here, the concepts of space, field, topology and imagination are included in the philosophical discourse, which makes it possible to consider spatial, social and historical perspectives as equivalent to one another. Topological characteristics make it possible to describe the transformations of social systems and communities. Indeed, the editors also write about this assertion, proposing the spatial turn as a "heuristic tool" that allows the investigation of the "complex and multifaceted relationship" within theatre history and theory (Fischer-Lichte & Wihstutz, 2013, p. 5). In other words, I may think of theatre in terms of performance. According to the collection's authors, it is precisely this mode of theatrical existence – in its spatial-temporal boundaries that separate it from everyday social life – that provides the co-presence of social and artistic content in theatre, which constitutes its transformative potential (Wihstutz, 2013, p.186).

Additionally, in Benjamin Wihstutz's observations of the processes in the European theatre of the 2000s and early 2010s, I recognize the agenda present in the context of Russian-language theatre. I pay close attention to his article, "Other Space or Space of Others? Reflections on Contemporary Political Theatre" (Wihstutz, 2013). In it, the author proposes to draw attention to a phenomenon that "has been observed in a variety of venues across Europe since the turn of the century" (Wihstutz, 2013, p.187): the middle-class audience's great enjoyment of theatre.

... in the presence on stage of the socially and culturally underprivileged, who, all of them lay actors, play themselves and embody the marginalized classes of contemporary society: the homeless, asylum-seekers, pensioners, the disabled, the unemployed, and the sick move into the theatrical spotlight, leaving their social anonymity behind. Because of its alterity, the viewing public perceives this type of theatre as inherently political. (Wihstutz, 2013, p. 187)

I assume that the "spatial" optics offered by German colleagues – editors of the collection *Performance and the politics of space* collection (Fischer-Lichte & Wihstutz, 2013) – allow me to highlight below certain subtle tensions and connections between Russian pre-war theatre and society.

Theatre as heterotopia: Wihstutz in dialogue with Foucault

To understand the phenomenon surrounding the presence of a "special" person on the repertory theatre stage, Wihstutz, who studied this topic a decade before other researchers, arrives at the need to address theatre's fundamentals to look at it anew – through the politics of its space. A dialogue with Michel Foucault becomes key in this regard as it contains a critical re-evaluation of Foucault's concept of heterotopia (Foucault, 1997). This concept is an "other" place that materializes in relation to a place found in "normal" life (a prison, a psychiatric clinic, a library, a cemetery, the territory of colonies, a ship, etc.), as well as the location of social life's truth. Heterotopy as a method allows us to imagine the features of cultural processes in which various themes and traditions are woven and special principles of spatio-temporal dynamics operate.

Wihstutz disagrees with Foucault on the assertion that theatre can exclusively be heterotopia as a space of representation (Wihstutz, 2013, p. 187). He believes that theatre can be attributed to any type of heterotopia

and shows this in the chapter, “Theatre as Heterotopia.” Wihstutz sees immense potential for theatre as a “crisis” heterotopia which remains geographically specified while also being a unique space outside the laws of everyday social existence. Crisis heterotopias are places for people in a “borderline” state: having lost one social position, they have yet to assume another. The crisis associated with the lack of a recognized and stable social identity is overcome through places that blur clear boundaries between normal and abnormal, deviation and acceptance, visible and invisible. As such, heterotopias become “special places.” The researcher sees their political potential in the fact that a) they allow us to debate existing orders without undermining these orders in reality, or b) the laws and norms of these isolated spaces can be more subversive than those which we encounter in everyday life and which usually play the role of stabilizers of the social order (Wihstutz, 2013, p. 190).

This potential of crisis heterotopia is constantly being challenged. According to Foucault and Wihstutz, this potential disappears, giving way to heterotopias of deviance, “in which individuals whose behavior is deviant to the average or norm are placed” (Foucault, 1997, p. 334).

Wihstutz asks the following: Does theatre not become a heterotopia of deviance when, during the production process, it takes care of socially disadvantaged groups? For example, in his view, theatre that aims to briefly give a voice to those who do not have it in ordinary life, bringing them out of the shadows, “runs the risk of merely simulating other relations or encounters, and, ultimately, confirming the old demarcations” (Wihstutz, 2013, p. 194). In this sense, Wihstutz sees the danger that this type of theatre can bring. He calls us to understand the type of heterotopia being constructed on stage – deviance or crisis – since the rules of these heterotopias require different “policies” (Wihstutz, 2013, p. 194).

An inclusive project in a repertory theatre: The Meeting Project – *The Conference of the Birds*

December 2015. The theatre program of the 4th St. Petersburg International Cultural Forum⁴ opens with the premiere of *The Conference of the Birds*.

4 St. Petersburg International Cultural Forum (2015). <http://2015.culturalforum.ru/ru/sections/2>

The appearance of social theatre at this nationwide cultural event was an important step that legitimized theatre involving people with disabilities in the cultural field. In addition, it was a case of including a production with “special” people in the repertoire of a national theatre. As of this writing, the play is still being performed occasionally on the Small Stage of the BDT. It was also entered in the St. Petersburg May Showcase, representing Russia on the international theatre market. The piece was also shown at the prestigious Territory Festival in Moscow in October 2016, and was nominated for a Golden Mask Award in the Experimental Theatre category. It was well received by the press. However, despite this seemingly successful start, the team produced no other pieces for the BDT stage. It seems that the presence of people with different intellectual conditions on stage invariably involves a heterotopia of deviance (Wihstutz, 2013). The frame of the theatrical setting does not allow the process to go beyond the situation of a middle-class audience watching a performance created by “special” people. The more a space is laden with its history and mythology and the more it is targeted to its regular audience, the more palpable the tension is.

It is also essential to consider the artistic specifics of this first experience as they relate to the group. The performance’s formative principle is the visual and auditory representation of utopia. *The Language of the Birds* has a hermetic structure in which the presence of performers with ASD is never a role; rather, it is always spontaneous and safely integrated into the frame of the overall artistic solution, leaving room for flexibility and improvisation. The classical theatre space itself dictates this form to a large extent. The space created in *The Conference of the Birds* is still a fundamentally closed system, a narrative performance. The philosophical poem by the Sufi Persian thinker Farid ud-Din Attar, written around 1175 and adapted for the play, is based on the story of birds wandering the world in search of the legendary bird king Simurgh. They find him by seeing their reflection in a lake (Simurgh means “thirty birds”). Throughout the performance, the group of 19 characters, who all differ in their way of talking, moving and interacting, gradually acquire through moving, singing, playing instruments and performing short monologues, a common language – “the speech of the birds,” the utopia of unity. The metaphor of the utopian kingdom is visually embodied in the final procession of figures: the participants, all dressed in various outlandish costumes and masks, parade across the stage in time with the music. After the applause is over, the performers play a piece of music, inviting the audience members to contribute to the musical score

of the play; interestingly, this is the only time they violate the boundaries of the audience space.

It is important to stress that this performance is still a rare (if not the only) example of inclusive repertory production in Russia. However, after Boris Pavlovich left the BDT, the theatre's interest in this production faded; as a result, its work with amateurs, not to mention inclusive activities, was over. I was lucky enough to attend several performances of *The Conference of the Birds*: one of the premieres (when the group was still a part of the BDT) and two when the neurodiverse performers had already quit the theatre. Relying solely on personal experience as a theatre critic, I would say that the performance gradually froze in its original theatrical form, thereby losing its drive. This subjective impression is supported by the fact that in the last three years, the play, which had been only rarely performed previously, has practically disappeared from the repertoire.⁵ The Other – be it a neurodivergent person, a school student or a neurotypical amateur actor – fails to take over the space of the academic theatre. A neurodivergent actor causes such visible tension that a performance with this Other, even if “wrapped” in a familiar theatrical form, finds itself out of place in a traditional theatre space. It will be recalled that the otherness – or *alterity* as Wihstutz (2013) calls it – makes theatre political, or, in terms of Jacques Rancière, violates the “police” regime. Rancière understands politics as a regime subverting the orderliness inherent in this regime and as a place where “police,” i.e., the normal order, meets equality (Rancière, 1995). In the case of *The Language of the Birds*, I see a non-obvious manifestation of politics. This political tension is both the radicality of the artistic statement and the degree of conservatism of the “police,” the state art production system, which centuries-old traditions are embodied by the BDT space.

The weekly training sessions (the play's source), which continued over a year, ceased in 2017. Boris Pavlovich, director of the project and, at the time, head of the social and education department at the BDT, choreographer Alina Mikhailova and all the foundation's students left the theatre. They continued their work in *The Apartment*, an independent space they created with the Alma Mater Foundation⁶ and producer Nika Parkhomovskaya (Parkhomovskaya, 2018).

5 According to the KuDaGo events guide, the production was performed three times in 2016, four times in 2017, three times in 2018, twice in 2019 and once in 2020 (<https://kudago.com/spb/event/spektakl-yazyk-ptic>).

6 <https://amfoundation.ru/en/about-the-foundation/>

Inclusive project among people: *The Apartment*

Leaving BDT was certainly a political gesture made by the company. Several choices made by the group seem fundamental to me: the choice not to occupy the territory of an external institution but to build its own “secret” space, i.e., not one labeled as a theatre and located in a residential building; the choice of non-theatrical space: no stage floor or “hall/stage” mode; the blurring of both spatial and temporal boundaries in the first performances at the new location; the versatility of the space. In 2017, the team was radically restructured for the first time in its history: *The Apartment*, an inclusive space at 40 Moyka Embankment, attracted a strong group of independent young theatre-makers from St. Petersburg who have been shaping the project’s development in recent years. While the space existed, the team staged four productions, two of which got nominated for the Golden Mask National Theatre Award (one received it). Over the years, the members of the team also won several other local and national prizes. I have previously described some aspects of the project: in particular, the training sessions during the first year of the group’s work, the performance *Conversations*, and how the performative space in *The Apartment* worked (Dunaeva, 2019, 2020).

Having replaced the theatrical space with that of a former communal flat along with performers and a mixed audience in this space, participants came close to creating a heterotopia of crisis (Wihstutz, 2013), a special place outside formal social institutions that offered a liminal, borderline experience of interaction.

Much is to be said about the spatial component of *The Apartment*. This space is shaped by its geography (the house where *The Apartment* is located in a typical St. Petersburg courtyard), architecture and production style. Created by an art team led by Ekaterina Andreeva, it is rich in mythological content that unites several historical spaces and cultural myths. One of the most important in this regard is the image of the flat owned by philosopher Leonid Lipavsky where Daniil Kharms, Alexander Vvedensky, Nikolay Oleynikov, and other members of the Chinari circle gathered in the 1930s, creating their non-conventional space of the strange (Dmitrenko & Sazhin, 2000).

To clarify the significance of the political effect of *The Apartment*, I must return to Foucault’s text. I would point out that he sees not only

heterotopia but also utopia as locations that are “in rapport in some way with all the others, and yet contradict them” (Foucault, 1997, p. 332). I am interested in the image of the mirror that emerges in Foucault’s text and the philosopher’s statement that heterotopia as an intermediate enclosing and reflecting space does not exist on its own but always in conjunction with utopia (Foucault, 1997, p. 332). *The Apartment* can be seen as the experience of creating a “Foucault mirror,” or a “virtual point,” allowing one to look at oneself in the moment from an outside utopian reality. It is clear that behind the specifics of place, the flat in the Moyka utopia existed on equal terms. One might speak of utopia as a director’s optics, an image borne by one person; but one might also speak of a “bundle of relations,” (Foucault, 1997) that requires taking steps toward realization. The most important element of Foucault’s metaphor is the necessity of having the mirror as an intermediate experience between utopia and heterotopia. According to Foucault, many spaces are heterogeneous (Foucault, 1997).

We need a “mirror,” or intermediate experience, to identify heterotopia. It seems that *The Apartment* has given form to this experience. Through interacting with this space and each other within it, a specific topology was created as a system of locations for team members and guests – in sum, an intricate network that allowed bringing the experience of *The Apartment* outside its walls. This network was formed in regular training sessions and born out of the the participants’ deep involvement in the production.

When I interviewed the creative team of *The Apartment*⁷, the performers articulated their way of interacting with things in it:

[Boris Pavlovich:] Indeed, the Soviet in its Sovietness has no value for me, and all these things... In this sense, we, including myself, are here under the significant influence of being together with the guys.⁸, because at a certain point, you begin to see things in a slightly different context: as colour spots, as texture, as a source of the sound, since you begin to look for something to rustle with, to knock. So I do not perceive this millet and grits as some reflective element anymore because we have it due to our “pop mechanics”, which removes the historical background.

The desire to see a thing freed from powerful narratives, form and function as a way of working with the thing is probably chosen consciously (Dunaeva, 2020). The material world of *The Apartment* can be viewed as a

7 The creative team of *The Apartment* interviewed by the author on 18 February 2018.

8 This refers to the group’s neurodiverse members.

point of meeting with autistic people, and its work method can be viewed as a search for direct sensory contact with things and space. Speaking of the “chemistry” of this “Foucault mirror” (Foucault, 1997), as one of the participants in the events, I can testify that it is the feeling of being the Other. On the one hand, it is the development of empathy, probably much more developed in the project performers and other people who spend time in a neurodiverse environment than I do; on the other hand, it is the setting of our boundaries, without which being in such a group might cause burnout.

The “mirror” of the new connections formed during *The Apartment* work allowed the team to exist for a year without having an actual space. The experience of creating spaces compensated for the lack of their own space. The group discovered the possibilities of utopia by applying the “mirror” to different fragments of everyday life.

It is telling that the formal reason for closing *The Apartment* was a lawsuit filed by a neighbour, who was unhappy about the noise being made in his stairwell and the “special” people coming there. Thus, a manifestation of politics also reveals the totality of the “police.”

Inclusive project nowhere and somewhere: *Conversations*

Despite receiving the recognition of the theatre community, including awards and wide interest from both media and producers alike, *The Apartment* group folded in 2019. The team lost its space at 40 Moika Embankment, ended collaboration with producer Nika Parkhomovskaya, and renamed the project *Conversations*. Then, Actresses Veronika Abdulmuminova and Valeriya Zolotukhina joined the team. After leaving *The Apartment*, the group lost their home for a long time. Rehearsals were first held at the Museum of Theatre and Music; then, because of the coronavirus pandemic, on Zoom. After self-isolation, they were held at Dom Radio on Malaya Sadovaya Street.

This staging of the team’s work is characterized by a dispersion of its spatial and political presence. Thus, the project *Gorod. Razgovory (City. Conversations)*⁹, carried out in 2019–2020 in St. Petersburg, Yekaterinburg, Copenhagen and Moscow, involved the project’s participants entering the

9 Project webpage: <https://amfoundation.ru/en/portfolio/gorod-razgovory-2/>

city. Unexpectedly for most, the performance space in this invisible theatre became a bar, cafe, library hall, classroom and any other place where “experts of the everyday,” according to Rimini Protokoll group¹⁰, told their stories through the mediation of project participants. In 2021, *Allo! (Hello!)*¹¹ was performed during the pandemic by telephone. The podcast, created as part of the project by actresses Mariya Zhmurova and Aleksandra Nikitina, can also be attributed to the auditory space.

Several other projects have been carried out in an online environment. In the spring of 2020, the group held a spontaneous artistic campaign supporting one of its members, Vladislav Mayorov (Dyurin), who had been diagnosed with cancer. On 13 April, the project’s head playwright, Elina Petrova, offered a lot on Facebook to help the fundraising effort to pay for Vlad’s treatment: she listed all her talents and everything she had to offer fans, from a crash course in playwriting to the opportunity to take a photo with her cat, Patefon. I see an artistic gesture in Elina’s message: starting with her artistic skills, which require a high degree of expertise and dedication, she moves on to more ridiculous propositions. The mention of the cat bookends this sad list, which is, on the one hand, an homage to the early absurdist aesthetics of *The Apartment*. On the other hand, it points to the artist’s limited means, desperation and helplessness as an independent artist with no resources who is trying to help her equally vulnerable colleague who is living with ASD. Soon, other members from *The Conversation* willingly joined in – all of them wanted to support Vlad. As part of the campaign, these performers put up several items to be bought for donation; a one-day marathon was held that included events, online meetings, readings, etc. Tellingly, *Conversations* became one of the items that was performed online (i.e. it was their second performance in *The Apartment*). As a result, their goal was achieved, and Vlad received the treatment he needed. Space – the virtual one in this case – was mobilized in the project by a collective effort to once again briefly become a “mirror” (Foucault, 1997), reflecting a potential utopia of equality, fraternity and solidarity.

Notably, the first large-scale production the team has produced since leaving *The Apartment* has gone almost unnoticed. *Chelovek. Effekty*¹² is a

10 <https://www.rimini-protokoll.de/website/en/text/the-experts-of-everyday-life>

11 Project webpage: <https://amfoundation.ru/portfolio/allo/>

12 Performance page on the website of Alexandrinsky theatre <https://alexandrinsky.ru/afisha-i-bilety/zdes-i-seychas-teatralnyy-diptikh-chelovek-effekty/>

diptych production comprised of one-act performances *A Sound of Thunder* (based on a Ray Bradbury story, directed by Jana Savitskaya) and *Paketik, kotoryy khotel byt' nuzhnym* (*The Baggy That Wanted to Be Needed*, based on the eco-play of the same name by Gulnara Nasyrova and directed by Pyotr Chizhov). Presented by the *Conversations* team and co-produced with the actors of the Social Art Theatre,¹³ the diptych has been performed once on 27 October 2020, on the New Stage of the Alexandrinsky Theatre (excerpts from it have also been played separately at festivals).

Before concluding, I will return to Wihstutz's article again. Wihstutz praises theatre's capabilities as a space for re-enactment of one's life; it is neither a demonstration nor a social message but rather a safe reproduction of oneself before an audience (Wihstutz, 2013). Regarding Pyotr Chizhov's performance, I believe it was the first time I encountered such a poignant and uncompromising articulation of the norm's problem in a theatre. The actors of *Conversations* were not aestheticized or represented as participants in a possible utopia, as in *The Conference of the Birds*. Here, the framework of the performance was conventional. For instance, they did not build a utopia in a single space that was specially organized to make possible a meeting of neurodiverse people (unlike in the *Apartment* performances). I would call the strategy of the creators of *Paketik*... a politicization because the performance interpreted and problematized the presence of people with ASD and Down's syndrome. Although we all, spectators and the independent neurodiverse theatre group alike, were guests at the repertory venue, they managed to take over the space for the duration of the performance. They were before our eyes in the entirety of their presence, inaccessible to either professional actors with or without ASD. However, they were not presented as victims of society or representatives of a "special" world into which we were allowed insight. The performance invited us to discern (or at least notice) each other "here and now" and pay attention to the fact that the eco-warrior Starling (one of the characters) was only one of the roles being offered.

Only a few reviews were published about the diptych. Meanwhile, the issues addressed in the project offer an entirely new perspective on inclusion in the geo-political space of Russia. The problem of the norm's shifting boundaries naturally extends to environmental issues and touches on the political dimension as well. Without explicitly using the ecological

13 Theatre webpage: <https://www.sht.spb.ru/>

discourse now famous in European art criticism, the performance reflects on humans' explicit and implicit impact and effects on nature, society and other humans. Maybe this project was a Russian version of *Disabled Theatre*, the famous performance by Jérôme Bel (2012/2014; see also Umathaum & Wihstutz, 2015), which turned the idea of performances with people with disabilities upside down and made the European theatre community equate inclusion and politics.

Performance as a process, process as a performance

Having left the state theatre in 2017, the inclusive theatre project, whose different incarnations have been discussed in this text, returned in 2020 to the stage of another significant repertory national theatre, the Alexandrinsky, with the play *Chelovek. Effekty (Human. Effects)*. Why did this happen? What has changed in the theatre and group since this time? In order to answer this question, it seems essential to follow our German colleagues in defining the boundaries of the phenomenon described. However, the paradox is that by defining the boundaries, one needs to do the opposite of what Wihstutz does in his paper. "A performance can only be regarded as art," he insists, "if it establishes external boundaries, framing it as 'impact-reduced' (*konsequenzvermindert*)" (Wihstutz, 2013, p. 185). This reduction of impact is the price that theatre pays for its nature, ensuring the ambivalence of theatrical space that allows it to be both a space for art and social interaction.

However, with the theatrical project in question, it makes sense to expand the boundaries of the theatrical event, making them as open and moveable as possible. Based on the participatory theory of Claire Bishop, who defines process art as "art in which people constitute the central artistic medium and material" (Bishop, 2012, p. 2), I suggest thinking about the entire spatial-temporal span of the projects *The Meeting – The Apartment – Conversations* as a single processual performance (2014–present), with a series of intermediate results in the form of performances, media events, concerts and lectures; and if the starting point can be agreed on, the final point has not yet been determined. In contrast, *The Language of the Birds* is not to be measured by the number of performances, as it began with the first meeting of its future participants, or perhaps with the director's first visit to the Anton Tut Ryadom Foundation, continuing on to this day. It is the problem of interaction between Me and Other that has always been at

the centre of the group's search. The group's development and transformation dynamics determine the methods of searching for various communities' "common places," including those excluded from public life for a long time and invisible in urban spaces in the Russian context as people with cognitive disabilities are.

In this regard, the project's director, Boris Pavlovich, made an interesting observation in recent private correspondence with the author: "I struggle to come up with a play for *Conversations* because the most important thing is already happening there" (personal communication, September 16, 2021). I saw that for myself when attending training sessions at *The Apartment* in 2017–2019. Regarding changes in the group, the company's history appears different than when it did with regard to its productions. In this case, people were the central material and object of the artistic impact. This point, however, allows us to stay within the framework of the spatial turn narrative proposed by Wihstutz and Fischer-Lichte (2013), thereby considering the metamorphoses of the project's space as the changing settings of a big production.

If one follows Wihstutz's logic and limits the theatrical event by marking entry and exit points, which gives the event a political charge by breaking boundaries, we deprive the project of its emancipatory potential. The participatory theory by Bishop (2012) disputes this assertion, although one may talk of a weakened political effect if this occurs. If this happens, analyzing the project over time becomes all the more critical.

This model of "weak" resistance (or resistance of the weak) became crucial in the pre-war crisis year of 2021 and after the invasion of Russian troops in Ukraine in February 2022, when any active protest was severely suppressed by force. The experience of building a community, the "Foucault mirror" as reinvented in the *Apartment* today gives personal freedom to dozens of young people who support neither the war nor the regime. From the projects *The Meeting – The Apartment – The Conversations* grew the project *L.E.S.*¹⁴ (*The Forest*). The initiator of the project was theatre director Boris Pavlovich. *The Forest* started in 2021 as an independent theatre laboratory, within which various people (mainly professional actors from the St. Petersburg theatres) met once a week to discuss the texts of Vladimir Bibihin.¹⁵ The entrance to the laboratory was open, and information was

¹⁴ Project webpage: <https://les-bibihin.ru/>

¹⁵ Vladimir Bibihin (1938–2004), Soviet and Russian translator, philologist, and philosopher.

distributed through word of mouth; there were no specific goals or budget. After a year of regular meetings, several solo performances and chamber projects “sprouted” in the larger project. The project’s producer Alexey Platunov came up with the concept of “foresters” when anyone could try out being a producer of a creative project in L.E.S. The degree of participation was determined by the person’s capabilities and team’s needs. Following the open system of creation and production, a flexible system for promoting performances was invented, including an open SMM system, when any project participant had the option of taking responsibility for a particular project’s social networks. Thus, the authors of the performances were not the only artists here – indeed, all members of the group contributed to the overall form of the artistic process. Laboratory, procedure, readiness for a long, painstaking joint effort, the absence of hierarchies, and faith in the capabilities of each person as a creator – these factors permeated the independent inclusive art of the 2010s, and all this was embodied in *L.E.S.*

Conclusion

In the final part of his text, Wihstutz again recalls the counterintuitive effect that theatre carries and, at the same time, does not carry beyond its boundaries. Quoting Rancière, he claims that, “The politics of artis at once a played out the state of exception and, during the game, an emancipatory promise” (Wihstutz, 2013, p. 198). Wihstutz also values “the appearance of an unstable border between fiction and reality, and between a politics of art and a politics of social reality” (Wihstutz, 2013, p. 198).

Wihstutz’s logic helped me to identify the project’s boundaries and thus trace the stages of life of *The Meeting – The Apartment – Conversations* group as well as capture the point when participants did not need space anymore as permission to be present. In local projects, such as *Chelovek. Effekty*, I saw a Rancièrian promise of emancipation:

... [it] presupposes that in addition to the ignorant teacher and the emancipated student, there is always something third, a book or a piece of text that has nothing to do with either. This is something third to which the student and the teacher can turn in order to jointly certify what the first one saw, what he says about it and what he thinks. (Rancière, 2018, p. 18)

A theatre where the Other can be self-represented without theatrical mediums (such as a role) is gradually emerging. Behind this presence of the Other in the conventional situation of theatrical performance, I discovered a seemingly accidental, fragmentary (but in fact already undeniable after a few years) co-presence of us as the Others in our shared space.

The *L.E.S.* project creators took this co-presence experience with them. *L.E.S.* is creating new islands of inclusive spaces – in Moscow, Yekaterinburg, Kirov and other cities all over Russia. The opportunity to utilize your own body, create something of your own free will and consciously express your position in a group of like-minded people without being pressured by law enforcement agencies is already a luxury for artists working in Russia today. Furthermore, so far *L.E.S.* has operated in this territory and remained hidden in the folds of modern Russian reality from prying eyes – both in Russia and from foreign media. Without directly confronting space, these theatre practices present a silent form of resistance.

Author biography

Aleksandra Dunaeva graduated from the St. Petersburg Theatre Academy in 2009 and then continued with a Russian equivalent to a PhD in Theatre Studies. She is a theatre historian, critic, and curator of socially engaged art projects. Her research interests are social theatre, theatre of citizens, inclusive theatre projects, theatre and migration, art pedagogy. From 2013 to 2020, she observed the social theatre field in Russia as a researcher and journalist. From 2019 to 2022, she worked as a senior researcher at the School of Contemporary Humanities Research, RANEPa in Moscow. Now, she is based in Finland and continues as an independent researcher.

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CHAPTER 7

Towards an Intermodal Merger: Somatics, Disability and Brazilian Collaborative Performance

Ciane Fernandes Federal University of Bahia, Brasil

Abstract: The text presents a general overview of the marginalization of disability within Brazilian academia in the performing arts as well as current initiatives towards overcoming it. This is particularly relevant in regards to decolonial theories (which are currently being highly emphasized in many Brazilian academic activities and arts programs), which, while they expose and criticize specific processes of exclusion, keep marginalizing disability. In this regard, the text relates colonialism and logocentrism, also criticizing education in general and decolonial theory for maintaining a neurotypical hegemonic superiority. Somatics and intermodal performance, on the other hand, are neurodiverse modes of integrating and creating new possibilities for a more egalitarian and participative world. The creative artistic processes described include: eperformances in fluid environments with my severely autistic son along with my graduate and undergraduate students at Federal University of Bahia/Brazil, in a modality I have called *Merger as Research*; and an online group performance given in 2020 by the A-FETO Dance Theater Collective (which includes my son), under my direction since 1997. This intermodal online performance intended to call attention to the theme of disability within an event that focused on other (major) minorities.

Keywords: neurodivergency, Somatics, performance, Artistic Practice as Research, accessibility, decoloniality

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Introduction

This text takes on my perspective as a Brazilian mother and caregiver of a severely autistic young adult to discuss an educational system which perpetuates neurotypical models, an academic context that excludes disability from social justice debates, events and actions, and a society that insists on erasing the perspective, experience and unique contributions of people with disabilities. The place of the caregiver deserves recognition within the context of disability, especially when we are talking about the majority of caregivers being women (Diniz, 2012; Polo, 2022). So this is my perspective and experience while writing this text. The closed system which reproduces such an hegemonic neurotypical model based on logical verbal and written language acts at many different levels, from the family sphere to social and political circles, consistently excluding not only divergent bodies but also a full spectrum of every human being's sensory experience. This also has many repercussions in terms of accessibility, which implies multisensorial versions of knowledge far beyond logical verbal and written language.

This neurotypical emphasis implies a dualistic mind-body fragmentation and power relationship, neglecting embodiment as the means of our experience with and within the world as our main source of knowledge. For this reason, the use of somatic practices (Eddy, 2009), in association with performance, has guided my aesthetic explorations, which are exposed in the text in both technical and compositional terms.

In my experience, along the last thirty years as an artist, researcher and teacher, added to my daily life as a mother and caregiver of a severely autistic person for the last nineteen years, I have widely perceived and explored the affinity between Somatics, performance and neurodivergent perception. According to Diego Pizarro (2020), the word "Somatics" (starting with capital "S") stands for the transdisciplinary field of knowledge, while "somatic" is used as an adjective to qualify techniques, approaches etc. We can describe the affinity between Somatics, performance and neurodivergent perception as a merging or "intermodal" quality (Manning & Massumi, 2014). According to Erin Manning and Brian Massumi (2014), while neurotypical perception tends to separate objects and environment within an antropocentric and functional relational hierarchy, neurodivergent perception relates to a world of textures within which all elements are merged with the same importance:

[T]here is a tendency within autism to immediately perceive the relational quality of a welling environment that dynamically appears in a jointness of experience [...] prior to the distinction between active and passive, subject and object. [...] Modes of existence are always plural and relational [...] existence can be found not only in beings, but between them [...]. Modes of existence are *intermodal*. (Manning & Massumi, 2014, pp. 7–8)

This text attempts to follow such merging ways of perception, unraveling those different levels of the hegemonic models by fluidly going from a more personal to a broader and more social perspective. Therefore, in accordance with the text, some of my daily routines and experiences with my son will gradually shift to social pursuits as well as artistic and creative approaches.

The first section initially focuses on my personal perspective as a caregiver, criticizing the lockdown during the pandemic and, later on, proposing an approach with my students which explores creative embodiment in open spaces. The second section brings a more critical view of the educational system, as well as of post-colonial theories with regard to disability, briefly exposing particular initiatives in Brazil towards resisting ableism and disability exclusion.

The last section details the online performance *Home Alone No Number*, created and presented by the A-FETO Dance Theater Collective, under my direction since 1997. This piece was chosen to demonstrate how performance with a somatic approach can expand the borders of perception and interaction, breaking through neurotypical impositions as well as provide the opportunity for disability to be recognized as a fundamental theme in today's world, especially in the arts and in the context of a supposed "social" justice which still tends to exclude people with disabilities.

We can therefore summarize the main research questions as follows: What are the unequal conditions within the Brazilian context in which Practice as Research contributions are made necessary and, more importantly, fundamental in terms of disability? How can the association of Somatics and intermodal performance promote and even create a meaningful shift from neurotypical hegemonic models to neurodiverse ways of perceiving, living, learning and relating? What are some possible technical and aesthetic means and implications through which such contributions and shifts might happen?

Neurodiversity, practice as research and the environment

“Stay home,” said the campaign to prevent the spread of Covid-19. Even before the pandemic took place, my son and I had found it incredibly difficult to leave our home for more than a decade. Yet at that time, nobody really cared much about our situation, and there was no international campaign to tell people to stay indoors. Autism has not been an on-trend topic (yet as the number of autistic people is growing fast, this will change) and, as such, does not come as often in the media as COVID-19 has done. Autism is not contagious, and it does not cause the wheels of commerce to freeze. On the contrary, it helps support two of the world’s richest industries – that of pharmacies and “health” care. Distinguishing itself from COVID-19, Autism Spectrum Disorder (ASD) remains hidden, all the better for a controlling neurotypical society, which by the way has a higher number of deaths by suicide than by COVID-19 itself.

Unfortunately, in Brazil many irresponsible people ignored the pandemic, rejecting any kind of preventive protocols, some people even promoting crowded open parties. But these actions did not include those who have been in lockdown at home their entire lives, much less going to public parties, and who need and deserve to go out against all the odds, especially to meet their fundamental needs. Or who would want to keep an adult with ASD and frequent aggressive episodes locked inside an apartment for six months straight? My close neighbors surely wouldn’t.

In fact, for the two of us, being outdoors in natural open air places has always been much safer than staying at home or going out in public. We went through a violent traumatic experience together when my son was only 18 months old; incredibly, we were chased by that same person for two years running and had to sneak out whenever we left our building. So, to get away from this situation, we moved out to the countryside to Lençóis BA at the Chapada Diamantina National Park, where we performed at several outdoor sites between 2009 and 2015. Some of these ecoperformances included my students at the Graduate Program of Performing Arts at Federal University of Bahia (UFBA). These were special trips organized as part of the research course I have taught since the program’s start in 1998; it is called the Performance Laboratory (Fernandes, 2012).

For the past ten years, I have developed somatic activities in fluid environments that are then applied to teaching undergraduate theater

students as well as graduate performing arts students. I have called this mode of research in fluid environments *Merger as Research* or *MaR* (“sea” in Portuguese) (Fernandes, 2019); it in turn is part of the Somatic-Performative Approach (Fernandes, 2020). This approach is a Practice as Research (Nelson, 2013) modality I have developed over the past 18 years. It combines the Laban/Bartenieff Movement System (LBMS) (Bartenieff & Lewis, 1980), Authentic Movement (AM) (Pallaro, 1999), dance theater, performance and other forms of art that are all part of a growing research process (e.g. Bharatanatyam, free diving and Body-Mind Centering, among others). The field of Somatics was initially identified by Thomas Hanna (1976) to name a group of body-mind disciplines; since then, it has grown to include diverse techniques and methods “where the sensory, cognitive, motor, affective, and spiritual domains mingle with different emphases” (Fortin, 1999, p. 40). These expanded field performances have taken place in different fluid locations and with different groups, such as with my son, by myself, with undergraduate students at the School of Theater of UFBA, with graduate students of the Performance Laboratory course as well as with research peers from Bahia. These performances have also taken place in different locations outside Bahia and Brazil, including Portugal and Germany.

It is always an unpredictable experience to explore merging with a fluid environment in an open air location, usually in expanded time frames (minimum 3 hours, but usually an entire day).¹ We don’t have control over the weather, the tide or even the public. When swimming in the sea on the island of Itaparica (Bahia), my son and I stay in the water from 2 to 5 hours at a time. This is in part because it takes at least an hour for my son to get acquainted with his surrounding environment. There are several unpredictable moments when he starts interacting with me in between the tidal flow (it is quite challenging to run long distances at alternating speeds). I have to be very attuned to my own sensations, subtly encouraging my son to interact with the environment and not pushing him to do something “correctly.” Rather, I try to help him play in a back and forth rhythm that imitates the sea. There are magic moments when he opens up in very spontaneous full-body expressions.

In whichever situation – by myself, with my son, with students and research partners – the environment itself, including the forest,

1 Further details of these activities are available at C. Fernandes (2019).

sea and rocks, creates safe and supportive surroundings that allow revisiting, releasing and creative transformation of embodied traumatic memories. Indeed, the environment is an active participant in an ecoperformance, creating a whole world of textures with no separation between subject and object, active and passive. In other words, MaR is essentially neurodivergent in its expanded intermodal means. After all, neurodiversity is as crucial for human beings as biodiversity is for the environment (Blume, 1998).

The focus on fluid environments, in particular for me and my son, has been reestablishing our sense of flow, movement phrasing and body parts connection. In the middle of our highly stressful lives, we need to discover ways of coping with each situation and becoming resilient. Personally speaking, these explorations have inspired me in all of my research endeavors, be they studying, teaching, writing, dancing or singing, most of which I do with my son (either in his presence or by managing his activities at a distance, for example, when working in a nearby room).

In the Somatic-Performative Approach, especially in MaR, I encourage students to move and be moved by their research, weakening the boundaries between subject and object, passive and active. Based on cellular wisdom – intelligent forms of knowing that are constantly being constructed by our bodily systems, their relationship among themselves and with the surrounding environment – we engage in a world of textures in intermodal compositional processes that overlap personal, cultural, ancestral, spiritual, social and political dimensions.

Disability and the decolonial debate

Much has been said and done in the last few years in Brazil with regard to promoting human rights in special groups based on ethnicity, gender and social equality. A special focus has been placed on relevant racial issues within the decolonial context through what are modest attempts to include a diversity of cultural perspectives and validate all forms of knowledge, for instance, in university curricula. Nonetheless, especially in the arts, disability is still placed within a medical realm and thus kept apart from the great majority of events and activities.

Education in general has great difficulty generating neurodiverse means, not only because of the lack of professionals with a specific background to deal with special needs students, but also because neurotypical children

lack support from family members and society alike to deal with their colleagues' neurodivergency. Obviously, a great deal of the problem lies in society in general, which validates only neurotypical means of communication; consequently, an autistic child must adapt to this ableist environment in order to survive.

In fact, education is the place where this entire set of neurotypical communication rules (established by society and reinforced by families in private circuits) is perpetuated. In this context, there is no place for a perception based on a world of textures, which I have associated with somatic merging. Inclusion in traditional academic settings implies an effort to become part of the neurotypical linguistic dominant mode, thereby sacrificing a (neurodivergent) joint experience.

For this reason, Somatics in education functions as a revolutionary act which integrates all elements intermodally, without assigning privilege to verbal language and front cortex logocentric knowledge over embodied modes of wisdom.² Indeed, neurodivergent merging perception seems closer not only to somatic approaches but also to indigenous modes of living, both of which are based on humans' full integration into the environment. Indigenous representative Casé Angatu Xukuru Tupinambá said recently at an event held at the School of Visual Arts at Federal University of Bahia: "We are not the owners of the land. We are the land itself" (Tupinambá, 2022).

Neurodivergent, somatic and indigenous people share ecocentric, merging modes of perception between themselves and the environment, which goes far beyond the anthropocentric subject-object duality based on profit and function. As explained by environmental performance artist Annette Arlander:

Our tendency to assume ourselves as subjects in a world of objects is intensified in a manmade environment such as a contemporary city. Surrounded by commodities, which function like fantasies, the subject is more likely to see what it has made, rather than feel itself to be connected with, or part of, what has made it. (Arlander, 2012, p. 2)

Although the field of Somatics has been increasingly associated with indigenous cultures and cosmogonies (Djukurnã Krenak, 2022; Torralba et al.,

² For more information on somatic learning, please see T. L. Horst (2008).

2022), neurodivergency is still waiting to be connected with indigenous traditions as well as to the decolonial debate. However, this situation is starting to change. In Brazil, for instance, the non-governmental organization *Acessibilindígena* was created in 2022 by indigenous people with disabilities from different tribes in Brazil to fight for their rights.

Within the decolonial debate, the focus on colonization and coloniality in general seems to be unrelated to disability, as if there is no relationship between these topics and their historical entangling. We often see debates and theories on decoloniality that mostly exclude any debate on disability. As explained by Shaun Grech and Karen Soldatic (2015):

While postcolonial theory and associated fields (e.g. critical theory and cultural studies) have engaged with race, gender and ethnicity in the exploration of themes of identity, representation, space, historicity and the neocolonial, they have almost wholly bypassed disability—paradoxically limited to the historical subjectification of the able-body, or rather disembodied colonialism and the postcolonial terrain. [...] While the notion of ‘disablement’ is sometimes included in postcolonial readings, ironically there are few references to processes of disablement for disabled people in this scholarship. (Grech & Soldatic, 2015, p. 1)

By excluding disability from the debate, decolonial theories insist that the segregation of a group is based on a medical model that classifies them as not belonging to the category of productive citizens. Under this excludent perspective, the disabled are taken as an invisible category which does not contribute to society’s productive machinery; on the contrary, they live in it for free. In this precarious condition, their lives do not really matter, and their deaths are actually necessary to protect the lives of people who are truly “alive” (defined as productive). This precarious condition is exposed by Judith Butler (2010) in reference to certain populations such as the homeless and indigenous; once again, no regard is given to the disabled, who seem to be invisible, even within these other invisible categories.

Disability has been mostly removed from the decolonial debate because its emphasis is on race, gender and ethnicity. After all, intersectionality (Crenshaw, 1989) has continually proven that these categories are not totally separate or separable. There is historical evidence in Brazil (Lobo, 2015) and other countries like South Africa, for instance, of the close relationship between slavery and disability, entangling the genocide of the “non-ethics of war” (Maldonado-Torres, 2007, p. 247) to questions of ethnicity, gender and disability, all bound to the hegemony of a rational Eurocentric being

whose identity is founded on language. In fact, neurotypicity is considered another name for anti-blackness (Fred Moten as cited in Manning, 2016, p. 4).³ The intersectionality between autism and the LGBTQIAPN + (lesbian, gay, bisexual, transsexual/transgender, queer or questioning, intersexual, asexual, other non-binary identities) community has sometimes united both movements in the double minority effect (Byers et al., 2012; George & Stokes, 2018).

The decolonial debate does not include disability, especially in regard to neurodivergency, by still being based on a neurotypical model. That is why the association between Somatics and decolonial studies is so important, especially with regard to disability. Somatics does bring the discussion to the level of embodiment and beyond purely frontal cortex reasoning (a major feature of neurotypical construction of and relation to the world). Founded on the hegemony of a neurotypical human being, the analysis and criticism of colonial processes are based on (verbal and written) language, which is still considered to be the main mode of knowledge construction.

The frontal cortex linguistic model excludes not only neurodivergent people who are unable to communicate or relate through linguistic reasoning and means but also excludes all non-verbal and non-shareable sensations, such as pain (Scarry, 1985), creating a huge dualistic gap between body and mind, experience and communication, self and environment. This is particularly relevant in cases of Hidden or Non-Visible Disabilities NVD (Meehan & Carter, 2021), which often accompany neurodivergency. It is precisely at the level of this imposition of a rational and neurotypical linguistic construction of knowledge that a major colonization process resides:

‘Science’ (knowledge and wisdom) cannot be detached from language; languages are not just ‘cultural’ phenomena in which people find their ‘identity’; they are also the location where knowledge is inscribed. And, since languages are not something human beings have but rather something of what humans beings are, coloniality of power and of knowledge engendered the coloniality of being [colonialidad del ser]. (Mignolo, 2003, as cited in Maldonado-Torres, 2007, p. 242)

According to these principles, being outside the realm of language, in particular verbal and written language, is to be non-existent as a social-political-cultural being. The colonial power establishes itself through

3 “This comment was made by Fred Moten in his review of this manuscript” (Manning, 2016, p. 236).

hegemonic neurotypical means, erasing and dominating everything that is outside reasoning and language. The outsiders are erased as having no identity and producing no knowledge. So we can actually state that the neurotypical communication model, based on language and frontal cortex reasoning, works as a colonial power structure that supports both the colonial process and decolonial debates. And this situation is almost taken for granted; that is, neurotypical language as the only possible way of constituting identity and knowledge is used as an instrument of power, domination, exclusion and destruction of neurodivergency. Yet this neurotypical model is not even recognized as such, because it is taken as the *a priori* “normal” way in which things are supposed to be (said, done, built, seen and recognized). In other words, this ableist constitution of the hegemonic system is a very perverse colonization process according to the neurotypical communication model, which has invisibly supported the colonization process as much as the supposedly decolonizing one.

The relationship between coloniality and the neurotypical model, or between a colonizing ego (which erases otherness) and a thinking ego (which identifies itself only through pure reasoning) is actually quite close. According to Maldonado-Torres (2007), the colonizing ego (*ego conquiro*) provides the structure for the thinking ego (*ego cogito*) to establish itself:

The Cartesian idea about the division between *res cogitans* and *res extensa* (consciousness and matter) which translates itself into a divide between the mind and the body or between the human and nature is preceded and even, one has the temptation to say, to some extent built upon an anthropological colonial difference between the *ego conquistador* and the *ego conquistado*. [...] If the *ego cogito* was built upon the foundations of the *ego conquiro*, the ‘I think, therefore I am’ presupposes two unacknowledged dimensions [...] we are led to the more complex and both philosophically and historically accurate expression: ‘I think (others do not think, or do not think properly), therefore I am (others are-not, lack being, should not exist or are dispensable)’. (Maldonado-Torres, 2007, pp. 245, 252)

Not by chance, hegemonic neurotypical education, based on language as well as verbal and written communication, is also the basis of the colonial project. The decolonial project then takes this for granted when favoring all minorities except disabled people, especially those who do not speak or write; that is, those who are outside of the closed hegemonic circuit of verbal and written language.

While accessibility is necessary, it is not enough. The empowerment of people with disabilities implies the transformation of dualistic and neuro-typical education and communication, both of which overemphasize pure reasoning at the expense of the (still colonized) full body experience. While accessibility implies having access to the knowledge produced in a variety of places and contexts, empowerment implies being the autonomous producer of knowledge. It also implies being fully and equally recognized as such in all places and contexts.

Ableism in the Brazilian performing arts academic context

I am particularly interested not only in making the production of mainstream knowledge available to people with disabilities (through accessibility) but also to highlight the specific ways in which artists with disabilities construct remarkable, relevant and unique knowledge. This knowledge deserves the same recognition by both the mainstream and all the other (major) minorities that have been gaining attention and visibility in artistic fields, and especially in academia. While some groups are getting more and more space, fighting for their well-earned rights and being recognized in face of an enormous amount of historical, political and social injustice, disability is still being pushed under the carpet by many people, including some (major) minorities or the people who defend them. In other words, in Brazil, disability has still not performed its social role with respect to equal rights as the other minorities in the academic arts have done (with a few notable exceptions).

Although there have been throughout the years several events, debates and research on disability in Brazil, we have just recently started to include accessibility and the theme of disability at national events and in large associations. For instance, since 2018, the Brazilian National Association of Research and Graduate Studies in Performing Arts (ABRACE) conferences and meetings have highlighted the themes of plurality, diversity and human rights. At the same time, there was no forum or working group dedicated to disability; and among hundreds of book openings, none were about disability.

In 2022, ABRACE had sign language added to its panels and presentations for the first time, thanks to the efforts of activists such as Carlos

Alberto Ferreira. In the 2023 ABRACE's National Conference, a round table discussion which included me, Carlos Alberto Ferreira, Gislana Monte do Vale, João Paulo Lima and Marlíni Dorneles de Lima actually proposed a Forum on Cultural Accessibility. This proposal was widely approved, and it will be part of all meetings and events of the association from now on.

Since 2020, Ferreira has also been the organizer of an annual national event on disability entitled Performing Arts and Cultural Accessibility: Practices and Unlearnings [*Encontro de Artes Cênicas e Acessibilidade Cultural: Práticas e Desaprendizagens*]. In 2022, the event had a hybrid format and hosted 1,963 participants (of which 1,200 were present). At the event, artists with disabilities – including black women with disabilities – from all over the country were present teaching workshops and giving lectures, participating in panels and performing live or on video.⁴ In 2023, the event had 4,315 participants who gathered live at Rio Branco (Acre, North of Brazil); this event included workshops, lectures, round table discussions and performances with representatives from all over the country.

Since 2021, the Brazilian National Association of Dance Researchers (ANDA) has had discussions on disability and providing accessibility to all of their events under the management of Lucas Valentim and Yara Passos for the 2021–2023 period. In 2022, ANDA has created a committee on accessibility composed of three members, two of which are artists/researchers with disabilities: Natália Rocha, Moira Braga and Ednilson Sacramento. Also, ANDA does not have any special forums or working groups on disability.

Carlos Eduardo Oliveira do Carmo (2020) – a wheelchair choreographer and dancer with international acclaim and a professor at the UFBA's School of Dance – is an important Brazilian artist and researcher who has developed several projects on disability. For instance, in 2010, Carlos Eduardo Oliveira do Carmo, Fátima Daltro and Eleonora Motta organized the *1st Meeting of Inclusive Dance. What Is This? (1o Encontro de Dança Inclusiva. O que é Isso?)* in Salvador BA, a remarkable initiative in the country. One of his recent projects included the November 2022 online seminar series *Crip Talk (Conversa Aleijada)*, with all production teams comprised of people

4 Some of these national artists/researchers with disability included: Ariadne Antico, Carolina Teixeira, Cristina Gonçalves, Estela Laponi, Gislana Vale, Ida Mara Freire, Jéssica Teixeira, Mona Rikumbi, Renata Mara, Renata Rezende, and Sílvia Wolff. Local artists with disability who comprised the events' teachers, performers and technical team include 23 professionals. Their names and detailed information can be seen on the following link: <https://docs.google.com/document/d/1huqgkcQL9NPMCmxJfO06liRBfMZG75zjVXnTSARc3my4/edit>

with disabilities. In each one of the talks, he interviewed one outstanding artist with disability, most of whom are also part of other minority groups, providing a broad view of disability from an intersectional perspective.

In spite of the growing number of studies, publications and research groups on disability dispersed through different institutions and companies in the country, disability is still often excluded from a wider debate on (supposed) diversity, social justice and equal rights. Disability is still pushed aside from these general discussions and contexts; as a result, it is only dealt with in separate and specialized groups. The overemphasis on separate categories on the one hand empowers one specific group (be it based on race, gender or disability); but, on the other hand, it excludes minorities which *a priori* could also belong there (such as people who belong to two or more categories). And when most separate categories join together for the sake of discussing diversity, social justice and equal rights, it is neither coherent nor fair; actually, it is completely wrong to exclude the disabled (again) from these discussions.

Contemporary interartistic forms such as performance and dance theater provide fertile ground for the interplay of this artificial and unfair separation of categories which overlap one another in daily human life. It also calls for disability to be acknowledged as a central issue in today's world. The following section presents and discusses one example that shows how such embodied art forms can contribute to this social challenge.

Performing disability, accessibility and intersectionality

The dance theater group which I created and have directed since 1997, the Coletivo A-FETO (which in Portuguese stands for both “affection” and “fetus”), has been performing at the groundbreaking Mostra de Performance da Galeria Cañizares (Performance Show of Cañizares Gallery, curators Prof. Dr. Ricardo Biriba and Wagner Lacerda) at the School of Fine Arts, Federal University of Bahia, since this event first started ten years ago. This is a major event in the city, and it has also gained visibility across the whole country, especially during the COVID-19 pandemic, when it was all online and included participants from different regions and abroad. Since 2018, the event has focused on the theme of black heritage and culture, especially as concerns racism, violence and black art. In 2020, the event opened up

to include issues concerning indigenous cultures. It was held online on November 30th, December 1st and 2nd, 2020.⁵

That year in particular, I decided to propose a provocative performance which would push the theme of social justice a bit further. Bothered by the idea of another year without one of my main concerns being in focus, I decided to propose a performance about disability – but without telling the organizers (not even revealing it during the first planning meeting). I immediately remembered the film *Home Alone*, when a child is forgotten by his parents, who go on a trip for Christmas with all their other kids. In spite of this fact, the forgotten child ends up having a lot of fun, meeting different people and having quite interesting and unexpected experiences. Probably the A-FETO proposal itself was already a performance, as we were stating from the outset that our main thematic choice had been excluded from both this event's title and the great majority of academic events in the arts (or in any field, as a matter of fact).

As in the series of films with this name, I decided to add some numbers after it to indicate the continuation of a long process of disability exclusion in the arts in academia. Nonetheless, I preferred to include “no number” after it. While the title *Esqueceram de mim s/n* [*Home Alone No Number*] was meant to be a joke, it was far from funny: “No Number” was a reference to something which is neither cataloged nor counted. Indeed, it is underestimated, such as the infinite number of people with disabilities who are marginalized and not considered part of a functional, productive society.

It is unacceptable that in the arts – a field with a special and crucial role in transforming society, its individuals and their ways of perceiving and relating to the world—we keep repeating the social stigmas imposed on us by all other areas of society. On the contrary, the arts should precisely question and destabilize these stigmas through their powerfully creative means.

I sent the invitation to the process to several people who had worked with the A-FETO over the past decade, many of whom are actually living outside Bahia but could join in because the event was online. In the invitation, I made myself clear that the performance would be about disability, in counterpoint to the event's title. The group ended up with 19 people (plus seven others who joined the group but did not participate effectively in the creative process), all with different backgrounds, experiences and

5 Link to the recorded evening of the online event: https://www.youtube.com/watch?v=Eb3TP_cyXoE. Accessed Jan. 11th, 2021.

interests regarding disability. There were six artists with disabilities in the main group, including my son, who has performed several times with the A-FETO Collective.⁶

We had six two-hour online meetings which were totally dedicated to artistic explorations, with a few minutes for exchanging experiences, suggestions and ideas at the end. Discussions and impressions were mostly done by the *Whatsapp* group, which shared creative processes, readings and critical perspectives. Some of these were directly included in the performance itself, such as discussions or opinions on disability or a song performed by Carla Vendramin for her sister, who has a learning disability.

The whole process became interwoven with inter-artistic exchanges and critical discussions on disability and accessibility. Our aim was to explore various sensory and somatic possibilities that could expand any daily limitations and destabilize common hegemonic patterns of movement, communication and learning as well as validate all forms of perceiving, relating and interacting with/in the world.

Messages at the *Whatsapp* group were recorded to make the exchanges available to Thales Lopes, an artist with visual impairment. Líria Morais, a choreographer and dancer with hearing impairment, used a microphone, sound boxes and audition equipment, as part of her performance to demonstrate the difficulties of listening and dealing with different virtual apparatus. Morgana Gomes' poems on silence as well as key-words in her whispered readings (such as exclusion, segregation, inclusion, difference, silencing, efficiency deficit, colonization, symbolic violence, miscegenation, minority, major minorities, Brazil) were translated by Kassiano Rosa to Brazilian Sign Language (LIBRAS) and taught to the group, although only Priscylla Lins and I dared to perform a few of them during our own performances. Victor Gargiulo and I alternated doing a few audio descriptions whenever possible; although we had never been trained to do this, we took the risk, and I actually used Laban/Bartenieff Movement System to do so. Lucio and his perfect timing happened to have a tremendous crisis during the performance, yet I turned on the microphone anyway in spite of his

6 The artists/researchers who created this performance in a totally collaborative process across Brazil are: Alba Vieira, Carla Vendramin, Ciane Fernandes, Carlos Eduardo Oliveira do Carmo / Edu O., Eduardo Rosa, Felipe Florentino, Giorrdani Gorki, Iane Garcia, Kassiano Rosa, Lenine Guevara, Líria Morais, Lucio Di Franco, Morgana Barbosa Gomes, Patrícia Ragazzon, Priscylla Lins, Ricardo Fagundes, Vera Solange Pires Gomes de Souza, Thales Lopes, and Victor Gargiulo.

caregiver trying to hide him and make him quiet so as “not to interfere in the presentation.”

Throughout the online performance, which lasted about thirty-five minutes, we kept changing our names so that even we did not know who was who, or who was doing what. This came up during our first meeting, and we used it not only as a reference to disability’s invisibility but also to call attention to specific issues by naming ourselves as words like invisible, marginal, absent, erased, forgotten and unnamed.

These words were always accompanied by the word “body” to indicate that whatever or however or whoever we are, we are always an embodied entity. This has been one of the dance research projects conducted by Giorrdani Gorki over the past four years; it has gradually spread out to many of us at the A-FETO Collective in diverse activities, from classes to events, and, this time, performance. So, for example, I would start out as *body-ciane*, and gradually turn into *body-forgotten*, *body-glass-shard* (inspired by the windows broken during my son’s crisis at home), *body-deforestation*, *body-land*, *body-with-no-land*, *no name* and *oceanic*; then, towards the end, we would all turn into *a-feto*. This ending also came up during one of our meetings, when we silently started to come together as an act of affective solidarity and support.

We also wanted to address the fact that many of us are not disabled, so we did not want to show anyone up; rather, we preferred to give space and visibility to artists with disabilities through showing their images and videos. The few times those without any disability showed their faces, they were covered, which was also a reference to masks in the Covid-19 situation. I actually only showed my face covered by my hair while slowly and methodically combing it forwards, totally covering my face. This action was inspired by my son, who for years now has combed his hair like that in spite of my attempts to teach him how to comb it sideways. Of course, his hair is much shorter and does not cover his face as mine did during the performance, but this makes people laugh at him, anyway. So, before we leave home, I usually try to comb his hair with him in a duet that moves it a bit around so it looks somewhere in between his way and the way neurotypical people comb their hair.

This mid-way conviviality was a crucial strategy at our technical rehearsal, four hours before the performance started. As soon as we started entered the virtual room, we noticed that the organizers were going to stay as well. Perhaps not by chance, we needed to rehearse the exact scene

where Victor Gargiulo read the human rights laws, including the people with disability section. This was gradually overlapped by Carla Vendramin's comments made during our group discussions, where she openly argued and questioned different aspects of a performance dealing with disability. We had about five minutes to rehearse before being this scene gently interrupted by the organizers, who were concerned about the event's title. We ended up arguing for nearly two hours, which seemed like a performance in itself.

During this general rehearsal, the whole A-FETO group was quite calm and supportive while practicing somatic listening. Yet we were also very straightforward and made many justifiable statements, such as a critique of the event's emphasis on the same topic for three years in a row (by Lenine Guevara), although this year the theme had been expanded to include indigenous peoples. As much as the chosen topic for the event is an absolute must, especially in Brazil and, even more so, in Bahia, where the largest number of black people live in Brazil, there are other topics which can be addressed without diminishing – rather empowering – the one chosen for the event. This was my argument when intersectionality was mentioned (Crenshaw, 1989); how these different minorities overlap one another (no wonder we talk about “major minorities”), although the singular rights of each group's needs against discrimination should be specified.

Of course, we could only dare to put on this performance in a context that was open and affective to us as this one, and we did feel we had been invited and well received. At the same time, we did have to make our point. After all, that is what performance is all about, and the organizers were quite receptive to our arguments. Besides, some of the performers were indeed dealing with the title's topic in quite a direct manner, and two of them – Alba Vieira (who has been developing dance research with indigenous tribes in Brazil for many years) and Solange Pires (a theater educator who is of direct indigenous descent and has been diagnosed with a psychiatric disorder) – were quite serene and powerful during their statements as to how our performance not only focuses on disability and addresses the title's topic, but expands it to other realms. It deals with social oppression and injustice at a cellular level. To our great surprise, the evening performance pleased both organizers and public alike.

Lived embodied experience and mutual respect and care have always been our artistic focus on any topic prior to any given situation, context

or request. This has been our supportive foundation during more than twenty years of A-FETO, creating an intermodal world of textures where life and art, personal and communal, embodiment and research, meet. Such diverse and merging means have unfolded unimaginable connecting venues that are often hampered by imposed limiting and fragmenting views and attitudes which people have taken for granted as the given and ideal order of the world. Against all odds, my son and I are not “home alone” not anymore. Merry Christmas. Disability is a creative gift for those who are ready to learn from and with it.

Author biography

Ciane Fernandes is a performer and researcher as well as a professor at the School of Theater at *Universidade Federal da Bahia – UFBA* [Federal University of Bahia], Salvador, Brazil. She is a founding member of UFBA’s Graduate Program of Performing Arts and the recently created Dance Doctoral Program at UFBA’s School of Dance, the first one of its kind in the country. She holds an M.A. and a Ph.D. in Art and Humanities for Performing Artists from New York University, a post-doctoral degree in Contemporary Culture and Communications from UFBA and a Certificate of Movement Analysis from the Laban/Bartenieff Institute of Movement Studies, where she is also an associate researcher. She is the founder and director of the *Coletivo A-FETO de Dança-Teatro* [AFFECTUS Dance Theater Collective] at UFBA since 1998. She is the author of *Pina Bausch and the Wuppertal Dance Theater: The Aesthetics of Repetition and Transformation* and *The Moving Researcher: Laban/Bartenieff Movement Analysis in Performing Arts Education and Creative Arts Therapy* in addition to being an editor of several academic journals on dance theater and Somatics. Since 2009, she has been conducting research on somatic practices in expanded fields, especially as applied to Post-Traumatic Stress and Autism Spectrum Disorders. These are topics included in her latest book (*Dança Cristal/ Crystal Dance*, 2018), which presents the principles of the Practice as Research approach she has developed over the last 18 years, otherwise called Somatic-Performative Research. She has also lectured, performed and published internationally.

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CHAPTER 8

The Potential of Visual Arts in the Reinforcement of Citizenship for Individuals with Intellectual Disabilities in Norway

Daniela Musli Health and Care services sector, Norway

Abstract: This chapter advocates the use of visual arts as an everyday tool to enhance citizenship in individuals with intellectual disabilities and guided by ethical principles from Norwegian social educators, the Convention on the Rights of Persons with Disabilities (CRPD) and the human rights model. The methodology involves analysing pertinent policy documents, research findings and real-life case studies.

The results suggest that incorporating visual art into healthcare and support services for people with intellectual disabilities could reshape societal perceptions and attitudes toward those who are seen as different. Contemporary art, with its wide array of techniques, approaches, and interpretations, has evolved into a culture blending genres, becoming in turn an integral part of everyday life. Sharing narratives that challenge prevalent stereotypes is frequently associated with social and political efforts to counteract societal oppression.

When artists with disabilities share visual narratives about various facets of their lives, their personal experiences become a part of the group's socio-cultural environment. Their contributions have the potential to create and co-create their own artistic expressions, which then can disrupt dominant notions and stereotypical representation. Nevertheless, producing art without relying on traditional techniques or established art forms can pose difficulties related to an artist's technical skills, communication and artistic growth. These challenges underscore the need for additional research.

Keywords: visual art, intellectual disability, ableism, cultural citizenship, health-care services

Art belongs to everybody and nobody. Art belongs to all time and no time. Art belongs to those who create it and those who savour it. Art no more belongs to the Persons and the Party than it once belonged to the aristocracy and the patron. Art is the whisper of history, heard above the noise of time. Art does not exist for art's sake: it exists for person's sake.

Julian Barnes, *The Noise of Time* (2016)

Introduction

Culture has interested me for as long as I can remember; I have always wanted to seek to understand why it arises, who defines it and how it affects people's lives. Culture may be defined as the spiritual, material, intellectual and emotional characteristics defining a society or social group. Beyond arts and literature, this set of complex characteristics encompasses various aspects of lifestyles, cohabitation patterns, value systems, traditions and beliefs (Institute for Statistics of the United Nations Educational, Scientific & Cultural Organization (UIS), 2009, p. 9). Culture also intersects and amalgamates diverse human attributes such as ethnicity, gender, age and social class, along with legal systems, values, traditions, ideas, acquired behaviours and ideologies. Individuals learn about culture through social interaction in both an explicit and implicit manner. Values, practices and behavior imposed by culture are seen as normative in society (Beaman, 2016, p. 852).

As a young adult, I settled down in southwest Norway. Later, after having become first an expat and then a social educator, I learned that there are numerous differences between Eastern and Western European culture; nevertheless, a common denominator between them was art. Indeed, art helped me build a new social network while studying Norwegian language and culture. Years later, after graduating with a degree in social education, my interest in culture and engagement in the lives and living conditions of developmentally disabled people led me towards pursuing a master's degree in citizenship at VID Specialized University in Stavanger, Norway.

Presently, I continue to actively engage in visual art while serving as a manager in private health care services for individuals with complex needs. Nonetheless, I have often noticed how I am met with scepticism when mentioning the lack of opportunities for persons with intellectual disabilities to engage in the arts, particularly when it comes to making visual art. Many professionals and researchers seem to disbelieve these people's capabilities,

often pointing to their cognitive impairment or, in some cases, completely ignoring the topic. The research question in this chapter therefore asks about the potential of visual arts in the reinforcement of citizenship for individuals with intellectual disabilities in Norway.

The structure of this chapter can be outlined as follows: the *Background* section delves into my professional and academic motivations for undertaking this research paper. In *Methodical, Ethical and Theoretical Frameworks*, I outline the guiding principles that shape my research approach. Additionally, I introduce the concept of citizenship within this context. The *Discussion* section begins by exploring the concept of ableism and the factors contributing to the negative identity that intellectually disabled individuals often face in their cultural environment. It then examines the nature of art and its potential relevance to the article's subject. Finally, in *Conclusion*, I summarize my arguments and highlight the necessity for further research to be conducted in this area.

Background

Over time, persons with intellectual disabilities have frequently experienced isolation from society; as a result, they have been confined to segregated and, at times, institutionalized settings. They were either placed in institutions away from public view or left to perish due to neglect (Nussbaum, 2007, p. 15). This group is still regarded as *the others*, often segregated, discriminated, excluded and marginalized (Lid, 2017, p. 20).

Developmental disability includes persons with impairments of both an intellectual and adaptive nature (Kolstad, 2011, p. 36); quite often, they have additional diagnoses and disabilities. A functional disability may be defined as the loss of, damage to- or deviation in a body part or in one of the body's psychological, physiological or biological functions (NOU 2001: 22, p. 17). When facing various barriers, the individual is prevented from fully participating in society on equal terms with the rest of the population (CRPD; United Nations, 2006, Article 1). An intellectual disability is often an invisible – yet significant form of disability. There are also large individual differences in the degree of cognitive impairment within the group of disabled persons. Their level of functioning is dependent on the resources provided by their surrounding environment. Factors that affect disability include support and relationships, attitudes, services, products, technology, systems and policies.

The prevalent form of democracy, including that found in Norway, is representative democracy. And while there are several characteristics that must be present in a democracy, at the core lies active participation. Therefore, it is important that all citizens are allowed to exercise their right to speak out about things they believe should be changed in society. They may do so by voting, participating in demonstrations, expressing themselves verbally or performing. For instance, Section 92 of the Norwegian Constitution states that all authorities must uphold and safeguard human rights as established in international conventions ratified by Norway. This obligation applies to both municipal and state authorities (Constitution, 1814, § 92). Human rights can never be denied based on a person's level of functioning. In 2013, to counteract discrimination due to disability and ensure equal respect for individuals' civil, political, economic, social and cultural rights, the Norwegian Parliament ratified the Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006). In Norway, people living with disabilities are nevertheless more exposed to violations of human rights than those living in other countries (The County Governor for Oslo & Viken, 2022). The municipalities play a vital role in fulfilling Norway's overall obligations under the CRPD.

Health care services for the intellectually disabled are anticipated to empower users and their families by enhancing their control over factors that influence their quality of life (The Norwegian Directorate of Health, 2021). The phrase "quality of life" can be understood to be both objective and subjective. The objective quality of life is about how good an individual's living situation is with respect to their health, material living conditions and/or work situation. The subjective quality of life is about how life is experienced, including both positive emotions (such as peace and joy) and positive assessments (such as life satisfaction) (Nes, 2019). An overall sense of life satisfaction, or happiness, is conceived in the mind; happiness lies in the activities that satisfy our aspirations (Kraut, 2012, p. 312). This perspective links happiness with doing something that gives our minds the possibility to follow our aspirations.

The right to art

Individuals with intellectual disabilities encounter social prejudice-based discrimination daily; this is because discrimination exists because of people's network of beliefs, processes or social practices. A number of these

discrimination mechanisms are highlighted in this chapter under the subtitle *Ableism*. However, CRPD's Article 19 recognizes the equal right of all persons living with disabilities to live in a community and have choices that are equal to everyone else's choices. Article 21 ensures that individuals with disabilities can exercise their right to freedom of expression. Article 24 establishes their right to develop their personality, talents, and creativity. Article 29 guarantees their participation in political and public life on an equal basis with able-bodied people. Article 30 mentions the right of persons with disabilities to take part on an equal basis with others in the arts so that they can develop and utilize their creative, artistic and intellectual potential – not only for their own benefit but also *for the enrichment of society* (United Nations, 2006).

Yet in spite of the passage of the above Articles, I overheard my social educator peers saying: "Artists with intellectual disabilities? Well, art must be good therapy for them!" Such statements reveal a medically based comprehension of disabled individuals, which is unusual among social educators. A pathological mindset aims at finding ways of preventing, curing or caring for disabled persons by focusing on individual defects in their intellectual and bodily functions; but these approaches deny acknowledging the defects in the surrounding environment (Deborah, 1997, pp. 86–87). At the same time, the possibility that artists with intellectual disabilities may contribute with unique perspectives to the art field is excluded. On the contrary, art history provides us with many examples of great artists who diverged from the *norm*. For instance, the Dutch painter Vincent van Gogh likely suffered from a bipolar disorder in combination with several comorbid disorders (Nolen et al., 2020, p. 7). Despite all these problems, he was a great and influential painter. Michelangelo met the criteria for being on the autism spectrum (Arshad & Fitzgerald, 2004). Norwegian artist Edvard Munch suffered from anxiety, depression and hallucinations.

Around the world, disability advocacy has advanced toward promoting an individual's self-awareness, self-reliance, and self-expression (Tilley et al., 2020, p. 1163; Wexler & Derby, 2015, p. 94). Having a disability should no longer be about impaired functioning but rather about the natural diversity that exists among humans and their universal rights. The way we are able to encounter and accept others determines our society's level (Ripamonti, 2016, p. 68). Unfortunately, Norway still has a way to go, even though the concept of citizenship is in theory a leading idea in the country.

A paradigm

Two examples of intellectually disabled people who have gotten an opportunity to succeed in Norway are Herleik Kristiansen (1947–2023) and Torstein Nilsen (1951–1959). Herleik Kristiansen was born in Nesna, a small village located on the western Norwegian coast of Helgeland. He was categorized as *not suitable for training* in the early 1960s (Rossner, 2009, p. 33). As a teenager, Kristiansen moved to Trastad Gård, an institution for the mentally disabled that was opened in 1954 as northern Norway's first centralised institution for persons with developmental disabilities (Southern Troms Museum (STMU), n.d.). In 1991, after the passing of the healthcare reform for the mentally disabled (HVPU), the responsibility for intellectually disabled individuals was transferred from the counties to the municipalities (Söderström & Tøssebro, 2011, p. 5). Institutions were closed, and municipal services for care and education were created. From Kristiansen's presentation on the Norwegian Graphic Artists (*Norske Grafikere*, n.d.) website, we learn that it was a teacher who first saw his creative talent and then facilitated his further artistic development. This was the start of a solid artistic career for Norway's best-known *outsider artist*. Outsider Art is person-centred form of visual art that is mainly created by self-taught artists who work outside the established visual arts systems. It constitutes a paradigm for artistic expression within the peripheral boundaries of established art institutions and the artist's detachment from the conventional art environment. The artworks emerge from personal experiences; they often materialize in an improvised way, rooted in the idiosyncratic presuppositions of the creator (Rossner, 2009, pp. 31–32).

Today, Herleik Kristiansen is regarded as an established visual artist who worked especially with graphics and ceramics for over 40 years. His artworks have been bought by a number of institutions and municipalities, including the Culture Council, the National Gallery, the Art Museum of Northern Norway, Nordland County Municipality, Troms County Municipality, the Art Foundation of Northern Norway and the Nordenfjeldske Art Industry Museum (Norwegian Graphic Artists, n.d.).

Torstein Nilsen shares the same Trastad Gård background with Kristiansen (STMU, n.d.). His artwork has been acquired by the Museum of Decorative Arts and Design in Oslo, and he was responsible for decorating the Bjarkøy swimming pool (Johansen, 2019). Both Kristiansen and Nilsen are members of Northern Norway's Visual Artists Association



Figure 1. Caption: Herleik Kristiansen. *Black-headed Gull (Hetemåker)* (n.d.)

[Nord-Norske Bildende Kunstnere] and have held several large exhibitions and decoration commissions (STMU, n.d.) throughout the region.

Methodical, ethical and theoretical frames

The methodical arguments for this article are based on literary studies, my own work experience and policy documents; further, human rights are a fundamental element of all of these arguments. For example, I provide artwork by Arnstein Aano, a disabled artist who has given me permission to publish his work. The English translation of the details he provided through his affiliate social educator is my own. In addition, the research material includes another artwork (licensed copy) from a famous Norwegian disabled artist, Herleik Kristiansen.

The ethical guideline for Norwegian social educators is based on human rights, CRPD and democratic values; it calls for solidarity with vulnerable groups in the work for social justice and social change (Norwegian Union of Social Educators and Social Workers [FO], n.d.). Healthcare services are pivotal for intellectually disabled people's participation in society as equal citizens. The design and provision of these services should therefore be continually updated according to national and international ethical guidelines and political aims. These normative guidelines prioritize equal status and participation for all individuals. Accordingly, visual art could be an important addition to healthcare services for a practice in compliance with CRPD.

This chapter promotes visual art's potential as an element of a human rights model of practice in healthcare services for intellectually disabled persons. The UN's CRPD committee has recommended that Norway adopt the human rights model in all regulations regarding the assessment of functional impairments (Meld. St. 8 (2022–2023), 3.3 (Norwegian policy paper)). The model is described by Theresia Degener (2014) as based on the CRPD; the model values disability as part of human diversity and adheres to theories of justice, which is similar to the capability approach (Degener, 2014, p. 17). Human rights are unconditional. They do not require an absence of impairment; thus, disability cannot restrict or prevent the capacity for human rights (Degener, 2014, pp. 6–7). In all aspects of life, human rights are universal. In terms of citizenship, equality must be sought along the entire range of human rights: civil, political, economic, social and cultural (Degener, 2014, p. 8). The human rights model encompasses the individual's embodied experiences with disabilities as a struggle not only for the global collective of disabled persons but also a fight for people's respect and recognition of the disabled individual in society (Degener, 2014, p. 17). Impairment-related identity policy must not only address impairment but also gender, race, sexual identity, age and religion as all may contribute to an individual's multi-dimensional experience of oppression (Degener, 2014, pp. 17–19). Prevention is an important part of the human rights model; equal access to general and specialized healthcare services for intellectually disabled persons must include prevention and treatment of underlying health conditions in a frame of dignity and barrier disabling (Degener, 2014, p. 25). Overall, the model draws a roadmap for change by demanding strategies and goals that are empowering through active and equal participation (Degener, 2014, p. 28).

At the core of this research lies the theoretical frame of cultural citizenship, which is understood as being, performing, belonging, and becoming a citizen.

Ableism

Cultural generalizations emerge from systematic cross-cultural studies and pertain to prevailing trends within specific populations, avoiding as such the labelling of individuals. An individual may align with predominant group tendencies to varying degrees. Conversely, stereotypes are not about description but rather judgment. Instead of broad and adaptable generalizations, stereotypes are rigid and constraining; they are by definition incapable of fostering further understanding or encouraging the expansion of knowledge. Stereotypical cultural norms can systematically erode the characteristics of certain groups, which changes the premises for their cultural participation. Visual culture reflects who we are; performing visual art helps shape our thinking about ourselves and the world (Freedman 2003, p. 91). Cultural norms are often significant for the way in which society defines its cultural assumptions.

Ableism is basically built on the misconception that *the others*, for example persons with intellectual disabilities, are *less capable*. This is why ableist portrayals, interpretations and patterns of actions can create burdens and obstacles for specific groups by treating them unequally. The term *ableism* refers to the mechanisms of prejudice-based discrimination, which are key factors when pleading for an increase in disability awareness (Wexler & Derby, 2015, p. 96). Ableism works in the same way as racism or sexism; they often appear together, as persons with developmental disabilities can also belong to other minorities; *they* can be immigrants, Black, women, queer, disabled. These systems of inequality “intersect” to create and mutually reinforce dynamics and effects known as intersectionality (Center for Intersectional Justice, n.d). Identity, discrimination or highlighting differences often lead to stigma, which has three functions: exploitation, social norm enforcement and disease avoidance; persons who are the target of stereotyping, prejudice or discrimination expect stigmatization by others, which leads to negative physical and psychological health outcomes (Bogart & Dunn, 2019, p. 645). Furthermore, discrimination may include one or several processes that increase the odds for exploitation. It is all about normative and political processes that make individuals and groups lose influence and become “not-belonging” (Turner, 2016, p. 146).

At the same time, the cultural norms are constantly changing in time with societal developments. Visual art has played a significant role in all cultures throughout history. Tobin Anthony Siebers (2010) writes that all human-made objects are “in some way a making and remaking of the

human, as well as that [...] if aesthetics and the human are inseparable, it is because art is the process by which human beings attempt to modify themselves” (p. 136).

Citizenship: Knowledge, ideal and practice

Ideas and attitudes in society are continuously developing as new perspectives arise. The idea of citizenship can be seen as a series of theoretical frameworks that mark the differences in society. Additionally, it can provide a solution to ableism: by calling out exclusions, citizenship can also contain strategies for creating a more inclusive society.

Citizenship is a wide and ever-changing concept that is influenced by the society evolving around it. Its definition may have been given by Thomas H. Marshall, who first referred to it as a status given to full members of a community (Marshall, 1950, p. 149). Marshall’s focus on formal membership is defined as the access to rights within the boundaries of civic engagement and nationality. From here, the concept of citizenship has expanded to include Martha C. Nussbaum’s (2007) perspective on social justice. As expressed in her theory “the capability approach”, Nussbaum points out the importance of having culture, recognition and respect to counteract inequality; in other words, they provide an answer for people who are disabled and therefore powerless. Further, Sandrine Berges (2007) outlines a real-life example about how these same factors can influence lives. While both an English and a Turkish middleclass girl have the right to a free education, having this right might be irrelevant for the Turkish girl. This is because in a cultural context where the community is hesitant to permit girls to attend school independently, it is likely that her access to free education will be restricted and therefore of no use at all. In addition, she might have no knowledge of her rights, feel it is her duty to stay at home and help her family as she is not allowed to take the bus alone to school (Berges, 2007, pp. 18–19). So, while the Turkish girl has the potential to learn, cultural norms within her community may hinder her actual learning experience. Similarly, all citizens have equal rights to free education in Norway. Nevertheless, having this right is often irrelevant for intellectually disabled people, as they do not have real access to higher education or schooling beyond upper secondary school. (Meld. St. 18 (2010–2011), p. 67). There are many disability barriers in the education system, related to physical, legal and organizational conditions as well as those related to attitudes, culture, communication and social norms.

Thomas P. Boje (2017, p. 168) describes citizenship in terms of four dimensions: rights, duties, participation and integrity. Civil society's primary justification is to ensure citizens' safety, social and cultural recognition (Boje, 2017, p. 345). Multiculturalism celebrates cultural variety and strives to foster a more inclusive and united society. It is upheld by a nation's legal framework, not only affirming the right to be different but also valuing these differences as significant contributions to societal progress (Boje, 2017, p. 187). Multiculturalism acknowledges and places importance on the presence of various cultures within a society, with the goal of advancing equality, respect and mutual understanding among people from diverse backgrounds. At this point on my rough citizenship timeline, defining citizenship highlights a more profound understanding of society's responsibilities. Consequently, I need to highlight the necessity of a practice model in healthcare services, which empowers persons with intellectual disabilities to be involved in everyday societal activities as active citizens because they have the right to be unique and valued members of society. Towards this end, healthcare workers need to create services based on individual wishes, preferences and needs.

A dialogical collaboration, which has been founded on appreciative work with interpretation, is a feature of a narrative understanding of active citizenship (Fjetland & Gjermestad, 2018, pp. 141). These perspectives lead to a novel approach in understanding intellectual disability. The term *citizenship* cannot be built on laws only, it also needs a set of norms, practices and meanings within society, ergo: culture. The cultural perspective links the performative aspects of citizenship to its definition. Becoming a citizen includes challenging habits and thereby transforming them: a change in focus from what people *say* (opinion, perception, attitudinal surveys) to what people *do* (Isin, 2009, pp. 371–372). Exercising rights may therefore involve claiming, negotiating and performing rights. Performative citizenship can involve citizens, non-citizens and social groups who are engaging in political and social struggles over who may or may not act as a subject (Isin, 2017, p. 501).

The performative aspect of citizenship highlights the continuous endeavour of individuals to establish themselves as citizens by actively co-authoring the cultural context of their lives (Glørstad, 2022, pp. 151–152; van Hensbroek, 2010, p. 1). Thus, an important aspect within a cultural view on citizenship is the challenge to the stigmatization and marginalization of being different (Beaman, 2016, p. 853). A diverse democracy like Norway should be able to integrate all citizens. Democracy is a form of government

based on a system that ensures fundamental human rights (United Nations Association, 2023). Cultural citizenship brings diversity to public attention in an attempt to democratise culture. Cultural rights across race, ethnicity, culture, and dissimilarity for all citizens are pillars in the development of a Norwegian multicultural society. Cultural citizenship must include both citizenship in the cultural sphere and cultural aspects of political citizenship; otherwise, dissimilar citizens are voiceless. An inclusive society must fully recognize the disability culture, as described by the experiences of disabled persons (Swain & French, 2010, p. 580).

The State and society are responsible for strengthening citizenship, regardless of individual status. Citizens' rights, including equality and equal opportunities, are highlighted in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006, Article 19). Nevertheless, to be able to participate in society and cultural life, many persons with intellectual disabilities are dependent on public support (Skarstad, 2019, pp. 74–76). This dependency can potentially lead to this group being perceived as recipients of care rather than as citizens entitled to rights and responsibilities (Lid, 2017, p. 19).

Analysis and discussion

Lifeworld

A turning point in art history emerged in 1917, when a urinal entitled *Fountain* (Marcel Duchamp) was submitted to the Society of Independent Artists exhibition in New York, challenging conventional definitions of art: Could an everyday object be a work of art? (Wohl, 2021, pp. 11–12). The artwork was not admitted to the exhibition, and it created a scandal, as it broke with the period's traditional depictions of art. If a urinal could be considered a work of art when a famous artist selected and placed it in a gallery, then the definition of art could not be solely based on its inherent characteristics; instead, the art institutions themselves could establish the standards for what qualified as art. This situation was not unique in art history. Many artists that wanted to cross cultural boundaries struggled to gain access to meaning-making against the *cultural collective and its conservative cultural spokesmen* (van Hensbroek, 2010, p. 319). Wondering what can be considered art is just as difficult as questioning what is *truly* cultural. Yet, metaphors are often present in artworks, communicating

meaning, protest, inspiration or other human emotions. Minimalist artists in particular continued to dissolve conventions about colour, texture and shape (Wohl, 2021, pp. 12–13). Approximately eighty years after the *Fountain* attempt, modernist Andy Warhol created *Dollar Signs* – which is one of the artist’s most powerful images. The strength of this series lies in the message it communicates: the dollar is a central muse, and big-time art is big-time money (Gagosian, 1997).

In the present time, contemporary artists have creative autonomy; they aim for the distinctive and the interesting in their artworks (Wohl, 2021, p. 14). Contemporary art opens up the mind to idiosyncratic perspectives. Metaphor is a way of generating meaning through its pointing out critical socio-cultural issues. For instance, Chinese artist Ai Weiwei placed the Coca Cola label on a Han Dynasty urn. The artwork illustrates the replacement of old Confucian values by consumerism in contemporary China (Metropolitan Museum of Art, n.d). Together with its use of various media, the increasing unconventionality and newness of contemporary art increasingly belong to the masses. Artists often refer to themselves as witnesses (Nancy, 2010, p. 95). These witnesses express themselves visually by depicting moments of thoughts and emotions.

With its diversity of media and techniques in various approaches, publications and ways of understanding art, contemporary art has become a culture-mixing genre and part of everyday life (Pöllänen, 2011, p. 114). It happens outside of museums as well as in homes and public spaces. In the vast diversity of media and techniques, artists can break with tradition and create new traditions. A contemporary fine art gallery recently stated that: “Art is a universal language that bridges cultures and forms human connections” (Eden Gallery, n.d). There is no reason that individuals with intellectual disabilities cannot use this language, similar to what the artists presented earlier in this article (Herleik Kristiansen and Torstein Nilsen) did. Engagement in art-based practices can increase a person’s awareness and ability to regulate their emotions as well as the willingness to express these emotions (Ho et al., 2020, pp. 6–7).

Disabling the impaired functioning

The various artistic processes that over time link the artist’s life and relationship with the outside world, the creation of the work and the viewer’s reaction to the art, changed the lives of Kristiansen and Nilsen; they were

able to realize their creative ability and become true artists (Federhofer & Høvik, 2019). As shown previously, Trastad artists Herleik Kristiansen and Torstein Nilsen are pioneers in the art movement *Outsider Art* in Norway. The movement comprises art that has been created spontaneously by the artist and not something they have learned as an art form (Rossner, 2009, p. 32).

Nevertheless, Kristiansen and Nilsen benefited from the work of their teacher at Trastad, Sigvår Riksheim, who significantly impacted the growth of practical-aesthetic instruction at Trastad. Her background in art education played a crucial role here, bringing transformation in students' thought processes and practical implementation of them (Linde, 2005, pp. 25–28). Producing art without relying on learned techniques or established art forms might be challenging for many artists with respect to their technical skill level, communication ability and potential for artistic growth, as purely spontaneous art may struggle to engage viewers on a profound level. Without exposure to different art forms and styles, the artist's artistic vocabulary could be limited, which could in turn affect their ability to fully express their artistic vision, complex ideas or emotions through their work. Without any foundation in learned art forms, artists could also find it challenging to progress in their practice and develop their skills over time. That said, there's no one-size-fits-all approach to art; creating art spontaneously without relying on learned art forms can also lead to unique artistic expressions. However, when balanced with an understanding of the foundations of art, the likelihood of artistic development becomes more promising. Being an outsider artist seems therefore to point out a possibility that the artist's work might easily be marginalized or dismissed by established art institutions, galleries and critics.

The term *disability art* presents another avenue for advancing the citizenship of intellectually disabled persons. This artistic movement encompasses creations by disabled individuals who draw inspiration from their disabilities. Artists and media experts are currently reshaping our understanding of disability; they are adopting new aesthetics and strategies to engage audiences, empowering persons with disabilities to confront the stereotypes imposed upon them in the public arena (Hadley & McDonald, 2019, p. 2). Disability art often tells stories that depict disabled individuals as multi-dimensional, resilient and empowered, countering the one-dimensional portrayals often broadcast in mainstream media. The artworks primarily participate in crafting depictions of real-life encounters with disabilities,

often by means of advocacy (Gould, n.d.). The otherness in the art of intellectually disabled persons has the potential to be unconventional and provocative. The concept of disability is frequently linked to efforts in social and political spheres aimed at addressing and alleviating social oppression (Oliver & Barnes, 2010, pp. 548 -549; Swain & French, 2000, p. 469).

Currently, Norway lacks statistics on intellectually disabled artists, potentially indicating underrepresentation and ableism in the field of visual arts for individuals with intellectual disabilities. However, the estimated proportion of persons with developmental disabilities who are employed is between 22–25 percent (Meld. St. 8 (2022–2023), 8.2). I assume that the statistics would be lower in the field of visual art, or, in the best-case scenario, equal. It is not possible to estimate how many intellectually disabled persons are missing out on the opportunity to develop their artistic talent. However, I did meet an artist who had taken the opportunity to become an artist during my professional journey. His name is Arnstein Aano, and he is an artist with disabilities living in a Norwegian residential care facility. Arnstein started to draw many years ago because at the time he felt *an urgent need to express himself* (Anne Brit Sæther, Arnstein's representative, personal communication, February 2023). His drawings illustrate aspects of everyday life.



Figure 2. Arnstein Aano (n.d). No title.

(Anne Brit Sæther, with Arnstein's permission. Personal communication, February 2023)

Together with Anne Brit, Arnstein holds presentations and lectures that combine insights into life on the autism spectrum with his own artistic creations. His largest audience to date has been at an SOR conference, where there were over 700 people in the audience. The SOR foundation focuses on information dissemination, with an emphasis on values development and increasing awareness of practical challenges and growth opportunities for disabled artists (The SOR Foundation, n.d.). Arnstein wishes to emphasize the significance of having one's voice heard and understood; he also wants everyone to have the opportunity to lead an active and meaningful life (Sæther, personal communication, February 2023).



Figure 3. Arnstein Aano (n.d). No title.

(Anne Brit Sæther, with Arnstein's permission. Personal communication, February 2023)

Arnstein composes breezy artworks that are rhythmic on diverse levels as well as rigorous and free at the same time. The lines flow from perceptual depths that contrast with the raw colors. Between well-chosen areas, bravely and honest colors, lights, or even white areas, circle around in the compositions. His art rises from his inner experiences and expresses itself through a visual language. He does this after having had no formal training; his work is based on his own creative ideas. Working in isolation from art communities and networks, Arnstein lacks access to resources that could

enhance his artistic vocabulary, and the lack of opportunity to exhibit his art hinders his ability to reach a broader audience.

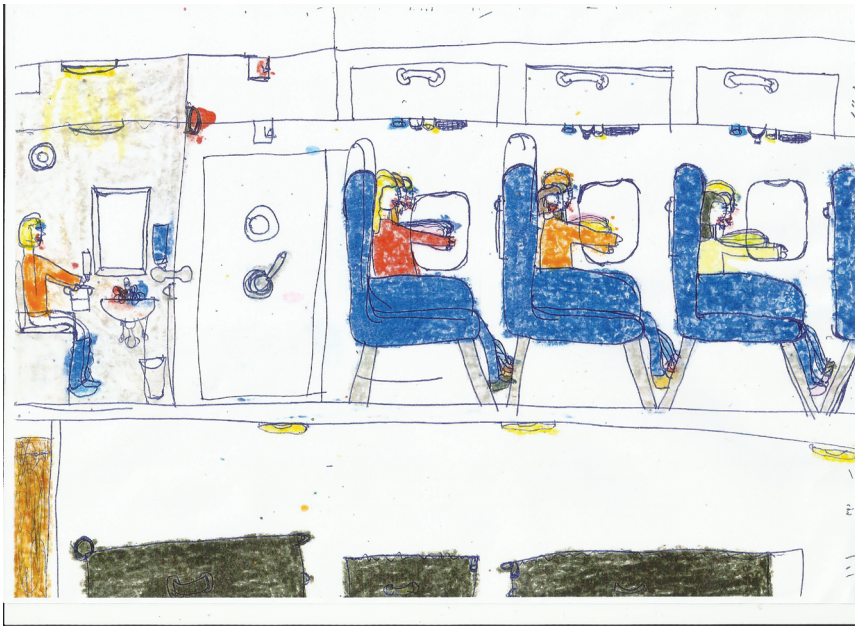


Figure 4. Arnstein Aano (n.d). No title.

(Anne Brit Sæther, with Arnstein's permission. Personal communication, February 2023)

Furthermore, by not receiving the same level of analysis and scholarship as mainstream art forms, the depth of discourse around Arnstein's world is minimal. This restricts his access to training and support systems that other artists within the mainstream art world enjoy as it supports their artistic growth. Despite his artistic potential, Arnstein faces challenges in locating a supportive learning environment to foster his artistic development, which may end up negatively affecting his overall quality of life.

Encouraging skills development in outsider artists may inadvertently push them towards more conventional artistic practices and potentially compromise the unconventional nature that defines outsider art. In addition, if valuing authenticity gains outsider artists increased popularity, their work may be co-opted by the mainstream art market, potentially diluting the authenticity that made their work unique in the first place. Nevertheless, it can also inspire new ways of approaching art that form something entirely new. Examples like the artworks of Kristiansen and Nilsen suggest that the lines between outsider and mainstream art have become more fluid.

Conclusion

In Norway, persons with intellectual disabilities are still struggling for equal opportunities like choice, inclusion, education and work. There is little knowledge about, and low expectations of, the abilities and possibilities of the intellectually disabled in both school and working environments; there is also a lack of knowledge about alternatives, supplementary communication and welfare technology use; employees in Norwegian municipalities have little knowledge of the group's human rights (Meld. St. 8 (2022–2023), 3.3). In the pursuit of overarching goals centred on enhancing life quality and self-sufficiency, healthcare and support services for individuals with intellectual disabilities are expected to empower both users and their families, enabling them to exert greater control over the determinants of their well-being, thus enabling them to lead fulfilling lives according to their own beliefs, ambitions and needs (The Norwegian Directorate of Health, 2021). Persons with intellectual disabilities may seldom have difficulty expressing their own beliefs, attitudes and values. Notwithstanding, learning takes place based on cognitive connections; some of these are related to emotions, and more connections mean greater learning (Freedman, 2003, p. 66).

Persons with disabilities often encounter significant obstacles in Norwegian society; these obstacles hinder their ability to participate fully and on an equal basis with others, which may be due, among other things, to attitudes in society (The Norwegian Directorate for Children, Youth and Family Affairs [Bufdir], 2015). Stereotypes, misconceptions and generalizations still follow them. These negative perceptions have been developed within a cultural context. It is therefore the cultural context that has the potential to fight back against ableism and gain citizenship for these individuals; that is, if intellectually disabled persons do get a real opportunity to access and become part of the culture. By visualizing and actualizing public perceptions of the reality and living conditions of persons with intellectual disabilities, stimulating emotional evaluation, reflection and empathy, art has great potential to educate society. Participation in art-based practices can increase a person's awareness and the ability to regulate their emotions as well as their willingness to express those emotions (Ho et al., 2020, pp. 6–7). Intellectually speaking, disabled individuals can widen normative cultural perceptions of Norwegian society. Their art can modify social beliefs, attitudes and values associated with the phenomenon of being

different or having atypical behaviour or utterances by engaging people and influencing their personal and cultural approaches to the world (Freedman, 2003, p. 66). When disabled persons tell stories about different aspects of their lives, including issues about their skills, emotions and citizenship, revelations from their lives enter into the group's sociocultural milieu. Their contributions challenge the stigma and stereotyping associated with intellectual disabilities. Being able to produce and co-produce their own image, the art of intellectually disabled persons can disrupt a society's dominant notions and stereotypical representations (Wexler & Derby, 2015, p. 44).

The group's rights are anchored in the CRPD. Among other forms of legislation, the CRPD guarantees everyone's freedom of speech and participation in cultural life on an equal basis with everyone else. Addressing some of the misconceptions regarding functioning impairment, in this chapter I provide examples of well-known artists who have also had a cognitive disability. The selection of these examples is deliberate and aimed at challenging the limited definitions that some colleagues and peers may hold regarding artists' identities or characteristics. *The Fountain* (Duchamp, 1917), the *Dollar Sign* (Warhol, 1997), *Han Dynasty Urn with Coca-Cola Logo* (Ai Weiwei, 1995), are artworks chosen to illustrate changes in the meaning of what art is. Art is continually evolving and transforming, and, in a similar vein, the artists themselves do likewise. Art-based activities can be chosen for its value and what it produces (Kraut, 2012, p. 39). Today, visual art is a contemporary language that is part of everyday life's cultural mix. By making visual art, the intellectually disabled can learn to speak out and exercise their right to enjoy freedom of speech. This may contribute to increasing their quality of life by allowing them to engage in meaningful cultural activities. Being able to tell stories in a community on your own terms is part of our western culture. I choose to believe that Norwegian democracy grants its citizens universal rights, disregarding their functioning level, as pointed out by the CRPD. And, as the CRPD and human rights model highlight, human rights are universal, and so is art. Kristiansen and Nilsen's journey from being deemed unsuitable for formal training to achieving recognition as artists underscores the significance of believing that every individual, regardless of their level of functioning, possesses inherent capabilities and growth potential. Engaging in visual art provided these individuals with a platform to accumulate experience, connect with others and delve into their unique and collective identities through unconventional avenues. This engagement potentially contributed to breaking

down social barriers, diminishing or even substituting society's ableism with a more inclusive appreciation of diversity. Their examples show that persons with disabilities need to and can create/ co-create their own aesthetics and community by providing alternative narratives and promoting empathy, seeking to reshape perceptions and create a more inclusive and understanding society. They possess the complete capacity and entitlement to engage in acts of citizenship and co-author the cultural context in which they live. Anticipating Kristiansen and Nilsen's progress in development would, nevertheless, be challenging in the absence of Sigvår Riksheim's influence. Talented individuals like Aano need support to complete their artistic development.

To conclude, when adopting a citizenship framework and considering the CRPD, I suggest revitalizing our approach to the disability field by embracing a human rights-oriented framework for healthcare services that incorporates cultural elements. There are many ways to support the intellectually disabled in the cultural sphere. Public and private support, communities and technology can facilitate art education and experiences, interaction with other artists, exhibitions and other forms of cultural participation. There may be a tension between developing skills and views of authenticity when trying to understand outsider artists.

However, the primary aim of this article has been to explore the potential of visual arts in the reinforcement of citizenship for persons with intellectual disabilities in Norway and thus initiate a discussion about the use of visual arts as a daily instrument for enhancing citizenship among individuals with intellectual disabilities as well as inspire further exploration of its potential.

Author biography

Daniela Musli holds a BA in Social Education and a MA in Citizenship from VID Specialized University. Currently serving as a Department Manager in the Health and Care services sector in Norway, she is deeply passionate about shedding light on pressing issues like citizenship for vulnerable social groups, social justice and equality, culture, and for leadership. Daniela is also a visual artist specializing in painting and book illustration (please visit www.artmajeur.com/daniela). With a strong academic background and professional experience, she is dedicated to enhancing the quality of health and care services, striving to make a positive impact in her community.

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CHAPTER 9

Representation of Disability Identity in Sinhala Theatre

Nimal Wijesiri University of Peradeniya, Sri Lanka

Abstract: This chapter addresses issues related to disability identity representation in Sinhala Theatre in the Sri Lankan context. For this purpose, the study utilizes a qualitative approach to explore intersecting ethnic, racial, gender and disability identities, with a particular focus on disability identity in Sinhala theatre. The overarching theoretical lens of this study is Critical Disability Theory. Producers and performers who have participated in art therapy, speech therapy, theatre workshops and theatre festivals that the Sunera Foundation organizes around Sri Lanka are participants in direct research. Spectators who have watched festival performances are also research participants. In the Western context, disability theatre attempts to interpret and represent disability as a valued human condition. By contrast, in the sense of identity representation in various disciplines, the South Asian approaches show inequity among different social groups. In comparison, the Religious/Charity Model of disability has been dominant in Sri Lankan culture more than in the Western context because of Buddhist religious influence in recent centuries. The results reveal that Sinhala theatre practitioners do not represent disability identity in a broad sense; rather, they tend to generalize everyone as human and therefore do not see, reflect critically upon or represent diversity in theatre.

Keywords: Sinhala theatre, disability theatre, Karma, Sunera Foundation, religious charity model

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Introduction

The study centralises the socially determined concept of *disability*, which denies certain individuals equal social, cultural, educational, employment-related and political participation opportunities based on disability identity. The overarching theoretical approach, Critical Disability Theory, is combined with Identity Theory and Intersectionality to address the question of how disability identity, and the other marginalized identities with which disability identity intersects, is represented in contemporary Sinhala theatre. I conducted a case study and collected data in connection with the *Samanalayaya (Butterfly Plane)* Theatre Festival, which had been organised by the Sunera Foundation in Sri Lanka. Some scholars have explored the historical representation of disability in the Western context (Hentrich, 2007; Kafer, 2003; Moss & Schipper, 2011; Stewart, 2011). All of these scholars identify ancient representations of disability in religious texts, with special reference to the Bible.

In a broad sense, this Biblical representation of disability can be identified as the Moral or Religious Model of Disability. Although this model has historical roots in ancient religious texts, it has not been completely excluded from the contemporary world. There is a slight recognition that the legacy of colonization and Christian religious influence have motivated South Asians to see disability from empathetic perspectives. However, this study reveals that the Buddhist *Karma* concept is the most influential phenomenon with respect to the Religious/Charity Model of Disability in the Sri Lankan context. This religious influence challenges the critical thinking capacity of Sinhala theatre practitioners in different ways. These research findings provide implications for policymakers, playwrights, theatre companies and educational institutions to reflect upon, represent and acknowledge different lived experiences, which in turn will enhance a better understanding of people with disabilities.

My personal experience of the research problem

I utilised my experiences as an academic, novelist and playwright to undertake this study and investigate how disability identity and other intersecting identities are represented in disability theatre in Sri Lanka. My first theatrical drama, *Porakaya – The Raw Death*, was produced in 1999. This play

was based on the murder of a physically impaired girl who was working as a domestic servant. I published my first novel, *Nirasha*, in 2000, which is based on a story about sexual harassment against women based on their social and economic status in Sri Lanka. My second drama, *Kalabheda* (2007), derived its plot from a Buddhist Jataka story called *Dharmadwaja*. This play was about political and social corruption in systems and institutions. My second novel, *Jala* (2006), was based on a culturally marginalised boy's experiences of social discrimination. My third play, *Pembara Bhuthaya* (2017) – *Lovely Ghost* – was an adaptation of Girish Karnad's *Nagamandala* drama, which discussed certain issues related to married women's sex lives in urban society.

In 2005, I completed my bachelor's degree in Sinhalese language and literature at the University of Peradeniya, Sri Lanka. I learned about both Eastern and Western theatre traditions as this topic was one of the main components of my bachelor's study program. Next, I studied modern Indian theatre during my master's degree studies at Delhi University in India. I am currently working as a senior lecturer at the University of Peradeniya in Sri Lanka. All of these academic and creative experiences motivated me to do my doctoral research at the Queensland University of Technology in Australia. I have written this book chapter based on the findings of my doctoral thesis.

Sunera Foundation

There was a performing arts workshop for people with disabilities in Sri Lanka that was initiated as a collaborative work by Sunethra Bandaranayake Trust and AMICI Dance Theatre Company in London. Based on the experience of that workshop, Sunethra Bandaranayake established the Sunera Foundation as a registered charity in Sri Lanka. The foundation's vision is "A society that fully recognizes and accepts the contribution of persons living with a disability."¹ There are 38 workshops conducted weekly around the island; there are on average 25 participants at each workshop. Team members who have extensive training in the performing arts use art and speech therapy as main elements of these workshops. Drama therapy that includes different activities, movements, songs, puppetry and mime is used by trainers as a form of art therapy.

1 Sunera Foundation. (2018). *Search Samanayaya theatre festival*. <https://sunerafoundation.com/>

The Sunera Foundation employs Language and Speech Therapy graduates from the University of Kelaniya to conduct speech therapy at only five workshops.

I, Nimal Wijesiri (2022) pointed out Executive Director of the Sunera Foundation Chandrika Subasinghe's expression on the workshop and its performances as follows:

We at Sunera Foundation firmly believe that persons with disabilities have latent talents which are not recognized by those around them, including their families. This leads to them being ignored and marginalized. As a result, they remain isolated and unable to communicate with others, which is a miserable existence for them. We decided to follow the footsteps of other organizations abroad to use Performing Arts as a therapeutic tool to develop them, strengthen their minds/bodies and instil self-confidence in them. For this purpose, we have created workshops where there are around 30–40 young disabled individuals participating in a variety of activities, including physical exercise, yoga as well as drama and vocal performances. Each workshop is conducted by young, highly skilled trainers who relate well to these children and understand what each child's hidden talents are. These knowledgeable trainers pay attention to each student while working with them. In other words, it is not a herd approach, but rather an individual and focused approach. After a considerable length of time, each student developed their talents and abilities to such a level that we were able to create student-led stage performances consisting of song, dance and theatre showcased periodically to the public. The shows are accompanied by music, colourful costumes and plenty of movement. In this way, the audiences begin to realize how creative and self-confident these young people are, which is often contrary to their previous beliefs and assumptions. This is the best way to integrate them into society where they will be welcomed and accepted. Over the years, Sunera Foundation has created not only stage performances in Sri Lanka but also major productions which have been taken abroad. To date, we have performed in England, Australia, Norway and India. (Wijesiri, 2022, pp. 106–107)

The current study analyses the Sunera Foundation's main event, *Samanalayaya (Butterfly Plain)* Theatre Festival, to explore how disability identity and other similar marginalized identities are represented in contemporary Sinhala theatre. The study explores the foundation's deep and longstanding local and international collaboration with different organizations. It also analyses the foundation's longstanding commitment to developing relationships and skills to achieve goals that strengthen minds/bodies and instil self-confidence in persons with disabilities.

It is a matter of identification between *self* and *other*

The first use of identity-related concepts by scholars appears with Erik Erikson's (1993) phrase stating that an "individual's ego" aligns with their self-concept. Nelson Foote (1951) described the role position of a person by using the term *identity* in his writings. According to Greg Stone (1962), "a person's identity is established when others place him [*sic*] as a social object by assigning him [*sic*] the same words of identity that he appropriates for himself [*sic*]" (Stone, 1962, p. 143). After initiating identity theory through the writings of George Herbert Mead (1934), the theory was further developed through the contribution of William James and colleagues (2007), Sheldon Stryker (1987) and Charles Horton Cooley (2017). Each person may have several identities because people have multiple selves. Cooley studied the significance of the correlation between oneself and others:

The concept of 'identity' has been interpreted in different perspectives in both Western and Asian discourse for centuries. However, in Western phenomenology, the idea was taken from nineteenth-century discourse. From the phenomenological position, Diana Dimitrova explains that "the 'other' has always been intertwined and linked to the 'self' as a subordinate relation. It describes the 'other' according to what subjectivity knows of it" (Dimitrova, 2014, p. 1). The 'self' has a dominant role in various aspects such as defining, constructing, domesticating, and marginalising toward the 'other'. Jack Reynolds identified this characteristic of the 'self': "the other is always partially domesticated by self's horizons of significance" (Reynolds, 2001, p. 31). (Wijesiri, 2020, p. 2)

Multiple identities are interconnected

Kimberle Crenshaw (1989) introduced the term *intersectionality*, which refers to the complexity of identity. She elaborated that different identities, including disability, gender, sexual orientation, ethnicity, race, class and other forms of identities, are interconnected. In the development of the concept of intersectionality, Crenshaw (1991) illustrated social movements related to discrimination and violence against socially marginalized women of colour and immigrants. However, Nivedita Menon (2015) argues that there is a gap between empirical application of intersectionality and its theoretical production in the context of the Global South. Anuj Kapilashrami,

Ramila Bisht and Sundari Ravindran (2016) discuss the Southern perspectives of intersectionality based on Nivedita's argument:

Nivedita's piece rests on three core arguments, which we summarise here: first, what she eloquently describes as "imperialism of categories," whereby certain universal categories, often defined from a western perspective, are increasingly imposed on non-western ways of understanding the world. Second, popularity enjoyed by intersectionality must be seen in light of its endorsement by the United Nations and other agencies and their agendas, which, as argued in Carbado et al. (2013), threatens or neutralises the political project it aims to address. Ironically, in this argument, there is an implicit acknowledgment of the political and subversive potential of the concept. Third, Menon questions the utility of intersectionality for India (and other post-colonial states in Global South) where women's movements have a longstanding history (and politics) of engaging with multiple identities. (Kapilashrami et al., 2016, p. 173)

According to Kapilashrami and colleagues (2016), there is an equal attempt within different contexts in both the Global South and North to shape and understand intersectionality in both its theoretical development and applications.

Social construction of disability

There is historically recorded evidence that impairment has existed in all cultures. However, disability can be seen as a cultural construct in these societies and cultures (Albrecht, 1992; DePoy & Gilson, 2004; Wright, 1983). Kirsty Johnston (2016) tends to interpret disability as an idea in western modernity. Most cultures and societies have identified disability as an abnormal phenomenon. According to Romel W. Mackelprang and Richard O. Salsgiver (2016), people with disabilities, including physical disability, intellectual disability and acquired physical disabilities, have been marginalized by societies throughout history. The western approach to disability could be identified through different models of disability that include the Religious/Charity Model, Medical Model, Social/Critical Model and Human Rights Model.

Religious/Charity Model

Scholars identify the historical representation of disability in religious texts (Hentrich, 2007; Kafer, 2003; Moss & Schipper, 2011; Stewart, 2011).

Religious beliefs and their interpretations of the concept of disability have produced a negative impact on people with physical and intellectual impairments (Livneh, 1980; Wright, 1983). Nora Groce (2005) illustrates how disability is interpreted by religious beliefs. Religious interpretations on disability convey a relationship between birth and later life; accordingly, this connection reveals that disability is a divine punishment of an individual or community.

South Asian perspectives of disability have been deeply rooted in the Religious/Charity Model. The ideology of *Karma* plays a main role in conceptualizing disability in Indian philosophy (Liyanage, 2017; Vimal, 2018). As a fundamental doctrine in Buddhism, the *Karma* concept allows people to believe that an individual's previous life impacts their current personal action and experience. "Indian philosophy largely discusses disability as the consequence of misconducts of previous births" (Vimal, as cited in Wijesiri, 2022, p. 47). There are five elements in the Buddhist Karma concept that can collectively affect an individual in their next life. These elements include *kamma-niyama*, *beeja niyama*, *utu-niyama*, *citta-niyama* and *dharma-niyama*. According to this categorization, karma is only one factor of many that determine individuals' physical and mental differences in their next life (Liyanage, 2017, pp. 252–253). Disability is identified from the perspectives of the Religious/Charity Model in the Sri Lankan context.

Chandani Liyanage (2017) explains that in Sri Lanka, disability is conceptualised from a charity perspective. She elaborates on this idea by stating that people with disabilities are negatively distinguished with a language unique to Sri Lanka. A vocabulary, including words like *andha* – blind, *bihiri* – deaf, *golu* – mute, and *arbadita* – disabled, is used to differentiate people from normal to abnormal, abled-bodied to disabled, well-being to ill-being; as a result, this fixed identity carries stigma and discrimination (Liyanage, 2017, p. 252). The Charity Model sees people with disabilities as tragic victims who need care and help (Kumar & Subudhi, 2015). The majority of non-disabled society members consider this fixed disabled identity as a source of merit – that is, disabled people deserve help – and so meet their simple survival needs with food, clothing and other basic necessities (Liyanage, 2017). Yet while this Charity Model applies to helping disabled people, it does not apply to other historically marginalised people who may also be "disabled" in terms of participating in social, educational and employment opportunities. For instance, queer people are not "meritorious" and deserving of help under the Religious/Charity Model. (Wijesiri, 2022, p. 48)

Medical Model

The Medical Model is centred on the clinical diagnosis and treatment that emerged during the enlightenment period in Europe and the United States. Mackelprang and Salsgiver (2016) explain that thinkers of the enlightenment era believed that they could cure any issues related to human beings, including physical and intellectual disabilities. Fundamentally, this model classifies disability as an individual's issue. Simon Brisenden illustrates that “the medical model of disability is one rooted in an undue emphasis on clinical diagnosis, the very nature of which is destined to lead to a partial and inhibiting view of the disabled individual” (Brisenden, as cited in Wijesiri, 2022, p. 41).

The UNICEF Report (2003) reveals that Sri Lanka uses Community Based Rehabilitation (CBR) programs to provide support services that include speech therapy, physiotherapy, wheelchairs, hearing aids and crutches for persons with disabilities. Sri Lankan scholars have identified even more is needed to support people with physical and mental impairments (Fernando et al., 2010; Gunaratnam et al., 2003; Rodrigo et al., 2010). For instance, Rodrigo and colleagues explain the need for a hospital-based study to assess intellectual impairments related to diverse socioeconomic factors. According to Sunera Mayanthi Fernando and colleagues (2010), patients with mental health issues face inconvenient circumstances because of Sri Lankan doctors and medical students' stigmatizing attitudes. Henry Roche Gunaratnam and colleagues (2003) elaborate that a victim of landmines in Jaffna with physical injuries face more psychological issues due to a lack of functional ability, social relationship and other cultural practices.

Social/Critical Model

A discussion held by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 provided the fundamental facts for establishing the idea of the Social Model. Michael Oliver (1990) conceptualized this model in 1983 based on UPIAS discussion. The key factor of the Social Model is centred on the difference between the terms “impairment” and “disability”. This model understands impairment as an inability or difficulty that affects an individual negatively. Disability refers to societal restrictions that do not provide equal attention or consideration to disabled individuals. According to Oliver (1990), the Social Model does not exclude medical intervention for persons with disability. However, the power imbalance

between patients and doctors remains in many areas that impact persons with disabilities. The Social Model emphasises the significance of sharing powers in a mutual understanding between doctors and patients; this is because patients are positioned as powerless while doctors are empowered by the medicalisation process surrounding disability:

In short, the social model of disability means that society is disabling people. This model interprets disability as a socially-constructed concept that can be applied to different social groups such as women, queer people, transgender people and people from ethnic and racial minorities, who are also denied social, educational, employment or political participation opportunities, whether they have “impairments” or not. (Wijesiri, 2022, pp. 42–43)

Richard Devlin and Dianne Pothier (2006) contributed to developing the Social Model into a critical theory. Alison Kafer (2013) explains how to understand disability as a social construction. Elizabeth Ellcessor (2017) discusses how able-bodied people behave with regard to humanity, justifying unequal treatment of persons with disabilities.

Human Rights Model

The Human Rights Model of Disability (Degener, 2016; Lawson & Beckett, 2021; Retief & Letsosa, 2018) is a model in disability studies growing in popularity; it shows how human rights are connected to persons with disabilities. While this model is an extension of the Social Model of Disability that interprets disability as a social construction, it is also unique because it “encompasses the values for disability policy that acknowledge the human dignity of disabled persons” (Degener, 2016, p. 34).

Samanalayaya Theatre Festival

This annual theatre festival started in 2006; each participating workshop represented the Sunera Foundation. Workshop trainers are the playwrights and directors, and each workshop culminates with a performance of a short play. Workshop participants who have intellectual or physical impairments have the opportunity to develop their creative talents, and their self-confidence is strengthened by performing for the public. The festival aims to raise public awareness of the talents and abilities of people with disabilities.

I selected a short play named *Plilia* (a parasitic plant) for this study. This play was written and directed by Nishanka Dharmathilaka, the trainer of the Kandy workshop connected with the Sunera Foundation. All the performers were people with Down's syndrome. Some parents of the performers had a supporting role in the play to assist their children.

The script was only one-page long; it provided basic guidelines and points on which the play was to be organized. This performance is more physical than dialogue-driven. Nishanka believes that Down's syndrome performers feel more comfortable when there is less dialogue in the script. She has developed a full story and concept in her mind even though her script contains a great deal less information. Therefore, the playwright must be the director and producer as well.

A story of contemporary social issues

The drama selected for this study is based on one of students' life experience who have been avoiding their dancing class. The dancing teacher, an old man, has an accident during a training session. One of the parents sees her daughter massaging the injured teacher. Although there are many other students helping the teacher, this mother has not observed this. She then expresses her displeasure and withdraws her daughter from the class. This action results in all the parents pulling their children out of dancing class. One mother urges the teacher to stop teaching the class. The parents do not want to continue their children's aesthetic education, so they start sending their children to other classes. Yet these new classes that follow an exam-oriented syllabus do nothing for students' social development. A drug dealer sees a chance to enter the class and starts strategically distributing drug-infested sweets to the students. The children are unaware of what they have consumed, and they are now addicted to a dangerous drug. Many people enter their lives and make them worse because of this drug addiction. The parents see their intoxicated children lying down in the classroom. Finally, these parents revisit the dancing teacher and ask him to restart the dancing class to make their children happy.

Methods

I adopted a qualitative approach to this study that includes textual analysis of contemporary productions, observations of the theatre group and

the audience through a recorded format and interviews with production personnel and – most importantly – spectators to record some of their responses to the contemporary performances. I completed a critical instance case study outlined by Ashley Crossman (2020) to produce this research. I used identity, intersectionality, disability, contemporary Sinhala theatre and contemporary disability theatre as criteria to select the case and participants. There were seventeen participants in the semi-structured interviews, including two playwrights, five performers and ten spectators. There were ethical issues connected with interviewing Down's syndrome performers; I therefore had to avoid these performers, instead interviewing parents who had a supporting role in the play. Five other performers with physical impairments who performed in different plays in Sunera Workshops were also included. I used the thematic analysis method as a qualitative approach to analysing the data collected from interviews, audio and video recordings, social artifacts, archival data and publications. Virginia Braun and Victoria Clarke (2006) informed this analysis of applying six phases of thematic analysis: (1) familiarising yourself with your data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, (6) producing the reports. I used the following themes for the data analysis:

1. Perceptions of different lived experiences
2. Construction of disability by social ideology, systems and infrastructure
3. Multi-cultural theatre group excludes some identities
4. Theatre practitioners' commitment to understanding different identities
5. Making limits on critical thinking
6. Different theatre companies for disability human rights
7. Vocabulary issues of disability

I used participants' real names with their consent in the report. I provided them with consent forms before the interview, asking to use their names and images. After the interview, I provided the transcribed script for their approval before writing the report. The Down's syndrome performers' parents provided consent to use images. My overarching theoretical approach is Critical Disability Theory (Campbell, 2009; Devlin & Pothier, 2006; Goodley, 2016; Hosking, 2008). This study is considered to be low-risk field research that was awarded a low-risk human ethics clearance from the Queensland University of Technology Research Ethics Committee.

Representation of disability identity

Initially, I explained to the research participants what I intended to do by using the term *identity*. I told them about seven categories associated with identity, including disability, gender, sexuality, race, religion, class and caste. The participants then gave me various views regarding their own identity.

All are human

Some of participants did not wish to talk about different identities. Their common attitude was to simply identify all people as human beings. Other participants revealed a few selected identities. However, the attitude that “all are the same” is based on participants’ experiences and understanding of social stratifications. People may not wish to reveal their own identity because they have experienced discrimination based on it. People who represent privileged identity categories in the Sri Lankan context may also think that discussing identity issues could hurt unprivileged people in society.

Sandun was a theatre trainer who was promoted to be the assistant field manager of the Sunera Foundation. He believes that everyone is equal because he does not like to divide people into different identity categories. Sandun mentioned his identity as a Sinhalese Buddhist male based on his birth certificate. Thanuja, a playwright and theatre trainer attached to a regional workshop, introduced herself as a human being. She does not like to identify intersectional identities such as race, ethnicity, disability or gender. Both playwrights’ attitudes of identity support the belief that “humans are humans”, which is popular among many people in the Sri Lankan cultural context.

Identity theory seeks to explain the specific meanings that individuals have for the multiple identities they claim; how these identities relate to one another for any one person; how their identities influence their behaviour, thoughts, and feelings or emotions; and how their identities tie them into society at large (Stets & Burke, 2009, p. 3).

There is a difference in Sri Lankans’ common attitude towards the identity concept from the Western perspective because of the religious element in their thinking pattern. Participants agreed that theatre can represent identity. However, they do not necessarily want to acknowledge different lived experiences. A religious ideology in Sri Lanka motivates

people that no one should be treated unequally because all are human beings. This historically developed ideology stimulates empathy towards certain communities instead of treating them all in an equal manner. Able-bodied people facilitate in many ways for persons with disabilities based on compassion and charity. This practice and attitude are a result of the Religious/Charity Model that has been developed throughout the history of Sri Lanka. Therefore, many people do not have a sense of the difference between equality and equity.

I interviewed five performers for the study, all of whom have performed in different occasions in Samanalayaya Theatre Festival. The following table shows their responses to the question I raised regarding their own identity.

Table 1. Different identities of performers at the Samanalayaya Theatre Festival.

Number	Performer	Disability	Race	Religion	Gender	Sexuality	Caste	Class
P19	Ruwani	Physical	Sinhala	Buddhist	Female	Not mentioned	Not mentioned	Lower middle class
P20	Chathumini	Physical		Buddhist	Female			Lower middle class
P25	Veronica	Not mentioned		Buddhist	Female			Not mentioned
P32	Oshani	Physical		Buddhist	Female			Not mentioned
P33	Mekhala	Blind		Buddhist	Female			Lower middle class

(Derived from Wijesiri, 2022, p. 130).

Three performers used wheelchairs because they had walking difficulties. One participant revealed her blindness. None of them stated their sexual and caste identities. All performers were Sinhalese Buddhist females. Two participants did not want to mention their class status, while the other performers revealed that they belonged to the lower middle class in Sri Lanka. Oshini’s perspective of disability differed from the other performers:

Although I have a physical impairment, I do not like to introduce myself as a disabled person. I have got an inclusive education in a government school. However, I had to stop my studies after leg surgery. That surgery was also unsuccessful. I do not like to divide people into different identity categories. (Oshini, as cited in Wijesiri, 2022, p. 131)

Sometimes, this performer may not wish to acknowledge their different lived experience in Sri Lanka. However, this attitude shows the oppression of people with disabilities in mainstream society. Disabled people worry about their impairments and lives because of the religious ideology of *Karma*.

Karma

Sri Lankan religious institutions advocate using the concept of *karma* to interpret disability. However, Thanuja mentioned that Sunera trainers could change their workshop participants' attitudes related to this concept. She explains that this attitude cannot be applied to mainstream society. There is also a contradiction between these two ideas. Suppose one theatre company can change attitudes of its workshop participants through theatre activities. In that case, why do other theatre companies not follow a similar practice of addressing the issues related to identity constructions in the Sri Lankan context?

I interviewed ten spectators for this study. Many of them strongly believe that having a disability is an unavoidable result of the individual's bad behaviour in their former life. Buddhist religious institutions are responsible for promoting this attitude among Sri Lankans. For instance, Tennakon is the father of a performer with disabilities. The following statement explains his understanding of disability:

As a Buddhist, I firmly believe that disability is a result of the previous birth. Our temple's chief incumbent said a disabled child is a parents' merit. As parents, we earn value for our next birth, treating these types of people. We are happy to help the child because of this attitude. We have dedicated our comfortable life and many opportunities for the pleasure of our child. A disabled child's parents cannot enjoy life well compared to other parents. Therefore, we plan our everyday life-giving priorities for this child. (Tennakon, as cited in Wijesiri, 2022, p. 151)

Another spectator, John, who has a disabled daughter, mentioned that their daughter was born with impairments because of other family members' merit. She referred to a statement provided by their temple's Buddhist monk that a disabled child has gone along with sin through her reincarnation. John agreed that there are scientific reasons for disabilities. However, she still accepts the Karma concept because it helps her tolerate the situation and concentrate on looking after her child.

Another example is Mahesh, who participated in this study as a spectator. However, he has his own theatre company that works with the disabled community. He strongly believes the Religious/Charity Model is the main barrier to establishing the Social/Critical Model in Sri Lanka:

According to Buddhism, one of the reasons for disability is *karma*. However, Many Buddhist people believe that *karma* is the only reason for disability. We must spend at least more than two years with a disabled person to understand that there are many other reasons for disability. Some politicians misuse this religious approach for their benefit. They try to make an awareness among the public that difficulties such as poverty and disability result from people's previous birth. Some Buddhist monks also promote this political involvement in society. The people who highly acknowledge that idea do not struggle for human rights. Therefore, many disabled people cannot identify how they are marginalized or suppressed in mainstream society. Suppose someone explains to disabled people how they have been suppressed. In that case, they realize that there are many other reasons other than *karma* for disability. Otherwise, they have not developed their thinking pattern to understand their vulnerabilities as social facts. Thus, this *karma* concept is one barrier that we attempt to overcome through theatre performances. (Mahesh, as cited in Wijesiri, 2022, p. 152)

All participants, including playwrights, performers and spectators, agreed that because of the religious ideology of Karma's strong influence, Sri Lankans are bound to continue the social construction of regarding disability with sympathy and compassion. Consequently, many of them do not come forward to demand human rights for persons with disabilities.

Issues of theatre-making process

Spectators have identified the differences between rehearsals and a play's final performance that impact Down's syndrome performers negatively. For example, Ekanayake mentioned that one able-bodied performer made an unexpected move and voice change during the performance. Yet the Down's syndrome performers had not experienced these changes during rehearsals. Therefore, a certain number of performers changed their own behaviour in unexpected ways. Nonetheless, one performer did say that she had been asked to make some voice changes by the director before the final performance.

According to Menik, the play's music and singing component created a noisy environment. She said that both the performers and audience felt uncomfortable with the theatre's sound system.



Figure 1. An illustration of the performance of *Pilila*. (Photo credit Chandana Wijerangana).

Personal commitment and institutional support

At the beginning of his work, Sandun realized that his knowledge was insufficient to work with disabled people. He said that he did not know the meaning of various terms related to intellectual and physical disabilities. To rectify this situation, Sandun completed a diploma at the National Institution of Education (NIE) in Sri Lanka to understand the concept of disability. This diploma was helpful to him when developing his skills as a teacher and trainer of disabled students. The chairman of the Sunera Foundation provided some foreign trainers to do with an advanced training program. Then, the Sunera Foundation sponsored Sandun to gain foreign training at the “Unlimited Program”, which is an art commissioning program that distributes disabled artists’ work in the United Kingdom. From Sandun’s point of view, the foreign training was useful to him for enhancing his knowledge about script writing and producing dramas with disabled people. He started to write a silent script for Sinhala Disability Theatre after having completed his foreign training.

Limitations on critical thinking capacity

According to Thanuja, the Sunera Foundation has advised all playwrights to write happy ending scripts for their performances. She is careful not to hurt disabled people's feelings because of this directive. Thanuja believes that people with disabilities should not feel badly at the end of a play. She explains that a happy ending is vital for workshop participants (people with Down's syndrome) because it is socially acceptable. Parents of performers with disabilities want to see their children happy at the end of a performance. Able-bodied people, including playwrights like Thanuja, often assume that people are worried about their disability. Yet this is not always the case for people with disabilities. Therefore, a play with a happy ending does not necessarily address the issues and attitudes in mainstream society. Although there is a social ideology promoting the idea that disabled people are worried about their life based on the karma concept, Thanuja believes that orthodox attitudes must be changed through theatre activities. However, Thanuja's idea is radical because directors in the Sunera Foundation are supposed to produce "socially acceptable" drama.

Lack of knowledge in creative industry and disability

Various common terms related to disability that are used by the Sinhala community are insulting and inconvenient for people with disabilities. Sometimes, people are not aware that these terms are inappropriate to use because they have long been established as acceptable words in the Sinhalese language. However, Sunera workshop trainers do not use such insulting or inappropriate language in their productions.

The conventional Sinhala term for disability used to be *abadhitha*, which was officially removed from government documents because the term conveys a negative impression of people with disabilities. The English term *disability* is not used in the Sri Lankan context. There was another term – *differently able* – that was also removed from official documents after a short period of time. Although there is no common agreement, the current term used in the Sri Lankan context is *special needs* (*vishesha awashyatha*). Some participants used this term in the interviews, while others were critical of this terminology. Both the literature

review and case study revealed many inappropriate words in the Sinhalese language that were used to introduce different lived experiences. Thus, various institutions and people have been attempting to introduce new alternatives for the English term *disability* and Sinhala word *abadhitha*. However, the word *abadhitha* is still used in Sinhalese oral tradition. I believe that interpreting the term disability in accordance with the Social/Critical Model is better than removing it from the vocabulary altogether. In the case of the Sinhalese word *abadhitha*, I propose a new term, *sabadhaka*, which means “having barriers.” This word applies not only to disability as a result of impairment but also to other people who face social disablement. This new term is also in accordance with the Social/Critical Model.

Awareness of disabled people’s human rights

Understanding disability human rights is not standard for many Sri Lankans. Some participants mentioned their displeasure at the current rules and regulations for disabled people in the country. There are several people who do not have any idea about constitutional laws. However, the common understanding is that the government must provide facilities for all people with disabilities. Some participants complained that the government has failed to protect the human rights of disabled people.

For his part, Mahesh has a clear idea of disability human rights in Sri Lanka. He sees a failure at the administrative level to enforce rules and regulations. Mahesh believes that disability theatre performances can raise awareness of human rights for this community:

All human rights laws are from ten to fifteen sections in the third chapter of the 1978 constitution. The United Nations approved thirty sections of human rights laws in 1948. The Sri Lankan constitution includes only a few of them. There was not any line for disabled people in those constitutional laws. However, the United Nations established a new human rights section for disabled people on December 13, 2006. Sri Lanka also signed this act in 2007. The Sri Lankan parliament approved discussion of this matter on December 23, 2015. Then it was amended to the constitution on February 8, 2016. Therefore, there is a constitutional law for disability rights in Sri Lanka at present. (Mahesh, as cited in Wijesiri, 2022, pp. 158–159)

Education policies

There is a need for essential change in education policies to address issues related to the disabled community in Sri Lanka. Each year, Hapitigama training college produces teachers with inclusive education training. However, these teachers do not practice inclusive education at schools. According to Menik, the reason for this departure from inclusive education is that neither the government nor the private sector recognize or appreciate it.

From Mahesh's point of view, Sri Lankan students have not learned about human rights at school. Nonetheless, while recent curriculum revision has included a certain number of sections on human in the subject area of Civic Education, it has not included disability rights.

Conclusion

This study was based on the Samanalayaya Theatre Festival organized by the Sunera Foundation in Sri Lanka. I selected one performance for the analysis; seventeen participants, including two playwrights, five performers and ten spectators, were interviewed. Many participants had little awareness of the concepts of identity, intersectional identity and disability. Only one playwright, Sandun, was familiar with the Social Model of Disability because of his foreign training. Many participants believed that all humans are equal. They were not aware of the difference between equality and equity. Some spectators endorsed the Religious/Charity Model acknowledging disability because of the Karma concept. However, other spectators asked if it was useful to change attitudes and shift to a rights-based approach to disability identity and citizenship in Sri Lanka. Theatre companies make limitations on theatre practitioners' critical thinking capacity. According to my position in this study, society does not identify me as a playwright with disabilities. The study reveals that people with disabilities have not engaged as theatre practitioners in Sinhala theatre. There was no report of any spectator with disabilities in the case study. Performers with disabilities also have limited opportunities to represent Sinhala theatre in Sri Lanka. As this research implies, theatre companies could perform best practice while engaging inclusive theatre in all of their components – that is, lessons, practical activities and workshop activities – providing opportunities for intersecting identities. I myself plan to establish an inclusive theatre group

at the University of Peradeniya, Sri Lanka. These findings encourage other playwrights to reflect critically on their creative work. As to future research areas, the involvement of NGOs in the theatre industry and people with disabilities is yet to be investigated in-depth in the Sri Lankan context.

Author biography

Nimal Wijesiri completed his Doctoral research on the topic of “Representation of Identity in Sinhala Theatre: the impact of the Religious/Charity Model” in the Queensland University of Technology, Australia in 2022. He completed Master of Arts in Comparative Indian Literature in the University of Delhi, India in 2011. Wijesiri obtained his Bachelor of Arts with specialization of Sinhalese language, literature, and culture from the University of Peradeniya, Sri Lanka in 2005. He is a senior lecturer at the University of Peradeniya, Sri Lanka at present. His research interest is unfolded in the field of disability theatre, and identity.

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CHAPTER 10

Celebrating Embodied Agency in Disability Performances in Zimbabwe: The Case of Blessing Fire's *Broken Pavement*

GugweLihle Ngwenya University of Zimbabwe, Zimbabwe

Courage Chinokwetu King George VI Centre in Bulawayo, Zimbabwe

Kelvin Chikonzo University of Zimbabwe, Zimbabwe

Nehemiah Chivandikwa University of Zimbabwe, Zimbabwe

Abstract: This chapter analyses how Blessing Fire, a physically impaired dancer, uses dance as a vehicle of liberation and resistance against imposed forms of oppression of disabled people. Studying a hip-hop dance production called *Broken Pavement*, the chapter examines how Blessing Fire resists and dismantles stereotypical constructions, and representations of people living with disabilities. The chapter employs a qualitative performance analysis approach, supported by interviews and observation. The chapter also utilises critical disability theory and the affirmative model, in order to investigate forms of subversive, affirmative identity construction and resistive agency, which are imbedded in the performance text of *Broken Pavement*.

Keywords: Disability, communication, theatre, agency, liberation

Introduction

Cognisant of the fact that in Africa performances, such as theatre and dance, are media for aesthetic engagement and socio-political communication (see Abubakar, 2009; Chifunyise, 1997; Gordon, 1994 ; Oketch, 2006; Zenenga, 2011), this chapter valorises the resistive agency of Blessing Fire who, through performance, challenges demeaning and derogatory representations and stereotypes associated with people living with disability. In tandem with Petra Kupperts (2003), the authors demonstrate how Blessing Fire transforms performance space into a site for celebrating and communicating disability corporeal politics. Consequently, Blessing Fire turns the dance text into a performance that empowers his voice to articulate his story, not from a position of victimhood and charity, but rather from a position of agency and victory, revealing the joys, pains, aspirations, achievements, and pleasures of the impaired body. Focusing on the dance piece *Broken Pavement*, in which Blessing Fire was the main dancer and choreographer, the authors argue that disabled performers can use dance performance to recognise and assert their bodies as complex sites of aesthetic signification, and socio-political communication on corporeal politics. While acknowledging that African scholarship (see Amkap, 2006; Gordon, 1994; Goulet et al., 2011; Zenenga, 2011) recognises that dance and theatre are potentially subversive art forms grounded in the body, the authors extend this argument beyond normative ableist aesthetics, to include disabled bodies. The chapter is broadly guided by the following research question: How does Blessing Fire use dance to resist and challenge stereotypes of people living with disability in the area of performance making, choreography in particular, and mainstream society in general?

Through qualitative performance analysis, and drawing from data collected through observation of live and YouTube recorded performances of *Broken Pavement*, and intensive interviews with Blessing Fire, the researchers identify the manipulation of impairment for aesthetic spectacle. By broadly employing critical disability theory, and the affirmative model more specifically, the authors argue that *Broken Pavement* is not just a practical negotiation of impairment-induced limitations, but a strategic site and medium of communicating and challenging the discrimination of disabled bodies within and beyond the performance space. Given that the non-disabled body is always considered ideal for both everyday and aesthetic beauty, the authors examine the impaired body in the performance

space as instrumental in subverting greater marginalisation and stereotypes of its impaired being. Thus, negative perceptions of the disabled body are central to its marginalisation and subordination.

Disabled people are often ridiculed, romanticised, pitied, and excluded because of their bodies (Davies, 1995; Paterson Hughes, 1999). In other words, this marginalisation of disabled people in the performance space is based on the erroneous assumption that only non-disabled bodies are suitable for performance (see Goodley & Runswick-Cole, 2011; Saur & Johansen, 2013). As will be highlighted in the subsequent section, *Broken Pavement* is profoundly involved in aesthetic signification and the communicative aspects of dance performance, as well as disability body politics.

Background and context of production

UNICEF (2013) reports that about 900,000 individuals, of a total of 13 million people in Zimbabwe, have some form of impairment. However, curiously the performance arts sector seems to have the lowest number of disabled artists. In light of this, *Broken Pavement* can be seen as a commendable effort to empower Blessing Fire as both a citizen and an artist. The dance piece features a group of non-disabled dancers who assist Blessing Fire in retelling his narrative. Not only does the group of non-disabled dancers act as characters within the narrative of the dance piece, but they are also a platform for negotiating the limitations of Blessing's impairments. Blessing notes this in an interview as follows:

My journey to becoming a dancer was because of a guy who saw me doing tricks with my hands and was so impressed. At that time, I was just experimenting with what I could do with my hands since my legs were not that useful to me. So this guy *akandiona* (he saw me) one day *akanditi blaz moda zvekutamba here* (and he asked if I was interested in dancing). I said yes and I followed him to this house where guys were rehearsing and I showed them what I could. From then on I was a dancer, and these guys changed my life. (Blessing Fire personal interview, 20 May, 2018)

The above interview excerpt shows that Blessing Fire acknowledges the relational dimensions of *Broken Pavement*, which are anchored in a combination of both collective and individual artistic dance creations. *Broken Pavement* is an emotionally compelling story performed by 10 dancers of different bodily configurations, who are all members of the 4GO10 Tribe

(Blessing Fire Personal interview, 2018). It is a dance piece that is built around, shares, and retells the real life story of the lead dancer, Blessing Fire, born with an impairment and wheelchair bound for his entire childhood (<https://youtu.be/UNa7dmnRV9A>). The story narrates his experiences and his journey towards becoming one of the best dancers Zimbabwe has ever seen.

The dance piece tells Blessing's story from birth, growing up, trying to fit into a discriminatory society, and the triumph of discovering his talent and using dance to conquer ableist discrimination through a fusion of breakdance, contemporary dance, the spoken word, music, and traditional mbira music. Other members of the 4GO10 Tribe include: Brian Geza, a non-disabled dancer and director; Blessing Fire (lead dancer); and non-disabled dancers, Tasnim Mahomed, Felix Mwale, Sarah Kabiseni, Kudzai Chikowe, Sean Mumba, and Sylvester Shonhiwa.

Broken Pavement incorporates a variety of hip-hop dance moves. The dominant movement in the piece is breakdancing. Also known as breaking or b-boying, breakdancing is a sporty kind of street dance (Hooch, 2011). According to DJ Hooch (2011), breakdancing originated primarily among Puerto Rican and African-American youths, many of whom were previously associates of street mobs, during the mid 1970s in the Bronx, USA. It spread worldwide through its popularity in the media. This dance is heavily influenced by Kung Fu films, which were instrumental in shaping its movements and style. Also, many of the acrobatic moves in the dance, for instance the flare, indicate gymnastic influences. Breakdancing has many variations, but it consists mainly of four kinds of movements: toprock, downrock, power moves, and freezes, all of which feature prominently in *Broken Pavement*. Musically, the piece is dominated by hip-hop music, complemented by other genres, such as epic and live mbira music

Theoretical framework

This chapter is guided by critical disability theory. Supported by the work of various scholars, critical disability theory analyses the cultural, historical, social, and political inequalities that entrench the oppression of people living with disabilities (Olivier, 1990; Quinlan & Bates, 2008; Siebers, 2008). Critical disability theory also deals with the designing of strategies of recuperation and resistance, which enable oppressed impaired bodies to liberate themselves from structural forms of oppression. As such, it provides

pathways through which people living with disabilities resist and defy these inequalities. In this vein, critical disability valorises the resistive agency, voice, and the centrality of disability as the focus of attention in various academic disciplines. It centres disabled bodies as the focus of spectacle, and advances the needs, aspirations, and empowerment of disabled bodies from a position of agency, rather than victimhood and charity, in order to curtail demeaning constructions of disabled people (Goodley, 2013). The tenets of critical disability theory include: resistive agency, voice, difference, diversity, participation, empowerment, and transformative politics.

Critical disability theory disrupts charity, medicalised, and traditional perspectives by decolonising the body through a critique of ableist hegemony and socio-spatial activism (Goodley, 2011). Critical disability theory considers how interactions between non-disabled and disabled people are fraught with political tensions (Goodley, 2013). In critical disability theory, renewed focus is on science, charity, medical science, and popular culture, and how these are all implicated in marginalising and dislocating disabled people. This interest in material culture cannot avoid focusing attention on the materiality of the impaired body (Garland-Thomson, 2002). Thus, critical disability theory complicates the relationship between disability (oppression of people with impaired bodies) and impairment (biological condition of body limbs which might not perform 'typical' body functions) (Shildrik, 2007, 2009). The argument is that the materially impaired body has to be centred because it matters (Paterson & Hughes, 1999), since the impaired body has a material impact on the lives of disabled people (Shakespeare, 2006). The experiential realities of impaired bodies are real and critical, irrespective of prevailing socio-economic conditions (Goodley, 2011; Shakespeare, 2006). The immediate interest in this study is that the objective realities of the impaired body can limit the specific physical and cognitive aspirations of disabled people and their everyday experiences (Goodley, 2013).

The chapter also employs the affirmative model approach, in order to explore the communicative possibilities associated with creating space for agentic practices for disabled people in dance performances. The affirmative model is an apparent 'extension' of the social model of disability (Freund, 2001; Cameron, 2010; Swain & French, 2000). The social model focuses on socio-political barriers and normative power politics, relating to structural issues that limit the participation of disabled people in mainstream society (Oliver, 1990, 1996). Proceeding from the above attributes

of the social model, the affirmative model shifts attention from structural issues to the lived realities of people with impaired bodies (Swain & French, 2000).

The affirmative model challenges the tragic view of impairment (Cameron, 2010). The model was developed by the disability arts movement (Cameron, 2008, 2010; Swain & French, 2000). The primary objective of the affirmative model is to assert the positive identities of impaired bodies, and the lived experiences of disabled people (Swain & French, 2000). One could say the affirmative model seeks to validate embodied experiences of disabled people (see Cameron, 2008, 2010). Critically, this model views bodily differences as positive human diversity that should be celebrated (Cameron, 2010). The lived embodied realities of impaired bodies are therefore legitimate sites for pleasure, socio-cultural interaction, and socio-political engagement.

The above conceptualisation avoids popular terms, such as loss, defects, deformity, and limitation, which pepper the medical model (Cameron, 2008). This simply means that impaired bodies are different, but equal to others (Cameron 2010).

According to John Swain and Sally French (2000), the foregoing highlight four critical elements within the affirmative model, namely;

- The experience of being physically different and how to think and theorise about bodily difference.
- Affirming bodily differences in society.
- Challenging stereotypes and assumptions about disabled people, and asserting specifically positive aspects of their lifestyles.
- Embracing and celebrating differences.

Subsequent sections will examine how *Broken Pavement* resonates with the above elements of the affirmative model.

The disabled body as medium for disability agency: The solo performance as voice

This study involves a disabled young person, whose body normative society presumes to be incapable of artistic creation (see Conroy, 2009; Koppers, 2003). This perception is especially regrettable in Africa, because African aesthetic agency is eloquently expressed in body-based forms, such as

movement, mime, and gesture (Chivandikwa et al., 2014). Performance space has therefore been one of the sites through which Africans communicate and confront colonial and neo-colonial cultural hegemony, and all forms of marginality and oppression (Amkpa, 2006; Sunni-Ali, 2010). The deployment of body-based aesthetics has created cultural nationalism rooted in anti-colonial discourse (Sunni-Ali, 2010). Elsewhere, this process has been described as an embodied approach to pedagogy, which can be understood as a site for decolonisation (Goulet et al., 2011). In other words, the marginalisation of disabled bodies, in both everyday and performance contexts, is a form of colonisation, which critical disability theory is beginning to confront through activism and counter-hegemonic discourses.

As a concept in broader critical disability theory, the affirmative model speaks to the artistic agency of disabled people in communicating their joys, aspirations, pleasures, and achievements. The notion of agency is at the centre of critical disability perspectives (Freund, 2001; Shakespeare, 2005; Sibers, 2006), because it challenges ableist normalisation that perpetuates myths about the docility of impaired bodies. Considering the material realities facing impaired bodies, critical disability perspectives prioritise relational or collective agency over extreme individual autonomous agency, as propagated by neo-liberalism and ableist perspectives and practices (see Furlong, 2003).

Contrary to the normative understanding of voice as vocal sounds, dance performance speaks in verbs of silence, and other elements of non-verbal communication. Through techniques of composition and choreography, Blessing Fire uses non-verbal communication to convey resistance. Contrary to the idea that the impaired body must be hidden, owing to stereotypes that marginalise it, Blessing Fire makes the visually impaired body the centre of spectacle in the dance production. The spectacle is not centred on merely revealing how it is disabled, but rather by showing that anybody can create movement and tell a story. In one sequence of the production, Blessing uses the wheelchair to challenge semiotic constructions of confinement and imprisonment. As he enters the stage in a wheelchair, there are semiotic readings that the wheelchair brings into focus: the wheelchair as a prison and space of confinement. The first impression one makes as an observer is that he will probably dance in the wheelchair, and move only in so far as the wheelchair allows him to move. However, in an act of challenging such a stereotype, Blessing moves out of the wheelchair, and leaves it in a manner signifying the liberation of the disabled body from

a space of confinement. He then performs acts of weight transfer, body mapping, and creation of shapes through various levels of vertical space. He performs radial and axial movements, which reveal his flexibility and tolerance for pain and adventure. He uses horizontal space to create floor patterns and movement pathways, which depict his ability to compose pictures confirming that the disabled body is not an unable body. He unveils great kinaesthetic control and balance. This is done in a solo performance where he is the centre of focus and attraction.

Blessing Fire employs his body as a site of unique aesthetic significance, as opposed to an object of pity or medical attention. He exploits his impairment for a unique aesthetic spectacle. For instance, Blessing manipulates the handstand and flare, hip-hop dance movements to add spectacle to the performance. In all these movements, his hands are on the floor to support his torso and legs in the air. He performs the flare, which is an acrobatic move whereby he alternates balancing his torso between his arms, while swinging his legs beneath in continuous circles. He also does the handstand, which is a gravity-defying move, with one hand on the floor flipping over in every direction, whilst his legs are in the air. In the basketball scene, with his hands on the floor, he uses his legs to bounce the ball in the air. As such, one can note that Blessing Fire subverts the limitations of this impairment by using it as a source of spectacle, rather than using it to draw pity and sympathy. His arms are stronger than his legs; hence he uses them for balance and spectacle, while the assistive gadgets in his legs make captivating rhythmical sounds.

Blessing Fire unleashes unique aesthetics based on the material realities of his body, and in the process expands his aesthetic and human agency in pursuit of liberation. Such presence of the disabled body in dance performance elicits the recognition that the body is both a biological fact and a social construct (see Siebers, 2008). In this particular instance, Blessing's invention calls attention to the fact that aesthetic excellence based on bodily movement and gestures is a social construction, based on societal discourses that construct artificial, and usually exclusionary, corporeal hierarchies (see Goodley, 2013; Lindeman, 2008). Such body hierarchies ignore the corporal experiences of disabled people (Quinlan & Bates, 2008). By subverting such hegemonic aesthetics, Blessing Fire's impaired body becomes a strategic site to communicate body politics, and celebrate disabled bodies more broadly, and his body specifically, by offering opportunities for self-assertion, self-love, and enhanced agency.

This solo performance is a great choreographic decision loaded with verbs of liberation. First, the body is not there to perform a cameo role in a world filled with domineering and dominant able bodies. Rather it is the centre of storytelling, and hence the primary vehicle of spectacle and focus. Although the body needs to be supported by the wheelchair, the disabled body does not necessarily need the support of abled bodies in order to create movement and performance. Rather than having the spectators view the wheelchair as an obstacle, Blessing Fire transforms it into a prop on stage, which enables him to perform choreographic positions of being on top, going over, going through, and flying over. These bodily propositions also change the stereotypical constructions of the wheelchair as an obstacle, and rather use it as a prop that represents a prison. It is in this transformability of the wheelchair that he reveals he is not confined to some limited space, and hence he has a liberated body. The disabled body then becomes a body worth celebrating, because of its acrobatic capabilities. It becomes a body not to feel sorry for, but a body that has to be embraced and celebrated as a differently abled body.

While Blessing Fire uses the wheelchair for walking in his everyday life, he transforms and manipulates it for aesthetic purposes in the dance piece *Broken Pavement*. The wheelchair is used as an artistic prop, and it helps in the creation of various movements in the dance. Blessing Fire manipulates the wheelchair for aesthetic picturisation, balance, and swift movement onstage. Through an intimate interaction with the prop, he manages to balance his hands on the armrest, as his torso rests on the backrest of the wheelchair, in a bid to achieve balance and aesthetic picturisation. He also uses the wheelchair for the swift exploration of stage space, moving from one place to another, in spite of the fact that his legs do not allow swift movement. As such, the wheelchair not only exists on stage as a symbol of disability and a means of motion, but also becomes part of the dance. The wheelchair is used in the opening scene where Blessing Fire discovers his ability to dance on his hands, and it also becomes part of the classroom dance scene. To this end, use of the wheelchair enables Blessing Fire to break the limitations of his impairment, as he is able to move on his own and to dynamise his movements. Koppers (2003) recognises that wheelchairs can increase the potential of disabled dance performers to achieve hypervisibility, which deconstructs negative perceptions of disability as passive and dependant. In this case, the authors argue that the wheelchair enabled Blessing Fire to move through space and time in dynamic and

complex ways. Further, Merry Morris (2015) argues that wheelchairs enable disabled performers to develop a new aesthetic sensibility in dance. While Morris maintains that this new aesthetic sensibility enables disabled dancers to develop self-sufficiency, the current authors maintain that in the case of *Blessing Fire*, he achieved both interdependence and self-sufficiency. In short, the use of the wheelchair created an intimate and interactive partner, “a mode of human expression, a means of interaction and support and a medium of motion and exploration” Morris (2017, p. 9), in ways that enhanced *Blessing Fire*’s extension of the self and increased confidence. This had a huge impact on communicating broader issues of disability body politics, while simultaneously deepening the visual artistic expression of the dance piece.

This focus on the materiality of the impaired body has significant resonance in performance, in that the impaired body should not only be viewed as a metaphor for disability experiences, as has been happening all along (Kuppers, 2003), but has become a significant site for exploring the politics surrounding the standards, competencies, possibilities, and limitations of non-normative bodies. It is this increased socio-political focus on the impaired body that has inspired performance theorists to explore the significance of the presence of the impaired body in the performance space, where it is not normally expected to be found by hegemonic ableist culture (preference for the non-disabled body at the expense of disabled bodies). Performance heightens passion and corporeal awareness (Lindeman, 2008), and it can generate hyper corporeality (Park-Fuller, 2008). Consequently, performance becomes a critical site for communicating corporeal politics (Bretell, 2013), because performance tends to engender sensitivity to corporeality (Park-Fuller, 2008).

Collective aesthetics: The ensemble sequence

Collective aesthetics here refers to the collective way in which the performers work together in the production. The authors recognise that collective aesthetic agency is usually looked down upon by society, which overstates individual triumph (see Zarranz, 2013). Cognisant of this observation, the authors therefore analyse the way *Broken Pavement* typifies collective aesthetic agency, to communicate the way society wittingly or unwittingly relegates forms of agency associated with disabled people. Although the

solo act liberates the disabled body, it may still convey innuendos of a solitary body that has to dance alone, being differently able. Blessing then crates an ensemble performance, in which he dances alongside other abled bodies in 4GO10 Tribe. The question in spectators minds was, is the disabled body just as capable as the abled body, and can these bodies relate together without producing innuendos creating some form of otherness for the disabled body? In this ensemble performance, there is a basketball match presented through breakdance movements. Through the choreographic technique of dancing in succession, the disabled body performs moves that have the same energy level and choreographic density as the abled bodies. Blessing is able to perform pairing and mirroring sequences with other dancers, without showing weariness or tiredness. He therefore demonstrates that he has the same stamina, physiological endurance, and flexibility as other abled dancers.

Blessing Fire and his dance crew manage to break the limitations of impairment through collective aesthetics. While the story is about Blessing Fire as the central character, Blessing does not perform most of the dances on his own. Only in the opening dance sequence does he dance alone. The rest of the performance features Blessing dancing with the other group members. At times, they do most of the dancing while he looks on, only then to come in and join in the dance. For instance in the classroom scene, Blessing Fire is part of the dance routine with the rest of the group, although he falls behind. The dance then shifts from the group to focus on one, and then two non-disabled dancers, while Blessing Fire and the rest of the group look on. Blessing Fire then later joins in the dance with the other two members, with the rest of the group joining in at the end. The collective aesthetic technique is important to facilitate Blessing Fire's negotiation of his impairment in the dance piece. It follows that instead of individual excellence, the performance relies on collaborative excellence. Implied here is the point that alone, Blessing Fire might have struggled to tell his story, but through collaboration he manages to express it more effectively. As such, the collaborative nature of the dance production allowed Blessing Fire to effectively communicate his narrative, while it also cast light on his individual achievements and agency, in the face of both the material realities of his impairment, and negative societal prejudices and attitudes to bodily impairments. This agency is complimented by the collective creative input from other non-disabled performers. This collaborative effort also allows Blessing time to rest, which is crucial for

his execution of difficult dance movements that require a high level of stamina and energy.

In essence, the disabled body in performance ceases to be a mere instrument of aesthetic virtuosity. Blessing Fire's body becomes a site to reveal how the body is embedded in aesthetic and everyday communicative practices, in ways that unveil how his body is a site of interactional politics. His individual autonomy and agency is superseded by relational autonomy and agency. The notion of relational participation is useful in this section. Relational participation refers to a process of active partnership among participants, which is defined by interdependence, equality, respect, and shared responsibility (Jupp-Kina, 2010). There are several implications of the notion of relational participation in the context of performances by and with disabled people. First, as has already been noted, disabled participants are not imprisoned by orthodox and formal processes in dance movements and postures. For example, Blessing Fire did not necessarily pursue rigorous or 'classical' movements, which require extreme 'agility' and 'fitness'. The nature of his artistic activities was informed by the range of available bodily configurations, and was not necessarily predetermined by orthodoxy. Here, care and sensitivity to the varieties of available bodily configurations is of paramount importance (see Sandahl & Auslander, 2005). This section has shown how Blessing Fire's disabled body in the performance space did not necessarily pursue selfhood and narrowly-defined aesthetic quality. Rather, the focus was on communication, building strong relationships through body contact (see Kurtz, 2012), exploring the potential of diverse bodies, and thus challenging oppressive body-based relationships. While extant African/Zimbabwean literature celebrates the inclusive and participatory aspects of African dance and theatre performances (see Abubakar, 2009; Chifunyise, 1997; Gordon, 1994), such inclusivity, collectivism, and participatory dimensions in art production and consumption are not examined in the context of disability. Having examined the way Blessing Fire negotiated the limitation of his bodily impairment through collective artistic agency, the next section analyses his individual agency in manipulating his impairment to deepen the aesthetic spectacle of the dance piece.

Resistive consciousness

A great concern in moments of collaborative productions between abled and disabled people is stereotypical power relations that arise from such

synergies. There is usually a problematic element, where able-bodied dancers control most of the production process, in terms of the generation of the production concept and the choreographic process. The authors therefore found it important to interview Blessing Fire, and establish whether he was in control of these production decisions, and whether he was aware of the notions of resistance and self-empowerment through performance. It is therefore not enough to explore Blessing Fire's prowess in performance, without establishing whether the decisions he made in both collective and ensemble sequences were his own.

The data from interviews with Blessing seem to confirm that he did not wish that he was someone else. His major concern was his struggle against ableism, using the very body that society perceives to be weak, as reflected in the interview excerpt below:

GG: What are you celebrating?

BF: Life... Happiness... But most of all, I think I am celebrating freedom, the strengths in my weaknesses. Like I told you before, my disability became my ability. I don't know if I would be one of the most talked about dancers in the country had I not been disabled. But I am disabled and I have managed to be one of the most talked about dancers because of this disability. Shaz (friend), I have been featured on BBC of all places. That's worth celebrating.

GG: Saka, can we say *Broken Pavement* is more of a testimony rather than a campaign...?

BF: It is both. I am raising awareness on issues that disabled people face, but at the same time I am testifying to how these issues do not necessarily stop us from transforming ourselves and being winners. I remember at first I wanted to term this dance piece 'In my Shoes' or "Shangu" to give people an insight of my experiences in depth. I then opted for *Broken Pavement* because I understood that a broken pavement still remains strong despite its cracks, it is never useless, you can break it but it still works. (Interview, 20 May 2018)

By emphasising his impaired body as a sight of struggle, celebration, and achievement, Blessing Fire did not necessarily deny the realities of pain or discomfort occasioned by impairment (Cameron, 2008, 2010). As the above interview excerpt shows, to Blessing Fire such experiences of pain and discomfort, real as they are, should not be used as the sole marker of the identities of disabled people. This de-emphasis on pain and discomfort is a strategic response to the realisation that pain and limitations have been used in both popular culture and the medical model to propagate the supposed inferiority of disabled people (see McCormack & Collins, 2012).

Blessing Fire's attitude to his impairment resonates with the affirmative model discourse, which views impairments as legitimate aspects of diverse human experience (Cameron, 2010, p. 24). The affirmative model valorises the unique 'benefits' and exceptional experiences of both impairment and disability (Swain & French, 2000). As evidenced above, Blessing Fire celebrates his exceptional success occasioned by the very impairment, which ableist society looks down upon.

It is significant to note that Blessing was actually inspired by this self-love and enhanced agency to come up with the concept of this performance, as reflected in the interview excerpt below:

Well, the story was birthed out of my experiences as a disabled. But the major reason that pushed me to tell it is that I am now more confident than I was before as a human being. Dance has allowed me to be someone I was not. Before I was just a cripple, but now I am an award winning dancer. *Mukombe nditorinawo shaz* (I have awards my friend). The struggles that I have gone through and the victories that I have had through *mukutamba ikoko* (dancing on its own) made me do *Broken Pavement*. (Interview, 20 May 2018)

The above remarks reflect a heightened level of self-love and self-invention that is based on the consciousness of one's bodily realities. In other words, there is no shame in one's impairment, which one can use to reinvent oneself through art. This awareness and affirmation of impairment is also coupled with a realistic appreciation of the limitations, realities and pain of impairment, which as previously noted, is not found in the social model, which emphasises socio-political systems at the expense of the materiality and carnality of the impaired body and its joys and limitations. To a large extent, the title *Broken Pavement* also speaks to the brokenness (impairment) of the pain, and the challenges of his impairment. The following quote from Blessing Fire sums up this reality:

Broken Pavement... the title was inspired more by the experiences that I underwent. My life was not easy. It was difficult growing up with this disability. The treatment I faced as a child left me broken. I lost my self-esteem, I lost my confidence, I lost my childhood. You can say my life was broken, broken due to the disability I have. *Asi* (But) despite all, I survived. Especially thanks to dance. Dance reinvented me and gave me a new life. *Ndosakandakazoti* (That's why I termed it) *Pavement*. A pavement is strong and durable. It can break, yes, but *kuzoona maipedza munengema mbozama* (to see you destroy it all you would have struggled). So I am a broken pavement. I have suffered and have been broken, but I am a pavement, strong and long-lasting.... (Interview, 20 May, 2018)

The above quote speaks to the understanding of the meanings of bodily difference in critical disability theory. Difference of bodily form is understood not in the sense of the superiority-inferiority binary, but in terms of physical variation where all bodies have different capacities and limitations (see Kuppers, 2003; Shildrick, 2007). Hence in the above quote, Blessing Fire does not gloss over the pain and challenges that were occasioned by the material reality of his bodily impairment. Yet at the same time, he uses the same body for self-invention and aesthetic signification. In this process, Blessing Fire essentially destabilises normative notions of aesthetic virtuosity and body perfection, without necessarily overlooking the challenges of the impaired body (see Breeden, 2008; Kuppers, 2003).

Conclusion

This article has examined the ways in which Blessing Fire challenges the physical limitations imposed on his body by impairment, in the creation and performance of his dance. To this end, the article has revealed how Blessing Fire uses performance to negotiate and defy limitations placed on him by his impairment. In *Broken Pavement* Blessing Fire not only negotiates the limitations of his impairment through artistic expression, but more fundamentally, the dance performance becomes a site through which he confronts the oppressive effects of institutional and interpersonal power which 'others' his body. Through casting, choreographing, and dancing (solo and ensemble), Blessing Fire displays his agency to confront and trouble "cultural misrecognition about impaired bodies" (Davies, 2005, p. 11). The authors posit that the performance meanings and experiences that emerge from this process are part and parcel of affirmative identity construction, because in the affirmative model, identities are fluid and not fixed, and they emerge from struggles in given contexts (see Cameron, 2010, p. 11). Therefore the performance space, this inquiry, is a critical site of resistance and liberation.

Author biographies

Gugulethu Ngwenya is a recent graduate from the University of Zimbabwe, where she graduated with an honour's degree in theatre arts and she is currently preparing to register for Master's degree in Theatre and Performance. She won several academic and performance awards at

the university. Gugulethu has worked for several NGOs in development communication work. She has also participated in several applied theatre projects on body politics involving young women and young people with disabilities.

Courage Zvikomborero Chinokwetu is an applied media practitioner with particular interest in drama for social change, theatre of the oppressed and arts therapies. Currently she is a PhD candidate with the University of the KwaZulu Natal. She also recently obtained a Certificate in Drama for Social Change from Radio Netherlands Training Centre (RNTC). In 2013 she was awarded the Southern African Drama Therapy Association Best Research Award. She has facilitated arts-based workshops on sexual and reproductive health, mental health, hypertension and diabetes management. She believes art creates new avenues for self-expression which can allow individuals to re-write their narratives.

Kelvin Chikonzo (PhD) is an Associate professor in Theatre/Performance and Film at the University of Zimbabwe. He is interested in identity driven models of empowering and recuperating marginalised/subaltern voices. He deploys applied media with clear strategies of structure and form that not only unveil instances of subtle oppression but possible means of resistive agency imbedded in stories told from below. As a direct outcome of his doctoral studies, he developed a transformative media model which is being piloted in the making of documentaries, docu-dramas and verbatim performances on disability, gender based violence and substance abuse.

Nehemiah Chivandikwa (PhD) is a Professor at the University of Zimbabwe and holds a PhD in applied theatre and development communication from the same university. His major researches, focus on applied media development communication with a particular emphasis on disability, gender and rural development in theatre, television, participatory video and community radio. He has a particular interest in audience studies/reception of political theatre and radio/television programs on politics in Africa. He researches on how structural factors impact on the production and reception of media and theatre productions. In the past three years, professor Chivandikwa has convened Media against Phobias conferences and Media and Crisis Communication Workshops.

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CHAPTER 11

Promoting Ownership through Joint Improvisation on Ephemeral Ideas: Lessons for the Field of Social Work from Exploring the Methods of Theater nonStop, a Professional Ensemble of Artists with Intellectual Disabilities

Hilde Guddingsmo Nord University, Norway

Abstract: Teater nonStop is an ensemble of 15 professional actors with intellectual disabilities. Its original goal is political, stated to be societal change through advocacy of the actors' perspectives through art, as well as a learning arena for social educator students. To succeed, it has developed its own working methods to promote ownership of the artistic product. This is knowledge that can benefit the field of social work, based on documented challenges to fulfil similar objectives. This chapter seeks to explore what dimensions of Theatre nonStop's ways of working help to promote such ownership. The research material consists of a conversation between the artistic director and me, the author, articulated as a constructed narrative of our common understanding, built through our collaboration over time, describing both cross-sections and contrasts between the fields of art and social work. The core elements are understood and explained, utilising the author's previous research on residential care homes. This discussion reveals a contrast between Teater nonStop's methods and the institutionalised logic of the residences, rooted in a diametrically different philosophy in which creative work succeeds by offering empowering levels of openness and recognition.

Keywords: disability arts theatre, intellectual disability, improvisation, social work, human rights

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Line: What did I say that time, then?

Me: You said something like: “I don’t know what we’re going to do, but there will be a Christmas show, and I have such an idea. I envision an image of a fur coat”.

Line: Yes! (Laughs).

The above quote refers to a conversation between Line, the manager and artistic director of Teater nonStop, and me, a social researcher exploring everyday life in group-homes for persons with intellectual disabilities. We have been collaborating through our institutions for 10 years, with me having follow-up responsibility for social educator students whose practice arena is the theatre. This conversation became crucial to my professional understanding by pointing out important differences between Teater non-Stop’s work-forms and the field of social work, with which I am connected through my research.

The fact that Line based something as important as an artistic production on something as ephemeral as envisioning a fur coat, represented a stark contrast to more purposeful and rule-bound ideals within social work. The contrast represented an anomaly: an undefined – but gradually redemptive – picture of the inherent possibilities in theatre’s working methods. It would therefore be interesting to let the anomaly become a contribution to knowledge, by exploring it and explaining it in light of theory (Timmermans & Tavory, 2012). This can help explain why one succeeds through disability arts, but not quite through social work, despite relatively similar intentions to realise social participation through self-determined and/or participatory processes, based on ownership of perspectives.

There has long existed a significant amount of professional artist ensembles within the field of disability arts, which focus on promoting the perspectives of people with intellectual disabilities. These ensembles have arisen on the basis of the problem that people with intellectual disabilities are not taken seriously as artists (Hargrave, 2015). However, in these ensembles people with intellectual disabilities have strong ownership of their own artistic expression from processes of co-production. Simultaneously, it is a well-known challenge within social work that the field’s own ideals of realising basic human rights, such as participation in society and self-determination, are not fulfilled (Mapp et al., 2019). These are values that must also be founded on the individual’s ownership of the perspective to be realised. Therefore, one has the potential to learn

through examining the working methods of the theatre, by seeing these in contrast to social work in order to build the foundation for new, improved practice. In this way, it will be interesting to use the experience-based knowledge Teater nonStop has developed over many years and write a chapter on what the field of social work can learn from disability arts to fulfil its actual mission.

The wonder of the anomaly led to a new conversation between Line and me, which became the data basis for this chapter. Here she described the working methods of the theatre based on the last two productions of the ensemble, and we analysed and explored them in light of findings from my own research. The result is a text that seeks to describe the theatre's working methods, and to understand them in contrast to a somewhat darker picture: exploring the contrast between what Ellen Saur and Oddbjørn Johansen (2013a) refer to as the art discourse and the help discourse. My purpose is not necessarily to provide a direct representation of reality, but rather to use knowledge that has been developed over time in Teater nonStop to improve social work practice by exploring the question: What dimensions of Teater nonStop's methods of creative work with actors with intellectual disabilities help to promote ownership in ways the field of social work can learn from?

First, I describe Teater nonStop, accompanied by a contextual description of social work in the everyday lives of persons with intellectual disabilities. Then follows a section on methodological approach, followed by analysis, and finally, discussion.

Teater nonStop

Teater nonStop is a professional theatre ensemble of 15 actors with intellectual disabilities and six social educator students, started in 2008 by Ellen Saur and Oddbjørn Johansen, as a research project in the social education programme of Nord-Trøndelag University College, now Nord University. Teater nonStop's stated purpose was political, contributing to social change by being a voice for people with intellectual disabilities as a group (Johansen & Saur, 2010). This happens through conveying the actors' own experiences and stories (Saur et al., 2012), promoting their aims and interests artistically and politically (Saur & Johansen, 2013b), plus developing tools in working with artistic processes (Saur & Johansen, 2013a).

Early key productions were *The Story of Me*, describing the actors' own thoughts and experiences, *A Cup of Coffee, Perhaps?*, a documentary piece about the actress "Anne" who was sent to a special school far away from her family as a child, and *I-You, Us-Them, Inside-Outside*, which explored contradiction and belonging through jazz improvisation and dance (Saur & Johansen, 2013a).

Since 2013, Teater nonStop has been owned by Namsos municipality and led by Line Strøm, a professional dancer and choreographer. The descriptions in this chapter are based on Line's work and methods developed from 2013, building on an already established foundation by Saur and Johansen. The ensemble has always practiced an exploratory approach, evolved by testing a variety of methods. With improvisation as an important element, themes initiated by the actors have been worked on to become plots and sequences (Saur et al., 2012). The work has, however, been further developed in recent artistic productions, notably through collaboration between Line and jazz musician Stina Moltu, in the productions *When the World Is Quiet* and *Sparkling Stick*. These were created through working with smaller parts, and pilot screenings, where one develops and tests material for larger productions over several years.

Some of the actors have worked in the ensemble since its inception, while the social educator students change every year. Therefore, students and actors are not equal in terms of artistic experience. The actors become carriers of the ensemble's culture, and are given a training function vis-à-vis the students, through the transfer of work methods and learning expressions and productions (Saur & Johansen, 2013b). This was also the background for the establishment of Teater nonStop as an alternative practice arena for social education students, justified by Saur and Johansen (2013a), by referring to the difference between a theatre-discourse and a help-discourse. The help discourse will be elaborated on in the next section, and is the one that characterises most lives of people with intellectual disabilities. The theatre discourse can be understood through the disability arts tradition. This has emerged as a criticism of the fact that artistic processes for people with intellectual disabilities have mainly had a therapeutic or educational focus, which provoked a movement demanding recognition as professional artists on a par with others (Hargrave, 2015). Teater nonStop can be framed within this discourse, by focusing mainly on the artistic product and performance (Hargrave, 2015).

Social work in everyday life for persons with intellectual disabilities

The help discourse can best be understood through existing knowledge of the everyday lives of people with intellectual disabilities, and their position in society. Historically, people with intellectual disabilities have experienced severe oppression, and are also currently marginalised due to low levels of citizenship and advocacy (Witsø & Hauger, 2020; Østern et al., 2023). Therefore, the services offered to the group in the Norwegian context are based on strong political intentions, with an emphasis on normalisation and human rights. Norway underwent a deinstitutionalisation reform in the 1990s, in which people with intellectual disabilities moved to live in ordinary homes receiving help in their own municipality (Tøssebro, 2019). Norway has further, in 2013, ratified The Convention on the Rights of Persons with Disabilities, CRPD, from 2006 that consolidates the human rights of people with intellectual disabilities, by shifting several key paradigms thus enabling the achievement of human rights for the group (Skarstad, 2018). One moves away from a medical definition of disability based on the individual's impairment or diagnosis, to a human rights/relational understanding, in which disability is seen as the gap between the individual's prerequisites and the demands of society along with its disabling barriers (Molden & Tøssebro, 2009). Thus, it is emphasised that the achievement of human rights should not be dependent on the individual's specific capacity, but something that can be realised through supporting relations (Skarstad, 2018). In this way, lack of facilitation is understood as discrimination (Skarstad, 2019), and the convention marks the transition to a feminist orientation, where people are understood to be mutually dependent on each other (Mackenzie, 2019).

Although the definition of social work varies between countries, the field is based on a relatively common purpose and values, focusing on assisting vulnerable groups and ensuring human rights, especially related to self-determination and participation in society (International Association of Schools of Social Work (IASSW), 2018). For people with intellectual disabilities in a Norwegian context, these empowering relations are assigned to the social educator profession, a uniquely Norwegian hybrid between social worker and nurse.

These ideals were the background for my own research, focused on the human right to self-determination for persons with intellectual disabilities

living in group homes. What I found is in line with existing research in the field, across borders, when the contexts are otherwise comparable. The right to self-determination was not realised due to institutionalisation within group-homes (Björnsdóttir et al., 2015; Guddingsmo, 2019; Löve et al., 2018; Murphy & Bantry-White, 2020). This climaxed when the participants stated, ‘The House decides.’ We see here a system where one is subject to norms one has little or no control over, one just had to comply (Guddingsmo, 2019). By this logic, staff became gatekeepers, with the power to inhibit or promote the individual’s power in everyday life (Guddingsmo, 2020). This created a situation of resignation, where they felt there was little point in putting their own perspectives into words – both because they thought they would not be accepted, but also from a lack of facilitation on the part of the staff to help uncover these perspectives (Guddingsmo, 2019). From this, my study revealed a need to develop methods to facilitate processes in which persons with intellectual disabilities themselves deliver the premises (Guddingsmo, 2022).

Method

The story of this chapter is based on a conversation between me and Line in the spring of 2022, dealing with the core of the working methods of the theater. It consisted of an already adapted narrative, created to accommodate our shared understanding, and encompassed what we perceived as interesting in the meeting between our academic communities. The focus was initiated by me, based on my knowledge of being involved in the work of the theater’s processes via the students, through whom I have developed an experience of issues I felt should be described and further explored. Similarly, Line’s storytelling is based on her own experiences of her work as artistic director. It describes how she prefers to work as an artist, but also her experiences of the best approach to use upon in the theater. Thus, the description becomes a narrative, which is a constructivist synthesis of our common reflections and experiences, our core opinion of the current “best practice” artistic work form of the ensemble.

Our joint experiences are further based upon arts-based, action-oriented, experimental processes conducted over a long period of time. This implies conducting research through artistic processes based on the ontology and epistemology of action research, whose purpose is to help the world fulfil its unfinished business by developing knowledge for the benefit of the

research participants (Finlay, 2011; Gergen & Gergen, 2008; Laursen, 2014). This implies, on the one hand, that knowledge lies implicit in the event itself – representing a form of causal truth by actually happening (Laursen, 2014). At the same time, knowledge is also developed over time through a constant spiraling process of action and reflection (Coghlan & Brannick, 2010). Thus, knowledge production is something that takes place primarily through practical implementation (Laursen, 2014). This chapter describes the result of such a process in terms of an experiential model, developed over time in interaction with actors, students, and other professional artists since 2014. The presented knowledge must therefore be understood as being based on years of analytical work, from within the theatre's constant reflective development processes.

Therefore, the research must also be recognised to include some autoethnographic aspects, being based on the lived experiences of myself as well as Line, making us both researchers and participants at the same time (Anderson, 2006). However, the material has been split in its further presentation. A description of the theatre work methods has been subjected to further analysis, while the perspectives from counter-descriptions of the field of social work form the basis for the framing and discussion part.

The conversation lasted one hour and 45 minutes, and was audio recorded and transcribed. Descriptions of the working methods of the theatre were further analysed by a narrative approach inspired by Catherine Riessman (2008), with the intention of keeping the story about the form of the work as intact as possible. The text was divided into sequences, which were each given a name and description, based on the theme they represented in the narrative. The content of these was further condensed, based on what could be interpreted to constitute the core of each theme. Thereby, the analysis distilled characteristic elements into a condensed narrative of Line's work. To tie this more closely to her voice, all quotes reproduced in this chapter are based solely on her statements.

Ethical considerations

Persons with intellectual disabilities may constitute a vulnerable group in research by being subject to the stigma of their diagnosis. Research on the group must therefore take special care not to exacerbate their position in any way, either personally or on the societal level. Therefore, the analyses in this chapter are based on technical descriptions of the actual working

methods, which are further understood on a general level, based on already published research that deals with the group per se, not the individual actors. Because of this, the strength that could have come from including the actors' own perceptions is missing. Simultaneously, the uncertainty embedded in the current description allows us to address issues that would be problematic if they had been linked to recognisable, employed actors.

The guiding principle of Teater nonStop is that students and actors participate equally in the artistic processes. However, there is a need for students to take on both helper and leadership roles in the daily running of the ensemble. Thereby a power imbalance may arise. That is why I use the terms "actor" and "student", respectively, even though they work together artistically.

Opening up the practice of leading Teater nonStop

In this sub-chapter I conduct a thematic analysis of the research material, the recorded conversation between me (the author) and Line. The main themes examined through the analysis are: *a process for ownership; interacting with abstract impulses; structured improvisation; individual diversity; and, a professional artist mindset.*

A process for ownership

I have always been fascinated by getting things out of individuals. ... That everything should be owned and personal, before it comes out in some expression.

Line describes this as her personal orientation, but also as an overarching goal of the theatre: to promote empowerment in the creative process, and ownership of the artistic product by the individual.

That's the way I like to work. And then of course it has to do with things I've done in the past as well, as a performing dancer, that it's sort of the way of working ... you get something personal from those you're working with.

The work is described as a process, starting with a basic idea initiated by Line as the artistic manager. This idea is focused on a main goal: That it will be a performance, but is otherwise very little bound by form. The process is open-ended:

A process that goes on, all the way until we finish the product. We don't know what happens through the process, right.

In this way, Line describes emphasising the promotion of ownership of the artistic product by the actors, by means of offering both an idea to hold on to, and an openness for actual involvement.

Interacting with abstract impulses

The performance is further built around developing expression based on input from abstract impulses, that sometimes appear ephemeral even to Line herself.

I do envision lots of images, all the time. It's like a... I don't know, it's like a dream often, or it becomes sort of fleeting, fragments like. Who gets meaning anyway and fits together in the end. ... It could be objects we're working on. Or clothes. Or costumes. Umbrellas. Anything.

The forms of expression are varied. Words do not have to be performed as text, but conveyed through song, as writing, or played as a soundtrack. Thus, the working method consists of working with fragments, images, and detached pieces, which become sequences that make sense and fit together in the end, in a holistic expression. The elaboration process is facilitated through active co-creation, where Line leads the processes interacting with the actors.

I'm open to anything they come up with ... some nuggets or something that we can work on. Or we get a new idea based on what they create. ... The production or what we're working on is constantly in that kind of flow, where one thing leads to something else, based on what they come up with. ... It could be a sentence in a text they've prepared. And somehow, then, where some symbolism emerges, for example, then ... I imagine something in the form of movement then, or physical theater, something that we can work specifically with, and explore.

The individual's personal quality of movement could be an impulse to base the work upon.

Quality of movement fascinates me. You move, that is, if you are out dancing, freely, then you have such peculiarity. ... And then, just to sort of, grab, exactly, your quality of movement. What can we make from it?

Concurrently, such important impulses can be anything, and appear at any time.

It happens in every rehearsal. These things. Something appears, either from something done, or a comment towards what we're doing. Something we can address somehow!

Thus, Line describes how artistic expression is created from the juxtaposition of a synthesis based on smaller components developed from what emerges in an abstract, impulsive landscape.

Structured improvisation

Further, the expression is created through improvisational processes, based on the individual qualities of the participation they have there and then. Working through such improvisation helps ensure ownership.

If it's short pieces of planned choreography, it is theirs too, because first it was made from improvisation. Where everyone participated, and we took care to include everyone's moves. And then maybe I can work on it afterwards, right, giving it a different quality or dynamic. Work on such things afterwards.

The improvisational approach is also included in the performances, which expand the possibilities for expression.

There is something about that space and that openness ... Something like that creates less stress, I think, for the actors. And there's another nerve in it too, because they have to constantly research what they're performing.

From this, the expression is perceived as more genuine, through being immediate. Simultaneously, the expression is held together through co-created processes, similar to the preparation phase, but now between actors and musicians.

Interaction is alternate. Sometimes it's the actors who get a cue from the music. And then other times, in the same scene, it's the actors who give a cue to the musicians.

So, the work is bound by what Line calls structured improvisation, as there are frameworks and/or a concrete focus to work upon.

... when we worked with tranquillity, a part of this water theme, then we worked on focusing on breath, and sort of feeling if the body is ever completely at rest. There's always something moving. And then they explored it sort of from the core of their bodies. And then the movements have evolved and increased, but all the movements come from breath and from the core. ... like water running in the body, or like insects. That's the starting point But you're standing in a space in the room, and then you can start moving on it. This is where the structured comes in, by researching different ways of getting movement out from the core.

Thus, structured improvisation promotes the actor's voice in the expression, by offering a framework for interactive collaboration, emphasising immediacy and genuineness.

Individual diversity

Line also bases the creation processes on adaptation to the individual preferences and needs of the actors.

Because they like different things. ... Some lean more towards instruments. Yes, some actors love to dance. Some would like to speak.

These preferences are likely interpreted from how the actors relate in the situation.

If we're working on something, and that person might not have been so into exactly that, but then suddenly that person pulls towards the band.

Concurrently, varied ways of working help to maintain concentration and interest among the actors.

It's something they've expressed themselves too Yes, it's cool that we work on this and that part before lunch, and then there's text work afterwards, or vice versa.

The individual's unique involvement can further become impulses for expression in the performance:

One day, an actor is working really well on what we're doing right then. Then this might become a solo.

Thus, individuals have room, while collaboration requires adaptation:

One has to learn to not lose what you're doing, but rather make what one is doing become part of what the others are doing.

However, this requires a special involvement on the part of the actors in terms of concentration and openness. In this way, the working form is described as flexible, offering space for individual diversity, to make the work inclusive and motivating. This same flexibility is simultaneously demanded from the actors, craving them to work professionally.

A professional artist mindset

That's what's so cool about the actors in the theater, that they're open to trying everything out. ... If you work with other professionals or in other arenas, schools and such, you can get a different attitude. You can't work well enough with what you want, because they might think things are a bit like... weird or lame, or 'I don't want to do this', but... Well, it's such a safe environment in the group, that they can go along, trying anything out. New things. ... So, there is such good focus and calm in the group, when we're working. Once we've finished talking, of course.

Thereby work in the theater is described as demanding for the actors, something that must be considered.

It can be demanding for anyone, to work physically and creatively. You have to think and come up with things during a whole working day. So, yes. ... Artists don't need breaks, right, but you have to have some breaks. A variety, who keep their focus and desire to contribute.

Simultaneously, Line acknowledges the challenge of resisting the impulse to keep going when in a productive state. There are proper artistic processes going on, with all that hard work entails. Thus, the students' function in the theatre depends on their being able to adopt an attitude as equal actors in a co-creative process and perceive themselves as artists. This can be demanding, since at the same time they are social educator students in the process of being socialised into a slightly different professional role.

I think, probably, at the start of the theatre practice, they suppose they're there as... helpers. When working creatively, it could be like: 'I'm not doing this movement,

I'm only here to make sure that she gets off the floor'. But they're not, right. ... They're there to be creative together. They don't always get that right away.

Line observes that the actors have high standards for their input, due to their openness towards explorative processes. This brings an artistic professionalism to their work, demanding that the social educator students follow up by interrelating on equal terms and perceiving themselves as artists. This shift, however, reveals conflicting definitions of the students' perception of being 'helpers' versus co-creators of art.

Providing space for creativity – a discussion bringing in theory

The analysis reveals a working method that is open-ended, process-oriented, and based on collaborative interaction between the actors, students, musicians and Line herself. As artistic director, she constantly retains some form of control of the process but bases it on focusing on promoting the voice of the actors through the work. This is resolved by beginning with fragmented inputs, and providing structured improvisations where actors explore based on their own impulses. Thus, the final product emerges from a collaboratively constructed framework, offering containment to further expression, which is improvised and immediate, while being jointly owned by all the performing artists. The working method thus consists of a synthesis of improvisational dance, music and theatre – because these are the approaches the instructors in Teater nonStop have used. Thus, principles of improvisation underlie the work form as a fundament. Line describes the method as being based on how she prefers and has learned to work, as an artist and through her education. From this, what is described is not specific to this ensemble, but represents common ways of working in similar artistic fields (Sommerro & Steinsholt, 2006).

The data material for this text, originates, as stated, from a conversation between Line and me, founded on a joint exploration of the differences between our fields of work: the methods in the theatre opposed to findings from my research. In the conversation, the contrast was described through 'The House', a theoretical construction based on the research participants' reference to the group-home as a living organism with overarching power in everyday life (Guddingsmo, 2019). These narratives correlate with other research, stating that despite political intentions of normalisation,

group-homes for persons with intellectual disabilities tend to develop institutional features (Murphy & Bantry-White, 2020; Witsø & Hauger, 2020). According to Goffman (1968) existence within such institutions is subject to formal administration, since life is regulated by rigid structures where the inmates are completely subject to the staff's control. When pronounced control is carried out through rules and restrictions in areas where one would otherwise act freely, the result is conditions completely destructive to the autonomy of residents (Goffman, 1968). My study participants said they needed to ask The House for permission (Guddingsmo, 2019). On closer inspection, however, it was the staff who were in power, whereby the participants defined their own self-determination to be what they were permitted to decide, when the staff had decided they were allowed to decide something themselves (Guddingsmo, 2020). The criterion for being granted self-determination, was whether they were going to make the decision the staff perceived as right (Guddingsmo, 2020). Thus, they had few other options than to be 'good' by adapting to the norms of The House (Guddingsmo, 2020). This put the residents in an unfortunate position, because they needed to perform as well-functioning and well-adjusted to be recognised as autonomous persons (Guddingsmo, 2020). Because of this they were excluded from gaining a positive identity as intellectually disabled, since they had to adapt and appear to be a person without intellectual disabilities to be allowed to decide for themselves. In this way, a real opportunity to convey one's own perspectives disappeared along with an opportunity for ownership (Guddingsmo, 2020, 2022).

From this, it becomes clear how work in the theatre represents a completely different openness, by offering a different space to create on behalf of oneself. The openness is embedded in the very basic philosophy of Line's work, described as being oriented towards "whatever the actors can come up with". The individual's input does not have to be expressed in any particular way, but emerges from an active search for the actor's perspectives through involvement on Line's part. The search occurs through several means, including emphasising explicit statements, and improvising based on an individual's authentic qualities and presence, with a focus on their core expressed through breathing and movement. This means that perspectives that would otherwise be tacit are conveyed. Simultaneously, openness exists in improvisation itself, from the obvious premise that expression will become somewhat different every time. Thus, a framework is offered that both opens perspectives, but also becomes something to hold on to – a

point of reference that ties everything together. Such structured formats can thus conceivably offer extra potential for artists with cognitive disabilities, because they are offered a tool that both helps staying focused and expands the space of possibilities.

Thereby, openness in the theatre can be understood to be based on a completely different recognition of the individual's rationality and individuality than *The House*. According to Axel Honneth (2007) recognition is always based on reciprocity, founded on the expectation of respect for each other's honour, dignity, and integrity. It is described on three levels where: *love* is about being met by others by virtue of one's needs; *legal recognition* is about being perceived as a rational person; and *solidarity* is about being recognised by virtue of one's uniqueness – not by your contribution, but by who you are (Honneth, 2008). For people with intellectual disabilities, however, the challenge is often like in *The House*. Here recognition is threatened when the individual's rationality, opportunities, and value are measured on the basis of the individual's specific capacity, since disability is understood within a medicalised, individual model (Guddingsmo, 2022). This oppressive situation is often reinforced by the stigma that accompanies the diagnosis, in which the perspectives of people with intellectual disabilities can be given less value or labelled as irrational, regardless of their actual quality (Kittelsaa, 2011).

However, in debates on participation and ownership, independence must be regarded as both an ideal and a challenge. It is, to a certain extent, a stated ideal within both disability arts and disability research, that leading functions should be held by persons who themselves have disabilities (Hargrave, 2015; Oliver, 1997). This attitude is based somewhat on the premise that genuine liberation takes place from the bottom up, on the oppressed person's own terms (Freire, 1970). Despite good intentions, one simply cannot trust that those who are not in the same situation can know the exact problems or represent the group's genuine attitudes. Therefore, the highest levels of participation precisely describe processes that are managed independently of other helpers or facilitators (Arnstein, 1969).

However, this ideal of independence to attain rights and advocacy becomes problematic, given that one needs help from someone. Having intellectual disability entails, for example, having challenges with learning or remembering things, and denying this would also be discriminatory (Tøssebro, 2010). Therefore, requiring independence as a basis for understanding an expression as authentic will provide a capability-oriented

approach, where the individual's recognition on the level of solidarity is not linked to the individuality of the individual, but rather to the individual's contribution (Honneth, 2008). This is why CRPD is moving to use a relational understanding of disability: The need for support shall not be an obstacle to human rights achievement. In this feminist, relational paradigm, all people are understood to constantly live, and function, interconnected with each other (Mackenzie, 2019; Skarstad, 2018).

In this way, the working methods of Teater nonStop also represent extended recognition through facilitation itself, by offering empowering relations through an active search for the actors' perspectives. When Line grabs the inputs that comes along and processes them towards a stronger and more expressive artistic product, she offers a facilitative interaction. In this way, the work becomes a common interactive matter, where the individual artist makes an impact through their unique contribution. This thus reflects a relational understanding of disability, similar to that used in CRPD, where problems and solutions are understood in relation to both the individual and the structural level (Tøssebro, 2010). At the same time, Line also takes an affirmative position, through treating disability as a natural part of the human being, as well as of artistic expression (Stober & García Iriarte, 2023). This opens the door to being a creator of one's own norm, and the tool becomes liberating through dialogue based on recognition (Freire, 1970). However, such relationships can become inhibiting through helpers taking on a gatekeeper position where you are deprived of the power to define, if you do not say or do the *right* things, or express yourself in the *right* way (Guddingsmo, 2020). However, Line uses a broad understanding of what should be understood as expression in her facilitation. Everything becomes language, not just the verbally spoken. Ellen Saur and Alexander Sidorkin (2018) argue for precisely such an understanding of language, by showing the need to switch to a posthumanistic approach to dialogue, because this expands recognition of the human to encompass more than a traditional understanding equating rationality with verbal expression.

Returning to the beginning of this chapter, the quote by Line helps substantiate the sole importance of using ephemeral ideas: The vagueness in imagining, for example, a fur coat, seems to secure the bottom-up perspective. When the goal first and foremost is conveying *something*, this opens the possibility for not conforming to perform on other people's terms, by not requiring specific levels of achievement or understanding to facilitate communication. The ephemeral and diffuse ideas provide

space for the individual to give them content based on their assumptions. Thereby, the improvised and abstract ensure an experience coming from the stage expression, however unique to each performer and audience member, because nothing is required to be told or experienced in a specific way. This makes the format more inclusive for both performers and audiences.

This necessarily also provides space for authenticity. To clarify, this is a different understanding of authenticity than the anthropological cultivation of *the original*. People with intellectual disabilities can hardly be understood to be more 'real' than others, since they, as mentioned, must often put strong restraints on what they express and do, to be recognised by their surroundings in everyday life. Rather, this refers to the authenticity required to ensure real ownership within an empowerment-oriented understanding, which is the very prerequisite for the oppressed to be able to own definitions of themselves, their own oppression, and liberation (Freire, 1970). There is always a danger that oppressed people would rather take on other people's definitions to avoid stigma. This is what Catriona Mackenzie and Natalie Stoljar (2000) refer to as the socialisation problem: How can one know that a perspective is one's own, if you live in an oppressive environment? Carl Rogers (1961) points out that an open attitude in therapeutic relationships, built on basic respect for the other, will lead to the self-actualisation tendency to kick in, and will allow the individual's own wishes, wills, and perspectives to emerge in the consciousness, together with a more positive view of oneself and one's own identity. And even if the purpose here is not therapeutic, one must realise that participation in society requires that the voice one should contribute to the context vocals the person's or group's actual, not token, perspectives (Arnstein, 1969). As I see it, the story of Teater nonStop's work form contributes important knowledge of how to create just such a space. At the same time, it shows that much of what has traditionally been framed by cognitive impairment is the result of oppressive structures in the environment. In this way, the working method can be understood to curb both social and biological barriers to creativity. On the one hand, it is not really so strange that work in theatre facilitates this in a good way, since you need to be able to be authentic, to be truly creative (Thomson & Jaque, 2017). At the same time, it is also important to point out that art has its limitations. There is an assumption that it is redemptive to be involved in creative processes. However, one must realise that not all artistic involvement is either liberating or based on

authentic expression (Hughes & Nicholson, 2016). This implies that underlying attitudes, rather than art itself, holds the power of securing ownership.

Concluding remarks

The anomaly of imagining a fur coat pinpoints how the theater's work form provides completely different spaces for expression than what is presented within social work, through allowing ownership and empowerment. The work forms inhibit appreciative attitudes towards the actors, which both enables free creativity, and also empowers through facilitative relations in open-ended, collaborative processes, creating a dynamic space for expression. This prevents the risk of the actors adapting to perceived expectations, which is often the case in everyday lives in the group homes, characterised by a completely different conformity hindering the conveyance of personal perspectives. The theater's commitment to openness and creativity provides an alternative model for social work to learn from – one that values individual input, and actively seeks diverse expression. There is reason to assume that this model also affects the students' learning outcomes in practical training. However, their participation in the ensemble is multidimensional. It includes both participation on an equal footing in the joint artistic work processes, and professional responsibility for facilitation in the same arena. The role of the student has not been elucidated at this point, but the results from this discussion provide a basis for further exploration of theatre as a learning context for social work students.

Author biography

Hilde Guddingsmo has a PhD in social work from NTNU Norwegian University of Science and Technology, and works as an Associate Professor at the Faculty of Nursing and Health Sciences, Nord University. Her research delves into the realms of pedagogy, theatre- and drama methodology, creativity, human rights, social work, inclusive methods, participatory processes and disability arts. She is particularly focused on self-determination for persons with intellectual disabilities living in group-homes, exploring the use of creative methods in research to enhance empowerment and participation. Her work seeks to amplify the voices of this marginalized group, often overlooked in mainstream discourse.

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CHAPTER 12

Towards a Crippling of Research Practices – Peeling off Ableist Structures in an Arts, Culture and Disability Researcher and Commissioner Collaboration in Norway

Tone Pernille Østern NTNU Norwegian University of Science and Technology, Norway

Terje Olsen Fafo Institute for Labour and Social Research, Norway

Elen Øyen DansiT Choreographic Center, Norway

Lise Lien Norwegian Church City Mission, Norway

Lene Christin Holum Sunnaas Rehabilitation Hospital, Norway

Anne Ogunidipe Arts and Culture Norway

Kaja Tvedten Jorem Arts and Culture Norway

Abstract: This chapter offers a critical look at how five disabled and non-disabled researchers, and two commissioners experienced working with the project *Artist – an accessible profession? A research project about artists with disabilities in Norway*. Understanding the project as a collaborative learning process, they generated research material for a post-project study through writing reflective notes prompted by the two questions: *What surprised me? Were there specific learning moments in the project?* Dialoguing with theory from co-design research in critical disability studies, they scrutinize their own narrated experience and arrive at insights about: how *embodied knowing* and nuances of *crip time* – articulated as *slow time and timing, sustainable time, and time as a site of care* – could challenge ableist structures of *theoretical knowing, efficient time and timing, competitive time, and time as something to control*. Without conscious action, such ableist structures risk reproducing themselves not only in arts, culture, and society, but also in research projects that critically examine precisely these ableist structures.

Keywords: ableist structures, co-design, collaborative learning, crip time, shifting power in research

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This chapter is a critical inquiry into the collaboration between the researchers and commissioners behind a research project initiated by Arts and Culture Norway, titled *Artist – an accessible profession? A research project about artists with disabilities in Norway* (Østern et al., 2023). This was the first commissioned research project on disabled artists with a required participatory method by Arts and Culture Norway,¹ and as such it indicates a shift in the focus of the authorities funding professional arts in Norway, from which disabled artists have been largely ignored and excluded. In the project, interviews with disabled artists, as well as with leaders of arts and culture institutions, were the main research material generated and analyzed with the aim of revealing barriers and enablers for disabled artists in Norway (Østern et al., 2023). In this chapter, we scrutinize the collaboration in the project between the five researchers and two commissioners, who, in different capacities, worked towards identifying barriers and enablers for becoming and working as a disabled artist in Norway.

The five researchers who carried out the original research (Tone Pernille Østern, Terje Olsen, Elen Øyen, Lise Lien, and Lene Christin Holum) and the two senior advisers who managed the project on behalf of Arts and Culture Norway (Anne Ogundipe and Kaja Tvedten Jorem) have written this chapter together. In the original research project, the research team worked independently, and in accordance with established principles of academic freedom. Thus, the research team was responsible for choosing relevant theoretical perspectives and methodologies, and for carrying out the research. The arguments and findings in the resulting report (Østern et al., 2023) are entirely their own. Throughout the process, however, there was ongoing critical and constructive dialogue between the researchers and the commissioners, and both parties worked collectively so that the research project might produce as much insight as possible on the barriers to and enablement of becoming and working as a disabled artist in Norway. In this post-project study, we look back critically on our process, and ask: What insights on structural barriers for co-designed research can be learned from a collaborative process between disabled and non-disabled researchers, and commissioners in a research project about arts, culture, and disability in Norway?

1 <https://www.kulturdirektoratet.no/english>

We will first present a background for and summary of the original research project. Next, we present the backgrounds and experiences that we brought into the team. Then, we move on to the theoretical perspectives we dialogue with (Fraser-Barbour et al., 2023; Goodley et al., 2019), as well as a short methodological description of how we conducted this post-project study. Finally, we analyze and theorize from our collaborative process, offering insights that might be of interest to other collaborative teams researching arts, culture, and disability.

The geo-political context of Norway, and a short summary of the research project

The original research project is situated in the geopolitical context of Norway, a country with 5.4 million inhabitants in Northern Europe. While equal opportunity for all is a stated sociopolitical goal in Norway, through laws like the Working Environment Act and the Equality and Anti-Discrimination Act, reports and research indicate that equity is not fulfilled for people with disabilities. Statistics from Bufdir (The Norwegian Directorate for Children, Youth and Family Affairs)² (2023) reveal that people with disabilities are marginalized and underrepresented in several areas of Norwegian society. For example, only 41% of people with disabilities are employed, and 30% of those not employed wish to work (Bufdir, 2023). Bufdir's statistics further reveal that disabled students, to a clearly lower degree, continue on to higher education compared to non-disabled students (Bufdir, 2023). A survey on Norwegian cultural institutions and diversity from 2021 showed that only 36% of the surveyed institutions focus on disability (Rambøll, 2022). Our own research (Østern et al., 2023) uncovers similar structural ableism and discrimination in the arts and culture field in Norway. Our research correlates with similar European reports, which all point in the same direction: there are massive barriers in the arts and culture field, and in higher arts education for people with disabilities to become artists and work professionally as artists (Arts Council England & EW Group, 2017; Floch & Portoles, 2021).

2 <https://www.bufdir.no/om/>

The original research (Østern et al., 2023) utilized a qualitative design, using semi-structured interviews to generate research material, which consists of interviews with 45 leaders from the arts and culture field, including higher arts education, and 19 disabled artists. In the analysis the researchers activated system critical and critical disability theories to understand how arts and cultural institutions exist within a social and material field characterized by ableist norms, values, power structures, and organizational forms (Kuppers, 2001; Mark, 2006; Meekosha & Shuttleworth, 2009; Vassenden & Bergsgard, 2011). Summarized, the research found that the barriers for artists with disabilities in Norway are deeply rooted, multifaceted, and systemic. The two strongest barriers from the disabled artists' perspectives were identified as lack of access to higher arts education, and weak finances arising from a lack of collaboration between artist grants and disability benefits from NAV, the Norwegian Labour and Welfare Administration (Østern et al., 2023). Other barriers that the research identified, based on the artists' perspectives, were (Østern et al., 2023): the majority has the defining power; closed artistic networks; the Arts Council Norway and other funding authorities as gatekeepers; lack of interest in disabled artists by institutions that produce and present art; low representation in influential organs and positions; weak audience interest; stereotypical roles in film and theatre; artistic production and touring characterized by a demanding work culture on the majority population's terms; patronizing attitudes and low expectations; and weak universal design of workplaces, educational institutions, and webpages. The barriers often occur in clusters, where one leads to another.

The research resulted in 10 recommendations for long-term efforts with targeted measures, combined with more general sectoral change (Østern et al., 2023). One recommended field of action motivates this post-process study:

Field of action 9

Collaboration in artistic processes, as well as in research, should be developed as a guiding principle across the arts and culture field, educational institutions, and academia. The whole field should transform from *about* to *with*. Artists with disabilities should be given a clear voice in the creation of practices and storytelling in the field. (Østern et al., 2023, p. 22)

The backdrop for the research, and our trajectories into this team

In 2020, the Norwegian Ministry of Culture and Equality assigned the Arts Council Norway, now Arts and Culture Norway, the role as national coordinator for increased diversity, inclusion, and participation in the arts and culture sector (Ministry of Culture and Equality, 2020). Arts and Culture Norway is

the main governmental operator for the implementation of Norwegian cultural policy. Arts and Culture Norway functions as an advisory body to the central government and public sector on cultural affairs. Arts and Culture Norway is fully financed by the Ministry of Culture and Equality. (Arts and Culture Norway, n.d.)

Arts and Culture Norway thus wields a lot of power in the arts and culture field in Norway, and our research (Østern et al., 2023) reveals that they have previously functioned as a barrier to the development of the arts as a field available to disabled artists. Their new role as national coordinator for increased diversity, inclusion, and participation in the arts and culture sector led to a considerable shift towards a clearer focus on diversity and inclusion for Arts and Culture Norway, which supported the cultural political goal of a relevant, representative, and accessible arts and culture field (Ministry of Culture, 2018). Arts and Culture Norway, in their new role as national coordinator, promptly initiated a pilot project, which resulted in a report arguing in favor of knowledge-based, long-term diversity work (Ogundipe et al., 2020). This report was co-authored by one of the senior advisors, who acted as a representative of the commissioner for the original research and co-author of this chapter, Anne Ogundipe. The report reveals considerable gaps in knowledge about deaf and disabled artists, and a need for targeted efforts to remedy these gaps.

In addition to the report, a comprehensive dialogue between Arts and Culture Norway and relevant actors in the sector was led by the other senior advisor, who acted as a representative of the commissioner for the original research and co-author of this chapter, Kaja Tvedten Jorem. In a reflective article about what she calls “the ‘disability revolution’ in the Norwegian arts sector,” she writes, “Speaking to hundreds of artists, colleagues, activists, and institutions to inform our role, we had to acknowledge that we had

very limited understanding of people with disabilities as artists, cultural workers, and changemakers in the sector” (Jorem, 2023, unpaginated).

The report co-authored by Ogundipe, as well as extensive dialogue with the field led by Jorem, formed the background for initiating the research project *Artist – an accessible profession? A research project about artists with disabilities in Norway* (Østern et al., 2023). The call to apply for leading the research project was announced through an open competition in 2021 (Arts Council Norway). A requirement for applications was that the disability movement philosophy, “nothing about us, without us” (Charlton, 2000), would guide the research. This caught the original researcher group’s attention, as this was something radically new in arts and culture research commissioned in Norway – indeed a long wished for ‘disability revolution’ in this country.

The Fafo Institute for Labour and Social Research, in partnership with the Department for Teacher Education at NTNU Norwegian University for Science and Technology, applied for, and were assigned, the research project by Arts and Culture Norway. Fafo is an independent social science research foundation, which develops knowledge on the conditions for participation in worklife, organizational life, society and politics, the relationship between politics and living conditions, as well as on democracy, development, and value creation. Three researchers from Fafo participated in the project. Terje Olsen has been working with disability and participation for many years, with a special focus on hate speech towards and exclusion from the labor market of disabled people. Lise Lien has previously researched exclusion based in racism in the film industry in Norway. Lene Christin Holum, a psychologist, has researched inclusion and exclusion mechanisms in the labor market.³ Two researchers from the Department of Teacher Education at NTNU also participated. Tone Pernille Østern and Elen Øyen have a long history of working together as artists, researchers, and teachers in the fields of dance, performing arts, and education (19 years as this chapter is written). Through their collaborative work they challenge ableist normative ideas about dance, bodies, and education, and aim at expanding and changing arts, education, and society towards more equitable practices. They have critically scrutinized their own collaboration, and the dis/privileges they face in their work as disabled

3 Lien and Holum have since then moved to other workplaces.

and non-disabled partners (Østern & Øyen, 2014a, 2014b, 2015). Øyen has spina bifida and uses a wheelchair. Østern has a permanent position at the university, whereas Øyen was employed in a part time position at the department for 13 months, through the funding received for the original research project. As this chapter is written, Øyen is employed in a position as dancer and producer at DansiT Choreographic Center, whereas Østern continues at the university.

Thus, a research team consisting of five co-researchers with and without disabilities, and different routes into the field of critical disability research, took on the task of the original project. Representatives from Arts and Culture Norway – the commissioners – were involved in the process to support and have critical conversations about the emerging report throughout the whole duration of the research project from December 2021 to the launch of the report in April 2023. In this sense, we became a collaborative team and thus, as all collaborative teams, needed to work with the ableist structures that also occurred within our collaboration.

Understanding our research as a collaborative learning process

We think of our co-designed research as collaborative learning (CL), a learning process that implies groups of actors working together on learning and understanding in small groups. These are social processes, which involve joint intellectual efforts from smaller group projects as part of cooperative learning. CL has been applied in disability studies for at least a couple of decades, in a rather diverse manner. One part of the literature in this area describes a multitude of participatory action research, aiming to bring persons with disabilities actively into developing new knowledge and understanding in areas such as living conditions, welfare services or well-being (see Kninckel et al., 2019; Pollard et al., 2004). Another part of the literature in this area is focused upon developing new understanding, better services or improved schooling and educational resources, and emphasizes the situation for persons with intellectual disabilities and severe impairments (Aristizábal et al., 2017; Ashman & Gillies, 2013). A third part of the literature is technology-oriented, aiming to develop new and better technology, or utilizing already existing technology in new and better ways (see Adeleye et al., 2024; Jimenez et al., 2017; Ramos et al., 2022). These three variants obviously overlap in different ways, and our variant of CL

has a sort of kinship with all three mentioned above, aiming to develop new knowledge on the working conditions for artists with disabilities, as well as information about people's experiences with the education and admission requirements in academia, public welfare, and welfare administration routines.

We define CL in line with what Marjan Laal and Mozhgan Laal (2012) point out as five fundamental elements associated with the concept: 1) *Positive interdependence between the participants*. What you develop together is greater than the sum of what each individual would achieve alone; 2) *Individual and group accountability*. This implies that members have a shared responsibility to each other to understand and achieve; 3) *Interpersonal and small group skills*. This implies the ability and willingness to work together; 4) *Face-to-face promotive interaction*. This may be either direct face-to-face collaboration through physical meetings or by interaction in media such as Zoom or Teams; 5) *Group processing*. Participants contribute to the group's joint learning based on respective competences, such as bodily experiences, academic skills, and know-how.

We have all taken part in these collaborative learning processes from our different positions as performing artists, as persons with and without disabilities, as employees in public administration, universities, and the research sector. We participated in the processes from different positions and roles, and we brought our respective perspectives into the collaborative learning. Although we had not originally thought of our work in terms of CL, we have come to realize – in our post-project reflection – that such an understanding enables critical learning and peeling off ableist structures in our collaboration.

Theoretical perspectives: Crippling institutions and time

For this post-project study, we dialogue with two specific articles, which we have found helpful in generating insights from our own reflection on our process. In “Shifting power to people with disability in co-designed research,” Ellen Fraser-Barbour et al. (2023) explore tensions navigated by researchers and project leaders when involving people with disabilities in core teams of co-designed research in commissioned research. Co-design, originating from the design and technology sectors (Fraser-Barbour et al.,

2023, p. 3), is a way of conducting research, which is increasingly utilized in social as well as educational research (Bakker, 2018). Fraser-Barbour et al. (2023, p. 3) explain how “co-design enables social issues to be examined in collaboration with communities affected by these issues in an ethical way.” The value “nothing about us, without us” (Charlton, 2000), as in our project, gears research clearly towards methodologies of co-design. At the core of co-design research is the acknowledgement of lived experience and diverse ways of knowing, and to research “with” instead of “on” community (Fraser-Barbour, 2023, p. 3). However, as the co-design of research with disabled and non-disabled researchers in the core team inevitably takes place in institutionalized ableist structures, the working structures of the research and relationships themselves need to be worked on constantly (see Østern & Øyen, 2014b). The crucial insight that Fraser-Barbour et al. (2023) arrived at is how power shifts to the disabled participants are easily undermined by institutionalized norms that disrespect the co-design of the project. We are drawn towards *time* as a crucial aspect that turned up in different ways as a barrier in Fraser-Barbour et al.’s project, since the necessity to challenge ableist time and timing is also central in what we become aware of as we look back on our own process. Fraser-Barbour et al. point out how, when commissioners ask for research to be conducted quickly, which often is the case, this puts stress on the real co-design of co-designed research. In other words, “nothing about us, without us” might become tokenistic, in that disabled participants are there, but cannot have a real impact on the research. Fraser-Barbour et al. (2023, p. 18) conclude that “researchers should be working to ‘crip’ institutions and research practices.” In short, with *cripping* as a verb, we mean the resistance of ableist normativity from the perspective of disability. Carrie Sandahl describes *cripping* as something that “spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects,” thus “bearing witness to past and present injustice” (Sandahl, 2003, p. 28; here in Karlsson & Rydström, 2023, p. 401). Further, Fraser-Barbour et al. note that:

Generating change through co-design demands more of us to acknowledge ableist norms and structures and build structural change that supports the empowerment of researched communities through co-design processes that lend credibility as a legitimate and emancipatory way to perform research and evaluation. (Fraser-Barbour et al., 2023, pp. 19–20)

The other article we dialogue with is “Provocations for critical disability studies” by Dan Goodley et al. (2019). Goodley and colleagues (2019, p. 984) advocate for how bodies become materialized, in other words made “active, lived, felt, thought and enacted” through complex material/discursive entities. Goodley et al. (2019, p. 986) argue that ability is a less well-developed idea than disability, but that the notion of ability still feeds our institutions, such as schools and workplaces (Goodley et al., 2019, p. 985), and, we add, research projects, universities, and research institutions, as the most valued of human capacities. Goodley et al. (2019) offer a table, which shows the disability complex, and which we later in this chapter wish to add to with themes we discovered in our post-project study:

Table 1. The dis/ability complex by Goodley et al. (2019, p. 987).

Disability	Ability
Emotional	Rational
Mad	Sane
Dependent	Autonomous
Intermeshed	Atomistic
Sitting	Standing
Collective packs	Lone wolves
Crippling	Norming
Entangled	Alone
Many others	The same
Environment	Man
Nature	Civilization
Non-human	Human
Animal	Anthropos
Cosmology	Science
Sustainability	Growth
Bodies	Minds

Looking at this table, we join in Goodley et al’s question: “What do we want to keep of ability?” (Goodley et al., 2019, p. 987), and their statement that disability offers an opportunity, we add, for a world caught up in modernism and ableism. As Goodley et al. (2019, p. 988) argue, disability has the potential to shake up pedagogy, and is an affirmative phenomenon: “a chance to pause, re-jig and reorient education.” We add: and a possibility to cripp and reorient research and research institutions towards more real, co-designed, and sustainable research.

A word on methodology

For this post-project, critical self-reflective study, the researchers and the commissioners joined in looking back at the research process. Immediately after handing in the final report for publication, we jointly articulated two questions to inspire personal, individual reflective writing: *What surprised me? Were there specific learning moments in the project?* We set a one page per person limit, gave ourselves a deadline, and shared our pages with each other by email. As the narrated experiences kept arriving in our inboxes, we read the others' experiences. A collaborative "undergoing" (Dewey, 1934), through the opportunity to write and reflect, arose among us. From our narrated experiences, we could, inspired by thematic narrative analysis as described by Vera Caine et al. (2022), start to carve out themes of interest for critical inquiry. As we started the post-project, we had with us critical system theory and critical disability theories used in the original research (see Kupperts, 2001; Mark, 2006; Meekosha & Shuttleworth, 2009; Vassenden & Bergsgard, 2011). However, in this post-project study we were led towards theory focusing more on the work in co-design processes themselves. The work by Fraser-Barbour et al. (2023) and Goodley et al. (2019), as already described, became especially pivotal for our critical thinking.

Peeling off nuances of ableism, with a specific focus on embodied knowing, time, and timing

In this section, we scrutinize our own narrated experiences. We seek to carve out themes showing how navigation in the dis/ability complex (Goodley et al., 2019) occurred in our team.

Embodied knowing vs theoretical knowing

The first theme we wish to draw attention to is that of *embodied knowing vs theoretical knowing*. To enter this research project with embodied knowing based in lived experience as a disabled person, implied an affirmative experience through the project. The project affirms what Elen, the disabled researcher, already knows from her own life. For the non-disabled researchers and commissioners, it is different. Their knowing is theoretical, not

embodied, and thus they experience surprise where Elen does not. Elen (researcher) in her reflections wrote:

I participated in this project with many different hats. Dance artist. Disabled woman. Co-researcher. Living as a disabled woman for 43 years, you get used to all kinds of discrimination mechanisms. Interviewing the artists in this project, it became clear early on that these artists had experienced many of the same discrimination mechanisms as I have. Prejudice. Infantilization. The welfare system's total rejection and lack of support for disabled people's desire to live as professional artists. That rejection started already in primary school for many of the participants in the project. So that did not surprise me at all. Reflecting on this project makes me realize how unsurprised I am about the level of discrimination the participants experience. I have been discriminated against throughout my whole life. So, I think non-disabled people are more surprised by the results of this project than I am.

All of the non-disabled researchers and commissioners, despite their extensive theoretical knowledge about dis/ability, write about how they were surprised by both the extent of the discrimination, as well as the severe consequences of it. Anne (commissioner) was struck by how the discriminatory barriers identified in arts and culture are entangled with barriers in related sectors, like education and welfare. Anne wrote:

An insight that I find particularly striking and somewhat surprising, is that the barriers professional artists with disabilities face, do not solely stem from the arts and culture sector itself ... The interplay and cooperation between the arts and culture sector and other sectors – such as the broader educational sector, as well as the welfare sector – will be of great importance when working towards more equitable paths to becoming a professional artist. It has been both surprising and disheartening to learn that people with disabilities so commonly have their artistic aspirations shut down from a very young age.

Kaja (commissioner) experienced similar surprise as she reflected:

Reading the full report of the research a year and a half later, the biggest surprise is the extent of inequity mechanisms at all levels of our sector. These artists become artists despite, and not because of, a system that doesn't know the extent of talent that is overlooked. The fact that education and the welfare system are such central barriers was an eye-opener with regard to the institutional mechanisms of inclusion or exclusion, and this challenges us to collaborate in new ways for systemic change to happen.

Lene (researcher), in her reflections, was surprised by how few disabled artists there seem to be in Norway, and connected this with how barriers start to emerge very early on the road towards becoming an artist, already in educational institutions. Lise (researcher) was surprised that many representatives in the field had problems giving an example of an artist with a disability, pointing to the same problem with exclusion starting very early on in life for aspiring disabled artists. She wrote:

It became very clear that the process of exclusion starts at an early age and requires early and knowledge-based efforts.

Lise was also surprised at how little attention arts and culture institutions in Norway seem to give to disability, which Terje also wrote about in his reflections:

Although I have worked extensively with research on the situation for disabled people, I was surprised how little attention issues about disability seem to have in this field, even in the national institutions. Disability seems barely to be on the agenda. It has become more and more clear to me through our project that the structural features of the culture field are strong. Partly, this applies to the material aspects, and partly it applies to expectations and norms about who belongs and fits in.

Tone, having worked extensively as a practitioner in the field of dance and disability for many years, with a 19-year long history of working together with Elen, was still surprised to realize:

How weak the economy is for most of the artists with disabilities, and how disability benefits are the most important source of income for most of them. It became very clear that we are talking about a group, which is really marginalized from the privileges and positions that the adult majority population in Norway would expect to reach by a certain age. The average age of the artists interviewed in the study is around 40, and at that age a person belonging to the majority population in Norway would expect to have a somewhat secure and stable income. Financial stability gives freedom and possibilities to, for example, get a bank loan so you can buy your own apartment, have a rich social life, and travel. That moment released a deep understanding in me for the everyday, material, and real-life consequences of discrimination, marginalization, and exclusion. I experienced the shame of belonging to and having the privileges of the majority.

Our post-project critical reflection reveals that Elen, the disabled researcher in our team, is not at all surprised at the serious level and expanse of

discrimination and exclusion the interviewed disabled artists talk about. Their experiences are merely confirmations of her own experiences of discrimination. All the non-disabled researchers and commissioners, on the other hand, are surprised by this level and expanse of ableism into different sectors of society. This reveals that although these researchers and commissioners have theoretical insights into the ongoing discriminating ableist structures, they are unmarked by disability, and do not have the lived experiences of what this means in everyday life. As a theme learned in our research process, we would like to add to Goodley et al.'s (2019, p. 987) dis/ability complex the themes of embodied knowing and theoretical knowing, arguing that embodied knowing is crucial to fully realize the knowledge contributions of a research project.

Table 2. Adding to the dis/ability complex by Goodley et al. (2019, p. 987) with embodied knowing and theoretical knowing of disability.

Disability	Ability
Embodied knowing	Theoretical knowing

Nuances of time and timing

Time and timing are not part of Goodley et al.'s (2019) dis/ability complex, and we want to add them as themes relating to *crip time* (Berg, 2023; Wälivaara, 2022). Through our post-study self-reflective study, we have found time and timing to be at the core of the ableist structures at work in our project. Elen wrote:

The fact that I am a disabled co-researcher, was really an advantage in this project. One important thing I have learned from this project, is to be very clear to non-disabled people about time. The time frame of disabled and non-disabled people could be very different. When I told them [the non-disabled researchers and commissioners] about how disabled people often need more time than non-disabled people, it actually felt like I have taught them something. The whole society today is built around the time frame of non-disabled people, and that makes the pressure to do a good job more intense for disabled people: for me, as well as for the disabled artists being interviewed in this project.

In our post-project, we found time and timing to be at play as ableist norms in: 1) the ways the project was commissioned within tight time frames; 2) fast processes between the researchers; 3) how efficient time negatively

influenced the possibility to recruit disabled interview persons; 4) how time was organized in the working relationships between Tone and Elen at the university; and 4) how time was managed in the meetings between the researchers and commissioners.

Regarding the ways the project was commissioned within tight time frames, Kaja wrote:

Articulating the commission and seeing the response, I learned a great deal about the power and responsibility that lies with Arts and Culture Norway enabling and disseminating knowledge. However, despite genuine efforts to ensure an inclusive process for all involved, the fact that we still had the same deadlines and budgets as other similar projects, showed that we are also very much part of a fast-moving system that is based on the premise of non-disabled majorities.

The time frame of the project again influenced the timing of the workflow between the researchers, which was easier to cope with for the non-disabled researchers, who are socialized into fast and efficient time and timing, and difficult to cope with for Elen, whose timing is different. In the original research, the researchers also think of this fast and efficient time frame as a barrier in their own efforts to recruit disabled artists for interviews. They wrote:

In the recruitment of interviewees via organisations (artists' organisations and organisations working for various types of disabilities), the project was occasionally met with scepticism from some organisations that felt obliged to protect the interviewees in question. They justified this with previous negative experiences with researchers and research projects. The argument is based on the fact that research projects often take place on the research's terms, and that not enough time is taken to build relationships, create trust, and conduct interviews on the interviewees' terms. We see this criticism as both relevant and justified, also in relation to this project. One of the biggest challenges to creating more space for artists with disabilities, as a minority in particular, and artists from marginalised groups in general, is the structural aspect, that both art production and dissemination, education, research, and administration are permeated by majority discourse. This project also faced such structural challenges. Fast and efficient use of time, for example, is something that characterises the majority's way of dealing with working life, but it is not necessarily something that suits people with disabilities. We also found it difficult to find time within our set time frames for the slow relationship building we believe would have strengthened recruitment to the project. (Østern et al., 2023, pp. 117–118, translated from Norwegian to English)

Navigating time and timing also became an important part of Tone's and Elen's working relationship at the university. Tone in her post-project reflections wrote:

Elen and I were a close team from the university NTNU during the whole project. With Elen's and my collaboration at NTNU as a base, I have often been able to connect what the disabled artists talk about in the interviews, with obstacles that have kept presenting resistance for Elen as an employee at NTNU. The continuous comparison of the project and Elen's experiences as an employee at a large institution like NTNU, gave me theoretical as well as embodied knowledge which together created insights on how deep the structural discrimination is. I realized it will take determination and clear leadership to manage to change established structures into real inclusive ones.

Tone contemplated how she herself, as a senior researcher in a permanent and thus powerful position at a university, has a crucial role in changing the ableist time and timing from within the institution itself. It matters directly how she behaves in concrete micro situations, and in daily interactions between her and Elen, and it also matters what she demands from the university administration. For Tone, the days with Elen, who worked part-time at the university campus during the 13 months, implied more sustainable and healthy days than the days without Elen. Tone lowered her work tempo, took proper time to have morning meetings, not only to organize the day, but to say hello and show interest for how we both were doing, took enough time to have lunch, allow time to rest, and be satisfied for what we managed to do today.

Regularly during the project, there were online meetings between the commissioners and researchers. In these meetings, ableist, fast, and efficient time and timing proved to be a hurdle, which needed to be challenged. We usually had an hour reserved, and a lot of topics to talk through during the meetings. If not actively resisting the ableist timing, the meetings risked reproducing a fast pace, which the non-disabled researchers and commissioners were more socialized in. In fast and efficient meetings, the non-disabled researchers and commissioners were more used to claiming time and space for their arguments to be heard. The ableist timing of the meetings were never quite addressed or settled during the project, and not properly understood until this post-project study. However, Tone and Elen often talked about time, timing, order of talking, who gets to contribute and not, after the meetings. They found out that the meetings worked better if they

were together in the same room during the meetings, sitting physically next to one another, rather than in different, individual zoom rooms.

Based in our scrutinizing of how time and timing turned up as an ableist structure in several ways in our project, we wish to add to Goodley et al.'s dis/ability complex through several nuances of time and timing.

Table 3. Adding to the dis/ability complex by Goodley et al. (2019, p. 987) with several nuances of time and timing.

Disability	Ability
Slow time and timing	Efficient time and timing
Sustainable time	Competitive time
Time as a site for care	Time as something to control

Viewing our co-design research process through a dis/ability complex (Goodley et al., 2019), our post-project reflections reveal how ableist time and timing presented challenges for research organization and collaboration. In hindsight, the research project was not sufficiently attentive to *crip time*, a concept that addresses how time, as organized in society, is normative (Wälivaara, 2022), and that disabled people may live in profoundly different temporalities. Compared to normative time, which we could also call ableist time, which emphasizes speed and efficiency, crip time is slower, because disabled bodies embody and live time non-normatively. Eva Karlin Berg (2023, p. 11), referring to Wälivaara (2022), notes that “living in crip time but being expected to bend and fit into normative time can leave marks and trauma.” As the rest of the team did not have embodied knowing of crip time, Elen had to constantly remind us that slower time and timing was needed. The commissioners had not originally allowed longer than usual time for deliveries, however, they did so after discussing time as an ableist barrier.

Concluding insights from our co-design research as a collaborative learning process

The five researchers and two commissioners behind the research project *Artist – an accessible profession? A research project about artists with disabilities in Norway* (Østern et al., 2023) all have different trajectories into the project, and further into this post-project study. Only one of us, Elen, has embodied knowing with ableist discrimination and inequity mechanisms

at play in society and education, replicated in the arts and culture field. Our post-project study showed that she was not particularly surprised at the amount of discrimination taking place in the arts and culture field in Norway, and its nuances. While those of us who lack such embodied knowing were certainly aware of some of the challenges disabled people face – either through previous research, or through previous involvement in diversity work in the arts and culture field – we nonetheless underwent deep learning processes about the *extent* and *systemic nature* of ableist mechanisms. We thus, through this study, add to the dis/ability complex articulated by Goodley et al. (2019), the difference between *embodied knowing* and *theoretical knowing* of ableist structures. We argue that embodied knowing is a necessity for critical insights to become possible, and that the gap between what disabled and non-disabled participants experience, is a specifically rich space to dwell in. This supports the importance of doing research led by the motto “nothing about us, without us” (Charlton, 2000).

Elen’s embodied knowing as a core researcher in the original research (Østern et al., 2023) has been crucial in order to uncover the consequences of what it means to live with and without able-bodied privilege, not only in the arts, culture, and education field, but also in research, and at research institutions. Nuances of time and timing as ableist structures, reproducing themselves in the research project, have been possible to see and articulate through her participation. Her insisting on timing and organization that were not uncritically based in ableist norms and power structures, led us as a team to discover, appreciate, and to some extent, adjust to different timing. However, this was not fully understood until the post-project study undertaken in this chapter. In dialogue with Goodley et al.’s (2019) dis/ability complex, we have been able to carve out and argue for slow time and timing, sustainable time, and time as a site of care, as nuances of *crip time*, which could and should challenge ableist structures of efficient time and timing, competitive time, and time as something to control.

Fraser-Barbour et al. (2023) argue that power shifts to the disabled participants are easily undermined by institutionalized norms that disrespect co-design projects. We have found this to be true, and that institutionalized, ableist norms need to be recognized, acknowledged to be there, and then challenged from within the very research project itself, as the process is ongoing. Crippling research structures must be part of research projects trying to *crip* society, arts and culture. Co-design research under the ethos

“nothing about us, without us” is necessary to break through the blind spots, which are created through structural exclusion and discrimination, entrenched in arts, culture, education, and society. However, it is equally important to break through the same blind spots in research institutions and projects themselves. In a team consisting of researchers and commissioners, a critical approach and real listening to those with embodied knowing of ableist discrimination is necessary. Otherwise, the ableist system might repeat itself within the research, because the system is self-preserving (Kuppers, 2001; Mark, 2006; Meekosha & Shuttleworth, 2009; Vassenden & Bergsgard, 2011).

Finally, we want to stress the importance and difficulties of challenging time and timing in research, institutions, education, arts, culture, and society. We dare to say that if we challenge time and timing on a structural level, the whole modernist and ableist neoliberal project becomes challenged. This might enable the possibility for a more sound, healthy, sustainable, and caring society, beneficial to all, and which might produce more thorough knowledge contributions. We argue that attention to embodied knowing, and nuances of crip time and timing, has the potential to, in powerful ways, crip institutions and research projects towards more sustainable structures.

Author biographies

Tone Pernille Østern has a Dr. of Arts in Dance with a focus on dance and disability from the Theatre Academy (now University of the Arts Helsinki). She is Professor in Arts Education at the Department for Teacher Education, NTNU Norwegian University for Science and Technology, and Visiting Professor in Dance Education at Stockholm University of the Arts. She is active as artist/researcher/teacher with a special interest in inclusive and critical pedagogies, participatory arts, choreographic processes, and the performativity of research, learning and teaching. She co-authored *Artist – an available profession? A research project about artists with disabilities in Norway* (2023) commissioned by Arts and Culture Norway and co-leads the research group *How to do things with disabilities*. She is Editor-in-Chief of the peer-reviewed journal *Dance Articulated*.

Terje Olsen is Research Director at Fafo Institute for Labour and Social Research in Oslo, Norway. He holds a PhD in Sociology from Uppsala university, Sweden. His research interests include welfare state issues, disability

studies, inclusion and youth research. He has published extensively on research about vulnerable groups and their rights, legal protection, protection against abuse and hate speech. Terje is one of the editors of the anthology “Involving methods in youth research – reflections on participation and power” (2021). He is chair of the Norwegian network on disability research and Editor-in-Chief of the journal *Nordic Welfare Research*.

Elen Øyen is a dance artist, and dancer in the Dance Laboratory, employed at DansiT Choreographic Center in Trondheim, Norway. Elen was born with Spina Bifida and uses a wheelchair. She has lectured in different conferences, seminars, festivals in Norway and abroad, often together with Tone Pernille Østern. She has been co-teaching dance classes and lectures for students in higher education, and extensively lectured and published about her life experience as a disabled woman and artist. She has a BA in child welfare work and has further education as legal office worker, and she has work experience as an office employee.

Lise Lien is a sociologist and today works at the Norwegian Church City Mission. Previously, she has been a researcher at Fafo Institute for Labour and Social Research, where she used to work with research on inclusion and exclusion in working life. Her research interests have been on people on sick leave, groups with weak or no connection to ordinary working life, such as young people without completed upper secondary education, people with disabilities, convicts, and people with substance abuse problems.

Lene Holum is a Clinical and Organisational Psychologist with a PhD in Health Care. She has extensive experience working with youth and young adults, particularly in areas such as psychosis, substance abuse, and with minority groups. Her expertise also extends to forensic psychiatry. In addition to her clinical work, Lene is a researcher and project leader. She has been involved in various studies aimed at improving mental health care services, both in Oslo University Hospital and now at Sunnaas Rehabilitation Hospital, where she works as an Organisational Psychologist. Recently she has been involved in research at Fafo Institute for Labour and Social Research.

Anne Ogundipe (PhD) is a Senior Advisor in the Department of Cultural Analysis at Arts and Culture Norway. She works with a range of projects

involving analysis of and research on the arts and culture sector, including knowledge production tied to questions of diversity, equity, and inclusion. Ogundipe co-authored the report *Et kunnskapsbasert og langsiktig mangfoldsarbeid (A knowledge-based, Long-term Diversity Effort, 2020)*, and was project leader for Arts Council Norway and the Danish Arts Foundation's joint research program on art and social community (2021–2023). She has recently co-edited the book *Felleskap, konflikt og politikk (Community, Conflict and Politics, 2024)*.

Kaja Tvedten Jorem is a senior advisor at Arts and Culture Norway, developing their role as a National Coordinator for Diversity in the Arts. Tvedten Jorem has 15 years of experience from working with creative industries, diversity and international work in Europe, Africa and North America. She holds a Master of Business and Development Studies from Copenhagen Business School and a graduate diploma in Arts Management from HEC Montreal. Her research interests include creative industries in the global South and North, diversity and inclusion, and business development. She hopes to learn and challenge her views continuously through art and community.

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CHAPTER 13

Adaptive Dance and Physical Theatre at Dissimilis

Caroline Marie Sprott Artistic Leader Kompany D, Dissimilis National Competence Center, Norway

Abstract: This article provides an insight into methods for working with adaptive dance and physical theatre. With adaptive dance and physical theatre I mean that the lessons are designed for people with a developmental disability. Through adaptation, everyone can feel a sense of accomplishment, joy and get to move in their own ways. The methods presented here are developed in Dissimilis' national competence centre in Norway, a centre for people with developmental disabilities. Improvisation is then used as a starting point to explore the body and movement. Adaptive dance and theatre exercises should give the student an understanding of their own body and the opportunity to develop their own unique movement language. The lessons should contribute to increasing the student's self-confidence and their quality of life. The lessons must be suitable for people with developmental and physical disabilities. Through exploration, we dare to use alternative ways of thinking and explore physical differences. The purpose of this chapter is to inspire others to use our method in their own artistic and educational practice. In that way, all students who wish to work with dance and theatre have a chance to do so through programmes adapted to their abilities.

Keywords: Adaptive dance and physical theatre, Dissimilis national competence center, developmental disability, improvisation, inclusive teaching methods

About Dissimilis national competence centre

For more than 40 years, the Dissimilis national competence centre in Bærum, Norway has provided cultural education in music, dance and drama, offering both individual student lessons and group lessons. Over the years, Dissimilis has also staged several ground-breaking performances in the field of performing arts. Its teaching is rooted in the competence centre's core values: to increase the students' quality of life by offering adapted cultural activities for people with developmental and physical disabilities. The teachers have broad and diverse expertise in music, singing, dance, theatre and music therapy, and their work is based on objectives that concern the whole person. What the teachers offer is developed in line with their expertise as well as being based on the individual student's wishes and needs. In the individual lessons, the teacher usually teaches alone, whilst in the group lessons, several teachers collaborate on implementation.

Values underlying Dissimilis' work

Since 2017, I have been the main responsible for the adaptive dance and theatre lessons at Dissimilis as well as for the choreography in the Dissimilis productions. I have a BA in theatre (Mime school) from Amsterdam University of the Arts, and a two-year vocational education from what is now the University College of Dance Art in Oslo, Norway. The way I teach is inspired by these schools' research and theories.

At the intersection between physical theatre and contemporary dance

For some students at Dissimilis, verbal forms of expression are easily accessible, while for most of our students, non-verbal and more movement-oriented forms of expression form the basis of the creative work and artistic exploration. In group lessons, we often use exercises that come both from physical theatre and from contemporary dance. Through my experience, I have found that these disciplines positively complement one other.

In contemporary dance, the tasks and exercises deal with how the body relates to movement in time and space in the broadest sense. The performer is stimulated to work creatively with moving their body and to use their

own physical potential. Physical theatre in my experience lies somewhere between dance and theatre and has a lot in common with contemporary dance. Physical theatre often has a more theatrical expression, and the exercises provided can stimulate and trigger the imagination of the performer to express emotions, play with different characters and convey narratives through their use of movement.

Similarities between the two disciplines can be found in that both mostly use improvisation as a working method to begin with. Both contemporary dance and physical theatre build on ideas performed by the people and both fields stimulate the performers to make their own choices. Within both fields, the goal is to work with movement in an innovative way. For many students with disabilities, this comes naturally, as the body often has a unique starting point for moving. I therefore think there is much about physical theatre and contemporary dance that is relevant for students with disabilities. Art fields that are, by definition, open to diverse solutions, can give people the opportunity to build up a quality of movement that gives them access to the professional arts field. This will enrich the field of art as well as society. At Dissimilis, we have a desire and goal that our students should be able to take part in performing arts at a professional level.

Unload and upload – letting go and supplying

Another source of inspiration for me is the Misiconi dance company (NL), where I held an apprenticeship in 2019. The company works with “inclusive dance”, which means dance performed by people with and without disabilities, all of whom are treated as equal members. As described in the book by Joop Oonk (2017), the artistic director of Misiconi, the company works with the idea of “unload” and “upload”. In short, “unload” is about letting go of fixed ideas, while “upload” stands for seeing things in a new way and implementing new visions. The basis for the idea comes from the thought of stepping away from the traditional ballet and traditional dance techniques and highlighting new approaches and aspects within dance. By opening to what is new, traditional ways of doing things can be put aside. Instead, space can be made for something different.

This way of thinking is also used in the artistic work of and teaching at Dissimilis. By working in this way, students and teachers get to be in the moment and students get to create their own material. We mostly steer

away from choreography that sets up a framework for how movements are to be executed, thus observing the understanding of exploratory movement as articulated by Gunn Engelsrud (2006, p. 125): “The process of being in exploratory movement is experienced as a contrast to moving to reach an already defined goal set by others”.

When goals are set independently of the people performing the dance, a gap between body and performance can occur. There may be requirements that not all bodies can meet. By working in an exploratory and innovative way, the students build up their own movement language to express what they want. They gain ownership of their own movements. The idea of dance and theatre for all bodies is precisely the core of what we work with at the competence centre and can be summed up by the words of Engelsrud (2006, p. 119): “By using this as a starting point, that all bodies are good as they are, all bodies can also be seen from the movements that they make. In other words, everyone can be as they are.”

Practical implementation

In the following paragraphs, I write about how we divide the students into groups, describe the role of the teacher, share useful tools and creative exercises, and briefly present how the lessons are constructed.

Group and individual lessons

The lessons should be suitable for anyone who wishes to participate, and the student should get the possibility to develop their talents and express themselves based on their own individual movement potential. The groups are partly put together based on which students apply to participate, and partly by the students’ cognitive and physical skills.

Sometimes it can be challenging for new students to feel comfortable in group lessons. One option can be to give them individual lessons to start with. In these individual lessons, the teacher can then help the student gain an understanding of movement in their body and help them gain a sense of accomplishment in the exploration. Gradually, as they feel more comfortable, it may become easier for them to explore movement in a group setting. By working in this way, the teacher also has a chance to better evaluate and consider what group would be the most appropriate for the student and what might be a good fit for an already existing group.

The role of the teacher

The teacher must have artistic competence, be able to use different teaching methods, and by using their knowledge, have an understanding of how to help take the student's processes further. It is important that teachers use their competence and skills to find creative solutions and provide tools/exercises that do not limit student exploration. Students should not have to strive toward an aesthetic standard or ideal. What is often seen as a disability in society needs not be a disability on stage, but rather an enrichment. The same applies to people with developmental disabilities. Thinking "differently" or being spontaneous will give other impulses in exploration which again can add another dimension to the performing arts scene. It is important to give space to the students' thoughts and ideas so that they are included in the artistic processes.

Within both physical theatre and contemporary dance, the lines between the traditional, separate roles of dancer, choreographer, director, dramaturg, and producer are often blurred. The performer is usually a co-creator. Their input and ideas play a role, both in regard to the process and the result. When we work with adaptive dance and theatre, we can be said to have the same fundamental idea, but often it will be the director's responsibility to design the composition of the creative work. During lessons, this means that the teacher actively contributes to creative work together with the pupils, blurring the roles at times. Occasionally, the teacher participates in exercises, working together with students in the exploration. At the same time, we experience the importance of teachers having the overall responsibility for the composition and direction of the class. It is important to add, and to follow up with, necessary tools and elements when needed.

Improvisation as a method

Improvisation is an important method used to explore movement principles. The student is stimulated to work creatively, moving their body, and to explore their physical potential. Improvisation utilises the body's great competence for spontaneous and creative movement. There are many elements that can provide inspiration and that can be explored in improvisation, such as space, time, the walls and floors, different elements and objects in space as well as the other performers in the room. Improvisation can either be very free or more structured. I have experienced that most

students find it easier to focus when improvising within certain frameworks. We use improvisational tasks when doing artistic work and when developing material used for performances. By working in this way, the students work as co-creating performers and get to experience shared ownership of the performances.

Elements used for exercises and in improvisation

In working with improvisational tasks and exercises, it can be helpful to use elements other than movement. These can add something new to the movements and help raise the quality of performances. The elements can assist in providing boundaries, but can also open up opportunities. Some of the elements I find useful in improvisational work are music, use of voice, costumes, scenography and lighting, as well as different objects, such as a feather. For people with developmental and physical disabilities, elements such as these are found to be particularly useful in creative exploration and in searching for their own artistic expression. I have experienced that by using the right tools and elements adapted to the group or the individual student, several of our performers at Dissimilis can perform art that maintains a high professional level.

Concluding thoughts and remarks

In the last paragraphs of this article, I would like to share a few reflections on the work related to the concepts of art and therapy, process and product, as well as speak a little more about the aims and meaning behind the dance and theatre lessons at Dissimilis.

Art or therapy?

Working with art, in this case dance and theatre, can benefit health. Art and therapy are not mutually exclusive disciplines, but in these classes, we focus on art education and on the students' artistic development. It is important that students are allowed to express feelings, emotions, thoughts and opinions. In that way, they can create art of good quality, convey stories and share their art with an audience.

In the book *Inclusive Arts Practice and Research* (Fox & Macpherson, 2015, p. 24) the difference between inclusive art and art therapy is reflected

upon. I wish to refer to the quote by Mark Williams (director and founder of Heart 'n Soul):

If you present yourself as a therapist, that's what you'll always be. There are clearly beneficial and therapeutic aspects to our work, but that's not why we do it. It's always the art. One of the reasons we're able to attract such great collaborations is that we create an environment where anything is possible. Our singers aren't stuck in genres. They're not over analytical – they're just doing it. There is something about the purity that seems to be the essence of creativity. (Mark Williams, in Groves, 2012, Interview with *The Guardian*, here cited in Fox & Macpherson, 2015, p. 24)

Product, process and equality in the arts, set within a framework of increased quality of life

The aim of the teaching I have written about in this chapter is primarily focused on the artistic product and the development of the students. The aim is for the students to feel safe in their bodies and in their own choices. The focus is on the individual, and by adapting the classes, everyone can experience a sense of achievement and joy, feel challenged and get the chance to move in their own individual ways. In other words, artistic work is closely linked to the student's personal process and development. The lessons should contribute to increasing the self-confidence of the students.

Each individual must be seen and included in the classes and in the artistic processes. I also believe that an increased quality of life will affect the quality of the artistic work. In that way, the two complement each other, and are both important parts of the process. In dance and theatre classes, we strive to maintain a high level of quality in what is being created. The students should be allowed to participate in the performing arts in a dignified way. This gives the students a feeling of being respected and that we are working seriously towards a common goal.

Some students have ambitions and dreams of working professionally in dance and theatre. A long-term goal must be that students with talents can gain access to the professional field of performing arts and can work as equals together with other professional performers. This is something we strive for at Dissimilis, but where a change is needed from the entire arts community. Diversity in the arts opens for equality, mutual respect and a sense of belonging. In addition, it will add new and exciting dimensions to art, to the enrichment of all.

Author biography

Caroline Marie Sprott has a BA in theatre (Mime school) from Amsterdam University of the Arts (2017), and a two-year vocational Education in Dance art (2012) which is now called University College of Dance Art (Høyskolen for dansekunst) in Norway. Caroline has many years experience from working as a performer and maker in different performance art projects. After her studies she has been working mainly in the field of dance and theater, focusing on inclusive dance and adaptive dance at Dissimilis. In 2024 Caroline started as artistic leader for Kompani D (NO), a new inclusive dance company initiated by Dissimilis.

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CHAPTER 14

Theatre of the Deaf: An Amakhosi Theatre Experience

Cont Mdladla Mhlanga Founder and Head of Amakhosi Theatre Productions in Bulawayo, Zimbabwe

This chapter was written by Cont Mhlanga, the Zimbabwean Amakhosi Theatre's executive artistic director, in 2022. Shortly after writing this text, he passed away. Cont's family has allowed the editors to mildly edit and then publish the chapter in this book. In the chapter, Cont writes about actress and theatre director Gogo Thembi Ngwabi¹, who was also his wife. Gogo passed away in 2023. This chapter remembers, documents and makes tribute to their work for the deaf community in Bulawayo, Zimbabwe.

Amakhosi Theatre was founded in 1980 and staged its first play *The Book of Lies* at Stanley Hall in the Makokoba Township of Bulawayo in Zimbabwe in 1982.² Until the morning of the 5 December 2019, some 39 years of being a community-based and focused project for young creatives in the Mathebeleland region of Zimbabwe, Amakhosi Theatre in its daily operations and activities had not thought of producing theatre with deaf creatives.

In fact, for Amakhosi founders, management and ordinary members, they realized that there was a community of deaf people in the community they existed and operated in.

While they all knew that there are deaf people in some families and at the Jairos Jiri Centre³ for Special Needs Education in the Nguboyenja

1 <https://radiocontinentaldrift.wordpress.com/2023/12/30/thembingwabi/>

2 Amakhosi Theatre does not have a website, but there is information on Wikipedia, and they do have a Facebook page. About the social and political theatre of Amakhosi/ Cont Mhlanga see Glørstad 2005 <https://www.duo.uio.no/handle/10852/15505>, Glørstad 2013 <https://www.tandfonline.com/doi/full/10.1080/10137548.2012.838336>

3 <https://www.gzu.ac.zw/jairosi-jiri-centre-for-special-needs-education/>

Township, a neighbouring township to Makokoba, they now realized that the deaf people were a community with creative individuals who could write, rehearse, produce and present a play on stage.

What social and political issues would they write about? How would they be part of the Amakhosi Theatre considering the theatre specialised in a dialogue-driven art form and yet they have no voices? For Amakhosi Theatre, deaf creatives were not visible though they were part of the same community in which Amakhosi existed, in a community they served.

All this changed one morning in December 2019, some 39 years later.

The champion of deaf theatre

When Rosemary Zhira walked into the Amakhosi Theatre reception and found me behind the desk, little did I know that a champion of deaf theatre was standing in front of me. She was aged 27 years in 2019.

Instantly, there was a communication barrier in the room. From her bag, she pulled out paper and pen and after writing “Hallo my name is Rose” on the paper, she got straight to the point. She wanted Amakhosi to train her drama group of deaf-only members in play writing, acting, production and performance.

But they did not have any money to pay for the training because of all the 25 members of the group, she was the only one employed. This is why she came to Amakhosi, she wrote on the piece of paper, because she was told by her workmate that Amakhosi Theatre offers training to people who want to go onto the stage, produce a play and perform it in front of an audience. In exchange for the training, Amakhosi would keep the economic rights of the work created during the training.

Rose was born in the Chivi district to a family of five. Her mother and father were both deaf, and her father has since passed. Three of Rose’s siblings were also deaf. However, Rose’s daughter can hear and speak but she talks to her mother (Rose) through sign language.

Rose grew up in the community of Victoria Falls where she went to kindergarten but was always an outcast and ignored by other children when they were in the playing field. She stood on the side and watched them play. She could see other kids go or get involved in problems and challenges. She had ideas on how they could solve their challenges but could not communicate these to them.

The desire to assist others out of these situations made her realise the importance of everyone learning sign language. She wanted to teach others sign language so that she could share her thoughts and ideas with them to improve the situation they faced.

She moved to Bulawayo and went to St George Special School for people living with disabilities. For the first time she found herself in a community of her own. She started to share her ideas with others.

She then moved to Fatima Primary School in Lupane,⁴ to a special school for the deaf. It was at this school that she first came across the work of Amakhosi Theatre which once every year visited schools in the district to run performance workshops in theatre and dance for primary school children.

Her group would just come sit and watch other kids participate but they could not participate themselves. Rose remembered this very scenario growing up in Victoria Falls when she would just stand back and watch other kids playing.

There she was once again with her deaf friends, watching other kids participate in dance and theatre while they sat back and watched, only because they were deaf. The urge to change her situation came back to her full force and she wanted to change what she and her friends were facing.

After school she got a job as an administration assistant at the Association of The Deaf⁵ (Zimbabwe), based in Bulawayo. When the time came for her association to celebrate the International Day of the Disabled in 2019, she wanted to produce and present a play that communicated the concerns of deaf people.

She gathered deaf people to a meeting under a tree near the Centenary Park in Bulawayo and started to prepare a performance. None of them had any training or experience in play-making. By end of the day, there was nothing but confusion, and not a single scene was created.

She knew after that session under the tree that if she was going to get her team to produce a proper play, she needed some training for herself and for her members. She approached people who said they had knowledge on theatre production but would not allow them in their groups because they were deaf. People just told them to go and try Amakhosi Theatre. “Maybe

4 <https://zimsake.co.zw/notes/fatima-primary-school-73899>

5 They have a Facebook page.

Amakhosi will understand their story?” Rose told me as she narrated her need to get her group of deaf artists trained in theatre.

It was a very moving narrative for which Rose had to engage Mr Ncube, her workmate at the Association for the Deaf who is half deaf himself, to come and be the interpreter for our meetings. I told them that Amakhosi could give them training only on two conditions: first, that they had a good story to tell, supporting themselves all the way, and that they would not only produce the play but also perform in front of an audience, and second, that Amakhosi Theatre’s trainer and theatre director Gogo Thembi Ngwabi would be willing to train them and work with them for free as they had no money to pay her for her time. The Amakhosi Theatre would only be able to provide her group with free working space and nothing more as the theatre did not have any funding to support their training, play production and presentation.

Engaging theatre director Gogo Thembi Ngwabi and playscript Cont Mhlanga

A meeting was arranged with Gogo Thembi Ngwabi who, by that time, was in the village setting up base to practice as a traditional healer and medicine woman. She found time and travelled to Bulawayo to meet with Rose. They agreed to do the training.

She, however, told Rose that she was not a writer and only worked with plays that had scripts or scene breakdowns. For developing a story, they had to talk to a playwright to guide their story development. Rose was clear that no one would. I, Cont Mhlanga, had to come out of retirement to work with them to develop their story for training and production.

The stories

The first story is about **communication barriers** in public service provision.

A deaf girl is raped. She has to take a bus to the nearest police station to report her case. The police officer does not understand sign language. No officer at the station does, not even the public relations officers. They send her away to bring an interpreter. She goes to the hospital to report her case and get medical attention. No one at the hospital speaks sign language. They also send her away to bring an interpreter. She goes around

to find an interpreter, but the interpreter is in business and demands payment for the services upfront. She does not have the kind of money wanted by the interpreter. The girl goes home to her deaf parents to suffer serious depression. She can't go out of the house anymore because the person who raped her now knows the girl is deaf and is not able to tell anyone about the abuse. He keeps walking past her house searching for an opportunity to bump into her one more time and strike again.

The second story is about **social inclusion**.

A man is now living destitute away from his family and the community and is considered to be a person with a mental sickness and others think he has evil spirits. He was born to a hearing family. The family was not happy that their child was deaf, so they decided to keep him hidden at home avoiding associating him with the rest of the family members and the other children and people in the community. As he grew up, he did not enrol at school. When he was older and tried to integrate himself with other people he was totally lost because he did not understand spoken and written language. He could not even manage to integrate with other deaf people because he did not understand sign language. He eventually removed himself from his family and community, becoming destitute in the process.

Training and production

These were very powerful and touching stories, and theatre director Gogo Thembi Ngwabi committed to train the group and support them to produce these two plays.

We came to discover that the training was to start with us at Amakhosi learning sign language. This became unavoidable. There was no money to hire a sign language teacher. The theatre found one in a child whose parents are deaf, but she could hear. She came to the theatre and became the teacher to Gogo Thembi Ngwabi and the sign language interpreter to the whole group.

The whole process was very slow at the start but got faster as communication got better. After a full year of training, the group was able to perform the first Act of the first play to two different audiences within one month.

This is how the Theatre of the Deaf was born at Amakhosi Theatre.

After a full year, training was interrupted by the COVID-19 national lockdowns. Training was suspended for two years. They only resumed training in January 2022 when the normal school calendar started.

Challenges

After getting through the challenges of communication in the theatre sessions between the director and deaf artists, the real challenges of being deaf in a community of hearing people arose.

- In this group of now 31 deaf artists, only one is employed. The rest have to hustle for transport money every weekend to come to Amakhosi Cultural Centre. This is the reason why the group sessions had to be held only on weekends, even if they are all unemployed. Mid-week they would have to hustle for transport money.
- Secretarial and documentation services are required for this group to help them come up with a written script and a list of theatre excesses that they resonate well with. So that they can refer to the material when they are training their own trainers for other deaf artists who cannot come to Amakhosi at this time. As it is, the process of their work is not being documented.
- They have no production budget nor even money for creating good costumes. They have no resources to organise performances.
- The trainer director Gogo Thembi Ngwabi cannot be with the group every weekend as she must go and hustle for money herself at times. This means that because of difficult communication processes where no phone calls can be used, members of the group turn up to find that the trainer is not present. It is difficult for another trainer to stand in because it is hard for them to know what stage the group is working on.
- At training sessions, one can see that these people have strong will power, but they are just hungry and stressed.

Deaf culture

We did not understand the need for deaf culture spaces until this theatre training program. After every training session, we noticed that these artists, like all other artists, did not rush to go home.

They came together and spoke for a long time after each session at the work floor. As they walked out of the Cultural Centre, they would stand in groups for a long time talking. Then even when they went out of the main gate they would group up and stand there talking.

We then called Rose into a meeting and asked her if we were missing something when the sessions ended. She laughed and explained to us that deaf people do not get news from other common sources. They get social happenings when they meet at such spaces.

Unfortunately, they did not have such spaces except here at Amakhosi Cultural Centre when they came for training and rehearsals. This is the time they got to come together and share all community happenings and catch up with national and international news.

Rose then said to us, “Don’t worry, its deaf culture, we want everyone to know about it and be part of it”. At Amakhosi Theatre we had become part of it.⁶

Author biography

Cont Mdladla Mhlanga (1957 – 1 August 2022) was an internationally acclaimed Zimbabwean playwright, actor, theatre director, filmmaker, businessman and activist. He was also the founder and head of Amakhosi Theatre Productions, formed in 1982 in Makokoba Township in Bulawayo Zimbabwe. His work was inspired by giving the young generation skills in arts and culture to prevent marginalization. Mhlanga was a cultural and political activist, creating dramas for education, development and social and political critique of government in Zimbabwe. Some of his work has been banned, won national and international awards and he has been the inspiration to a generation of performing artists and the wider Zimbabwean citizens.

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6 Epilogue: Thanks to Rosemary Zhira and Amakhosi the deaf art culture blossom. They have received national and international funding and tell their stories in these facebookgroups: D.A.N.C.E – Deaf Art- Silent Stage <https://www.facebook.com/profile.php?id=61552215522947> <https://www.facebook.com/rosemary.zhira.50>

CHAPTER 15

AMANZI – An Inclusive Theatre Project in 2005 between Zimbabwe and Switzerland

Fortune Ruzungunde Freelance artist, Zimbabwe

Background information about the author

I am Fortune Anthony Ruzungunde, from Bulawayo, Zimbabwe. I have been in the arts for almost 40 years as a performing artist, arts administrator, writer, director and consultant. I have been involved in TV productions, I am one of the founding members of Amakhosi Performing Arts, and have performed in major arts festivals with them all over the world.

A collaboration is born

In my life as a performing artist I have had the pleasure of working with different institutions, and artists from different backgrounds. A new experience I had was working with artists with physical and cognitive disabilities.

In the project focused on in this chapter, I worked with artists from King George VI Centre from Bulawayo, Zimbabwe, and artists from Theatre Hora¹ from Zurich, Switzerland. King George VI² is an institution that caters for people with disabilities, as well as running art programs, while Theatre Hora is a theatre company with artists who have different disabilities.

I come from Amakhosi Performing Arts Workshop³, an institution credited for pioneering the performing arts in Bulawayo, and establishing the first cultural centre in the country.

1 https://de.wikipedia.org/wiki/Theater_HORA and <https://www.zuerich.com/en/visit/culture/theater-hora>

2 <https://www.kgvi.org/>

3 https://en.wikipedia.org/wiki/Amakhosi_Theatre

This was a rare collaboration with a woman, Waltraud Schafflutzel from Switzerland, who had so much passion for people with disabilities and for the arts. She was impressed by the achievements of these institutions, and wanted to start a collaboration between them. The collaboration began in 2003, and ended with the musical folk drama entitled AMANZI – Grosse und kleine Tiere [AMANZI – Big and small animals], which toured Switzerland in 2005. Laura Weidacher (2005), from Theater Hora, describes parts the collaboration like this:

For the first time, the anniversary production combines the European Hora team with physically disabled musicians and singers from Zimbabwe.⁴ (Weidacher, 2005, unpaginated. Translated from German to English by the editors)

Briefly, the story of the play is about the search for life-giving water, the powerlessness of large animals, and the triumph of small animals through their cunning. The moral of the story is: Together we are strong! (see Weidacher, 2005, unpaginated).

AMANZI – A creative and challenging rehearsal process

I wrote and directed AMANZI for this collaboration.

Our rehearsal schedule was simple. We would start the day with warm-ups and theatre games, and then we moved into the production. There was a lot of music in the production so we created a music team, led by Wanda Wolfensberger.⁵ We also created a dance and choreography team, as there were a lot of dances. Priscilla Sithole (a film maker based in Bulawayo) was in charge of dance and choreography, while Michael Elber,⁶ the co-director of Theatre Hora, and I worked with the actors.

The language barrier between Swiss German and English was one of the biggest issues, since we needed a translator all the time, which also slows down the pace of rehearsals. I also realised that in working with artists who have cognitive disabilities, you have to have patience. They are free spirits: sometimes they do what they want when they want. You cannot push them too hard, they do things at their own pace.

The whole rehearsal lasted two months, and in the end we created a worthy production that attracted full houses during its run in Switzerland.

⁴ <https://www.woz.ch/0502/theater-hora-und-amakhosi/fabelwelten>

⁵ <https://wandawolfensberger.ch/uber-mich/>

⁶ https://de.wikipedia.org/wiki/Michael_Elber

The production and collaboration received a lot of attention in Switzerland. Photos from press attention are included in Figure 1.



Figure 1. The author’s private collection of press clips from the Theater Hora and Amakhosi tour with “Amanzi – Big and small animals” in Switzerland in 2005.

One of the press clips says: “The audience is entranced. Big applause for the actors and musicians”.

My reflections

There is a need to have more such productions, which incorporate artists with disabilities and those without for the betterment of our communities, rather than segregating because of one’s physicality. If funds are available, it is necessary to invest in productions of this nature.

Author biography

Fortune Ruzungunde from Makokoba Bulawayo, Zimbabwe, has been in the arts for almost 40 years as a performing artist, arts administrator, writer, director and consultant. He has been involved in stage productions by Amakhosi Theatre such as “Citizen mind, Jazzman, Stitsha, Dabulpa to mention just a few. He has featured in local TV shows such as Stisha, Sinjalo, Amakorokoza, Sibahle and many more. He has also appeared in big screen movies like Steve Biko and a World Apart. He is one of the founding

members of Amakhosi Performing Arts and have performed in major arts festivals internationally. He is now a freelance artist.

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Attachment – The script of AMANZI

What follows is the original synopsis of the script for this collaboration. However, during the production and rehearsals it was totally changed to Swiss German for the benefit of the actors. Still, most songs were done in Ndebele and Shona, with a few exceptions. Pamphlets of the music and the meaning of the songs were distributed before each play, so that the audiences could follow them.

Amanzi!

Grosse und Kleine Tiere (Big and Small Animals)

Behind the curtain, beautiful singing and drumming.

Poem about the dryness of the land, encouraging people to come and work together and find ways to get water. People should come and work together, all to the background of a soothing song.

The song Mhondoro is heard in the background, backed by traditional drums and shakers.

The curtain opens to reveal a stage set-up of the Matopo Hills,⁷ with rocks and trees drawn on the background curtain, all resembling an early morning scene in the Matopos (Zim).

⁷ https://en.wikipedia.org/wiki/Matobo_National_Park

Enter storyteller with an Alphorn (Swiss traditional instrument) who blows it loudly

Storyteller

Background animal sounds

That sounds like an elephant.... That's what I thought...
 I have been mocked; they told me you are a little frog,
 you are a stupid weak little frog, you have a big mouth....
 I was sick of it and I went to Africa, I took the Alphorn
 with me and I played music with the elephants and all animals...
 they were sitting around me, imagine this ... sitting around
 me and waving their trunks and looking at me.
 Africa is beautiful, blue sky, no clouds in the sky but it's
 terribly hot... Hot, no rain for a long time.
 There is a skeleton, the bushes are burning, the bottles
 are empty, no water. I was thirsty, I was desperate, I saw
 a piece of clay under a tree and I picked it up and squeezed it,
 I hoped to find a drop of water but alas. The piece of clay
 started to talk and it told me a story.

Appearance of stoneman (more of a spiritual force)

A story about a giraffe, about a sad elephant, about a monkey, about a zebra who supported everything, about a snake and all the animals of the jungle.

Background sounds of animals in the jungle

Storyteller

...and now I have returned from Africa to tell you this story
 It was a long story, it took me a long time to understand.
 What a surprise, the story was about a little frog, a little
 weak frog, an unrecognised creature in the animal world.
 The stoneman wanted to teach me something. I
 understood the lesson. It's an important story for everyone.

Lion who called himself 'King of the Jungle' called a meeting for all the animals in the jungle.

The gathering

Entrance of the lion with drumming in the background as all the other animals enter.

Storyteller

When all the animals have assembled, lion speaks

Lion

Friends, we are in danger. Indeed. If it doesn't rain soon, we will all die. Indeed, let's unite, let's discuss this problem. Indeed. I need some ideas, I don't have a lot of time. What do we do, we all need water?

All the animals start discussing the issue but the fox is not participating. Marimba sounds in the background.

As animals discuss this issue fox stands and says

Fox

'I will not join you, I will find my own water, each one of us for themselves.'
All the other animals are surprised by fox and there is a misunderstanding among the animals, the giraffe speaks up.

Giraffe

Easy, easy, let this stupid fox go. Let him go we don't need him, by the way he is always boasting about being clever and intelligent. Let's forget him. By the way, I have an idea, let's dig a well right here.
Frog is sitting in the center.

Lioness speaks

Lioness

That's a good idea. Let's begin right away.
All the animals agree to dig for water.

Lioness

Hey you frog, stay outside. You are too small.
They all start digging and the lion is leading the way with music and dance.
They all dig

Storyteller

Day and night, they continued digging but could not find water. They lost their energy, but they went on, they got hungry, but still continued digging, and the frog, all the time he was sitting outside the well, as he was told that he was too small.

Frog

I haven't had my turn yet. I also want to dig.

Other animals

Sorry, what, you!

Frog

Yes, I also want to dig, am I not part of you? I also want to help. The other animals laugh him off, and others even mock the frog until zebra stood up and said:

Zebra

I agree with him, let's give him a chance, he should also try.

The other animals agreed, and when they took a break to go and find food, the frog is left to dig by himself.

In music and dance the frog is digging.

Choreographed dance.

Music out and enter fox

Fox

Ha, ha, ha, ha, haaaaa, no, no, no, mama mia!

There is no water and all of you will die!

Frog

Go away, you talkative.

Fox goes off stage laughing.

The frog continues digging and stoneman appears walking around the well and shouts

Stoneman

Amanzi – Water!

Stoneman disappears.

The frog continues digging and singing

Frog

Kokorokoko, water, kokorokoko water, kokorokoko water! Sings the frog as he continues digging with background sounds and instruments.

Another song begins and is sung in Swiss and kokorokoro (digging sound).

All of a sudden, the frog finds water, and the water starts gushing out furiously, and the frog is so happy, and runs all around the stage accompanied by singing and drumming.

Frog

Water, water, water. Amanzi!

Frog goes to the centre of the stage, and the other animals come and are surprised to find water. They are all happy and start to drink and play with the water.

There is dance choreography for all the actors playing animals.

Cut to the song of the lion boasting about his powers to the other animals.

Lion

Hey, little frog, you just scratched a little, I did most of the digging, you should all thank me.

All the other animals are laughing at the lion.

Lion roaring angrily

Zebra

Frog was digging too and is the one that found the water.

Lioness

No, the lion did the greater digging

Lion

Yes, I was digging the most.

At that moment the lion is angry, and starts to chase the other animals from one corner of the stage to the other

Elephant

No lion you can't do that, everybody was digging here. It was teamwork. What is important is that we now have water.

Gorilla

Now what do we do with fox.

Vulture

Let's hunt him down and kill him.

Giraffe

Leave him alone, let's just protect our water, he will not get water from here.

After a small debate, the animals agree to take turns to guard the water from fox. Elephant takes the first shift and the other animals go out in search of food.

Elephant's dilemma.

Fox enters the stage and seems to be enjoying and eating his honey.

Fox

Hallow uncle, how are you doing there?

Elephant

I don't want to see you here! Go away!
Elephant starts to chase the fox around the well.

Fox

Wait uncle. I am not here because of water. I have water of my own
I just wanted you to taste something.....

Elephant

What is that.....

Fox

This is honey, please taste my special honey. Hhmmmmmmmh, delicious

Elephant

Go away I know your tricks

In the end the elephant is tricked to taste the honey, which was very delicious.

The honey is so sweet that elephant asks for more.

Fox

If you want some more, I will have to tie your legs.

Elephant

Why tie my legs?

Fox

(laughing) Because this is special honey, you might go mad if I don't tie you up.

Elephant

Ok tie me up

Fox music

Fox smiles and ties up the elephant. Quickly fox dives into the well and swims leisurely and fills his containers with water while elephant is helpless.

Background music

Fox

Now I have to go.

Elephant

What about the honey?

Fox

What honey?

Fox laughs at the elephant's stupidity, and eats all the remaining honey and leaves before the other animals come back.

Elephant is left alone on stage worried and disappointed.

Song 'Mama I am crying'

Enter the other animals to find the elephant tied up.

Snake

What's up?

Elephant

The fox

Snake

Do you believe this?

All animals

No!

Enter storyteller

Storyteller

No animal believed the elephant could be tricked by the fox. This could not be true. So all the animals took their turns to guard the well, and each and every one of the animals was tied up by the fox.

Lion song background

Lion was next in line, and he boasted of being the king of the jungle, but in the end, he fell for fox's trick and was tied up. When all the other animals came back to find the lion tied up, they could not help but laugh at the lion.

As the animals discuss the issue of security, the frog, the smallest animal, rose up and volunteered to guard the well.

Frog

Please be quiet, give me a chance, I also want to guard the well.

The other animals think it's a bad idea, as the frog was too small for the fox but in the end, they resolve to give him a chance.

Giraffe

Remember the frog found the water, why are we complaining? Let the frog take a chance.

The animals help the lion up and untie him and leave the stage.

Frog song

The frog gets in the well and makes sure he is out of sight waiting for the fox.
Fox song as the fox enters the stage.

Fox

Who is here? Nobody! This is strange.

The fox, thinking that he has defeated all the animals starts to dance and celebrate by himself, boasting that nobody can touch him. He fills his containers and starts to swim in the well.

Frog catches the Fox

Meanwhile the frog is moving towards the fox and finally catches his leg. The other animals appear, to see the fox caught by the frog. He is brought out of the water and tied up

Celebration

Celebration song while the other animals are congratulating the frog and mocking the fox.

Storyteller

....and so, the fox was caught the other animals forgave the fox.

This is why we say: Together we are strong!

Song: Together we are strong as we are big animals and small animals, we all live together!

The End.....!

CHAPTER 16

(Lou)Cure-se!!! An Artaudian Approach to Existence in Scenic Instaurations at the Psychiatric Hospital Dr João Machado

Josadaque Albuquerque da Silva Pires Hospital Dr. João Machado, Brazil

Nara Salles Art Department of the Federal University of Rio Grande do Sul, Brazil

Felipe Henrique Monteiro Oliveira Centro Internacional de Pesquisas Artísticas e Acadêmicas sobre Antonin Artaud and Universidade de São Paulo, Brazil

Andrea Pagnes (VestAndPage), ArtEZ University of the Arts, the Netherlands

Translated from Portuguese to English with assistance from Maria Carolina Monteiro Oliveira

Abstract: The article discusses an investigation proposal for action research to benefit mental health patients, their corporeity and daily intersubjective interactions inside the Psychiatric Hospital Dr John Machado (Natal, Brazil). The project, entitled “Literacy in Contemporary Art and Creative Processes: Investigations About Madness”, was conducted by undergraduate and graduate students from the art department of the Federal University of Rio Grande do Sul, coordinated by professor Nara Salles and psychologist Josadaque Albuquerque da Silva Pires. It coalesced madness and art for five years, collecting patients’ responses through integrated teaching. Through participatory observation, the researchers explored hierarchical relationships, beliefs and ideas about madness that shape a psychiatric facility and how to relate art to them. The project developed in an artistic residency with the Cruor Contemporary Art collective and culminated with *(Lou)Cure-se!!!*, a series of scenic instaurations set inside a hospital pavilion every Saturday in July and August 2016. In addition to enjoying art and theatre, the attending audience had the opportunity to understand life inside an asylum.

Keywords: Artaud, scenic instaurations, psychiatric hospitals, co-existence, encounters

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A differentiated space

Visiting the Psychiatric Hospital Dr João Machado for the first time, one immediately realizes that it is built to host differentiated people. Its large walls, tall windows, gates and closed doors, the looks, speeches, gestures, actions and countless other perceptions impact visitors' gaze and sensitivity. One feels the physical and social structure that characterizes totalitarian institutions, where observation, control and treatment within an established logic of power, including force, when necessary, are their common denominators.

Understanding madness throughout history is essential. In the past, madness was not associated with illness. "The great internment" (Rabinow, 1984, p. 56) happened with the foundation of the Hôpital Général de Paris in 1656. "The internment of the mad is the moment when madness actually takes possession of confinement, while confinement itself is divested of its other forms of utility" (Foucault, 1988, p. 235).

The Hôpital Général de Paris was not a medical facility but rather an assistance institution. There was no treatment for madness since the insane were not considered sick. If anything, the mad were excluded because they were deemed unsuitable for social life.

Michel Foucault, writing about 17th-century internment houses, states that the mad had their mysteries and a loquacious language. They were endowed with animality, courage and creative impulses. Their wandering life about to fall into abysses and precipices made them beings with no guarantee of stability. However, it often led them to constant improvisation and transgression of social norms and standards. However, from the 17th century onwards, the measures of enclosing the mad in internment houses, and withdrawing them from social life, radically changed the perception of madness (Foucault, 1988).

It is commonplace to think of a mad person as someone lost or dangerous who needs to be cloistered. In that, it is worth emphasizing the historical influence of the classic psychiatric paradigm on interventional action and the quality of the human relationship in the treatment given to the mentally ill by health professionals. Brazilian psychiatrist Nise da Silveira (1981) highlighted how the 19th century was relevantly marked by the effort to analyze madness through specific medical parameters, classify mad people clinically and describe their symptoms in detail.

The classic psychiatric paradigm established in the second half of the 20th century disputed that mental illness could fit into the medical model,

for it is a phenomenon that occurs within the organism. Still today, mad people are considered mentally ill to be confined in psychiatric institutions, hence excluded from their families and communities.

A hospital space Artist Residency

From the 1980s onwards, the concept of Artist Residency has been deployed as one of the most distinctive ways of supporting and encouraging arts development. Artist residencies take place in a physical location, such as a house or an institution, aiming to develop artistic productions in a residential setting and interact with people living in the surroundings.

The artist residency at the Psychiatric Hospital Dr João Machado was meant to offer an artistic co-creative itinerary to its patients and realize a performance piece with them open to the public. Daily contact between the patients and the artists bound their relationships. Their names and physiognomies became familiar. Their stories, anxieties and intimate secrets were shared with kinship, empathy and complicity. Notwithstanding remnants of the asylum culture, where madness is predominantly treated as a disease, the collective undertook their investigation assuming that the condition of a disease is considered illness only within a culture that recognizes it as such (Foucault, 1988).

As representatives of a university art department, the collective intervened artistically in a socio-institutional reality. Their action research focused on finding and implementing effective teaching-learning strategies to benefit a particular people category host in a specific environment (Elliot, 1991). They shared their artistic practice and academic knowledge, dialoguing with everyone in the hospital whenever necessary, realizing that patients are fundamental to any hospital routine, whether therapeutic or creative.

Facilitating art practices is a relational process between oneself and the other. It involves ethical choices and aesthetic implications, which imply presence, dedication, the senses, and psychic and physical activation for creative expression. Music was deployed to create a relaxing atmosphere. Slow-motion movements and light control enabled nonverbal communication, leading several patients to regain possession of gestures complicated by inhibitions. Storytelling was dissected into its most basic components to experiment with forms of non-linear narration. Painting graffiti on walls collectively helped to re-awaken joyful feelings of liberation.

Creating a scenic instauration

Madness can even be poetic. However, psychiatric patients are often placed under the cloak of indifference, stigma and prejudice by society. They are often abandoned to their fate by families who do not know how to deal with their condition. The collective attempted to respond to this situation by interacting sensitively with patients through art-making and empathy.

(*Lou*)*Cure-se!!!* scenic instaurations were created for an aesthetic of rupture. Fragmentation, slippage and non-linear dramaturgy characterize each scene, and there is no continuity or direct connection between the stories that unfold. It is a performative method from Antonin Artaud's Theater of Cruelty, thought to shake audiences through gesture, image, sound and light (Artaud, 1994). Because he was considered insane, the French poet, actor and dramaturg spent nine years in asylums.

Similarly to Artaud, Cruor Arte Contemporânea proposed the integration of all artistic languages, including dance, performance, painting, and music, for, in this way, the possibilities are many, as long as they include and do not segregate anyone for any reason.

Positioning psychic patients undergoing treatment as subjects of rights and creative agents contributed to perceiving difference as an innovative source and improving learning to act proactively with individuals affected by mental illnesses. Sensitivity to the patients marked their narratives and produced new meanings, influencing the scenic instaurations' time, rhythm and climax.

Each scene developed from observing patients and dwelling with them in their environment, listening and sharing ideas co-creatively (Pires, 2016). Each artist worked daily with one or more patients. If someone refused to attend for some reason, others were invited to participate (Santos, 2021).

Indeed, subjective aspects of the researchers referring to the theme of madness and the asylum culture negatively influenced the investigative course. However, a dramaturgy and a script took shape. Improvisation was fundamental in each presentation, and audio-visual interferences always occurred. Teixeira Coelho (1980) argued that post-modern theatre ceases to present shows consumed by others. What happens are theatrical experiences, with no separation between stage and audience. It is not about representing but rather about giving oneself genuinely in the present moment.

The scenic instaurations took place in a hospital's pavilion designated by hospital management to host the artistic residency. This place was

previously the residence of patients who lived in the hospital, later transferred to a rented house that became an assisted living facility. The decision to host only ten spectators per session was because other activities inside the hospital pavilion followed their routine.

Concluding remarks

The function of art is a question that opens loopholes for infinite answers. What happens when art is offered to people who do not fit normative standards?

(Lou) Cure-se!!! worked because it proposed a poetics of interconnect-edness and an aesthetics of co-existence, strengthening the power of affection and encounter. Contemporary art cures life's illnesses. Several patients have returned to society thanks to this innovative project and the necessary therapies.

Eventually, the presence of the artist-researchers collective in the daily life of the Psychiatric Hospital Dr João Machado characterized art as an area of knowledge about madness to seek new meaning and challenge the status quo. The project helped inspire creative approaches to structuring, organizing, and transforming oneself and the surroundings. As a result of the scenic installations, reflections were stimulated, and connections were made.

Author biographies

Josadaque Albuquerque da Silva Pires (he/him) obtained an MA in Performing Arts from the Center for Human Sciences, Letters and Arts of the Federal University of Rio Grande do Norte, Natal, Brazil, in 2016. Today, he works as a psychologist and is the Hospital Dr João Machado director in the same city. With experience in the field, he is recognized for his commitment to offering individualized and effective treatments to his patients. His research interests are in mental health issues and how people stigmatized with madness deal with their interpersonal relations occurring in the everyday scene of a psychiatric institution.

Nara Salles (she/she) holds a PhD in Performing Arts from the Federal University of Bahia. She is a professor at the Federal University of Rio Grande do Sul and at the PROFARTES Postgraduate Program at UFRN in

Brazil. With extensive experience in dance, theatre, and contemporary art and an emphasis on differentiated bodies, madness, mental health, collaborative creative processes, and integrated transdisciplinary research projects, she is a member of the Brazilian Association of Mental Health-ABRASME. Her research interests revolve around clinical psychoanalysis, dance therapy, anthropology, social inclusion, urban interventions, and the oeuvres of Antonin Artaud, Pedro Almodóvar and Frida Kahlo.

Felipe Henrique Oliveira Monteiro is the founder and director of the International Center of Artistic and Academic Research on Antonin Artaud. Monteiro is also a performer and a postdoctoral fellow at the Postgraduate Program in Performing Arts at the Universidade de São Paulo. Monteiro holds PhD in performing arts from the Universidade Federal da Bahia. His research interests include: theater studies, performance studies, differentiated bodies, performance art, activism, post-dramatic scenes, Antonin Artaud and Frida Kahlo.

Andrea Pagnes (he/him) works with Verena Stenke (she/they) as VestAndPage. They explore performance art and performance-based filmmaking as “thin places” phenomena through their collaborative practice, artistic research and curatorial projects. Their psycho-geographical works move between the unseen and unforeseen, the oppressed and unspoken, the forgotten and the repressed. They are the founders and curators of the Venice International Performance Art Week, recipients of Best Film Awards at the Berlin Independent Film Festival (2018) and lecturers at ArtEZ University of the Arts (NL) and Unidee Academy (IT).

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CHAPTER 17

Including Irina – A Personal Retrospective and Sideways Glance from a Theater Critic on Being an Artist with a Disability in the 1980s and 1990s

Sara Granath Freelance Theatre Critic, Sweden

A personal experience – Art meets reality

I have worked as a theatre critic since 1989. But it was my connection to the International Federation for Theatre Research, that quite unexpectedly brought me to Bodø, in the north of Norway. There I had a conversation with a man who remembered everything: names, dates, places, and who could solve any mathematical problem in the blink of an eye. It was an unusual and rewarding experience. Afterwards I thought: I was talking to a Rain Man. Dustin Hoffman's portrayal of the title character in the American film *Rain Man* from 1988 (Levinsson, 1988) made my meeting with this Norwegian savant quite unproblematic.

The development of the relationship between art and reality

I then started thinking about the development of the relationship between art and reality over the years: from an empathic portrayal of a savant, directed mainly towards a mainstream audience, to artworks through

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which people with various kinds of diagnoses could express themselves, and be included in an artistic community as subjects, as themselves. I also thought about the ethical implications of playing, playing for, and acting with ‘people with disabilities’.

I also asked myself what measures have been taken to include people with disabilities in the community at large.

Sweden, a northern democratic monarchy

I live south of Stockholm in Sweden, a democratic monarchy in Northern Europe. One aspect of democracy is the right to vote. In Sweden women finally got the vote in 1921, prison interns in 1937, and poor people in 1945. Those with various kinds of mental disabilities gained the right as late as 1989.

My personal context

I have been interested in theatre my whole life. I have been a teacher on all levels from pre-school to university, always with theatre as the subject. Today I still work as a theatre critic at the *Svenska Dagbladet* (Swedish Daily), a national newspaper.

My first contact with people with cognitive disabilities

A lot has happened since my girl guide group acted in a play for an audience of so-called ‘retards’ at a special school in Sweden, in the early ‘60s. We improvised and used funny clothes and props. I have a vague, but positive memory of the occasion. What the audience felt and thought I have no idea, but we were invited back.

Changes in general attitudes

We do not talk of retards anymore. The labels and – hopefully – the attitudes have changed over the years. In Sweden, individuals with various kinds of disabilities, physical and cognitive, now sometimes call themselves *funkisar*, which could be translated as disabled.

The disabled appear in various media

In Sweden we have an ongoing TV commercial for a food store, resembling a little soap opera. One day a young man with Down's syndrome was introduced into the cast, and I remember reacting a little. Was this OK? And why did I doubt it? Disabled artists were already visible on stage and on TV, sometimes on their own, sometimes in integrated casts.

We have at least two very well-known theatre companies, in which disabled artists act together with nondisabled artists. *The Moomsteatern*¹ opened in southern Sweden in 1987, and *The Glada Hudikteatern*² in the north was established in 1996. The leader of that theatre group, Pär Johansson, has witnessed some parents' initial resistance to their adult children appearing on stage. They did not want them to look ridiculous, to be made fun of. And maybe that explains my gut reaction, too.

But is looking away the most considerate way of dealing with people who look 'odd' or behave differently? How would you feel if people never looked at you?

Irina's New Life – A special theatre production in Stockholm

A theatre production in Stockholm, Sweden, 1996, made a lasting impression on me. I thought it was moving and wonderful, but some people reacted negatively.

In *Irinan nya liv/Irina's New Life*,³ based on Irina von Martens' *Irinan bok/Irina's Book*⁴ (1994), the disabled characters were played by the ordinary ensemble of the Unga Klara,⁵ a division of the Stockholm City Theatre.

The question arose: Was it OK to 'make fun of' people with disabilities? Or make them appear funny? I remember that there were people who thought it was disrespectful of nondisabled actors to play disabled. But many years afterwards actors keep mentioning their experience of acting in or watching *Irina's New Life*.

1 <https://moomsteatern.com/en/start/>

2 <https://gladahudikteatern.se/en/>

3 <https://www.ungaklara.se/scen/marianne-lindberg-de-geer>

4 <https://libris.kb.se/bib/7846055>

5 <https://www.ungaklara.se/>

It seems it was sometimes considered ethically problematic both to have disabled artists on stage and have nondisabled artists play them. Was their very existence a problem?

Suzanne Osten, a brave director

Karin Helander (1996), who reviewed *Irina's New Life* in my newspaper, was delighted. She commented on the concerns I have mentioned, but she saw no disrespect. That is not surprising, since the director, Suzanne Osten, already had a long track record of dealing with sensitive subjects, such as parents' divorce, suicide, and the experience of living with a psychotic mother (her own). And it was mostly adults, not children, who worried about her subject matter. Osten thinks that it is more helpful than worrying for children to see their own difficult reality portrayed on stage.

Irina von Martens, writer and actress

I was fortunate to see Irina von Martens herself on stage, at a theatre festival in Hangö, Finland (2000). She acted with other disabled artists and showed great talent. The play, partly written by her, was a version of *Romeo and Juliet*, and Irina played Juliet's mother. The love conflict was here mainly about jealousy. The mother intervened when Romeo and Juliet were too cuddly with each other, and after tearing them apart, she hugged her daughter fondly. I really enjoyed the play, true artistic pleasure. Irina's theatre group is called *Duvteatern*.⁶ Some years later the group played in Stockholm with a version of Chekhov's *Three Sisters*, and I was sent to review the performance.

A version of Chekhov's *Three Sisters*

Irina von Martens played the eldest sister, Olga, a very strict teacher, suffering from severe headaches. A latecomer to school was punished physically. Much was expressed via dance and music. The youngest sister Irina did not say a word during the performance, but drove two soldiers crazy with passion. Brother Andrey's wife, Natasha, took control of the

6 <https://www.duvteatern.fi/eng/start/>

house by exchanging the paintings of flowers on the walls for her own, picturing cows.

In this version the sisters finally went to Moscow, which they only hoped and wished to do in Chekhov's original. There was a lot of action and no melancholy.

The ethical problem of writing a review

I really liked the emotional impact of this very expressive play. I had one problem, however. Should I mention that the actors were disabled or just write about the production as I would write about any other? A little doubtful I chose the latter way, focusing on artistic value. My review was published without objection from the newspaper, but some days later the director of the play was interviewed, and talked about the circumstances of the production.

Irina von Martens, the writer, born in 1963

Many years later I returned to Irina von Martens, the writer. I read her book, *Irinan bok/Ronjas nya liv (Irina's Book/Ronja's New Life)* (van Martens, 1994), and the dramatisation by dramaturge Nils Gredeby (1996).

Irina von Martens' father, Paul, is a writer, and she wanted to be one too, although people like her were considered 'unteachable' when she was little. In spite of such prejudice, she started writing, every day, after work.

Paul von Martens, father and editor

Paul von Martens later selected parts of her massive body of work for publication. In a foreword, he treats her with great respect, describing her as a writer with style, discussing her subject matter and themes. When I read this, I felt strengthened in my choice of writing about the Chekhov version like any other theatre production.

He also writes about helping to 'fix' her text, mainly spelling and interpunction. Like the ancient Greeks, she does not use punctuation at all, does not want to. But otherwise, the book was completed with her total cooperation and consent.

***Irina's Book* and the creator of Pippi Longstocking**

Irina's Book is about her daily life, her work, the people around her. But mainly it is written in close communication with the fictional world of the Swedish writer Astrid Lindgren (1945), creator of the motherless Pippi Longstocking, who lives in a house with her monkey and her horse. Primarily, Irina relates to the movie version of Lindgren's (1981) *Ronia, the Robber's Daughter* (Danielsson, 1984). It is—again! – a Romeo and Juliet story, with the children, Ronja and Birk, as the main characters. The children's families are two bands of robbers at war with each other, like the Capulets and Montagues in Shakespeare's Verona. In the movie, Ronia's mother, Lovis, is played by Lena Nyman, who is presented with her own name in Irina's text, while the father Mattis, Börje Ahlstedt, is called Börje Nyman.

Dramatisation and theatre production

Nils Gredeby's dramatisation focused mainly on Irina's relationship to Astrid Lindgren's characters and the actors playing them. The director, Suzanne Osten, combined this play with another piece by poet/dramatist Eva Ström, dealing with children with physical disabilities in 1996. I do not remember any objections to the actors' playing children with physical disabilities. Obviously psychological weakness was seen to be more stigmatising than physical weakness.

***Irina's New Life* (1996) by Suzanne Osten, the play itself**

In the second play on the bill, Irina herself was a character, and her Astrid Lindgren characters were played by actors playing disabled. In this 'double' roleplaying, they were very playful and fun. And that is when some people reacted negatively, maybe as a gut reaction, like mine regarding the man with Down's syndrome in the food commercial.

Suzanne Osten is a master of theatre as play, of play within play, of meeting controversial subjects head on, always with the audience in mind. Actress Ann Petrén, who played Irina, many years later remembers a scene where the actors were playing a band singing popular dance tunes.

There were several disabled people in the audience and they came up on stage, joined the cast, and danced to the music. The actors included them in the show, as best they could. This was a typical way of relating to the audience at Unga Klara.

Irina von Martens herself was part of the rehearsal process, to some extent, and she was satisfied, except for the actors' funny hats.

Both *Irina's Book* and Nils Gredeby's playtext are sometimes hard to follow. But on stage everything became crystal clear. This showed the power of theatre, the place where Irina really comes into her own, both as a writer and an actress.

Like Irina's writing, and the plays with her I have seen, it dealt with power relationships, violence, sex, childbirth, jealousy, and the love for a mother. These are serious things handled with energy and good humour.

The disabled artists themselves – What's in it for them?

My own trajectory, from acting in front of the disabled in the 60s, to watching their own performances with artistic and emotional pleasure, is matched by the development of Irina's home stage, *The Duvteatern*, in Finland. One of its directors talked about going from theatre FOR the disabled to theatre WITH disabled artists.

I have written mainly about my own pleasure in watching theatre with, by, and about disabled artists. But what is in it for them? In a series of shows on national Swedish television (2018), with famous and popular watercolour artist Lars Lerin, it becomes quite obvious that the disabled participants live, and have lived, quite sad and lonely lives despite their efforts and success in art. That would apply to theatre as well.

Art as a means of inclusion in society

In this chapter I have focused on the artistic experience itself, starting with the disabled as audience, continuing to disabled characters, and finally to the disabled as creators on various levels. Over the years much has been done to make art practically and legally accessible to everyone, on stage and off.

But in artistic creation, legal rights are only a framework. There the disabled can be creators in communication and cooperation with other people, as well as participate in and enjoy the artistic creation of others. They can be equal, valued members of mankind.

Theatre is a place where everyone can and should be able to take part.

Author biography

Sara Granath has a PhD in theatre studies from Stockholm University. She retired from Södertörn University in Stockholm, as Assistant Professor in Literature and Drama. She has also taught at the universities of Lund, Stockholm and Gothenburg and has practical experience of theatre – acting, directing, amateur groups – and publishing – warehouse, complaints, editing. Since 1995 she writes theatre reviews for the *Svenska Dagbladet*, a national newspaper, and is the secretary of the Strindberg Association. From 1989 on she has attended the conferences of the International Federation for Theatre Research and published papers with performance analysis and feminist research as her main focus.

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CHAPTER 18

Exploring Inclusive Art Practices in the Context of CRPD

Tine Skjold Producer and artist, Norway

For the past four years I have been the leader of *NUK – Ny ung kunst* (New Young Art), an annual, inclusive art festival for young people (14–20 years) in Norway. The festival was established in 1992, and is organised by and is a part of the larger festival *Festspillene i Nord-Norge* (The Festival of Northern Norway). During the festival, participants take part in creative workshops and reside together at a school; some establish lifelong friendships. The festival specializes in facilitating for people with general learning disabilities (14–40 years).

Ensuring human rights

I began writing this article by questioning how I could use the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) to further develop the inclusive art practices in my capacity as the director of an inclusive arts festival for youth. In the process, I have however, become aware of an underlying perspective and area of investigation that sharpens the original question, namely, the lack of focus on ensuring human rights in the development of NUK. I have not looked at the festival in relation to these rights before. It may seem strange, seeing as the festival facilitates for people with disabilities (*Festspillene i Nord-Norge*, n.d. 1). The minimum requirement for our activities should therefore be that we ensure the human rights of people with disabilities at the festival. This, I see now, is not necessarily the case. We are aware of the goals and

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basic premises of inclusive art practices, but we do not reflect on ensuring human rights as a fundamental part of our work.

As German philosopher Hans Georg Gadamer points out, one's understanding in the present always has its limits (Gadamer, 1990, p. 341). I wonder if my understanding of inclusive art practices is limited by the fact that I have not paid attention to the rights of people with disabilities when developing NUK. Therefore, in this article, I want to take a closer look at how, as the leader of NUK, I can facilitate the fulfilment of the CRPD to broaden my understanding.

Considering the understanding of inclusion that forms the basis of NUK, I will look at how the rights of people with disabilities are safeguarded in relation to the development of their creative forces and artistic and intellectual potential. I also want to question how, in relation to the CRPD, we can challenge our understanding of what measures are appropriate to take to ensure, to a greater extent, the human rights of the people that we work with.

The CRPD in a Norwegian context

The CRPD is intended to help combat discrimination based on disability and "(...) ensure respect for the existing civil, political, economic, social and cultural rights of persons with disabilities" (The Norwegian Government, 2022, 24 November). Norway committed to the CRPD in 2013, but the convention has never been incorporated into Norwegian law (The Norwegian Government, 2022, 24 November). However, on October 5, 2022, the Norwegian government, chaired by the former Minister of Culture and Equality, Anette Trettebergstuen, announced that a legal expert committee had been obtained to determine how such an incorporation could be achieved (The Norwegian Government, 2022, 5 October). On January 15, 2024, the Committee published its findings in a two-part report which until June 5, 2024, was out for public consultation (The Norwegian Government, 2024). Although the outcome of the process is still uncertain when finalizing this article, we know that the majority of the committee's members recommend incorporating the CRPD into the Universal Declaration of Human Rights (UDHR) with precedence, rather than use the CRPD to make new laws (Indreberg et al., 2024, pp. 147, 171). Considering these events, one could use this article to research how one can use the CRPD with precense to expand once understanding of the

UDHR. However, in order not to lose focus on my area of investigation, I choose to only use the CRPD as a tool for this analysis.

In relation to Chapter 30 of the Convention, this includes taking appropriate measures to fulfill the rights of persons with disabilities to access culture, cultural materials and places in accessible formats. It also includes designing measures that enable persons with disabilities to develop and utilize “(...) their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society” (The Norwegian Government, 2022, 24 November, p. 26). With the CRPD as the basis for one’s organization, one can thus understand that ensuring the right to access is closely linked to the organization’s ability to adapt and change in step with the people it accommodates: not only for its own enrichment, but also for the enrichment of others. In many ways, this aligns with some of the fundamental premises of NUK and specifically relates to parts of the understanding of inclusion on which we base the design of the festival’s artistic workshops. In further exploration of whether, or how, CRPD is fulfilled at NUK, I will take a closer look at one of the measures we implemented to give our participants the opportunity to develop and utilize their creative potential at the festival.

Understanding inclusion considering the CRPD

A fundamental premise of NUK is that young people with or without disabilities should be able to take part in the same artistic workshops on equal terms (Festspillene i Nord-Norge, n.d. 2, 3). Of the festival participants with disabilities, most have varying learning disabilities, and we therefore relate specifically to a discourse in the art field where inclusion is understood as “creative collaborations between learning-disabled and non-learning-disabled artists (...) [that intend] to support a mutually beneficial two-way creative exchange that enables all the artists involved to learn (and unlearn) from each other” (Fox & MacPherson, 2015, p. 2). Thus, an overarching goal of NUK is to develop methods and structures that enable everyone to take part in the festival in a way that is beneficial to the individual, as well as to facilitate and create an environment in which all those involved regard each other and themselves as equally important and relevant contributors to the process.

This understanding is consolidated in the design of the festival’s artistic workshops, among other things through the mission statement given to

each workshop leader. In their contracts, for example, they are specifically asked to design and implement a process-oriented art project in which all participants “shall be central and co-creative actors [in a way that] (...) is beneficial to all those involved, regardless of who they are, what they can do or what their physical or cognitive starting point or abilities are” (Personal communication with NUK, 19 May 2022). They are also asked to work to ensure that “an equal aesthetic exchange between all those involved in the project can take place” (Personal communication with NUK, 19 May 2022), as well as to “(...) initiate dialogue with companions and other support systems to strengthen the individual participant’s opportunities to participate beneficially in the project” (Personal communication with NUK, 19 May 2022).

The brief to the artists is an attempt to ensure that participants of NUK, regardless of their ability, can develop and utilize their creative, artistic and intellectual potential in formats that are accessible to the individual. Through the goal of facilitating equal aesthetic exchanges between participants, there is also an expectation that participants can develop and utilize their creativity in a way that enriches others. With our understanding of inclusion as the basis for the creative processes at NUK, we have thus in many ways designed measures that can be considered in line with the CRPD. However, we know from experience that putting these intentions into practice is easier said than done. I would therefore like to conclude by reflecting on one of the issues related to the understanding of inclusion that we use as a basis for developing artistic workshops at NUK.

Understanding the task at hand

The discourse of inclusion to which we relate, and which in many ways forms the basis for the artists’ understanding of what their mission is in relation to our participants, is closely linked to the view of people with intellectual disabilities and art:

In essence, it is an “aesthetic of exchange” that places the non-disabled artist in the more radical role of collaborator and proposes a shift away from the traditional notion of “worthy helper”. Through redefining this role and shedding the notion of the formally trained “expert” artist, we try to explore the valuable and skillful contribution that learning-disabled artists can bring to the arts. (Fox & Macpherson, 2015, p. 7)

Being able to fully comprehend what it means to work inclusively thus requires more than just a general description of what inclusive art is. It requires knowledge of everything that forms the basis for the art form or direction to exist in the first place – including the various models of disability that, among other things, describe how different understandings and definitions of disability work have consequences in practice (Edvardsen & Gjørum, 2021, p. 196). If you do not have any form of artistic training, how do you relate to the other person? To understand the assignment as a workshop leader at NUK, this suggests that one must have knowledge of the underlying perspectives and theories associated with the concept of inclusion in this context. For example, why is this shift from “worthy helper” to equal practitioner radical for artists without learning disabilities collaborating with artists who have learning disabilities, and what does this shift require from the practitioner without disabilities?

An introduction to theories that can help the artists at NUK to answer such questions is not currently given to the artists, nor is there a requirement to know anything about them. In light of the CRPD, however, one might wonder whether the basis for safeguarding people with disabilities at NUK is good enough to really ensure adequate access and safeguarding of basic human rights for our participants. The CRPD can thus perhaps be used as a basis for a common understanding of what we want to realise at NUK. Our participants with disabilities are not invited to the festival because we choose it. They are there because they have a right to be there. Using the CRPD as the basis for our activities makes this visible and forms a platform for conversations about what we and those who work for us are fundamentally obliged to facilitate.

CRPD as a guide for our future work

While working on this chapter, I have realised that the UN Convention on the Rights of Persons with Disabilities (CRPD) can be used to further develop the inclusive art practices at NUK. By viewing the understanding of inclusion that underpins the festival in light of the CRPD, I have discovered that the convention can act as an important sparring partner regarding the development of appropriate measures in safeguarding the rights of people with disabilities to develop and utilise their creative, artistic and intellectual potential. I have also found that the CRPD can challenge one’s understanding of what the appropriate measures are to

safeguard the rights of our participants to a greater extent. In my work on the further development of NUK, I will therefore continue to use the CRPD as a contribution to quality assurance at all levels of the festival. I hope others will do the same.

Author biography

Tine Eriksen Skjold is educated as a lecturer in drama and theatre from Oslo and Akershus University College of Applied Sciences (HiOA), specializing in the drama pedagogical direction of process drama. She has acquired solid expertise in facilitating and researching inclusive art processes through her education and wrote her master's thesis on how to open for equal co-creation in drama pedagogical work through selected performance theory perspectives. Since 2020, she has developed Festspillene i Nord-Norges inclusive art festival for young people, NUK. Her research interests include developing inclusive art methods and structures.

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How might inclusive arts practices strengthen active citizenship and community participation?

This is the main question that inspired the global collegial networks that led to this book project. The authors of the introductory chapter, 12 peer-reviewed research chapters and six practical encounters engage with theatre, performance, dance, visual arts and/or other cultural practices from critical disability perspectives in local contexts in the Global South and North.

The authors critically present and discuss methods and models for inclusive and innovative arts and cultural citizenship practices that leverage off of disability as the special driving force and game changer for a more open society. The perspectives and practices elaborated on reveal how art-practice in the community is a way of activating partnership and participation. With this book the editors and authors argue that through artistic citizenship practices, the space and possibilities of being a citizen develop.

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