

**ANDREA PAGNES**  
**FELIPE HENRIQUE MONTEIRO OLIVEIRA**  
**NICOLA FORNONI**  
**ENOK RIPLEY**

**EMBODYING THE DIFFERENCE –  
PERFORMING THE EXPERIENCE:  
ON PERFORMANCE AND  
DISABILITY**

## Resumo



This article stems from the author's experience as a performer, curator, and applied drama and social theatre actor, playwright and operator. It is based on his research "Inclusive Production Methodologies in the Performing Arts for Diversely-Abled Performing Arts Practitioners", supported by Fonds Darstellende Künste with funds from the Federal Government Commissioner for Culture and the Media (DE). According to the author, disability is not a sign of a lack, but rather a way to encourage people to reduce distances between one another, live in solidarity, and break commonplaces. Considering authenticity as a fundamental quality for performing, he discusses that disabled performers have a genuine immediacy to immerse themselves in the nowness of the action because their vulnerability on stage is unfiltered. In that, he sees stigma as a source of creativity and a qualifying sign capable of eradicating preconceptions and biases. Performance practices are not just a question of ability and skills collection but rather, in Grotowski's words, an eradication of blocks to adhere to one's true self. The performer's body is the *prima materia* to produce meanings that turn into living images and come into reality. This is regardless of the performer's physical condition. The article offers examples of performers affected by different forms of disability, such as Felipe Monteiro, Nicola Fornoni and Enok Ripley who report on their specific clinical condition. A particular reference has been made to the collective performance opera *Underscars* conceived and organised by the author, his partner German artist Verena Stenke and their collaborators in Venice in December 2023.

Palavras-chave:

Disability. Theatre. Performance art.

# EMBODYING THE DIFFERENCE - PERFORMING THE EXPERIENCE: ON PERFORMANCE AND DISABILITY

**ANDREA PAGNES<sup>1</sup>**

**FELIPE HENRIQUE MONTEIRO OLIVEIRA<sup>2</sup>**

**NICOLA FORNONI<sup>3</sup>**

**ENOK RIPLEY<sup>4</sup>**

---

<sup>1</sup> Andrea Pagnes (he/him) is a Venetian-born artist, performer and writer working with German artist Verena Stenke as VestAndPage. They are lecturers at ArtEZ University of the Arts (NL) and Unidee Academy (IT). They have gained international recognition in performance art, performance-based filmmaking, writing, social theatre, applied drama and temporary artistic community projects. VestAndPage are founders and curators of the Venice International Performance Art Week. ORCID: <https://orcid.org/0000-0003-3696-2503>. Email: [pagnes@vest-and-page.de](mailto:pagnes@vest-and-page.de)

<sup>2</sup> Felipe Henrique Oliveira Monteiro (he/him) is the founder, director and researcher of the International Center for Artistic and Academic Research on Antonin Artaud. He is a performer, a post-doctorate by the Graduate Program in Scenic Arts of the University of São Paulo and a collaborating professor in the Graduate Master of Arts Program of the Federal University of Uberlândia. ORCID: <https://orcid.org/0000-0002-3759-9139>. Email: [fhmoal@hotmail.com](mailto:fhmoal@hotmail.com)

<sup>3</sup> Nicola Fornoni (he/him) is a performer affected by severe Scleroderma since 2001. He uses performances and video art as languages to dissect social issues and the themes of otherness, committed connectivity, respect and union. ORCID: <https://orcid.org/0009-0009-1939-7515>. Email: [fornoni.nicola@libero.it](mailto:fornoni.nicola@libero.it)

<sup>4</sup> Enok Ripley (they/them) is a non-binary, transgender performer, contemporary dancer, and graffiti and tattoo artist active in Canada. They are chronically afflicted with painful swelling throughout the tissues in their body and high fevers that render them unconscious and threaten their life. From their clinical condition, they explore the dissonance of body images in their social environment. Ripley's body-based art practice is inspired by religious iconography and objects often overlooked, forgotten, subjugated or rejected. ORCID: <https://orcid.org/0009-0006-5655-3546>. Email: [enok.ripley@gmail.com](mailto:enok.ripley@gmail.com)

## PREAMBLE

Disability is a broad term encompassing a range of conditions, including skeletal, cognitive, sensory, and mental impairments. It can result from genetic, environmental, or accidental factors, and it can be present at birth or acquired later in life. Physical and cognitive disabilities are part of many people's lives. Essentially, they are characteristics that some disabled performers emphasize in their art practices in a non-stigmatizing manner to promote reflection on differences, diversity, and unjust discrimination.

Indeed, despite their will and brainpower, some people with severe physical disabilities cannot accomplish tasks that most of us take for granted, and "people with intellectual disabilities have few opportunities to be known by others as adults or to experience the forms of respect, autonomy, and recognition that come with giving care, living independently, or inhabiting relationships not defined by care at all." (MCKEARNEY, 2021, p. 11).

In light of that, the inclusion of disability within the performing arts field enables cultural and aesthetic diversity. The disabled body on stage challenges audience's expectations and traditional performance-making conventions. To some extent, its *mise-en-scene* can be understood as an aesthetic operation of political repositioning. Notwithstanding, it continues to raise polarising debates about whether diversely-abled performers are exposed and reduced to their disability or whether they have full agency over who they are and what they represent.

Historically, deformed human bodies have been considered symbols of weakness and deficiency: a body that provokes our most hidden fears because of its anomalies. In the past, disabled actors and performers often had to disguise their physical differences to play on stage.

From the 18th century onwards, with the appearance of the Freak Show, bodies presenting physical impairments were exploited and

spectacularized for amusement purposes. They were obliged to learn and perform unusual, risky activities like contortionism and object-swallowing (GARLAND THOMSON, 1996). Individuals whose bodies had marks, scarifications and alterations (resulting from cultural habits or made voluntarily) were also shown, seemingly paving the way for body art, as conceptualised in the sixties (JONES, 1998).

Eventually, in recent times, the staging of the disabled body has opened new directions for performance. Autobiographical narratives about disability, inclusivity, access, and spectator-performer relationships have become core elements of performative operations valuing existence as a whole while focusing on the inalienable rights to live and participate in the social life of every individual, regardless of their condition.

## 1. ORIGINS and DEVELOPMENT of DISABILITY THEATRE AND PERFORMANCE

The discourse around human rights and disabilities leads us back to the origin of disability theatre and how it gradually established itself in the contemporary performing arts scene. Formally, it arose out of the disability arts and culture movement in the 1980s in the United States and the United Kingdom. It became increasingly international in reach and orientation in the following decades (KUPPERS, 2017).

In several respects, the disability arts and culture movement coincided with, contributed to, and drew upon the rise of disability rights activism. Emerging first in the UK and USA in the 1980s, the impulse to link art and activism made the aesthetic and cultural political: by claiming a place for disability experience in the arts as worthy and valuably different, the movement took aim at hackneyed stereotypes and the recurring use of disabilities as metaphors for something else. Contributors to the lively opening debates on and discussions of disability arts and culture decried false media images, advocated for greater participation and inclusion of

disabled people, and sought to create art that expressed and explored disability as a valued human condition. Disability theatre was part of this ferment, addressing the displacement of persons with disabilities from audiences and the stage, and critiquing directly and powerfully the casting of disabled roles with nondisabled performers and the representation of disability in drama, theatre, film, media, and performance. As with the wider disability arts and culture movement, disability theatre artists engaged in both critiques of dominant modes of performing disability and explorations of new ways to put disability on stage. (KIRSTY, 2016, p. 21)

In those years, a whim to the disability arts and culture movement and disability theatre was given by a performative turn that emerged in the humanities and social sciences as a potential key factor and methodological approach for overcoming the so-called crisis of representation, the “hallmark of Western theatre and modernity” (DA COSTA DIAS, 2020, p. 1).

This paradigmatic shift enticed “a fluid borrowing of ideas and methods from one discipline to another” (MARCUS; FISHER, 1999, p. 7), providing additional tools to study human behaviour in all instances and everyday life.

With the performative turn, performance studies expanded as an interdisciplinary field to expose “tensions and contradictions driving today’s world” (SCHECHNER, 2006, p. 3) and explore how people use performance as a way to experiment with, act out, and ratify changes in their day-to-day life. Sourcing from a vast array of subjects, from anthropology to psychology, cultural studies, sociology, and communication, Richard Schechner (considered the founding father of Performance studies, together with Victor Turner) reads societal changes through the prism of performativity, locating the essential drama of human existence in conflict and conflict resolution (SCHECHNER, 1988).

Using a dramaturgical vocabulary, he analyses the ritualised nature of social interactions and the causes and effects that in-

fluence human behaviour, shouldering Erving Goffman’s assumption that all human practices are performed so that each action responds to a public presentation of the self in whatever time-frame, place, situation, condition (social, economic, corporeal, intellectual) and circumstance it occurs (GOFFMAN, 1959).

Theatre, dance and performance art have always been milieus for expressing human experiences and emotions. Under the impulses of the performative turn, they also became powerful means of promoting disability rights and inclusivity. They highlighted the experiences of people with disabilities and encouraged greater understanding and acceptance of disability in society.

Performing arts can play a significant role in challenging negative attitudes and indifference towards disability. By showcasing people with disabilities and their related lived experiences on stage, they can dispel myths and stereotypes surrounding disability. They can raise awareness of the many challenges faced by disabled people, for example, the barriers to accessing education, employment, and other opportunities in public life.

Theatre can promote disability inclusivity by casting disabled actors in roles that accurately represent their experiences. In the domains of applied drama and social theatre<sup>5</sup>, disabled actors and performers bring a unique perspective to the stage. They can offer a more genuine representation of disability than non-disabled actors. Casting disabled actors in mainstream roles can also challenge disability stigma and promote diversity in the performing arts industry.

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, founded in the US in 1967. Notable disability theatre companies founded in the eighties and early nineties

include the Compagnie de l'Oiseau-Mouche (1978, which became professional in 1981, consisting of twenty-three permanent actors with mental disabilities); Graeae Theatre Company (1980, UK); Theatre Terrific (1985, Canada); Back to Back Theatre (1988, Australia); Ramba-Zamba (1990, Germany); Theatre HORA (1993, Switzerland); Isole Comprese Teatro (1998, Italy).

All these companies bring together actors and performers with physical complications and cognitive impairments, e.g. affected by paraplegia, or Down syndrome or belonging to Autistic Spectrum Disorder (ASD). Their mission explicitly promotes diversity, accessibility and inclusivity by breaking down barriers to participation in the arts. They are committed to training performers with cognitive and physical disabilities and supporting them in their careers. They collaborate with other organisations to promote disability rights and engage in social activism and community outreach.

Their professional, thought-provoking theatre productions are widely acclaimed internationally. They showcase talented disabled performers and demonstrate their creative potential to challenge negative societal attitudes and ableist assumptions about disability. They range from original works to adaptations of classic plays. They often feature innovative staging and multimedia elements to change the often deficit-oriented public perception of people with cognitive impairments and draw attention to their sometimes-extraordinary abilities. Their innovative and inclusive approach to theatre stresses the transformative power of pro-

moting awareness and acceptance and understanding of disability and diversity in society. It is an approach beyond therapeutic and pedagogical justification that digs into the philosophical, personal, and political at the intersection of humanity.

In the late sixties, Robert Wilson pioneered disability through theatre serving as an educator in rehabilitation programs for children with severe degrees of cerebropathy. He helped them learn with minimal physical theatre exercises. He worked with the elderly and terminally ill at Goldwater Memorial Hospital in New York. He facilitated them with slow-motion movements and light control to enable psychic communication rather than verbal communication.

Experimenting with non-linear narration, Wilson acknowledged how movement fragmentation into its most basic components could lead the subjects involved to regain possession of a gesture complicated by inhibitions and illness. He “discovered what fever-sufferers can see and the depressed can bear.” (PILINSZKY, 1992, p. 56).

*Deafman Gance* (1970) is one of Wilson's ground-breaking, early theatre productions. The piece is mainly silent, partially inspired by Raymond Andrews, a deaf boy who became Wilson's adopted son. Wilson realized that Andrews thinks in images rather than words, understanding how this perceptual process may open infinite communication possibilities dictated by non-verbal language in theatre-making. Indebted to Byrd Hoffman, with whom he learned to correct his phonetic-motor disorders during his adolescence,

<sup>5</sup> Social theatre is a theatre of research. It also serves as a tool for community building. It is multifaceted and experimental. Its language and content have a socio-political derivation and orientation. The laboratorial process is crucial to the construction of the final performance. Real-life experiences and the involvement of performers and actors whose provenance derives from the elsewhere called “disadvantaged social categories” are its fundament and research matter. It is a kind of theatre that does not require a selected elitist public, as classical theatre usually requires. It explores and identifies new spaces of encounter and relationships for performers and viewers, implementing perspectives that arise from sharing lived experiences. Social theatre performances are often staged site-specific and not just in conventional theatre spaces. Its practice has a lot in common with performance art methodologies, focusing on the concept of authenticity and genuine expression of the performers, who have not to imitate or represent a character but rather to be themselves and perform their real-life stories and most personal concerns.

Wilson's operation with disabled performers and disabled people in general is to adapt, deconstruct and disarticulate his language to fully understand the other's reality, placing himself on the same communicative level.

For Wilson, "dumbness is speech that cannot be dumbed, and what is beyond beauty—whether beautiful or ugly—has a swan's neck too, everything is beautiful again." (PILINSZKY, 1992, p. 55). Poet Christopher Knowles (Autism Spectrum Disorder) participated in several Wilson theatre works, including *Einstein on the Beach* (1974), an opera in four acts composed by Philip Glass. Eventually, Wilson's approach to disability emphasizes the director's action of re-education of the actor/patient through the redefinition of functional language intended to produce social readjustment.

A further outstanding example is the late, legendary legless British dancer David Toole, who started his career as a performance dancer in 1993. He worked for the Royal Shakespeare Company and Stop Gap Dance Company for ten years. He had a leading role in the cutting-edge performance-based film *The Cost of Living* (2004) by DV8 Physical Theatre Company. In his performances, dancing using only his hands, Toole does not let his handicap or society's prejudices get in his way. Conversely, he makes the spectator reconsider dancemaking's accepted norms of grace, beauty and virtuosity.

Among those who have made significant contributions to ground the field of performing arts and disability studies, German-born scholar, poet, wheelchair dancer, and performance artist Petra Kupperts is undoubtedly among the most noteworthy (Figure 1). Her work emphasises the role of performance as a tool for social change, disability justice and community building (KUPPERS, 2019).

Her key concept of disability aesthetics refers to how disability shapes the creation and reception of art: it is not just about representing. It is about conceiving new forms of artistic expression that embrace the unique experiences and perspectives of disabled people to unders-

tand cultural context dynamics better (KUPPERS, 2003).

Figure 1 - Petra Kupperts. *Starship Somatics*. Video still. 2022.



Source: Video: *The Olimpias*. Courtesy the artist.

With particular reference to dance practices, she writes that "the aesthetics of disability dance can bring about an accessible dance culture. Accessibility does not only refer to impairment-specific alterations to the normal performance encounter but to providing conceptual space for a 'stepping back' to see our cultural framings." (KUPPERS, 2000, p. 129)

By bringing a distinct perspective to the stage through their embodied experiences, performers affected by different forms of disability can challenge traditional notions of what it means to perform. They can also disrupt ableist assumptions about performance and foster fresh embodied expression in performance-making.

In so doing, they promote disability justice principles to challenge systems of power and oppression and dominant narratives about disability.

By embracing these principles, all performing arts can encourage heightened inclusivity, diversity, and social change in the arts and society as a whole. This will give consistency to the idea of disability culture that Kupperts proposes, emphasising the creativity, resilience, and activism of disabled artists and socially disadvantaged people in general.

Disability culture shapes how disabled performers and audiences en-

gage. It provides a framework for understanding disability as a source of diversity, resistance and strength. This is rather than interpreting disability as an insufficiency or limitation.

## 2. PERFORMANCE ART AND DISABILITY

*I said bodies, tremble and turn in unison with my own... that is to the bodily and physical materialization of a total being of poetry.*

— Antonin Artaud

Performance art is an artistic practice that fosters encounter, sharing and visceral communication between the performer and the viewers. This is when a two-way energy flow is established, albeit in different modes. Energies collide, fuse and merge from this exchange: gazes are reflected in the other's gaze; bodies are mirrored in other bodies—carriers of meanings inscribed in the living flesh that, in the nowness of the performance, transform into living images.

Performance art de-disciplines specialisations opening new possibilities of what art, dance and theatre can be. Tackling social and political concerns, conflicts and inequalities, it recognises that everyone has distinctive values that must be respected. In that, it is a milieu to freely experiment with a sense of belonging to a cause and commonality of purpose.

When a performance is participatory, it may create a non-judgmental atmosphere embracing the idea of community, suggesting that people can live more purposefully, accepting each other's differences and responding collectively to the current state of emergency. Focusing on the hardships that people suffer in their everyday lives, performance artists navigate through the cracks of our haemorrhaging societies. They attempt to fill gaps and prove what is missing.

Performers marked on their bodies by a stigma (a mental or physical mark characteristic of a suffered injury or disease; or a mark of disgrace associated with a particular circumstance, be it associated with a condition of difficulty or discomfort), demonstrate alternatives

to suffering and lack. By performing, they break down our limitations. They confirm the right to opacity, violate commonplaces and stereotypes, disrupt low-cost feelings and hypocritical opinions, and stimulate corporeal perceptivity and insightful thinking. Creativity, in fact, often rises in circumstances of suffering and distress as a tool to challenge them.

For over two decades, I have operated in applied drama and social theatre as a playwright and actor, aside from performers indelibly marked on their bodies by congenital or contracted diseases (psychic and Down syndrome patients, blind and deaf people, and people in wheelchairs), or signed by challenging life experiences (inmates, sex workers, street children, refugees and former drug addicts).

Performing with them led me to understand the importance of social responsibility in performance-making and recognise that performative actions are often born precisely from the stigma that a performer carries.

I acknowledged how performers coming from disadvantaged social backgrounds could probe the weaknesses of a community and society, offering themselves to the spectator's gaze simply the way they are. Their stigmas make their presence genuine, unequivocally fragile but perturbing. It shakes values and beliefs that society takes into greater account, likewise an intruder uses a crowbar to bust open a lock.

On stage, a stigma can metaphorically reproduce societal conflict. After all, a performance art piece is often a hypertrophy of social, political and ritual habits. It holds onto something that has to do with the sacred mythical character proper to a religious act or a ritualised behaviour, sometimes up to sacrifice and self-sacrifice (TURNER, 1982), thus becoming a constitutional part of the existing anthropological commitment on which social dynamics, the construction of identity and interpersonal relationships are the strong points.

Performers carrying a stigma enter into a confrontational dialogue with the audience through their bodies. The actions and gestures they make,



even though they are minimal, exemplify the truth of human empathy and compassion. Despite performance temporal limitations, meanings emerge from physical restrictions and turn into live images.

Transformation occurs precisely as a matter of reconciliation of opposites: performing is ultimately a cultural, anthropological fact that implicates and bridges actively who is acting and who is watching. Performers with disabilities are “signs of their times: a point when extraordinary bodies have a currency as lifestyle accessories when any shock or alienation value is eroded by the ubiquity of difference that is consumed and repackaged” (KUPPERS 2003, p. 3).

Struggling to be fairly represented in the artistic scene, they test the very mechanism of performance. They suggest existence as an unfragmented presence. Their singular temporalities, extraordinary physicality and presence, threaten the idea we have of the human being, as does the idea we have of theatre, shaking up traditional codes of performance, both in art and in life, and our inclination for prescriptive, recognisable and regulative setups (BUGIEL; BEL, 2013).

Disability is commonly considered a situation “out of the ordinary, separate from the everyday life, a cause for pause and consideration” (SANDAHL; AUSLANDER, 2005, p. 2).

When health is taken as an absolute value, physical difference is an accident in life. Stigma is seen as an obstruction to the ideal life cycle. It is because medical ideology refers to health as an abstract hypothetical value and a subject of its exclusive competence. This assumption covers the fundamental experience of a human being—the recognition of death as part of life. Medical ideology annihilates our relationship with our physical constitutional limits, deficiencies, defects, diseases, and illnesses. This is true for our bodies, which constantly transform and decay during life. Of course, medicine - as a science - operates for good purposes, but for example, to heal from a disease is also to lose

in some way the relationship with the disease itself (and therefore with the body, as it was), which is consequently perceived as a liability and dependence.

In performance, however, disabilities, diseases, illness, lack, physical impairments and deficiencies can undoubtedly be considered essential elements for a more in-depth analysis of the presence of the human being in the world because they are different yet familiar aspects of the human experience, which imply our otherness, fears, losses, mortality, beauty, ageing, love, anger and longing to find each other within this shared fragility. Performances that address these topics are not always kind or comfortable, but never denigrate themselves as entertainment. (NEWMAN 2017). Australian pioneer performance artist Mike Parr (Figure 2), one of the most celebrated artists in his country, was born with a deformed arm that was amputated and replaced by a prosthetic one. He started his career exploring the question of identity, memory and states of being, undertaking extreme actions of endurance that challenged the physical limits of his body, using his disability as a performative aid (STILES; SELZ, 2012).

Figure 2 - Mike Parr. *Malevich (A Political Arm)* Performance for as long as possible. 2002. The performance at Artspace, Sydney, 3-5 May 2002.



Source: Courtesy the artist and Anna Schwartz Gallery.

Late Singaporean performance artist Lee Wen (Figure 3), who suffered from Parkinson's disease, often shifted his pain condition

into expressions of political beauty.

Figure 3 - Lee Wen. Journey of a Yellow Man No.11. 1997. Photo: ArtHop.



Source: Courtesy the artist.

Late American award-winning dancer and performance artist Lisa Bufano (Figure 4), took inspiration from her amputation. She had her legs and fingers severed when she was twenty-one years old after a staph bacterial infection raged through her body, shutting off blood flow to her limbs. But the loss of her legs has not kept her from moving and performing. She has explored disability and what a human body can do in situations of reduced mobility.

Figure 4 - Lisa Bufano. One Breath is an Ocean for a Wooden Heart. 2007. Video still of the performance in collaboration with Sonsheree Giles.



Source: Courtesy the artist's family and K-027, Extravagant Bodies, Zagreb.

Facilitating learning paths for disabled actors and performers requires a tailored approach considering their unique needs and abilities. Before starting any training program, it is essential to acknowledge the performer's type

and level of disability and how it impacts their life. It involves consulting with the performer's healthcare team or disability support network to understand their clinical condition better and have valuable insights into the performer's ongoing quotidian.

For example, performers affected by Down syndrome or on the autistic Asperger spectrum have an approach to performance that differs considerably from one performer to another. It depends on how severe the cognitive deficit is.

To facilitate performers who have lived or still live in a condition of hardship (inmates, former drug addicts, sex workers, refugees) is instead more a question of how to accompany them to transform the negative feelings they develop from their life conditions into something powerfully creative. Personal life experiences make us unique; for an artist, they are the magmatic subject matter, a source of expressive potential.

During the training sessions, it is vital to respect the performer's autonomy and work collaboratively and co-creatively with them to develop a training plan that meets their musts. Every performer has their strengths and weaknesses, and focusing on them and their interests helps to build their confidence.

Training techniques should be adapted to their specific disability types to develop their skills. These techniques include improvisation, sensory exercises, sign language interpretation, audio description, visual or tactile cues and other forms of accessible communication.

When the performer asks questions and seeks clarification, it is essential to stimulate their creative thinking. It is also essential to preferably offer them constructive feedback instead of definitive answers. This provides a supportive learning environment that encourages experimentation and growth.

I developed my teaching method at Isole Comprese Social Theatre School (Florence, IT), which I attended in the early 2000s. The school was founded on American psychologist James Hillman's propositions and the pra-

ctice of beauty (HILMANN, 1998). It was run by theatre directors Alessandro Fantechi and Elena Turchi, who worked with several theatre and film directors such as, among others, Judith Malina of the Living Theatre, Derek Jarman, and Armando Punzo, founder of Compagnia della Fortezza.

Over the years, I have integrated social theatre and Hillman's precepts in my teaching activity as a poetic antidote to contrast preconceptions, prejudices, stereotypes and stigmatisations that disabled people often suffer in society, thus fostering a sense of belonging, community and greater inclusiveness that celebrates diversity, for instance when training disabled and non-disabled performers in a same group (PAGNES, 2020).

What I deem essential in my teaching practice is to hold space and design training activities that encourage performers to express themselves authentically.

For example, to facilitate neurodivergent performers and actors requires a sensitive and nuanced approach. The learning path should have a clear structure and the instructions should be concise to facilitate understanding.

At the intersection of theatre and performance in a matter of disability, key factors are collaboration and co-creation, accessibility and interconnectedness, and diversity and inclusiveness, however not for therapeutic or assistentialist reasons.

I treasure disabled artists' unique perspectives and experiences as a radiant constellation of resources from which innovative performances may generate. By showing their wounds<sup>6</sup> in the performance space, a performer challenges crystallised norms and behaviours in society and traditional notions of art. In terms of performance and disability, for this to happen, it is essential to ensure that performers and actors with disabilities are represented authentically on stage, free from harmful stereotypes and clichés. They should never be reduced to their disability or portrayed solely as objects of compas-

sion or inspiration. They should be empowered to perform their experiences and perspectives on stage accurately and respectfully. This will bring the audience to a more in-depth reflection on human existence.

What I found by facilitating, performing and collaborating with performers endowed with certain types of disability, either physical or cognitive, is that they seem to share an innate quality—they produce comparative situations through actions and gestures that are always credible because they are unpretentious and not induced or artificially intentional. It is as if they delicately open the door into their world to offering the audience a new experience in an unknown territory, humbling and sublime at the same time.

Performances are controversial when they undermine our preconceptions and leave us dumbfounded. This is probably because we do not know how to receive them and are not without serious critics. "Fragile Body-Material Body" was the theme of the III Venice International Performance Art Week (the Live art exhibition project that I founded with Verena Stenke in 2012 and have curated since then). After the event, an anonymous audience member sent me an email with this criticism:

I have nothing to complain about the contents of many performances I saw. If performers decide to expose their bodies battered by a disease, they are free to do so. I appreciate the self-control, willpower, and concentration of all the performers and their need to identify themselves with the art they do. Nevertheless, for me, it remains unacceptable when they turn their bodies into a spectacle, especially when they suffer extreme health conditions. In all this, I see an almost religious celebration of the artist's cult and the disease itself. In other words, they sell their suffering for art. This choice is very unscrupulous because they sacrifice their dignity and respect for themselves, their body and the other's body for the sake of art (ANONYMOUS AUDIENCE MEMBER, 2016, unpagged).

To dismantle self-righteous and

<sup>6</sup> About his installation *Show Your Wound*, Joseph Beuys said: "And when I say: Show it! Show the wound inflicted upon ourselves during the course of our development, it is because the only way to progress and become aware of it is to show it." (BORER 1997, p. 25).

judgmental argumentation is a complex task. Such excessive moralism can lead to unnecessary polemics.

When I present performances that some spectators may find too controversial, as a curator, I have the responsibility to dialogue with them. I bring them to reflect on their excessive criticism and discuss their opinions constructively. To what degree does their criticism depend on commonplace statements and is affected by the standards of “the industrial culture of our times with its penchant for passing fads and glamorization?” (PROFETI 2009, p. 193).

To perform and reveal one’s true self by showing your wounds is, first and foremost, a necessity and a decision. It is not to represent but to objectify a subject. Still, there is a widespread tendency to watch and interpret a performance as a spectacularization of a subject (and of the self itself) because the human mind oscillates continuously between dichotomies and is heavily influenced by established cultural norms that make it challenging to avoid judgmental criteria.

However, the diversity of opinions around performance and disability and theatre disability demonstrates how complex and unsettling these practices are, which makes them vital in their own right. In the Artaudian, anti-Brechtian tradition, they manifest the urgency of connecting with ourselves.

When we are next to one another, what does the body in which we dwell and that of the other mean to each of us?

### 3. EMBODYING THE DIFFERENCE - PERFORMING THE EXPERIENCE

Under the lens of performativity, how can we define disability boundaries?

In one way or another, we are all disabled, different, and unique (CARLSON; MURRAY, 2021). Too often, we fail to recognise that we are all interconnected in diversity and opacity, so we should support each other to build a better society despite our differences.

From a physiological and phenomenological perspective, all bodies are disabled because they are finite. The World Health Organiza-

tion identifies disability as part of the human condition (WHO, 2011, 2017). From an ontological perspective, all human beings are disabled because they strive against their existential finitude (HEIDEGGER, 2008).

Almost every person will experience impairment and increased difficulties in functioning at some point throughout their lives. Thus, disability opens the ontological question of the meaning of being anew, not as beings-towards-death (finitude), but as beings-towards-disability (fragility). This certainly takes us beyond Martin Heidegger, a name tied to the finitude discovered in being-toward-death, but Heidegger will start us on the way (LALLY, 2020, p. 1).

In light of this, Brazilian scholar and performer Felipe Monteiro’s stances are illuminating. I have maintained a friendly and professional relationship with him for a decade. I learned from his writings that disabled performers (or performers with differentiated bodies as he defines them) echo Antonin Artaud’s ideas in *The Theatre of Cruelty* (1958); that is, they are actual outbreaks because their presence on stage pushes the spectator to an open confrontation with themselves in unknown territories, thus pondering upon human finitude outside their comfort zone (MONTEIRO; SALLES, 2018).

Monteiro argues that the presence on stage of performers with differentiated bodies confirms the urgency to dismantle dominant cultural schemes that make it difficult for them to access the performing arts scene and public life. He advocates a politics of care in that sense, focusing on the inalienable human rights of the individual.

With the term differentiated body (MONTEIRO; SALLES, 2013), Monteiro does not refer to medical and social disability models. For him, and because of his direct experience of disability, the clinical model aims to discover the causes of a person’s disability. It tries, through medical interventions, to normalise them and make them socially acceptable. Indeed, social models of a given society link disability to misfortune and other societal perceptions that create barriers and lead

to social exclusion and stigmatisation of those with bodies deemed unfit for the norm (GOFFMAN, 1963).

Monteiro's concept of differentiated bodies springs from the idea that bodies are not homogeneous entities. Instead, they are shaped by a range of social, cultural, and historical factors as well as by their physical characteristics. This idea is crucial for understanding the experiences of marginalised groups in society. This is particularly true for those who are often excluded or overlooked because they are subject to different forms of discrimination.

Monteiro's notion of differentiated bodies can help us recognise that disability is not simply a matter of specific physical or cognitive impairment. Everyone may face additional barriers and challenges due to their race, gender, sexuality, or socioeconomic status that intersect in complex ways. To recognise how different forms of oppression and marginalisation entwine and reinforce one another inside the culture that produces them, we may acquaint ourselves with what the experience of disability means and implies.

In that respect, Monteiro offers a thoughtful framework to reflect upon the complexity and diversity of the human experience. He brings us to consider that it is by valuing the diversity of bodies that we can work towards a more inclusive and just society for all.

In terms of performance as a way to embody the experience of disability, Monteiro refers to French playwright, poet, and theatre theorist Antonin Artaud for he theorised that theatre should aim to create a visceral, immersive experience for the audience, one that engages all of the senses and allows the audience to embody the experience of the performers fully. In the context of disability, this could involve using physical theatre techniques to help the audience understand and empathise with the embodied experiences of disabled performers.

Artaud also advocated breaking down the fourth wall between the performer and the audience for a more direct and intense communication among them. In the context of disability,

this stance could involve creating performances that challenge traditional ideas of what it means to be a performer or an audience member; claiming a more direct and participatory form of engagement; eventually reimagining language to create new forms of meaning, thus challenging traditional ideas of what it takes to connect with others.

Performances that push the boundaries of what it means to be a performer or an audience allow us to explore our innermost fears and desires. While Artaud did not explicitly address disability in his writings, Monteiro linked his theories to differentiated bodies in performance, strengthening the idea of embodiment.

In other words, a performance should not be a purely intellectual, artistic exercise but rather an immersive experience that involves the body and mind, challenges expectations and assumptions about what bodies can do and highlights disability's unique experiences. Performances of this kind are cathartic. They engage spectators to change their gaze upon disability and consider reality from unusual perspectives.

Monteiro keeps the score in his live performances. He reveals intimate moments of suffering, pain, heartache and rupture. In so doing, he converts the private into the political, aiming to unlock and communicate peculiar truths about his clinical condition and related social concerns towards the culture of intolerance and indifference he deals with, which might not otherwise get articulated in his ongoing quotidian.

Exposing his vulnerable body, he unleashes more factual narratives about human frailty and love. From his viewpoint, his performance operations have similar effects to the Artaudian Plague. A differentiated body in the performance space, while occupying it, inhabits the cognitive and affective spheres of the audience, encouraging their thoughts in matters of acceptance and inclusiveness.

Looking at how Artaud revisits the philosophical concept of catharsis in a transgressive manner (PHILIPPE, 2022), Monteiro redefines

it through his body-based performance practice. He rejects traditional narrative structures, focusing on creating visceral, sensory situations for the audience. He attempts to implement disability understanding by bringing to light not merely certain overlooked medical truths. Prioritising his embodied experiences over linear storytelling, he seeks to create a more immersive and interactive relationship between the audience and himself—the performer.

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

In Monteiro's approach to performance, the physical connotations of artists with diverse bodies are not concealed. They can reveal individual and collective cruelty. At the same time, they can disrupt spectators' biases by triggering their most elementary anxieties, for they cannot escape their voyeuristic gaze and personal preconceptions of the body. "From the human point of view, the action of theatre, 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. 31).

Monteiro's performances are acts of poetic revolt beyond stigmatization and a form of activism to demystify reality. This is done by responding to existing problems that constrain disabled people to live a hard life. At the same time, he contests assistentialism, protectionism and pseudo-inclusiveness (MONTEIRO, 2019).

In his performances *DES)VITRUVIANO* (Figure 5), he exposed himself as vulnerable, lying on the floor on a large canvas. Spectators could approach him, and write, draw or profile his motionless body on the canvas with pens and pencils. This is reprising but deconstructing *The Vitruvian Man*, drawn by Leonardo Da Vinci (1490 about) as a symbol of harmony, a canon of proportions and the epitome

of perfection.

Da Vinci's drawing is surrounded by notes based on the works of the Roman architect Vitruvius who lived during the first century BC. At the end of the performance, Monteiro's body is surrounded by sketches and words made by audience members. In the process of interacting with the performer's body, they created a composite graphic universe of their feelings.

Figure 5 - Felipe Monteiro. *DES)VITRUVIANO*. 2014.

Photo: Luis Carneiro Leão.



Source: Courtesy the artist.

Felipe Monteiro is a performer unable to move autonomously. His body is atrophied by progressive spinal amyotrophy, a rare neuromuscular disease of genetic origin and autosomal recessive inheritance that invades the lower motor neuron body in the anterior horn of the spinal cord, in which progressive muscle wasting and degeneration of motor neurons occurs but does not affect the sensory.

In his performances, Monteiro reveals the desire to complete himself as a human being, asking for physical contact with audience members. The possibility of experiencing a direct relationship with his differentiated body allowed spectators to engage in self-reflection and demonstrate that a simple act of sharing brings forth a valuable, collective experience for everyone involved.

*O problema é porque sou lúcido?!* is a ritual performance (Figure 6) Monteiro

performed in the foyer of Teatro Martim Gonçalves in the frame of the Festival Latino Americano de Teatro da Bahia – FilteBahia in 2018. Lying on a hospital stretcher, his movements were almost imperceptible. His breathing was enhanced by his non-invasive ventilation equipment. Spectators were free to come, stay, approach, touch his motionless body gently as they wish or just stand or sit and contemplate it, or leave the performance space as they pleased. (MONTEIRO, 2020).

I chose the title *O problema é porque sou lúcido?!* because sometimes I disagree with the care professionals that attend to me. They aim to offer me as much independence as possible at home and in the professional environment but they want me to be docile, and I do not deny it. Years ago, during a meeting, a social worker said the problem was that I was lucid. My body is physically deprived of locomotion, but I still have a voice to share my thoughts and concerns, which are often ignored. I depend on others to perform my daily tasks and professional activities and to minimize complications in the musculoskeletal and respiratory systems. As my muscles atrophied, my hands and feet have malformation. I lack strength to move (tetraparesis). I use a device intermittently, which helps keep my lungs open and my breathing muscles less overloaded. In the performance, I lay down on a hospital stretcher breathing through a non-invasive ventilation device. The sound of my heartbeat recorded from an echocardiogram exam 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 projection, while others watched me closely and asked to 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 nowness. By taking autonomously the decision of exposing my body vulnerable, unable to move but not docile, I revealed the desire to complete myself as a human being. I asked for physical contact with audience members to stir their emotions. What happens when you are in close proximity to a differentiated body like mine? May you imagine what it means to live inside a motionless body that hardly responds to the impulses of an active and lucid brain? The

possibility of experiencing a direct relationship with my differentiated body allowed spectators to reflect on human existence. How do we value it? I attempted to demonstrate that the simple act of sharing brings forth a collective experience for everyone involved, thus becoming co-creators of togetherness. The physical and spatial relationship of bodies in performative proximity encourages open, genuine, interpersonal communication. By performing with my differentiated body in conventional performance spaces, I define an aesthetic of invasion (as I call it) to express my concerns about indifference and let them be heard, at the same time, celebrating life (MONTEIRO, 2023, unpagged).

Figure 6 - Felipe Monteiro. *O problema é porque sou lúcido?!* 2018. Photo: Anonymous.



Source: Courtesy the artist.

A body stigmatized by a severe disease arouses fascination and, at the same time, bewilderment. It recalls Artaud elevating the diverse, unpleasant and frightening but somehow attractive to a supreme aesthetic act in his Theater of Cruelty. Artaud restores the body to life. While dwelling in life, Monteiro's differentiated body also inhabits the spectator.

Romeo Castellucci and Societas Raffaello Sanzio conduct this kind of operation antiphrastically, as in the tragedy. In their theatre pieces, such as *Julius Caesar* (1997) and *On the Concept of the Face, Regarding the Son of God* (2010), the skeletal, exhausted, tired, ageing, anorexic, scourged, suffering bodies express their opposite: they evoke human fra-

gility and love. Feelings of fear and piety that spectators may feel when confronted with a human body battered by severe physical condition change into beauty. For instance, in the *Julius Caesar*, the actor's body without the organ of language (the vocal cords) is the emblem of a body that is eloquent in itself.

Monteiro's performative operation is also that of Artaud's breaking down the wall between spectator and performer to allow proximity among them. Yet, by courageously exposing his frail body for spectators to approach it soothingly, he advocates that life is essentially people's interconnection and relation against indifference undertaking a performance process that profoundly affects the spectator's gaze, encouraging a more positive attitude toward life, ourselves, and reality.

#### 4. UNDERSCARS: A PERFORMANCE OPERA ON WOUNDS AND STIGMAS

*UnderScars* is a collective performance opera envisioned and devised by the artist duo VestAndPage (Verena Stenke and Andrea Pagnes) in collaborative work with Andriago & Aliprandi, Irina Baldini, Sabrina Bellenzier, Giorgia de Santi, daz disley, Nicola Fornoni, Marisa Garreffa, Fenia Kotsopoulou, Ash McNaughton, Aisha Pagnes, Enok Ripley, Sara Simeoni, Mauro Sambo, Joseph Morgan Schofield, Marcel Sparmann and Emily Welther. The opera grew out of Pagnes's research on "Inclusive Production Methodologies in the Performing Arts for Diversely-Abled Performing Arts Practitioners", supported by Fonds Daku (DE). It developed from the "Body Matters: Co-Creation Residency" organised by VestAndPage (June 2022, Venice) for the artists mentioned above.

With a focus on inclusiveness, *UnderScars* combines physical theatre, dance, body art, video and sound. Establishing a sense of temporary artistic community and focusing on collaborative, experimental art-making across boundaries, the artists collectively shaped the performance opera in its complexity,

which lasted two hours. In *UnderScars*, different experiences of vulnerability, hesitation, fragility, hope and the unspoken are nurtured through sustained encounters between participants. They challenge capitalism and patriarchy, tackling themes of disability, severe diseases, addiction, abuse and discrimination—the wounds and stigma they cause—identity, queerness and gender fluidity. The performance opera premiered at the European Cultural Centre in Venice (IT) in December 2022.<sup>7</sup>

The performance space was transformed into a dwelling site for interconnected performances and installations. It served as a social-narrative incubator coagulating inclusive and expansive life stories in response to existential emergencies. The artists' lived hardships were intertwined in poetic ways (Figure 7), accompanied by spoken texts and inspired by Antonin Artaud's *Interjections 1 Du corps sans organs et autres supplications* (1983).

Figure 7 - VestAndPage et al. *UnderScars*. 2022.

Photo: Lorenza Cini.



Source: Courtesy the artist.

<sup>7</sup> *UnderScars* celebrates the tenth year of activities of the Venice International Performance Art Week, founded by VestAndPage in 2012 and curated by them since then. Webpage: <https://veniceperformanceart.org/the-art-week/under-scars-2022>. Video link: <https://vimeo.com/800817125> (Password: underscars).



Young Italian performance artist Nicola Fornoni (Figure 8; 9) and Canadian transgender, non-binary performer and tattoo artist Enok Ripley (Figure 10; 11) have a core role in the performance opera.

Nicola Fornoni is affected by scleroderma, an autoimmune, rheumatic, and chronic disease that affects the body by hardening connective tissue. When Fornoni performs, he contextualizes his stigma. His afflicted body, reduced in motion by the disease that affects him, transforms into an organic poetic membrane and a vehicle that invites the spectator to reflect upon a broader dimension of existence:

I started performing when I was twenty-three years old to explore social issues about a humiliating society that alienates those with different anatomical potentials. Performance art could be said to be a practice that redeems oneself, somehow, from daily hardships and life itself, thus not only. I chose performance art because it was not enough to create energy and beauty. The most profound reflections - how to heal the world and whether we can do it - needed to be triggered. My first performance was about the notion of rebirth and how it can be applied in apparent stasis situations until the body produces movement through effort and fatigue. Many life events make us realize that we need a breakthrough; therefore, I realized that performance art was a necessary tool to express my ideas, their potential and their force. The mutation of the body throughout life is already an extraordinary and incredible performance. Many times, I wondered if I had performed without health problems: acute lymphoblastic leukaemia when I was five years old, with all its courses and the relapse when I was eight. Then I underwent bone marrow transplantation to heal from leukaemia, followed by a second transplant. Ultimately scleroderma—an autoimmune disease resulting from everything. It constrained me to sitting. All this characterizes my artistic research based on body art, love, body limits, the transformation and the relationship between bodies and personalities, in short, on life itself and its transcendence. I always act and put myself on the line. I always dealt with living in my skin, what I have been through in hospitals, without hiding anything, without running away from events. So then, during my third year at the academy, I understood that performance art was the way to

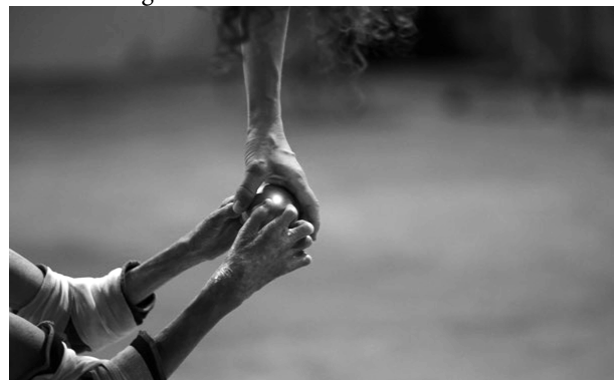
demonstrate my value to people. I embarked on a dialogue that also included social activism. My rebellion is expressed through this kind of art (FORNONI, 2017, unpagged).

Figure 8 - VestAndPage et al. Body Matters: Co-Creation Residency. Nicola Fornoni and Marianna Andriago rehearsing UnderScars. 2022. Photo: Lorenza Cini.



Source: Courtesy the artist.

Figure 9 - VestAndPage et al. Body Matters: Co-Creation Residency. Nicola Fornoni and Marianna Andriago rehearsing UnderScars. 2022. Photo: Lorenza Cini.



Source: Courtesy the artist.

Enok Ripley's neurodivergence is due to narcolepsy type-1. It is a disorder that impacts the brain's ability to manage the sleep/wake cycle, resulting in sleep bleeding into the waking world. The opposite is also true, with disrupted and fragmented sleep cycles and chronic insomnia. Narcolepsy is a neurological disorder triggered by illness. Ripley developed narcolepsy when Strep B bacteria caused an autoimmune response that damaged the neurotransmitters in the brain responsible for sleep regulation. They received their narcolepsy diagnosis in 2022 after experiencing an overall increase in sym-

ptoms over the last four years. Their narcolepsy has become the most disruptive of their illnesses due to the sudden increase in symptoms severity.

Enok Ripley writes:

Narcolepsy is not curable, and treatment of symptoms can be frustrating and expensive, as there are no specialists for narcolepsy in Quebec where I live. I have found many positive management techniques and medicines that help combat the more disruptive symptoms, and I am supported through a disability assistance program. Though narcolepsy is not considered fatal, injury and death due to unmanaged narcolepsy, such as accidents, are very common. I experience sleep attacks, which are common throughout the day. The severity of the attacks can be managed with medication, and I greatly benefit from a schedule that allows for frequent short rests. Luckily, I have found that sleep attacks generally last for fifteen minutes. I schedule three rest breaks into my days to control unwanted sleep attacks.

Automatic behaviour is a common component of narcolepsy, occurring when repetitive actions, such as walking or writing, are performed without conscious awareness. Usually, everyday tasks that are frequently performed are likely to become automatic. Automatic behaviour can be dangerous and life-threatening. For example, I can no longer drive since my symptoms have worsened. I often need to plan or have a person with me while travelling or walking in places I do not know well. From my perspective, automatic behaviour often feels like teleportation. It is extremely confusing and intimidating. I tend to enlist others for help or use my dog to anchor me in time and keep me safe. Often having a task to focus on keeps my mind engaged enough to combat automatic behaviours. Cataplexy is only present in type-1 narcolepsy and causes temporary paralysis and loss of muscle tone triggered by strong emotions (laughter, embarrassment, excitement, anger, fear). It can last for a few seconds to several minutes. It can happen many times during the day and result in temporary cataplexy, falling over or seeming drunk. The most intrusive component of cataplexy in my life is facial and hand paralysis. This affects my ability to smile and speak clearly. It causes my eyes to roll and eyelids to shut involuntarily and can make it extremely difficult to grip or hold objects. I am very embarrassed by this aspect of my narcolepsy. It often causes me the most discomfort and

distress when noticed. It is an unusual experience for me, and I have been misunderstood in moments where my paralysis is more severe, which has been heart-breaking. Narcolepsy also causes me vivid hallucinations. Usually, upon falling asleep or waking up, it is triggered by immediately falling into REM (rapid eye movement) sleep-dreaming while the conscious part of my brain is still awake. I frequently experiences visual and auditory hallucinations in various forms when exhausted or waking up. Though sometimes frightening, they do not last long. My peripheral neurological issues related to narcolepsy are nystagmus (involuntary eye movement), photosensitive migraines, blurred vision, and central apnoea. However, there could be positive aspects about my narcolepsy: I can solve problems in my sleep and use sleep space to organize my thoughts and ideas or draw and build concepts; I can sleep anywhere and experience lucid dreams (remarkably coherent and lifelike dreams); I have a solid visual processing memory; I never get bored because I always want to hear about your dreams (RIPLEY, 2023, unpagged).

Figure 10 - VestAndPage et al. UnderScars. Enok Ripley and Andrea Pagnes. 2022. Photo: Lorenza Cini.



Source: Courtesy the artist.

Figure 11 - VestAndPage et al. UnderScars. Enok Ripley and Verena Stenke. 2022. Photo: Lorenza Cini.



Source: Courtesy the artist.

During *UnderScars*, Enok Ripley tattooed my back for about half an hour (figure 12). They used the *stick and poke* technique, also known as a hand poked tattoo. This involves manually prodding my skin but without dipping the needle into the ink. They wrote on my back about their dreams while Nicola Fornoni's voice recounted poetically his experience with the disability:

Many life events make us realise we need a breakthrough. A humiliating society alienates those with different anatomical potentials. Daily hardships. The notion of rebirth is applied in an apparent stasis situation. The body produces movement through effort and fatigue. Its mutations throughout life are unique and show incredible results. Have I ever performed without health problems? The concept of body art, love, the limit of the body, transformation, relations, the transgression of life itself. I do not hide or run away. The origin of everything lies in the body, in the clash-encounter between atoms and cells. There is something peculiar about relating to ways of life not one's own. To conform, get used to, improve. Not only in a wheelchair, but with obstacles to overcome. The obsession with feeling useful. For example, what makes me crawl down stairs, limb after limb, at the risk of breaking my neck? Isn't it unnatural? A piece of architecture can be shaped to fit the body, and any object can be shattered. A roof can be a floor, and a railing or rigid rope can be a line. Without one hand, one leg, or one arm. With a stick. On a trolley. Being guided without wanting to. Will I become independent? Disability constantly raises this question. Novelty increases risk, and tension builds. Places change. Prostheses are indispensable to understand what is around you. Finding different movement methods. Never make rash decisions that harm or kill. Anything can be a minefield. You have to look down at your feet. Using a tool that glides, slides, rotates, curves, and oscillates in a backward motion, you can rotate. One hand remains stationary. The other pushes and holds. Coordinate the body: the back, the shoulders, and the head. Try to take things up there. No elasticity, no chance of stretching or squeezing. It all depends on the type of disability. Someone can fold their legs. Others do

not fully extend or flex them. They wouldn't even pass through a narrow passageway. You can't hide much under a bed sheet. Extend. Hold the position while melting, tendon by tendon, muscle by muscle. My body is based on Carthusian principles. The only assurance in a wader is the support of the ass and the comfort of sliding feet. Some obstacles contradict the ease theory, such as having to sleep on too high bunk beds. Step by step, one push at a time. You can't jump. Not even fall. It would mean facing a new trauma (FORNONI, 2023, forthcoming).

Figure 10. VestAndPage et al. *UnderScars*. Enok Ripley and Andrea Pagnes. 2022. Photo: Lorenza Cini.



Source: Courtesy the artist.

## CONCLUSION

We should all have a direct relationship with our stigmas and differences, not just in terms of personal experience but also as elements which can be objectified. A finite universe naturally supports chaotic classical motion. In the classical-to-quantum transition, the underlying fractal persists as wounds, stigmas, and scars. Humans are made up of fractal systems such as the lungs, circulatory system, nervous system, and brain neurons. Our behavioural patterns are also fractal in nature, both as individuals and from generation to generation.

Our human existence is based on love and pain, justice and injustice. These substances should be explored through both personal and cultural implications and effects in the social fields.

According to the theory of the symptom,

will is linked to pain, and creativity comes primarily from the soma (GARZELLA, 2012). Indeed, suffering can lead to unbearable physical slavery, but it can also stimulate extraordinary spiritual freedom; to discuss differences and difficulties from points of view unknown to those that our rational reason usually tends to consider and “challenge again and again the complacency of the frame, setting safe knowledge and embodied experience against one another” (KUPPERS, 2003, p. 3).

The etymological meaning of the word “suffering” involves terms such as— to allow, to occur or continue, permit, prevent, stand, to be made to undergo, endure, be affected by or be subjected to (pain, death, punishment, judgment, grief), but also to bear, carry or put under, endure with patience, resist, and tolerate. In this ambivalence, between agony and holding on, a semantic area is defined, which also implies imagination.

Is the human body obsolete? Stelarc argues that prosthesis must not be seen as a sign of lack but rather as a symptom of excess; not a replacement for a part of the body that has been traumatized or has been amputated, but an object that augments the body’s architecture, where vital now is not merely the body’s identity, but its connectivity, not its mobility or location, but its interface (STELARC, 2008).

From my perspective, undoubtedly obsolete is the ideal of perfection we chase about the human body. If, on the one hand, robotics, prosthetic devices, tech body extensions, body modifications and scientific discoveries can indeed address our evolutionary process in specific directions (thus remaining the question of whether advancements in technology are overall beneficial or detrimental to human life), on the other hand, the stigma, the wound, disability itself can represent an escape point, a deviation of possibilities, and the notions of “difference” and “diversity” can be a shifting point, a mutation, even genetic, of perspective, and finally a contingency of new encounters.

## REFERÊNCIAS

ANONYMOUS AUDIENCE MEMBER. Email addressed to Andrea Pagnes (VestAndPage). Email subject: **Fragile Bodies**. Message received by: pagnes@vest-and-page.de on December 17, 2016.

ARTAUD, Antonin. **The Theater and Its Double**. New York: Grove Press. 1958.

ARTAUD, Antonin. Interjections by Antonin Artaud. **BOMB** magazine, v. 7, 1983. Available at: <https://bombmagazine.org/articles/interjections>. Access on: May 7, 2022.

BORER, Alain. **The Essential Joseph Beuys**. London: Thames and Hudson, 1997.

BUGIEL, Marcel, BEL, Jérôme. Disabled theatre - Marcel Bugiel and Jérôme Bel. In: **RB Jérôme Bel: Texts and Interviews**. 2013. Available at <http://www.jerome-bel.fr/index.php?p=5&cid=220>. Access on: April 21, 2023.

CARLSON, Licia, MURRAY, Matthew C. **Defining the Boundaries of Disability: Critical Perspectives**. London: Routledge. 2021.

DA COSTA DIAS, Luciana. The Crisis of Representation, the Performative Turn and Presence: possibilities toward a Performance Philosophy. In: **Revista Brasileira de Estudos da Presença**, v. 10 n. 1, p. 1-20. 2020. DOI: <https://doi.org/10.1590/2237-266092575>. Accessed on: March 10, 2021.

FORNONI, Nicola. Email addressed to Andrea Pagnes (VestAndPage). Email subject: **Scleroderma**. Message received by: pagnes@vest-and-page.de on April 19, 2017.

FORNONI, Nicola. My Scar. In: VESTANDPAGE (eds.) **Co-Creation Live Factory**. Amsterdam: 4bid. Forthcoming in 2024.

GARLAND THOMSON, Rosemarie. **Freakery**: cultural spectacles of the extraordinary body. New York: New York University Press. 1996.

GARZELLA, Alessandro. Il teatro del dolore. Crazy Shakespeare, Nelle mani di un pazzo, Re nudo. In: D'INCÀ, Renzia (ed.). **Il Teatro del dolore, gioco del sintomo e visionarietà**. Corrazzano: Tivullius. 2012, p. 38-78.

GOFFMAN, Erving. **The Presentation of Self in Everyday Life**. Doubleday: Garden City, New York. 1959.

GOFFMAN, Erving. **Stigma**: Notes on the Management of Spoiled Identity. London: Penguin. 1963.

HEIDEGGER, Martin. **Being and Time**. New York: Harper Perennial. 2008.

HILLMAN, James. The practice of beauty. In: BECKLEY, Bill, SHAPIRO, David (eds.). **Uncontrollable Beauty**: Toward a New Aesthetics. New York: Allworth Press. 1998. p. 261-274.

JOHNSTON, Kirsty. **Disability Theatre and Modern Drama**: Recasting Modernism. London: Bloomsbury. 2016.

JONES, Amelia. **Body art**: performing the subject. Minneapolis: University of Minnesota Press. 1998.

KUPPERS, Petra. Accessible Education: Aesthetics, Bodies and Disability. In: **Research in Dance Education**, v. 1 n. 2, p. 119-131. 2000. DOI: <http://dx.doi.org/10.1080/713694266>. Access on: April 20, 2023.

KUPPERS, Petra. **Disability and Contemporary Performance: Bodies on the Edge**. London: Routledge. 2003.

KUPPERS, Petra. **Theatre and Disability**. London: Palgrave Macmillan. 2017.

KUPPERS, Petra. **Community Performance: An Introduction**. London: Routledge. 2019.

KUPPERS, Petra. **Eco Soma: Pain and Joy in Speculative Performance Encounters**. Minneapolis: the University of Minnesota Press. 2021.

LALLY, Roisin. **The Hermeneutics of Capabilities From Essence to Functions, From Functions to Capabilities: Preparing the Ontological Ground for an Ethics Inspired by the Capabilities Approach**. Preprint. p. 1-23. 2020. Available at: <https://www.researchgate.net/publication/338517246>. Access on: January 20, 2023.

MARCUS, George E., FISHER Michael M. J. **Anthropology as a Cultural Critique: An Experimental Moment in the Human Sciences**. Chicago: The University of Chicago Press. 1999.

MCKEARNEY, Patrick. The Limits of Knowing Other Minds: Intellectual Disability and the Challenge of Opacity. In: **Social Analysis: The International Journal of Anthropology**, v. 65, n. 1, p. 1-22. 2021. DOI: <https://doi.org/10.3167/sa.2021.650101>. Access on: April 17, 2023.

MONTEIRO, Felipe, SALLES, Nara. **Corpos diferenciados: a criação da performance 'Kahlo em mim eu e(m) Kahlo.'** Maceió: EDUFAL. 2013.

MONTEIRO, Felipe, SALLES, Nara. **Corpos Diferenciados em Performance**. São Paulo: Fonte Editorial. 2018.

MONTEIRO, Felipe. **Subjetividade(s) e(m) Performance: corpo, diferença e ativismo**. Curitiba: CRV. 2019.

MONTEIRO, Felipe. Email addressed to Andrea Pagnes (VestAndPage). Email subject: **O Problema É Porque Sou Lúcido?!** Message received by: pagnes@vest-and-page.de on January 23, 2023.

MONTEIRO, Felipe. O Problema É Porque Sou Lúcido?!: A performance-ritual de um corpo diferenciado. In: **Cadernos do GIPE-CIT Salvadorano** v. 23, n. 43, 2020. p. 22-34. Available at <https://periodicos.ufba.br/index.php/gipe-cit/article/view/35352/20421>. Access on: April 16, 2023.

NEWMAN, Lisa. VIPAW as T.A.Z. In: VESTANDPAGE (eds.) **III Venice International Performance Art Week, Fragile Body – Material Body**. Venice: Vest-AndPage press. 2017. p. 47-49.

PAGNES, Andrea. On Disability Culture, Performing Arts, Social Theatre and the Practice of Beauty. In: **Ephemera Journal**, v. 3, n. 5, 2020. p. 92-127. Available at: <https://periodicos.ufop.br/ephemera/article/view/4155/3465>. Access on: April 20, 2023.

PHILIPPE, Maxime. Artaud's Plague Theatre: Catharsis as Performance. In: **Contemporary French and Francophone Studies**, v. 26 n. 3, 2022, p. 267-276. DOI: 10.1080/17409292.2022.2076403. Access on: March 31, 2023.

PILINSZKY, János. **Conversations with Sheryl Sutton: The Novel of a Dialogue**. Manchester: Carcanet Press, 1992.



PROFETI, Maria Grazia. Traduzioni/Riscritture Teatrali. In: BUFFAGNI, Claudia, GARZELLI, Beatrice, ZANOTTI, Serenella (eds.). **The Translator as Author: Perspective on Literary Translation**. Proceedings of the International Conference, Università Per Stranieri of Siena, 28-29 May 2009. Münster: LIT Verlag. 2011, p. 193-210.

RIPLEY, Enok. Email addressed to Andrea Pagnes (VestAndPage). Email subject: **Narcolepsy**. Message received by: pagnes@vest-and-page.de on May 27, 2022.

SANDAHL, Carrie, AUSLANDER, Philippe. **Bodies in Commotion: Disability and Performance**. Ann Arbor: the University of Michigan Press. 2005.

STILES, Kristine, SELZ, Peter. **Theories and Documents of Contemporary Art: A Sourcebook of Artists' Writings**. Berkeley: University of California Press. 2012.

SCHECHNER, Richard. **Performance Studies: An introduction**. New York: Routledge, 2006.

SCHECHNER, Richard. **Performance Theory**. New York: Routledge. 1988.

STELARC. Extra Ear: Ear on Arm. Interview by Jens Hauser. In: HAUSER, Jens (ed.). **Sk-Interfaces. Exploding Borders: Creating Membranes in Art, Technology and Society**. Liverpool: Liverpool University Press, 2008. p. 102-105.

TURNER, Victor. **From Ritual to Theatre, The Human Seriousness of Play**. Cambridge: MIT Press. 1982.

WORLD HEALTH ORGANIZATION. **World Report on Disability**. 2011. Available at: <https://www.who.int/teams/noncommunicable-diseases/sensory-func->

tions-disability-and-rehabilitation/world-report-on-disability. Access on: January 20, 2023.

WORLD HEALTH ORGANIZATION. **Disability**. 2022. Available at <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>. Access on: January 20, 2023.

#### ACKNOWLEDGMENTS

Late Alessandro Fantechi, Petra Koppers and Elena Turchi, whose life, work and mission continue to be inspirational to my artistic research and performance practice.

## Resumo

Este artigo deriva da experiência do autor como performer, curador e também ator, dramaturgo e operador de drama aplicado e teatro social. É baseado em sua pesquisa “Metodologias de ação inclusiva nas artes cênicas para praticantes de artes cênicas com habilidades diversificadas”, apoiada pelo Fonds Darstellende Künste [Fundo de Artes Cênicas] com fundos do Comissariado do Governo Federal para Cultura e Media (DE) [Federal Government Commissioner for Culture and the Media (DE)]. Segundo o autor, a deficiência não é um signo de falha, mas antes um meio para encorajar as pessoas a reduzirem distâncias entre si, a viverem solidariamente, e quebrar lugares-comuns. Considerando a autenticidade como uma qualidade fundamental da atuação, ele discute a urgência genuína dos performers com deficiência na imersão do imediatismo da ação, já que sua vulnerabilidade no palco não é filtrada. Nesse aspecto, ele vê o estigma como uma fonte de criatividade e um sinal qualificador capaz de erradicar preconceitos. Em Grotowski, as práticas performativas não se resumem apenas a uma questão de habilidade ou coleção de proficiências e sim, a uma erradicação de bloqueios para adesão do verdadeiro eu. O corpo do performer é a matéria prima para produção de significados que se transformam em imagens vivas e se tornam realidade. Isso independe da condição física do artista. O artigo oferece exemplos de performers afetados por diferentes formas de deficiência, como Felipe Monteiro, Nicola Fornoni e Enok Ripley, que relatam sua condição clínica específica. Uma referência particular foi feita à ópera performática coletiva *Under Scars* (Sob Cicatrizes) concebida e organizada pelo autor, sua parceira, a artista alemã Verena Stenke e seus colaboradores para estrear em Veneza, em dezembro de 2023.

## Palavras-chave

Deficiência. Teatro. Performance.

Received in: 14 may 2023

Accepted in: 15 jun. 2023

Posted in: 30 oct 2023