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Missing Utopia: reconsidering the politics of time in the global disability movement

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URBAN UTOPIAS

Memory, Rights, & Speculation



Edited by
Barnita Bagchi

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U R B A N
U t O p i a s

MEMRY, RIGHTS,
AND SPECULATION

Edited by
Barnita Bagchi

Jadavpur University Press

2020



Urban Utopias: Memory, Rights, and Speculation.

Edited by Barnita Bagchi

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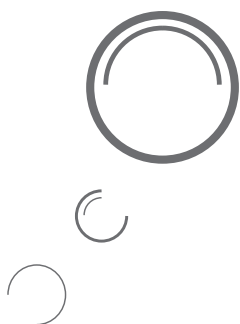
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MISSING UTOPIA: RECONSIDERING THE POLITICS OF TIME IN THE GLOBAL DISABILITY MOVEMENT

Paul van Trigt¹

INTRODUCTION

The *Guardian* recently published an article about accessible cities with the title ‘What would a truly disabled-accessible city look like?’ One of the reasons for this newspaper article was the recent United Nations’ declaration that poor accessibility ‘presents a major challenge.’ Although many countries ratified the so-called Convention on the Rights of Persons with Disabilities (2006), the reality on the ground—as *The Guardian* put it—can be very different. This is all the more surprising since in the 1990s several countries adopted anti-discrimination law with the aim to boost rights and access (Salman 2018). This begs the question as to why progress in the creation of accessible cities is so slow. There are of course many reasons for this, often determined by the specific contexts of particular cities. But one could also ask, as I shall do in this chapter, if there actually is a utopia in the global disability movement that could inspire people to work towards inclusive cities.

In this chapter, I shall investigate and reconsider the politics of time and

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utopianism within the global disability movement. My starting point is *Missing Pieces: A Chronicle of Living with a Disability*, written by Irving Kenneth Zola and published in 1982. The author uses the concept utopia to describe his experience of ‘Het Dorp’ (The Village), a fully accessible neighbourhood of the Dutch city of Arnhem that was designed to promote the optimum happiness of people with physical disabilities. The book is interesting in itself—we do not know much about utopias and disability except the fact that eugenic utopias exclude disability—but it has a broader relevance because it came to be seen as a classic of the global disability movement. We know that utopias often play a role in social movements (there is much literature about feminist utopianism for instance [Crawford 2003]), and *Missing Pieces* enables us to investigate the role of utopias in the global disability movement.

In the first part of this chapter I shall show, based on a close reading of the book, how Zola frames utopia, and argue that *Missing Pieces* presents the dominant perspective in the global disability movement. However, as I shall argue in the second part of the chapter, this perspective frames the Third World as a dystopia. It is not for nothing that this book has received only limited attention outside the Global North and is, as Helen Meekosha has argued more generally, insufficient for an effective global disability studies project (Meekosha 2004, 731). Therefore, I shall offer in the last part of the chapter a reconsideration of the politics of time that I hope will be productive for the global disability movement.

UTOPIA

The author of *Missing Pieces* is Irving Kenneth Zola (1935–94), a professor of Sociology at Brandeis University in the United States who spent his sabbatical year in 1971–2 as consultant-in-residence in the Netherlands Institute of Preventive Medicine in Leiden (Zola 1982, 3). There he was invited to visit Het Dorp, a part of the city of Arnhem specially designed to house 400 people with often severe physical disabilities. He visited Het Dorp for a day in January 1972, and five months later he was resident visitor for a week. Zola approached Het Dorp, in his own words, as ‘I do many things, exploring and uncommitted,’ but ‘it became the setting for this chronicle

and the stimulus for the search for my missing piece, my physical handicap.' As a result of polio and a car accident, Zola wore a long leg brace and a steel-reinforced back support. For a long time this was, as Zola wrote, 'just something that got in the way, another difficulty to be overcome,' but during his stay at Het Dorp and the process of writing about it, he discovered that 'overcoming is not the same as integrating' (Zola 1982, 3). I shall come back to this disclosure, but let me focus first on the way Zola writes about utopia.

He does not actually use the word utopia very often. He describes his first, one-day visit to Het Dorp under the title 'Several Hours in a Utopia.' It becomes clear that Zola is not using the word here in an unequivocally positive way. He was clearly impressed: 'Het Dorp was unlike any long-term care center' he had seen. But he had also observed that 'Het Dorp was so self-consciously a total institution, that it sought to provide everything, including happiness.' 'It was,' as Zola continues, 'rooted in the tradition of long-term medical care institutions and idealistically linked to the utopian communities' (Zola 1982, 34).

Zola's unease with the utopia of Het Dorp has to do with the fact that this utopia was not the utopia *of* people with disabilities but one *for* people with disabilities. This utopia did not come from the people with disabilities themselves but was imagined and realised by able-bodied people. The idea of Het Dorp came from Arie Klapwijk, a physician working on the rehabilitation of people with physical disabilities, who wanted as he put it 'to find and help severe invalids achieve optimal human development and optimal human happiness.' (Zola 1982, 9) Klapwijk wanted to realise a place, and here I quote from Zola's translation of the founding documents, 'where life could begin anew, where its physically handicapped inhabitants could live with dignity and independence, without the sense of futility and hopelessness of being restricted in medical institutions' (Zola 1982, 10). In order to raise the money, he organised a telethon—a twenty-three-hour radio and television marathon that became a success. With the help of television celebrity Mies Bouwman, 12 million guilders (34 million euros today) were collected in 1962, and when Zola visited Het Dorp in 1972 it was inhabited by 400 residents.

During the 1960s, Het Dorp was built as a neighbourhood of the city of Arnhem, following a design of architect Jaap Bakema of the Rotterdam firm Van den Broek and Bakema. According to Wanda Liebermann, we have to see his design as ‘an important effort to humanize post-war architecture for a community of people with physical disabilities’ and an ‘early example of barrier-free architecture’ because it provided ‘uninterrupted wheelchair access.’ Liebermann interprets Bakema’s design as part of his plea for the open society as ‘a humanistic ideal against a political setting that included the escalating Cold War and technocratic government building programs.’ She argues that Het Dorp on the one hand offered ‘a counterpart to the narrow and arid functionalism of high modernism,’ but on the other hand could not ‘escape prevailing social values about disability’ and showed ‘top-down decision making, limits in recognizing human diversity, and a medical and technocratic emphasis’ (Liebermann 2016, 158–9, 178; cf. Verlaan 2015).

This was exactly what Zola encountered in Het Dorp during his stay and what he is writing about in *Missing Pieces*. As he writes in his prologue, he had decided that ‘for a week I would resume the role of a functional paraplegic ... back into the wheelchair I went. I did everything from that position.’ He had hoped that this experience would provide an ‘added dimension.’ Furthermore, he ‘expected to take notes but without a specific purpose in mind’ (Zola 1982, 4). Well aware of being a stranger, Zola nevertheless participated actively in daily life for a week and spoke with many who worked and lived there. From his notes he produces what he called a ‘socio-autobiography’—in his own words ‘a personal and social odyssey that chronicles not only my beginning acknowledgement of the impact of my physical differences on my life but my growing awareness of the ways in which society invalidates people with a chronic disability.’ Despite his criticisms of Het Dorp, he evaluates the experiment as a success: ‘not the answer for those with severe physical disabilities but an answer’ (Zola 1982, 5–7).

I cannot give all the interesting details of Zola’s experience here, but his choice to use the wheelchair, combined with the fact that the residents knew that he was an American professor with a disability, led to many re-

vealing conversations. Het Dorp seriously promoted the six rights that the founders had specified: the right to privacy, work, recreation, religion, culture, and self-governance; but the very existence of this special village and the way the residents were approached showed the often unequal relations between the ‘handicapped’ and the ‘normal.’ Moreover, what the residents, including Zola, found important was often ignored (Zola 1982, 213–14, 84). To paraphrase one of the most important slogans of the disability movement (Charleton 1998): the utopia was produced for them, not with them. It was therefore not their utopia. His experience in Het Dorp made Zola realise that his disability was more important in his life than he had thought. During his stay he realised that he felt ‘truly on someone’s side, the side of the Village against the world’ (Zola 1982, 194).

DYSTOPIA

Taking into account Zola’s disclosure and his statement that disability is not so much a problem of people with disabilities but a problem for an ableist world, it does not come as a surprise that this text became foundational for the disability movement (Meekosha 2004). Zola’s perspective corresponds to the so-called social model of disability, in which disability is understood as a social construction instead of an individual deficit. *Missing Pieces* is therefore, along with inclusion in the literature on social science methodology, often quoted in disability studies literature. However, when we look more closely at the citations (using Google Scholar), we can see that Zola’s book is hardly used in and for the Global South.

In order to understand the role of utopias in the global disability movement, I want to focus on this limited use of *Missing Pieces* outside the Global North. As Helen Meekosha has argued, work like that produced by Zola is insufficient for an effective global disability studies project because it is difficult to integrate perspectives from the periphery within the disability studies discourse. She argues that disability has to be conceptualised within specific contexts, as has been done in the case of India, for example (Addlakha 2013); but she also states that ‘the key debates around disability and impairment, independent living, care and human rights are often irrelevant to those [and she is speaking here about people with disabilities

in the Global South] whose major goal is survival' (Meekosha 2011, 670).

When we read Zola through Meekosha's decolonial perspective, it becomes clear that the context of the book is the post-War Western welfare state that gave social security to people with disability, but often not the emancipation and freedom that they hoped for. What we see in the Anglo-Saxon disability movement, as inspired by Zola and others, is the fight against a paternalistic, welfarist utopia in favour of an inclusive society that gives people with disabilities equal rights, independence, and a voice. However, I doubt if this inclusive society is imagined as a utopia. Forms of independent living since the 1970s and anti-discrimination laws in the 1990s are often seen as the most important achievements of the Anglo-Saxon disability movement (Heyer 2015). These achievements both centre on the individual—independent living gives an individual with a disability the opportunity to live his or her own life with minimal dependence on others; anti-discrimination law gives an individual with a disability the possibility to go to court when he or she is treated unequally. These achievements are huge, especially given how people with disabilities were treated in the past, but I doubt if they reflect an alternative society or city—a utopia. I would not say that the Anglo-Saxon disability movement is without utopias and alternative imaginations of the social, but fighting against the utopias formulated by others and finding ways to improve the lives of individuals with disabilities seems to have become more urgent.

It is not by chance that Zola presents at the beginning of his book a visit to a rehabilitation centre in New Delhi, where his broken brace has to be repaired. Under the title 'With Hierononymous Bosch in India' he sketched a non-Western dystopia, before he started his critical investigation of a Western utopia. It is part of his narrative about disclosure; he ends the story as follows: 'my three-hour experience was just another piece of information, just another incident in their busy day, recorded and quickly forgotten. But not for me, not for me' (Zola 1982, 22). Zola presented his visit to India, which took place shortly before he visited the Netherlands, as a first step in the search for his 'missing piece.' So let us delve a bit deeper into this part of the book.

In India, Zola was shocked by two things—in the first place, people from India asked him directly what had happened with his leg. That is, as Zola writes, ‘as any American would know... hardly a typical opening between strangers’; it was an ‘intrusion into what Americans regard as so private a matter’ (Zola 1982, 17); second, he was shocked by what he saw when he entered the Nehru Rehabilitation Centre: ‘within comfortable touching distance was a panorama of physical suffering. An old man in a turban, toothless, blind in one eye, with his foot missing below the ankle, stood quite straight, almost proud; a young man, twentyish, wandered around, speaking to many but with no one returning the attention; countless children limped to and fro’ (Zola 1982, 18). After this description, Zola concludes that he ‘seemed to be the only one showing signs of discomfort’ (Zola 1982, 19). These shocks helped Zola to discover his disability, but also made clear that the way people from India dealt with disability was not really attractive to him.

Thus, in this founding text of the Anglo-Saxon disability movement a position is taken between a Western utopia and a non-Western dystopia, with some preference for the first. At its centre we find an individual who is uncomfortable with the interference of others. I think the emphasis on the individual in the dominant disability studies discourse has made thinking in terms of utopia more difficult, especially as this utopia has to be imagined in both the Global North and the Global South. This has not become easier with the increasing influence of the human rights perspective on disability. As critical human rights scholars have pointed out, human rights often were, and are, not enough. They ensure in particular ‘negative freedom,’ namely freedom from the interference of others; but they are often not part of a utopian view on how to improve society structurally, and do not take the situation of people with disabilities in the Global South sufficiently into account (Moyn 2018; Hoffmann 2016; Van Trigt 2019). Although the anti-utopian stance of the Anglo-Saxon disability movement has its merits, a reconsideration of the politics of time and individualism seems a useful contribution to a global disability movement.

Scholars from the Global South are already building their own body of knowledge, sometimes using the Anglo-Saxon disability movement as

an inspiration, while at other times criticising it (Addlakha 2013). In the subfield of disability history there is an increasing attention to (post)colonial histories of disability, often related to anthropological work (Livingstone 2005). In the tradition of New Disability History, the agency of people with disabilities is highlighted when possible in this historical and anthropological research. The individualism that underlies the attention to agency is, however, questioned from a critical disability studies perspective (Verstraete 2012). An interesting move beyond individualism, especially in light of this chapter's aim to address utopias, is Pieter Verstraete's and Frederik Herman's recent plea for commonality. Although their plea is based on the Western context, it seems relevant also for other parts of the world (cf. Staples and Mehrotra 2016, 41).

Against the background of an increasing amount of historical work that deconstructs the 'contemporary distinctions between able-bodied and disabled individuals,' Verstraete and Herman propose an additional 'historical venture that seeks to uncover commonalities: places where the distinctions between persons with and without disabilities are temporarily forgotten and/or erased, moments when the boundaries between the self and the other are being reconfigured.' By analysing sources related to the practice of rehabilitation after the First World War, they show how existing distinctions were replaced with new ones; but they also trace 'some moments of lived and shared commonality' in which 'human beings celebrate what they consider to be important' (Verstraete and Herman 2016, 11). Verstraete and Herman reveal only short moments of commonality, but would it not be possible to find places where the boundaries between the self and the other were more profoundly and structurally reconfigured?

In order to explore further the possibilities of this 'historical venture,' I turn to writing on living with people with cognitive disabilities, and in particular to a recent paper about agency written from an anthropological perspective. In his paper, 'Receiving the Gift of Cognitive Disability,' Patrick McKearney (2018) argues that people with cognitive disabilities have not been valued 'just as rational moral subjects, or simply as passive objects of care, but also as charismatic and intuitive agents who actively depart from standard norms of personhood' (McKearney 2018, 40). As an anthropol-

ogist, McKearney has worked in a L'Arche community, a Christian charity that 'places people with cognitive disabilities at the heart of their social life through making their care more communal.' In the literature it is often stated that L'Arche communities 'learn to look beyond a hierarchy of cognitive capacities to recognize the vulnerability they share with people with cognitive disabilities' (McKearney 2018, 41). Therefore, these communities have often been seen as a 'utopia of dependence,' a 'somewhat-utopian fulfilment' of a 'caring society,' and 'a powerful alternative to a wider culture that supposedly values independence, agency and achievement above all else' (McKearney 2018, 43, 53). Could such communities be an additional source of inspiration for the global disability movement? My answer will be yes, but not within the framework of the 'caring society.' Moreover, the vulnerability to the abuse of power within these communities requires critical attention as recently became clear from an external report about L'Arche founder Jean Vanier (L'Arche 2020).

McKearney contests the idea of 'utopia of dependence' and shows that carers are challenged to recognise people with (cognitive) disabilities 'as people who inhabit the world in a different way' and as 'agents who can powerfully affect the ethical lives of others' (McKearney 2018, 41). He does not deny that 'carers cultivate their own sense of dependence and passivity,' but observes also that they 'make themselves more like those they support.' Carers do this 'to make themselves more open to what these distinctly different agents can do to them' (McKearney 2018, 53). McKearney relates this finding to what is argued by anthropologists of ethics, who have pointed to 'the potency and the worth that people find in forms of agency that are less autonomous and reflective than the cognitively able subject' (McKearney 2018, 56). A promising observation in McKearney's paper is his remark that these communities do not (only) show an alternative society in which people without disabilities recognise their own vulnerability, but also a social order in which people show and are open to different ways of inhabiting the world. In the last part of my chapter, I shall argue that such communities could better be understood as heterotopias than as utopias, and as such could contribute to the global disability movement.

HETEROTOPIA

To Verstraete's and Herman's plea to highlight moments of commonality in the past, I should add that it seems worthwhile also to investigate historical moments and places of cohabitation in which the distinctions of (dis)ability were not erased, but in which agency was diversified and other ways of being in the world became possible. As McKearney's work suggests, these moments can be seen in particular when people with cognitive disabilities have lived together with people without these disabilities. In historiography, and in disability research more generally, these moments are hardly ever addressed; the attention is often directed towards oppression and the resistance of people with disabilities. These histories are indeed very relevant and cover much of what has happened, but I want to go beyond this dichotomy in this chapter. In doing so, I follow McKearney in using insights from the anthropology of ethics and morality. As I shall show in the following paragraphs, this research tradition includes on the one hand the post-colonial plea to engage seriously with diverse ways of being in the world (Chakrabarty 2000, 21), and on the other hand enables us to apply the (Anglo-Saxon) social model of disability in a new way.

In the attempt to articulate alternative narratives for the global disability movement, I find Laidlaw's *The Subject of Virtue* particularly useful. In his reflection on ethics and morality, Laidlaw builds on Foucault's attempts to see freedom not 'as being in a zero-sum external relation to power, but as an aspect of the configuration of power relations' (Laidlaw 2014, 98). According to Laidlaw, anthropologists have applied this insight in particular because existing social and feminist theory often does not allow us to appreciate 'ethical forms of life' in a non-liberal context. In her research about women in the Egyptian piety movement, Saba Mahmood, for instance, goes beyond the idea of agency as resistance and argues for 'the variety of ways in which norms are lived and inhabited, aspired to, reached for, and consummated' (Mahmood quoted by Laidlaw 2014, 140). As Laidlaw rightly points out, the 'liberal' understanding of freedom is far more complicated than is often suggested in the literature. Therefore it could be said that 'to portray idealization of autonomy, conceived as autarchy or external independence, as if it were a feature or failure specifically of

“liberalism” is not only a misleading perspective on European thought, but also parochial in relation to the ethnographic record more broadly’ (Laidlaw 2014, 161).

In his further reflections on agency, Laidlaw makes use of the analysis of responsibility by the philosopher Bernard Williams, who distinguishes the four elements of responsibility as—cause, intention, state, and response. With cause he refers to the idea that someone has brought about a state of affairs; intention asks if this state of affairs was intended; state is the condition in which someone was bringing the state of affairs about; and response concerns the question of who will do something about this state of affairs. These four elements ‘may be distributed among the entities involved in a network or a chain of events’ and ‘need not be located in one actor’ (Laidlaw 2014, 189–90). By stating that the ethical subject does not automatically coincide with the individual and the lifetime of the individual, Laidlaw can take seriously ‘notions of rebirth, circulation of souls between animals and humans, and karma,’ as Veena Das (2014, 491) has pointed out.

If we apply this approach, we create an openness to ‘what forms of agency are recognized, constructed and worked with in different ethnographic contexts’ (McKearney 2018, 56). In the context of disability history, we cannot limit ourselves to the moments when people with disabilities showed resistance or were unable to do so. As McKearney shows, there are cases that enable us to see other forms of agency, and in which we can learn from post-colonial and anthropological research traditions that have already been searching for different ways of being in the world (Chakrabarty 2010, 249–52). In these cases, working with sources that do not directly represent people with disabilities is often unavoidable—in McKearney’s research his main informants were people without disabilities. However, if we agree with Laidlaw’s decentring of the individual agent, we could also approach the agency of people with cognitive disabilities who have left few personal sources, embedding them in a broader network by using other sources. As I shall demonstrate with the help of the following case, this approach not only enables us to see other forms of agency, but also shows how this agency could result in change as intended by the social model of

disability—that is, not societal change in the first place, but the change of a person and/or a relationship between persons with the potential of having broader societal impact.

The case I want to discuss is that of Adam Arnett and Henri Nouwen. What I offer here is a short analysis of the book *Adam, God's Beloved* (1996, translated and published in Dutch in 1997) and not an extensive investigation of their relationship based on different sources. The book is mainly written by the theologian Henri Nouwen, but because of his sudden death in 1996, it was finished and edited by his friend Sue Mosteller. The reason for the book was the death of Adam Arnett, a man with severe disabilities who died a couple of months before Nouwen. Arnett and Nouwen got to know each other in the L'Arche Daybreak community in Toronto, Canada. Arnett had lived in this community since 1985, and Nouwen came there because of his sabbatical in 1995–96. Nouwen had planned to write a book about the credo—the confession of Christian faith. When Arnett died in February 1996, Nouwen started to write a book about him that turned out to be a book about faith. For Nouwen, Arnett was a friend, a teacher, and a mentor. According to him, Arnett was sent by God into the world to heal other people. Therefore, in his writing about Arnett's life he related it to elements of Jesus' life. Nouwen saw in Adam the image of God, just as Jesus is perceived in the Christian tradition as 'God with us' (Nouwen 1997, 11–14).

Although this book is profoundly religious, the relationship between these two men can also be understood without focussing on religion. Arnett and Nouwen developed a friendship because the latter was asked by the community to care in particular for the former. This makes clear that their relationship is not equal in every sense—there is a care and thus a power relationship in which Arnett's disabilities make him different from and dependent on Nouwen. In writing about Arnett, Nouwen balances difference and equality by saying that Arnett fulfilled his role as friend, teacher, and mentor in an uncommon way, because he could not communicate as people 'usually' do. At the same time, Nouwen stresses that Arnett was not extraordinary, not an angel, but a human being like everyone else. Interestingly, Nouwen challenges the view that he is the more powerful in

their relationship by calling Arnett not only a friend but also a teacher and mentor. As becomes clear in his book, this process was no less than a re-evaluation of values, as Nouwen wrote with an implicit reference to Nietzsche (Nouwen 1997, 12–14, 49, 54).

What Nouwen and others have experienced in their relationship with Arnett might therefore be seen as a variation on the social model—at the start they see people with disabilities as objects of care, but during the course of the relationship they learn to see their own view as disabled and to perceive people with disabilities as agents who inhabit the world partly in the same and partly in different ways. This re-evaluation is not without dangers: people with disabilities could be seen as ‘instrumental’ for able-bodied people to discover their own vulnerabilities, for instance. While being aware of this, it is nevertheless worthwhile to examine stories of this kind because they further diversify disability studies. If we address his responsibility for a changing state of affairs, we find that we cannot allocate it all to him, because we can say nothing for example about his intentions, and we know that the response is dominated by Nouwen’s view. Nevertheless, Arnett seems to have played a transforming role in the lives of several people, on account of his way of being in the world. Of course, we have to reflect critically on the fact that Adam is ‘used’ for religious narratives, but not more so than when reflecting on the more familiar resistance stories within the disability movement.

The case of Arnett and Nouwen not only reveals agency, but also points to the importance of space—which brings me back to utopias. In this case, as also in the research of McKearney, relationships were developed within a community in which people with and without disability lived closely together. It is striking that the agency of people with cognitive disabilities is respected and taken seriously, an attitude that cannot be taken for granted in society as a whole. Therefore, these communities could be seen as heterotopias, a Foucauldian conceptualisation of space applied by ethicist Herman Meijinger to the inclusion of disabled persons. Foucault considers heterotopias as ‘counter-sites’ that ‘have the curious property of being in relation to all the other sites, but in such a way as to suspect, neutralize, or invert the set of relations that they happen to designate, mir-

ror or reflect' (Foucault 1986, 24). On the one hand, heterotopias are a symptom of societies that exclude deviance, while on the other they can support the position of excluded people, because they occupy the space that society has abandoned as abnormal (Meininger 2013, 28). Meininger advocates heterotopias as spaces of encounter between people with and without intellectual disabilities because inclusion in public spaces 'often turns out to be a space of discrimination' (Meininger 2013, 24). According to Meininger, heterotopias offer a 'continuing dialogue between the "normal" and "abnormal" instead of adjusting "the abnormal" to the "normal", an adjustment that cannot always be avoided in the politics of inclusion.' Building on Kevin Hetherington's *Badlands of Modernity*, Meininger understands heterotopias as 'alternative modes of ordering' that are based nevertheless upon 'some idea of social improvement' (Meininger 2013, 32; cf. Hetherington 1997). In heterotopias, the meetings between 'we' and 'the others' result in experiments with 'new models of interaction, communication, connection, participation and power relations' and in 'laboratories of new meaning and of alternative modes of social ordering' (Meininger 2013, 33).

I agree with Meininger on the usefulness of Foucault's concept for disability politics, but tend to disagree with the following elements of his interpretation: in the first place, Meininger wants to see heterotopia as relational space and not as a specific geographical space. I think he underestimates the importance of living together in a concrete space. It is no accident that new ways of ordering and being in the world often originate in specific communities that live together. In her book *Unlearning Eugenics*, Dagmar Herzog points out 'a variety of literal and conceptual connections between avid present-day efforts to insist on full human subjecthood for the disabled, including especially the cognitively disabled, in all dimensions of existence, and an eclectic but vital handful of intentional disabled-abled life-sharing communities founded in the 1940s, 1950s, and 1960s in either direct or indirect reaction to the National Socialists' systematic mass murder project' (Herzog 2018, 11). The communities, as discussed by Herzog—the Camphill movement, L'Arche, the La Borde clinic of Félix Guattari, and the living experiments of Fernand Deligny and Duncan and Dan-

iola Mercieca—all have in common the fact that life-sharing takes shape in a specific material space and not in more abstract relational spaces (cf. McMorrow 2015).

Second, Meininger seems to lose the (Foucauldian) dimension of power when he characterises heterotopia in a way that tends to be idealistic and seems to be focused on challenging the participants without disabilities to accept the participants with disabilities (Meininger 2013, 37–38). In this way, heterotopias are likely to become one-sided tasks for people without disabilities. Foucault challenges us to make the distinction between disabled and non-disabled (among other differences) more complicated. The advantage of the concept of ‘heterotopos’ is that it refers to another or an alternative way of social ordering, which means that we stay critically aware of power relations. Foucault investigated the ethics of the Athenian elite, including (sexual) relationships between adults and young men, because that enabled him to address the question of ‘how to make oneself into a free subject among others in relations of power’ (Laidlaw 2014, 124). As Laidlaw writes, he ‘does tend to stress the agonistic aspect of the exercise of freedom, but what he describes is equally a matter of mutual recognition—the “game” is between players who acknowledge each other as such—of enabling (“empowering”) quality of relations that accommodate mutual recognition, where mutuality does not of course imply or require equality’ (Laidlaw 2014, 124). What Foucault did for the Athenian elite could be done from a historical point of view for communities like L’Arche. We know much already about how such places could be dystopias in which human rights are violated, but could we also articulate stories from heterotopias where people with and without disabilities live together in mutual recognition?

The history of people with cognitive disabilities seems in particular to contain such alternative narratives, although their history is rarely written from a more critical disability studies perspective. As already mentioned, the challenge of this history writing is that people with disabilities themselves have hardly ever produced historical sources of their own—the sources they have left are often reproduced by other people. However, we do not always have to focus on the perspective of the able-bodied actor

who dominates the sources, it also possible to go beyond the focus on the individual and to look at the relationship between people as part of a broader network (cf. Van Trigt and Legêne 2016). This enables us to articulate diverse ways of being in the world and to see how power relations could be shaped in order to make space for this diversity. Such investigations show how freedom might be exercised within relations with the other, and might therefore be useful additions to the dominant narratives within the global disability movement that so far focuses mostly on negative freedom.

CONCLUSION

In the first part of this chapter, I have discussed the politics of time in the global disability movement by first analysing Irving Kenneth Zola's book *Missing Pieces*. As became clear, the politics of time concerning disabled people, whether in a Western utopia or a non-Western dystopia, were critically evaluated by Zola. His ideal of the independent individual makes him critical of the interference of others and the imaginations of a common future—an ideal that is influential within the global disability movement today. In the second part of this chapter, I have addressed the increasing unease with the focus on the individual in the literature about disability, the Global South, and human rights: does the global disability movement not need alternative narratives that stimulate the imagination of a common future in addition to politics of time rooted in the independent individual? I proposed, therefore, in the last part of this chapter, to investigate heterotopias from a historical-anthropological perspective, as spaces where people with and without disabilities live together with mutual recognition. Heterotopias enable us to explore another politics of time, a social ordering that is open to different ways of being in the world and which enables people to exercise freedom in relation to others. The lack of such narratives about commonality may be one of the reasons why, for instance, the progress in making cities accessible to all is so slow. One may hope that disability history can uncover from the past more alternative narratives that will inspire people in the present to work on a common and inclusive future.

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