

<http://somatosphere.net/2019/integration.html/>

## Integration

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By Clara Devlieger

In one of several letters he wrote to me during my fieldwork, Serge addressed what he considered to be the problems of integration for disabled people in the Democratic Republic of Congo. Writing this letter in November 2013, he reflected on the upcoming International Day of Persons with Disabilities on the 3<sup>rd</sup> of December. “Across the world,” he wrote, “people living with disabilities commemorate the international day for their physical inaptitudes. But here [in Congo], the result is still negative, in society, there is no integration.” Serge was one of many people who had been affected by polio as a child. He had grown up with a malformed leg and a bent back, and he often told me he was frustrated with discrimination based on his appearance. As a man in his forties who managed a small kiosk for its owners, he often reminded his conversation partners that he was actually well-trained as an electrician but was unable to find employment because of discrimination. He frequently reflected on his childhood, and he had very strong opinions about what had gone wrong and why, in his opinion, disabled people were marginalised in Congolese society. In his letter to me he went on to point out that he and several friends had concluded that a person’s mental capabilities were more important than their physical appearance, and requested for people of good will to support the ideas of disabled people in order to “make progress against marginalisation, mendacity, in short, against incomprehension, to gain if only 55% of human value.” Serge often described discrimination based on disabilities as the cause of marginalisation, arguing that not only was wider society at fault but disabled people were partly to blame themselves: they often had a problematic mentality of discerning and desiring difference, he argued, which blocked their capacity to integrate.

During my long-term fieldwork (2013-2015) on informal livelihoods of physically disabled people in Kinshasa, I was often told that disabled people were not “integrated” into Congolese society. Although we generally spoke in a mix of Lingala and French, French is a local marker of education and prestige and Serge choose to write his letters in French as further evidence of his education. *Intégration* was a French word used in the local variant of Lingala, frequently used by my interlocutors to argue that disabled people were consistently marginalised by society: they were neglected by their families as children and by the state as adults, which

made it more difficult for them to go to school, work, marry, and ultimately support families of their own. Anthropologists working in Euro-American contexts have discussed a variety of responses to discourses of integration, from attempts at “passing” as “normal” in mainstream society (e.g. Edgerton 1967) to the use of “visual activism” (Garland-Thomson 2009) to engage a politics of recognition by drawing attention to disability. Someone like Serge, by contrast, did not necessarily want to blend in nor did he wish to stand out; rather he wanted disabled people to be socially valued as people and as Congolese citizens. Considering disability from the south thus may expand the idea of what integration can constitute. A perspective from Kinshasa demonstrates that integration is not an all or nothing situation, and that being integrated in certain respects and not in others is not necessarily a contradiction.

Many of my interlocutors remembered a not-all-too-distant past when disabled people had had moral and material entitlements they considered indispensable to public recognition and social value. During the regime of the dictator Mobutu (1961-1997), disabled people had been able to count on international charitable organisations that would regularly hand out food, clothing, and money. Through an official disabled persons’ card they were able to retrieve from the City Hall, I was told, disabled people had also had access to free public transportation and free medical care for themselves and others in their care. Rather than seeking the integration of disabled people, difference was recognised and compensated with such forms of special care. The 1981 International Year of Disabled Persons, the ensuing United Nations Decade for Disabled Persons, and the regime change in 1997 brought a whirlwind of changes. Many of the international aid organisations that had previously provided gifts eventually left, and those that remained shifted their focus from charity to trying to “integrate” disabled people into society by making them “independent” by providing training in trades. Meanwhile, understandings of disability shifted, as information campaigns fought stigma of disabled people as “useless” by presenting them as capable ordinary people able to work and support children. Emphasis shifted from disability as a category of people needing special care to disabled people as being “normal” people in need of integration, fitting into society like everyone else.

Part of these evolving ideas about “integration” centred around disability livelihoods. Unlike Serge, most of my interlocutors were polio survivors or amputees who made a living in specialised informal economies reserved for people with disabilities at the international border between the Democratic Republic of Congo and the Republic of Congo in Kinshasa. At the border, people with disabilities received informal, unregulated discounts on the ferry that crossed the River Congo as well as on customs taxes, and people hired them as intermediaries to transport people and goods at a discounted “disability” rate. These informal privileges had

been around since the 1970s, I was told, when disabled people used them to trade across the border and they were aimed at helping people who were otherwise unable to gain employment. In the 2010s, border work continued to be viewed as a kind of safety net for those in need, but many disabled border workers had also come to consider such informal privileges as key to their social integration: a regular income had made it possible for many to marry and support families, fulfilling the local demands of adult personhood and challenging a common stereotype of disabled people as “useless.” Having shifted from trade to brokering, disabled people acted as go-betweens at the border, but would shed this “liminal” position at home; the income made it possible for them to integrate into society by caring for families in the same way as other Congolese people. “Liminality” was thus not a static position or a permanent role but one that was adopted for work and dismissed in other domains of their lives (cf. Murphy 1995). And yet for others, such as Serge, by contrast, these activities were an example of how disabled people blocked their own integration: brokering was associated with illegal activities such as smuggling and customs fraud. Where some viewed brokering as a lifeline, an indispensable alternative to begging, and something that had helped change mentalities about disability, others viewed it as tantamount to criminality and detrimental to the wider reputation of disabled people.

Discussions about the value of brokering for integration were frequent: people often disagreed on the question of whether or not it was ultimately beneficial for disabled people to have informal privileges at the border, and whether or not it helped them to integrate into society. Towards the end of my fieldwork, I organised a conference to present and discuss the findings of my research. Everyone who had been a part of my research was invited, as well as anyone who was active in the domain of disability in Kinshasa such as representatives from international NGOs and the Ministry of Social Affairs. After my presentation the audience members engaged a lively discussion where integration was the question on everyone’s lips: did privileges at the border and the activities of disabled people help to further or block the integration of disabled people into Congolese society? Did border activities have a positive or negative effect on public perception and negative stereotypes of disabled people? Were these activities statements of citizenship or charity? Opinions were divided. One NGO representative argued for a paradigm change: she argued for a need to shift away from images and practices of charity, referring to a common understanding of border activities as “favours” from the state. In her opinion, a new law proposal on disability rights was instrumental to such a paradigm change. A blind border worker intervened to disagree: border activities were an indispensable safety net for people without work. They needed to be viewed as “rights” rather than informal favours, he argued, and they needed to be formalised rather than

dispensed with. This would stop border officials from harassing disabled people and enable their integration. Others countered that the very fact of engaging in illicit traffic at the border demonstrated that disabled people were not interested in integration. As the discussion went back and forth, all agreed that disabled people had a negative public image that needed to be changed, but what exactly “integration” was and how it was to be obtained remained the topic of debate.

Ultimately, however, brokering at the border allowed disabled people to create and insert themselves into a gap in the market. Capitalising on their informal privileges, they were able to create a professional niche where they did the opposite of integrate: they stood out, and this, in turn, enabled them to integrate in other domains of their lives. The informal discounts worked as a marker of difference for disabled people: they were given such privileges because of their physical status as disabled, and in the views of the NGO representative, they worked to perpetuate a public and social image of disabled people as defined by difference. For Serge, these privileges were particularly detrimental for the public image of disabled people, blocking their integration by associating disability with illegal activities. He considered such a reputation and a desire for difference on the part of disabled people as partly to blame for why he was unable to gain employment as an electrician. Many border workers, by contrast, considered the privileges as essential to their integration: the privileges at the border enabled them to counter stereotypes of disability as “useless” and enabled them to support families, attaining markers of adult personhood previously considered impossible for disabled people. For them, such economic capacity was far more powerful than stigma-fighting information campaigns had ever been. Considering disability from the angle of this livelihood can complicate the idea of what integration constitutes. Disabled people may be integrated in certain domains of their lives and separated in others; integration is not all or nothing, and it may mean different things to different people. The idea that one may be integrated into society in certain domains of life and not integrated in other domains is not always contradictory.

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*"Disability from the South: Toward a Lexicon"* is a series edited by Michele Friedner and Tyler Zoanni. Contributors in this series consider what changes in theorizations of disability when research is located in places marked "Southern" and offer reconfigurations of keywords and concepts typically utilized in the study of disability.

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