

What Are People with Disabilities Responsible For?

The Study of Political, Social and Family Responsibilities in the Context of Locomotor Disability (Cape Flats, South Africa)

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On 9 December 2015, the South African Department of Social Development ratified the *White Paper for the Rights of Persons with Disabilities* (WPRPD), a legislative framework that aims to align national and local policies with the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD). Firstly, this disposition reasserts the commitment of the government to the social issue of disability, an issue that had already been acknowledged in the 1990s during the transition from apartheid (1948–1990) to a multiracial democracy (Howell, Chalklen and Alberts 2006). Secondly, the WPRPD illustrates the growing reference to the notion of responsibility in South African policies. Indeed, a section of the text develops all parties' responsibilities and functions in relation to the matter, and this includes the state, the disability associations, the traditional or religious leaders, the media and advertising industry and the research and academic institutions. As such, the treatment of the issue of disability in South Africa seems an interesting starting point from which to study the current transformations of the discourses around, and the moral practices of, responsibility on the African continent.

Documented by an ethnographic research on the experience of locomotor disability in South Africa, this chapter questions the different forms of responsibilities that are at play. Locomotor disability has been defined as a lack of mobility due to an impairment of the lower limbs. The objective, as stated in the introduction of the book, is to move away

from an analysis that reduces the ongoing process of responsabilization to a modern form of liberal governance (see also Trnka and Trundle 2017). While we must not underestimate the socio-political transformations that have 'entailed a new conception of the subjects to be governed; that these would be autonomous and responsible individuals, freely choosing how to behave and act' (Miller and Rose 2008: 18), this chapter offers a consideration of other types of responsibility that are prescribed by social obligations or are embedded in personal relationships. In the field of disability, three discourses on responsibility cohabit: (a) the political aspect of responsibility that is presented in policies and other legal texts, (b) the idea of responsibility as an individual 'fault', and (c) the family and social responsibilities that are ruled by social norms. I argue that it is through the interactions between those legal prescriptions, moral norms and inter-individual expectations, together with the ways that individuals negotiate them, that the regime of responsibilities for disability emerges in South Africa. Each of these discourses is influenced by the history of the country, marked by centuries of racial segregation, by hopes relating to the new multiracial democracy, which was established in the 1990s, and, more recently, by the disenchantments that have arisen due to policies of liberalisation.

The discussion uses data gathered during eighteen months of fieldwork in Mitchell's Plain between January 2014 and April 2017. Mitchell's Plain is a 43 km² zone in Cape Town that has been developed as a Coloured township since 1974.¹ Its population exceeded 310,000 people in 2011 (City of Cape Town 2013: 2). Despite the abolition of the *Group Area Act* in the 1990s,² the area has remained predominantly Coloured. Moreover, Mitchell's Plain and its Cape Flats surroundings have shown little improvement since the end of apartheid in the fields of education and employment. The significant number of people with disabilities living in the township may be explained by the high level of drug and gang-related violence in the area, violence that inflicts disabling injuries. Another explanation relates to the low prices of housing, which make the area attractive to families whose incomes are strained by the situation of disability. However, Mitchell's Plain is also targeted by programmes of reconstruction. One of these programmes led to the opening of the most specialised physical rehabilitation centre in the country in 2006. The methods of research entailed participant observation and semi-directive interviews. The participants were selected through various organisations for the rights of people with disabilities that are active in Mitchell's Plain.

The first section of this chapter returns to the White Paper to understand how the notion of responsibility is used in South African policies in relation to disability. The second section questions the attribution of

a 'fault' to people with disabilities regarding their condition. The last part of the discussion focuses on family responsibilities in regard to housing and financial support. In conclusion, this analysis aims to show how these variegated forms of responsibility can influence, support, or compete with one another, forming, in the process, a specific regime of responsibility that is constantly in the making.

Political Responsibilities: *The White Paper for the Rights of Persons with Disabilities*, 2015

Although South Africa adopted national guidelines on the issue of disability in 1997, many observers criticized its lack of implementation (Dube 2005; Heap, Lorenzo and Thomas 2009; Watermeyer *et al.* 2006; Watermeyer 2013). Consequently, the WPRPD endorsed an outcomes-based approach that links the idea of responsibility with the notion of accountability. This human rights approach therefore aims at the development of 'people's capacity to demand accountability in two ways: firstly, by defining a minimum scope of legitimate claims (human rights), and, secondly, by strengthening the accountability mechanisms and processes to protect these claims (such as the justice system)' (DSD 2015: 32). However, the responsibilities described in the text do not have the same nature and the stakeholders' accountability therefore varies in its forms: it can be mandatory by law, a condition for accessing specific resources, or a simple injunction with no real incentive.

The South African state is the first actor mentioned in the WPRPD. It is responsible, firstly, for adapting its legal framework and plans to the principles of empowerment, inclusion, social participation and equality. Secondly, it has to finance different programmes to raise awareness around the issue of disability, to promote work and educational opportunities for people with disabilities, to make the physical environment accessible, etc. These objectives can be achieved through specific actions that target people with disabilities, quotas in projects, anti-discrimination rules or awareness around the issue of disability in mainstream programmes. Thirdly, the state remains the main actor for the collection, analysis and reporting of data relating to the actions that are put in place and their results. Nonetheless, the government cannot act alone. The state is one actor among others, and its fourth role is to coordinate the different actions that ensure and promote people with disabilities' rights: 'the South African state thus has the primary responsibility to guarantee the existence of circumstances in which every individual and community can exercise their rights' (*ibid.*: 31). In other words, public bodies have to

provide a capacitating environment that enables people with disabilities, their families and their representatives to act. This principle is embedded in the logic of empowerment that has been promoted by the ANC since its election in 1994.

Most of those responsibilities are a synthesis of obligations that are stated in existing international conventions or in South African legislation, such as the *Constitution of 1996*. For the rest, the different public bodies are responsible for actualizing their own regulations. Nonetheless, these means of accountability have shown their limits as they failed to materialise the guidelines of 1997. To enhance public accountability, the WPRPD therefore created the National Disability Rights Machinery, a platform on which state representatives meet the members of various associations in order to answer questions or criticisms regarding their actions. This mechanism of confrontation is believed to improve the capacity of the state's partners to hold it accountable. However, the South African participatory democracy has been criticized for limiting citizens' voices and their claims to representation through the associations or bodies that are recognized as legitimate interlocutors by the state (Brown 2015; MirafTAB 2004a; Pieterse 2008). The South African government thus distinguishes between 'invited spaces of mobilisation', in which demands and requests are defined as legitimate, and 'invented spaces of mobilisation' whose actors' claims are discredited (MirafTAB 2004b). The creation of the Disability Rights Machinery seems to reproduce this pyramidal logic and, consequently, the risk of excluding some actors from the discussion, including citizens who are not affiliated to any representative body, as well as small-scale organisations, whose voice is either silenced or limited to local discussions.

A second actor responsible for the enactment of the WPRPD is comprised of the associations of and for people with disabilities. Their functions include participation in the design, implementation, monitoring and evaluation of the various programmes that are relevant to the issue of disability. This also implies collaborating with the National Disability Rights Machinery. Moreover, representative associations are required to empower their members in various ways, namely, through informing, facilitating registration in different programmes, organising protests, and delivering services. These multiple roles are not enforced by law, as is the case for most state requirements. Nonetheless, the public financial support, upon which most of the civil organisations depend, creates a conditional responsibility: based on the monitoring and evaluation of actions undertaken, the public funding or status as a non-profit organisation (which allows an association to raise funds) can be withdrawn.

It must be underlined that these roles are not all regarded as being legitimate by the members of these associations. The political function of lobbying is usually accepted to be the main duty of organisations. However, as pointed out earlier, some uncertainties remain regarding the capacity of small-scale and local associations to be heard at the national level. On the other hand, the members often condemn the role of their association in the delivery of services to people with disabilities and their families. These functions are considered to be the government's duties and their delivery by the associations is understood as a local response to state neglect, as well as the consequence of the politics of indirect support, decentralisation and territorialisation. Indeed, many people with disabilities, particularly in the townships, wish for a more extended welfare state.

Another important actor identified by the White Paper are the families of people with disabilities. The 2015 text defends autonomous life inside the community for people with disabilities. Consequently, the state favours home support over specialised residential centres, drawing on the international critiques of these institutions from the 1960s (e.g. Goffman 1968), including the loss of individual liberty, the social isolation and the systematic segregation of people with disabilities and able-bodied people – a separation that mimics the racial divide imposed during the apartheid era. As such, the South African government sees residential facilities for people with disabilities as being a temporary (but necessary) evil for people with severe disabilities, whose hospitalisation costs too much (Office of the Premier 2002: 65). However, most of the discussion relates to the help given to people with disabilities, without taking into account people with disabilities' possible inputs, both inside the centres and towards their relatives: 'Disability does not only affect individuals, but also impacts on family members. Parents and primary caregivers in particular are often required to take life-changing decisions on what would constitute 'the best interest' of their children with disabilities' (DSD 2015: 74). The responsibility and care for people with disabilities is mostly perceived as being an (economic) burden for families, and especially for the women in them. We will see in the last section that this perspective must be nuanced as households may also benefit from indirect support linked to the inclusion of a person with disability. Family responsibilities can thus be conditional in particular situations.

Finally, the WPRPD also specifies some responsibilities for people with disabilities. Related to injunctions of participation and empowerment, these roles are mostly political and economic. Politically, people with disabilities are called upon to exercise their rights in the same way as any other citizen. Those include voting, being candidates at elections,

protesting, demanding justice when their rights are violated and so forth. We have seen that many of these political rights are channelled through associations for the rights of people with disabilities, but other entities can also be mobilized, e.g. Ward Committees or Workplace Forums. In the economic field, people with disabilities have to grasp work opportunities in order to become self-sufficient:

[The empowerment approach] includes encouraging, and developing the skills for self-sufficiency, with a focus on eliminating the need for charity or welfare in the individuals of the group. ... Medium and long-term emphasis has been on providing social grant beneficiaries with alternative income sources through gainful work and training, among others, through public employment programmes. (Ibid.: 93)

From this perspective, the WPRPD 'provides the poor with the power to demand accountability to overcome poverty' (ibid.: 32). It also implies that the opportunities given to people with disabilities must be used. In other words, citizens with disabilities are expected to demand their autonomy and to participate, to the best of their abilities, in the lives of their communities. Yet, there is no concrete apparatus to impose those rules on rights-holders.

The South African understanding of empowerment and human rights, as described in the WPRPD, shares some features with the logics of 'advanced liberalism', which imply 'a new relationship between strategies for the government of the self, situated within new relationships of mutual obligations: the community' (Rose 1996: 331). As such, the enactment of the WPRPD redefines the role of public institutions and reconfigures 'the understanding and the organisation of the social' (ibid.: 329), but does not imply its disappearance. Firstly, many roles are reasserted as being mandatory to the government and its representatives. Indeed, the WPRPD aims to clarify the fields in which the state remains responsible, as well as facilitating the process by which it can be held accountable for its actions. Secondly, due to its focus on the rights of people with disabilities, as described in the United Nations Convention, the WPRPD do not regulate direct financial transfers to people with disabilities, namely, the disability social grant and compensation for occupational disability or road accidents. Furthermore, these financial transfers are not conditional on certain behaviours: anyone who passes the medical examination and has an annual income lower than ZAR 78,120 is eligible for the disability grant.³ There are no conditions around research for work or the creation of a 'life project', as is more and more the case in what is nowadays called the active welfare state (Franssen 2006; Vidal-Naquet 2009). The South African political apparatus around disability thus remains a hybrid

combination that associates principles of social protection, private insurance companies and public employment programmes. If the weight of liberal policies cannot be denied, it would be too reductive to restrict analysis to this dimension. Yet, although the WPRPD does not imagine the means to impose obligations on people with disabilities, other responsibilities emerge from outside the political field. To probe this idea, the next section examines the perception of disability as evidence of an individual 'fault'.

The Individual 'Fault' around the Disability

As for any other bodily disruption, giving sense to an impairment answers a persistent question: 'why me?' or 'why him/her?' In other words, it makes the incomprehensible suffering intelligible (Scheper-Hughes 2007). However, such reasoning can quickly lead to the questioning of the responsibility for the misfortune: 'whose fault is it?' In South Africa, the disability can sometimes be understood as evidence of a sin or as a punishment from God (Hannass-Hancock 2009) or as an act of witchcraft (Hannass-Hancock 2009; Hund, Stuttaford, Ngoma 2004). While the first explanation mostly underlines the disabled person's fault, the second interpretation exteriorises the responsibility by placing it on a relative or an acquaintance. Although these ideas are not completely absent in Mitchell's Plain, there is a more specific sense associated with locomotor disability in this insecure, and often violent, environment.

Current statistics around traumatic spinal cord injuries in Cape Town show that men under thirty years of age are particularly affected (Joseph 2016). This trend is well known in Mitchell's Plain and, consequently, the responsibilities relating to physical disabilities are gendered. Tarryn, a woman in her thirties who was paralysed after a taxi accident, explained:

The thing is, that it is not all men that were stabbed or that were shot by a gang or... But most of them, the reasons that they are there [in the wheelchair] is that somebody shot them or they were stabbed, you know. When for women, let's just say that for us, it was more like a natural thing because it was a car. You didn't ask for it. *Whereas for men, if you were stabbed, it was obviously because you were doing the wrong thing.* And now you are sitting in this chair. You understand? So, for men, it will feel for people like they got to judge them, because *it was their own fault.* (August 2016)

On the one hand, Tarryn associated women with a 'natural' impairment, not in the sense of a birth impairment – that strikes women as much as men –, but regarding the nature of the accident that is external. She uses her own condition, a car accident, to make her point. It must be quickly

noticed here that this interpretation could surprise a reader informed on South Africa. Not only are there some women who have been paralysed by street violence, but South African women in the townships are often judged as responsible for their misfortune when occurring in a public space, especially in the case of rape (Gqola 2015; Salo 2003). The difference of judgements in these two situations, namely a disability or a rape, probably lies in the nature of this violence: while women are the primary target of sexual assaults – although cases of male-on-male rapes have been reported in South Africa (Jewkes *et al.* 2009) –, gang-related violence is specifically aimed at other men. When women are touched by this second type of violence, it is seen as an evil for which men are responsible. On the other hand, the perceptions of male disability are mostly stigmatising: men are said to be partly responsible for their state. In Mitchell's Plain, this representation is based on the high level of gang activity as well as the presence of a rehabilitation centre specialised in spinal cord injuries. In this context, male wheelchairs come to symbolise the endemic violence of the neighbourhood. However, men in wheelchairs' responsibility or 'fault' is not systematically acknowledged and many relatives try to clear their family member of any blame.

This moral question concerning the origin of the impairment is not considered by the law, except for potential compensations in the case of car accidents or occupational injuries. As said earlier, the disability grant is only conditioned to a medical assessment that focuses on the loss of functioning, not on the cause of the impairment. However, such ideas of fault in the apparition of the disability can influence the relationships between the functionaries and the users of public services. Nonetheless, the social judgement of people with disabilities' responsibilities and the prescriptions of the national legislation converge on another dimension, that is, the type of behaviour expected after the accident, once the disability is acknowledged.

In practice, the blame placed on men with disabilities is mitigated by the possibility of redemption. The social judgement moves therefore to the person with disability's behaviour after the impairment has been diagnosed. Tarryn's explanation continued as follows:

I feel in a situation like that [i.e. men being disabled due to their criminal activities], it all depends on what they're gonna do about it. Because you actually have a choice after that: 'I have done the wrong thing and this is the result of it'. So, what are you gonna do? Are you gonna change your life, or are you gonna keep doing the same thing? ... Most of them, they stay with the gangs, in my opinion. As far as I have seen, they remained the same. (August 2016)

Many men who have been hurt due to their gang involvement appropriate this narrative too: the redemption is therapeutic, as it associates the disability with a positive meaning and becomes the stepping-stone for a new identity. Sedik, a twenty-four-year-old man who worked for such a group during his youth while never officially joining the gang, testified:

I told you there is a reason why I am sitting in this chair. ... Because every day when I was with those people [i.e. the gangsters], when I was doing drugs, every day the same things over and over. ... [Then] I asked God to put me on the stand, so I will have a life where I am capable of doing things. And then this actually happened [i.e. the accident]. I didn't ask, 'God please do it this way'. If God had to take my life, so be it. But God put me in this situation. ... So [after a while] I prayed again and I thanked God, ..., while at the beginning it was anger, demands and frustration. (January 2015)

Sedik interpreted the car accident as God's way of answering his prayers. The accident became central to the young man's new perception of himself: it gave him a chance to redeem himself. However, in day-to-day experience, this change is negotiated in context, and some ex-gangsters find it difficult to completely withdraw from their previous networks and activities. Logically, the idea of redemption is less present in the women's interpretation of the situation of disability, since they do not need to answer to the same moral judgement regarding their impairment. Their speech thus mostly focuses on the personal amelioration that disability has brought into their life. From this perspective, disability becomes a challenge that strengthens individuals, a lesson to be learnt. In summary, these discourses interpret the disability as a 'blessing in disguise' (Goffman 1963: 11) and they challenge the negative representations of impairment, both for men and women.

Despite these narratives, people with disabilities must still face some expectations regarding their behaviour. For instance, disability and its related physical problems reinforce the mainstream injunction for a healthy lifestyle. Alcohol and cigarettes are medically prohibited, due to the risk of bed sores, to weaker vital organs, or to a more sensitive stomach. Although these sanitary guidelines are not limited to people with disabilities, they are strongly reasserted for this population. This is particularly evident in Mitchell's Plain, where the medical discourse is relayed through the physical rehabilitation centre. Furthermore, in the field of disability, sobriety becomes a condition for good health, and violence or road safety are part of the awareness-raising for disability and its causes. These behavioural norms are not trivial in the Coloured township, a place that is constantly stigmatised for its violent lifestyle, which is linked to gangs, drugs and alcohol. In other words, the section of the

population that is constituted of people with disabilities, a section which is said to be vulnerable and partly marginalised, is constantly reminded of general health principles, good behavioural norms and attention to the self. These self-responsibilities are, furthermore, extended to the need to raise awareness, as the WPRPD clearly states. Breaking these norms leads to social blame of a person who is said to be dependent or not well enough informed. As such, people with disabilities have a hyper-responsibility to themselves, but also, to some extent, to the rest of society. The similarities between public opinion on the behaviour of those with disabilities and the type of autonomous and responsible citizenship that is promoted by the 2015 White Paper are clearly identifiable here: in both cases, self-care, autonomy and participation are expected from people with disabilities. However, those with disabilities in Mitchell's Plain must also negotiate another type of responsibility, one that is not directed towards themselves or to the society at large. This last form of responsibility is embedded in family norms, and it takes place in household life, as the next section will show.

The Negotiation of the Social Norms of Solidarity

In Mitchell's Plain, as elsewhere, a hierarchy of responsibilities among family members can be identified: close relatives, like parents, spouses, siblings and children, are the most likely to take care of a relative who has a disability. After them comes the distant family. Finally, if relatives cannot take charge, then friends or neighbours will become involved. Despite these norms, it is not rare to see breakups or divorces after one of the partners has been injured. In these situations, the disability can offer a way out for an unhappy partner, but the disability can also just transform the relationship so deeply that it falls apart. The disability is a challenge: it must be endured, but it also tests family ties and reciprocal responsibilities. We have seen that the WPRPD comprehends these responsibilities as being a family burden. Three case studies will help to criticise and to nuance this perspective by presenting the variety of relationships and the role that interpersonal responsibilities play in residential arrangements. These examples also enlighten us to the impact of disability grants and other sources of income in the households concerned.

Case Study 1: Tarryn

We met Tarryn a few pages ago. This coloured woman was the oldest of three children – two girls and one boy. When her parents divorced,

Tarryn and her siblings followed their mother (Sandra) to Johannesburg, where Sandra remarried a few years later. Sandra had a third daughter from this second marriage. In the 1990s, Tarryn became paralysed after a taxi accident. She was nineteen. After her hospitalisation, she went back to her mother's. When Sandra died, in 2005, Tarryn moved to Cape Town to stay with her younger sister, Tertia. As Tertia started working for the police department, Tarryn helped her to raise her children, Jordan and Keith. As the children grew up, Tarryn's support became less necessary. She therefore moved in with her father and a stepsister from one of her father's other relationships. There, Tarryn took charge of the cooking as well as the laundry. She also paid a rent of 500 ZAR (around 30 euros) and participated in the food spending of the household thanks to her disability grant (1350 ZAR). In 2013, however, Tarryn grew tired of her stepsister's lifestyle, which involved a lot of partying at home. As a result, she rented a room in another part of Mitchell's Plain. In this new house, Tarryn was taking care of herself financially, thanks to the disability grant and some extra income from remunerated training. The only domestic chore that she was not performing was the laundry, because the washing machine was installed on the first floor, and it was only accessible by the stairs. Two years after Tarryn moved in, her landlord suffered a stroke. Being physically limited as a consequence of her injury, the landlord asked Tarryn to move out so she could occupy the room on the ground floor. After some hesitation, Tarryn returned to her father's house, where she took back her previous duties, as well as paying rent. Thanks to remunerated training, which started in September 2015, Tarryn also saved money for her niece's school fees. Although Tarryn stopped the training in January 2016, due to transport problems, she used her free time to look after her stepsister's baby, Bryan, while his mother took an administrative job in a nearby school. This arrangement lasted until Bryan reached the age when he could attend nursery school. In September 2016, some health problems prevented Tarryn from undertaking new training. Her condition progressively worsened and the young woman needed various hospitalisations, until her death in May 2017.

Firstly, Tarryn's story shows the dynamic dimension of residential arrangements in Mitchell's Plain, and it warns us about seeing people with locomotor disabilities as being immobile or necessarily 'stuck'. While looking back at her residential itinerary, the young woman described herself as a gypsy, always on the move. Secondly, this example portrays a difference between the treatment of Tarryn and her stepsister, although they both lived with their father: the former paid rent, but the latter did not. As Tarryn received a fixed amount of money every month, she could (and had to) contribute to the household expenses. On the contrary, her

stepsister, who was unemployed most of the time, relied on their father's support. Financial responsibilities towards relatives and housemates are not predetermined; they depend on every person's income. Everyone contributes, depending on what they have (Gollas 2003). In this context, the inclusion of a person with a disability whose condition is officially recognised becomes a strategy through which the head of the household can expand the resources of his residential group. Indeed, even when they don't pay rent, people with disabilities in Mitchell's Plain contribute to the household expenses, through food purchases or by paying for the television licence, for example.

More generally, this case study illustrates that living together reinforces household members' responsibilities towards one another. This logic is particularly important to understand in South Africa, where approximately 25% of the working population are officially unemployed. In this context, Stephan Klasen and Ingrid Woolard (2008) identify accommodation as a tactic that is used by unemployed people to strengthen their relationships with their relatives or friends who work. People who receive social grants are targeted in the same way (Mosoetsa 2011), including those with disabilities. These redistributive practices are so widespread that some people try to hide the fact that they receive a disability grant in order to avoid their relatives' financial requests (Kelly 2012). However, if being part of the same household strengthens interpersonal responsibilities, it can conversely be used to undermine those same expectations. In Tarryn's case, moving to another house cancelled any financial claims from her father and the rest of the family. She was financially independent, for better or for worse. As a result, the management of social grants in South Africa often creates family suspicions and tensions, especially when the beneficiary's ability to decide is contested, for instance, when old people, children, or adults with mental disorders are involved.

We see here that variegated forms of responsibility can support and reinforce each other: the responsibility taken by the South African state to provide some social security, but in a limited way, strengthens specific kinds of redistributive expectations among relatives. Yet, the current literature on family solidarity and household fluidity in South Africa often focuses on individual survival strategies in the face of unemployment and, as such, it fails to expand its discussion beyond the financial dimension of these relationships (Barh  2007; Harper and Seekings 2010; Klasen and Woolard 2008; N ve and du Toit 2012; Seekings 2008). Living together not only allows people to claim a share of one's income; it also creates a myriad of impactful actions of care. Tarryn's help with raising her sisters' children allows the two able-bodied women to leave their house and to start working. Nonetheless, Tarryn's example should not

overshadow the economic and social costs that disability can represent for some households. In a family with fewer resources, reciprocal responsibilities are more difficult to negotiate. The two following case studies give a very different picture of the experience of locomotor disability in Mitchell's Plain and its impact on family life.

Case Study 2: Chris

A young coloured man in his twenties, Chris was epileptic and lived with his grandmother in Mitchell's Plain. His mother, Maria, worked in town and rented a shack closer to the centre. After Chris's accident, which led to the amputation of his left calf and arm, as well as the ablation of a few fingers on his right hand, Maria visited him almost every day in hospital and she lost her job as a result. Unemployed, she and Chris moved in with Maria's sister in Mitchell's Plain. Soon, the young man's behaviour created tensions in the household: he was stealing from his mother to purchase alcohol and drugs. After a few months, his aunt asked him to leave. Without income, Maria couldn't pay for Chris's accommodation and had to beg their neighbours to accept her son under their roof for one or two nights. At this point, Chris and Maria depended totally on Chris's disability grant for their daily expenses, as Maria's sister offered her accommodation, but no food.

When I met Chris and Maria during a visit with their social worker, Maria explained that Chris had recently lost his ID and his SASSA Card, which are required in order to withdraw the disability grant.⁴ To get a new SASSA Card, Chris needed his ID, and Maria borrowed money to replace it. At the Department of Home Affairs in Mitchell's Plain, the mother and son were told that the loss of Chris's fingers did not allow them to order a new ID at this facility: they needed to apply to the main office in town. Maria had to borrow some more money for their taxi fare, and she started to sell some of her clothes to cover their living expenses.

In contrast to the previous case, Chris's story is characterised by the young man's growing vulnerability, as he 'conjugate[s] work precariousness and the fragility of close support' (Castel 1995: 13). In South Africa, the existence of social grants prevents, or slows down, the progressive dislocation of social relationships for poor families in cases where there are medical problems, a phenomenon that has been observed elsewhere on the continent (Diallo 2003). To put it differently, the South African social policy of support, materialised through direct payments to people with disabilities, facilitates the enactment of family responsibilities in a situation of disability. However, this dynamic has its limitations, as impairment remains an economic challenge for some families: e.g. due to

her visits to the hospital, Maria lost her job and became dependent on her sister. Chris's vulnerability thus progressively spread to her.

In regard to the young man's support, some other relatives (Chris's grandmother and aunt) withdrew their support, despite the receipt of the grant. Without referring to any financial matter, these women shared their moral concern: they criticised Chris for his behaviour, both before and after his disability. He was drinking and using drugs before the accident, and he kept doing so afterwards. The form of redemption that was expected after the injury did not happen. Chris's relatives therefore justified his exclusion based on a common principle in the Cape Flats, the idea of respectability (*ordentlikheid* in Afrikaans) (see Jensen 2008; Salo 2003; Ross 2010). The solution they required in order to keep their respectability intact was, then, to distance themselves from Chris and his condemned actions. We see here the similarities with Section 2: people with disabilities are asked to behave in a correct, responsible and respectable way, and to renounce their noxious habits. Failing to meet these requirements not only means being badly judged but can also cause social penalties and loss of support.

This moral element was also a concern for Maria. According to her, Chris had stopped using these substances during his hospitalisation and so she couldn't understand the reasons that drove him back to his previous lifestyle. Maria found herself stuck between the need to be financially independent, the social norms that enjoin a mother to take care of her child, and her responsibilities as a guest towards her sister. She managed this tension by respecting her sister's wishes and calling on her son to live a more respectable life: to stop the alcohol and the drug abuse, to wash himself more often, to stop lying, etc. These requests allow Maria to reassert her own respectability before her son's behaviour, while still trying to provide for them both. The responsibilities in a family and a household can be perceived very differently by their various members. The third and last case further exemplifies these discrepancies between household members.

Case Study 3: Auntie Maargie

Auntie Maargie, a coloured woman in her sixties, lived in a flat with her sixteen-year-old daughter, Gladys, and her son, Manuel, who was thirty years old. Auntie Maargie became disabled after she fell from her balcony on the third floor and broke her spinal cord. Since the accident, Gladys has had to quit school to look after her mother, while her brother has spent most of his time outside the house. According to Auntie Maargie, Manuel was only coming back home to eat or to steal from her

pension – an equivalent to the disability grant for people who are 65 or older – in order to buy his drugs. This situation created financial problems for the two women. Furthermore, due to the absence of an elevator, Auntie Maargie couldn't go out of her flat without her son carrying her down the stairs. Manuel was also needed to turn Auntie Maargie in her bed to prevent bed sores, since this physical task was too difficult for Gladys. Although the young man performed these actions when he was at home, his repeated absences caused missed medical appointments and the development of severe bed sores. The last time I had news from Auntie Maargie, through a common friend, she had been hospitalised to treat the necrosis.

Since Auntie Maargie's divorce, the responsibility of caring for her had fallen on her two children. Yet, care is usually gendered and Gladys found herself 'trapped' in this relationship after her brother deserted their home. This pressure on women to take care of their relatives, associated with Manuel's behaviour, led to Gladys's de-schooling, to financial issues, to Auntie Maargie's sequestration and to the degradation of her health. However, this story tells us more about family responsibilities in South Africa than about their gendered dimensions and the possible outcomes of relatives' desertion. Manuel was not so much avoiding his responsibilities as negotiating them by developing his own alternative definition of solidarity, including demands and acts of care. This situation relates to the reluctant solidarity that is described by Erik Bärhe. With this concept, the Dutch writer refuses to oppose conflict and solidarity. On the contrary, he states that

Conflict is part of solidarity. Solidarity is not opposed to conflict, nor does conflict necessarily take place outside of the realm of solidarity. Instead, rivalry, conflict, jealousy, and aggression can be at the heart of solidarity networks. ... After all, solidarity is the conflict about the parameters of inclusion. (2007: 52)

Erik Bärhe shows that there is no support or help without the possibilities of tensions around these practices, and that care can also be managed through violence or crimes. However, while Bärhe mostly studies money transfers inside the family, Auntie Maargie's story reminds us that these financial transactions take place within other networks of help and responsibilities and, as a result, should not be studied separately. In this context, violence offers an alternative way to exert one's perceived rights (Bärhe 2007; Bouju and de Bruijn 2014) and Manuel's abuses do not prevent acts of care. He did help his mother from time to time, and the sporadic dimension of this support should not deny its existence: it constitutes a counterpart that further complicates the household relationships.

Conclusion

The first objective of this chapter was to offer a contextualised ethnography of networks of responsibilities as experienced by people with disabilities in a South African township, Mitchell's Plain. While doing so, many aspects of what we can call today a 'regime of responsibility' were documented. Three levels of analysis have been detailed: the state, the individual and the family. I will here underline the transformations that are revealed by this entering into the concept of responsibility in the South African context.

The growing reference to responsibility and accountability in South African social policies relating to disability illustrates that the body remains a space in which power is exercised. However, the nature of this power has evolved since the beginning of the 1990s. Due to the influence of the international movement for the rights of people with disabilities, the disabled body has become more and more a means for demands, a tool through which to remind the state of its responsibilities. The National Disability Machinery illustrates this process, since it aims to create a space in which the state and its representatives will become more accountable. The actual liberalisation of South African policies must therefore be nuanced and would benefit from an analysis that focuses on its hybridisation. The historic social welfare system, put in place under apartheid, which combines social grants and public employment programmes, remains hand in hand with policies of empowerment and social participation. However, the extension of the number of beneficiaries after 1994 has diminished the individual impacts of the redistributive public plans, creating frustrations and disenchantment in the townships, where the population is more and more called upon to be responsible and autonomous, i.e. to find its own solution. In this context, the development of body policies offers public support, together with some financial stability, to people with disabilities, while both elements are denied to their counterparts.

This difference in resources leads to some expectations of redistribution in the family that partly challenge individual autonomy. The experience of people with disabilities shows the importance of solidarity within and outside households, and practices that diminish the impact of unemployment. In a context in which the plurality of norms is increasing, new tactics are put in place to demand a share of the resources and, inversely, to preserve one's means in the face of these requests. However, in the case of people with disability, living alone is also a way to prove their independence. These individual practices play a part in the current flexibility of residential arrangements, which must not be understood as

the disappearance of social relationships but, rather, as a result of growing tactics to multiply, to select, or to negotiate inter-individual responsibilities. In the process, new sources of conflict, suspicion, or blame assignation, appear within the household and the community, forming a breeding ground for ordinary violence. The idea and the practices of belonging are thus reshaped, an idea that is central to the notion of inclusion.

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Notes

1. The word 'Coloured' refers to one of the four racial categories established in South Africa by the *Population Registration Act of 1950*. These races were at the core of the segregation put in place by the Apartheid state. The heterogeneous group of coloured people originally comprises the heirs of the Cape population (the Khoisans) and of the former slaves. The other racial categories were White, Indian/Asian and Black. Today, these categories are still used in South Africa as subjective identities and for official statistics.
2. The *Group Area Act* is one of the most well-known pieces of apartheid legislation, which systemised racial segregation in settlements and housing.
3. Other criteria of eligibility include being between eighteen and sixty-five years of age, being a South African citizen, a permanent resident or a refugee in South Africa, and not being cared for in a state institution.
4. Since 2009, the South African Social Security Agency (SASSA) has put in place a biometric system for the payment of social grants.

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