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Parler depuis l’angle mort : Subjectivité politique et articulations du handicap

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To become classified as disabled opens up the possibility to access resources. At the same time, it fixes multiple and idiosyncratic experiences of impairment into a circumscribed status of different and lesser. In this article I am thinking about the contradictory nature of classification and citizenship with the complex case of Miriam, a Ghanaian woman who moved to the UK to study. Miriam suffered from increasing impairment of her sight due to long term effects of an allergic reaction to medication while simultaneously losing her legal status. The recognition of her impairment as medical blindness and her engagement with medical specialists over her rare bodily condition resulted in new capabilities, including a new legal status. Her case shows how categorizations such as disability status and permits to stay come together in different positionings. This article suggests understanding political subjectivities not so much as acts of breaking scripts, but as happening simultaneously along different scales ranging from everyday practices to institutionalized forms of support. These multiple enactments of subject positions can be seen as articulations of political subjectivities that turn a damaged body into a right bearing subject.

Keywords: political subjectivity; incorporation; disability; classification; migration; legal status

Etre classé comme handicapé ouvre la possibilité d’accéder à des ressources. En même temps cela regroupe des expériences multiples et idiosyncratiques de handicap sous un statut circonscrit de différent et moins. Dans cet article je réfléchis à la nature contradictoire de la classification et de la citoyenneté avec le cas complexe de Miriam, une femme ghanéenne qui a déménagé au Royaume Uni pour ses études. Miriam souffrait d’un handicap croissant de la vue dû aux effets sur le long terme d’une réaction allergique à un médicament. Dans la même période, elle perdait son statut juridique. La reconnaissance de son handicap en tant que cécité médicale et l’implication de spécialistes médicaux autour de sa condition médicale rare ont entraîné de nouvelles capacités, notamment un nouveau statut juridique. Son cas montre comment des catégorisations telles que le statut d’handicapé et le permis de résidence se rejoignent dans différents positionnements. Cet article propose de comprendre les subjectivités politiques non comme des actes de rupture de scénario, mais comme ayant lieu simultanément sur différentes échelles allant des pratiques quotidiennes aux formes institutionnalisées de soutien. Ces diverses expressions de positionnements du sujet peuvent

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être vues comme des articulations des subjectivités politiques qui changent un corps abîmé en sujet porteur de droits.

Mots-clefs: subjectivité politique; incorporation; handicap; classification; migration; statut juridique

How can we avoid colluding with and adding to the power and dominance of an order of the normal? (…) how can we avoid becoming involved in its exclusions and its disarticulation of alternative ways of living? (Moser 2005, 668)

When Miriam woke up in one of the large London hospitals having been run down by a car for the second time she realized that there was indeed a problem with her sight, although she was not yet prepared to call herself blind. A social worker came to her hospital bed to talk about the white stick and to sign her up for an initial training programme. At this first visit, Miriam simply refused to talk to her, instead turning to face the wall. However, at the next visit she not only listened but also asked some prepared questions. She was also visited by consultants from the dermatology and ophthalmology departments who were very interested in examining her eyes. ‘Because I am a rare guinea pig’ Miriam told me, ‘they have never met a case like me before’. She agreed to be examined by medical students and paid close attention when the consultant explained to his students what had happened to Miriam’s eyes. In the late 1990s, Miriam suffered a rare and extreme adverse drug reaction which severely affected the membranes in her eyes. At that point she had just finished her A-levels in her home country Ghana and was treated for malaria-like symptoms with a standard medication. She was the one person in 1–2 million each year who has an adverse reaction to this and other common medications in which the different layers of skin dissolve, just as in cases of severe burns. The body ‘burns from the inside out’, gets covered with large blisters and the skin eventually falls off. A secondary infection of the damaged areas of the skin and subsequent sepsis is very likely to occur. The reaction affects every part of the body that is lined with mucous membranes such as the nose, mouth, vagina, and the eyes. It can go deep into the tissues of the body often leading quickly to death.

After being in coma for several weeks, Miriam survived, but her eyes were gravely affected. She was flown to London for specialist treatment and her eyes were operated upon successfully. From this moment, she had to wear glasses, but otherwise her eyes recovered. She finished her A-levels in Ghana, applied to study in London, was accepted and moved to the UK. At first, life was exciting and light: she studied and worked, and was very active in her church. After two years, she noticed strange symptoms such as sensitivity to heat, frequent headaches, dizziness, and problems focusing when reading study materials. She used different lenses for her glasses and even worked with a magnifier, but it took too much time and she was not able to keep up with her work.

My manager called me and asked what was wrong. I was scared to lose the job and denied all my difficulties. When I was fired one came to the next: I could not pay my college fees nor could I keep up with the assignments and was kicked out of college soon after.

She lost her student status and was unable to renew her visa. Miriam had an uncertain legal status. That was when she was hit by a car for the first time. Luckily nothing happened, but the next time she was not so fortunate.²

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Miriam is one of those highly-educated transnational Ghanaians who move between Ghana and UK³ and whose daily lives are shaped by simultaneous engagement with both national contexts.
They travel on holiday or student visas back and forth, have relatives and friends living in both countries. Over the course of long-term fieldwork with migrants from Ghana and health practices, I followed her struggle to come to terms with her increasing visual impairment. This struggle included her learning to become disabled and her attempts to legalize her stay in the UK after she lost her student visa. The recognition of her impairment as a disability caused by an allergic reaction to a pharmaceutical and her engagement with medical specialist over her rare bodily condition eventually resulted in a new legal and social status for her. She could renew her student visa and enrolled at a prestigious educational institution as a blind student. She founded a local support group, started cooperating with other survivors internationally, communicated with eye specialists in her home country, and talked as a motivational speaker in Pentecostal churches about her experiences. It could be said that she became incorporated in multiple social, political and religious ways while finding positions to speak from via her disability. At the same time, her incorporation in terms of formal legal status was at stake.

Miriam’s story, and in particular the paradox that the very condition which caused the loss of her visa status eventually helped her to gain a permit to stay, made me rethink the relations between citizenship and disability. In the context of the British welfare state, being recognized as disabled provides the ground for claiming resources, such as the support by a social worker or the entitlement to certain aids at the work place. It is thus a form of social citizenship, a term introduced by Marshall in an historical essay ([1938] 1963) in which he explains how capitalist societies try to buffer the effects of increasing inequality, while guaranteeing the continuous functioning of the workforce. His terminology was taken up to describe how many European nation states introduced rights to housing, education and health care as part of their different modernization paradigms (Yalçın-Heckmann 2011; Briggs [1961] 2014). Although many of these tasks have been ‘abandoned or redistributed’ to other bodies of authorities (Eckert 2011, 309; Krause and Schramm 2011), being classified as disabled still opens up (however limited) possibilities to access resources (Staples 2005). Yet, at the same time, this classification fixes multiple and idiosyncratic experiences of impairment into a circumscribed subject position as ‘“different” and “lesser”’ (Monks 1999, 65).

The tension between simultaneously fixing and opening up can be seen as inherent to processes of identification. Stuart Hall (2000, 19) suggested thinking about this tension as suture: the meeting point of never matching attempts to cover up continuous and violating acts of misrecognition and misrepresentation. Hall’s idea of the suture allows us to think subjectivity without the recourse to an (inaccessible) inner self: there is no completely safe ground, there are only never-ending attempts to cover up. Thinking subjectivity as speaking from a suture and not from a heroic pedestal brings a different side of becoming a right-bearing subject to the fore than theorizations of citizenship that privilege acts (cf. Isin 2009). It calls for a more open understanding of citizenship, highlighting in what ways and through what kind of practices a person becomes a recognized subject and participates in social life. To ask questions of how, and in what ways, do not negate the imperative of gaining a legal status in the first place, but call for acknowledging the multiplicity of subject positions against ‘single stories’ about entitlements and membership.

For residents with an unsecure legal status the question is key whether the right to care outweighs having no rights to stay. And although a legal right to stay can make all the difference, (non)incorporation comes in varied forms and happens on different scales, as does becoming disabled. In what follows I will first consider Miriam’s case through theorizations of citizenship that centre around properties of bodies, before introducing an alternative conceptualization that allows for multiple articulations of subjectivities and thus does not presume a single stable subject.
Political subjectivities: belonging, citizenship and disability

The idea of social citizenship in terms of the resources somebody is claiming, and not from her formal citizenship status, has been taken up in enlarged notions of citizenship that look at forms of incorporation that are granted because somebody has a damaged or sick body.\textsuperscript{10} The terms used in this discussion range from biological (Petryna 2002; Rose and Novas 2005) and therapeutic (Nguyen 2005) to medical or biosocial citizenship (Fassin 2001; Fassin and D’Halluin 2005; Ticktin 2006). Adryana Petryna writes, with regard to people affected by the aftermath of Chernobyl, that ‘the damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims’ (2002, 5). Vinh-Kim Nguyen defines therapeutic citizenship in his study on the social and political life of HIV interventions in Burkina Faso as a ‘form of stateless citizenship whereby claims are made on a global order on the basis of one’s biomedical condition, and responsibilities worked out in the context of local moral economies’ (Nguyen 2005, 142). In a similar vein, grounded in different empirical contexts but also drawing on Marshall and Petryna, Nicholas Rose and Carlos Novas use the term ‘biological citizenship’ to denote citizenship projects of biosocial communities which are based on rare diseases and whose members engage in transnational activism and research (2005, 450ff).

Miriam’s case seems to fit well into these discussions, since she is also involved in groups (mainly based in the US) that organize around allergic reactions and try to sue pharmaceutical companies. So far, however, compensation claims have not been successful, because the allergic reactions are routinely listed as a side effect of many pills.\textsuperscript{11} Miriam’s story resonates strongly with the studies by Ticktin (2006) and Fischer (2013), both of whom analyze the troubling double face of care and control implicit in illness clause regulations through which illegalized migrants can claim a right to stay.\textsuperscript{12} These writings point to what Fassin calls ‘the biopolitics of otherness’ – the extreme reduction of the social to the biological, in which the body appears to be the ultimate refuge of a common humanity (Fassin 2001, 4). Taking up this thought, Ticktin identifies the problem that rights have been replaced by humanitarianism, and moralization has taken on the role of political action (Ticktin 2006, 34). The example of a letter Miriam wrote to appeal for leave to remain on humanitarian grounds shows how the mobilization of such moral references is also deeply entangled in colonial relationships (Ticktin 2011, 119ff).

This body of literature has been very important to make us understand how people develop citizenship projects based on markers of difference read from their bodies. These writings have furthermore highlighted how a politics of compassion like those underlying illness clause legislation privilege individual cases and fail to address wider issues of inequality and racism that are institutionalized in migration regimes. However, through its strong focus on a unified representation of the bodily conditions, this literature cannot attend to multiple articulations of, for instance, a disability. To only subsume Miriam’s positionality under the term biological citizenship would not do justice to all the other articulations of her being disabled that are not about representing a specific condition but are about, for instance, being chosen by God, belonging to disability infrastructure or being an African woman. Furthermore, while Miriam’s story can be read as getting access to social citizenship by staying incorporated in the care infrastructure (Langstrup 2013) via different routes (attending to her rare condition, attending to her as visually impaired), she could not translate this incorporation into tangible, further reaching rights (cf. Bosniak 2006, 3). It is thus rather unsatisfying to talk about therapeutic or medical citizenship in her case. What was happening can be better understood as new subject positions becoming available to her.

The process in which Miriam’s visual impairment turns into a recognized disability, so I argue, consists of the many different moments and constellations in which her impairment is socialized...
and categorized as a disability and as the long-term effects of a rare allergic reaction. In some interactions the bundle of strange bodily sensations is foregrounded, in others her declining sight, and in still others her battle to overcome health difficulties with the help of God. By looking at these different articulations and building on work of feminist Science and Technology scholars (Star 1991; Mol 2002; Moser 2005; Pols 2011; Driessen 2018), I attempt to contribute towards an understanding of interpellation that can attend to multiple moments of articulating subject positions – hence positionings (cf. Pols 2011). Positionings such as disability are then not regarded as stable objects but become articulated in different registers and modes of ordering.

Ingunn Moser (2005) in her seminal article on ‘becoming disabled’ uses the term ‘ordering’ to give attention to the many different ways in which ‘being otherwise’ is achieved by people who become handicapped following road traffic accidents. According to Moser, the denaturalization of ability and disability is commonly dealt with in Foucault-inspired genealogical approaches, which trace the construction of classifications and show their historical contingency. But they tend to identify a ‘singular discourse’ that ‘orders disability in a unified and coherent way’ (2005, 668). Instead, we should follow when and how disability is enacted. Disability then is not something one is or has, but something one becomes in different ways (see also Driessen 2018). Miriam’s subject position becomes articulated in different ways via her bodily condition, and that condition thereby becomes something different as well. In some articulations, it is the itching, heat sensitive body that gets foregrounded, in others the visual impairment. In regard to the wider concerns of the special issue, Miriam’s story shows the different kinds of articulations of political subjectivity and the multiplicity of addressees these entail: disability infrastructure, transnational disability networks, medical knowledge production, religious belonging and state bureaucracy.

**Becoming a knowledgeable ‘survivor’ and an everyday-expert in transnational networks**

In trying to come to terms with the challenges of her bodily condition, Miriam created a new realm of activity for herself. She founded an NGO that serves to connect people and to generate more knowledge about the syndrome. The insight that more knowledge is needed occurred to Miriam gradually as she realized that the initial allergic reaction had many more long-term effects than she had believed at first.

When Miriam accepted this fact, she adopted the position of ‘survivor’ to talk about herself. She knew this expression from an US-based webpage dedicated to information exchange about the allergic reaction and to networking among concerned people. The notion offered Miriam a position to speak from which conveys both the aspect of being a victim of the pharmaceutical industry and (more importantly) the status of being an active agent (Rose and Novas 2005, 446) in a situation of an unpredictable bodily condition. In speaking of herself as a ‘survivor’, Miriam enacted being an expert who helps producing knowledge about this condition. Her body, which still displays diffuse symptoms, became the very agent of this knowledge production. She has learned to view her symptoms as among the possible long-term effects of the syndrome because she reads online resources and exchanges experiences with other people who have had the same reaction. Furthermore, she agreed to be seen and operated upon by eye specialists who gain new knowledge in treating a rare case like hers.

But alongside her heroic survivor mode she constantly has to handle health issues which position her in yet another mode. Her body is very easily irritated: Her skin is oversensitive to heat, and reacts to sweating with red, itching rashes; her head hurts in a diffuse way; and her eyes are dry and scarred, can no longer produce fluid, and must be kept moist with drops, but never really feel comfortable, being raspy and swollen. Next to creating more recognition for the long-term effects of the sickness, the virtual platforms provide important possibilities of exchange
between affected people in which they share their knowledge of what to do, when and how: which eye-drops to use, how and when to regulate room temperatures or use humidifiers, or when to take certain creams and medicines to prevent possible extreme attacks of itching. As Pols (2014) has pointed out, this seemingly mundane experiential knowing makes a huge difference in the daily life of a chronic disease. It constitutes the everyday of being a survivor. Miriam’s incorporation in transnational networks thus enacts two different articulations of her subjectivity: becoming a knowledgeable survivor and somebody who has to live with an unpredictable condition day by day.

**Becoming disabled in the British disability infrastructure**

Becoming a survivor in transnational support networks opened up a space to bundle the very diffuse symptoms and to understand them as being long-term effects of the allergic reaction. This is a different articulation of Miriam’s political subjectivity than becoming blind within the British disability infrastructure. ‘Being blind’ only slowly became a marker of difference Miriam could interact with in productive ways. As mentioned in the beginning, she first did not consider that she was becoming blind, despite the accidents she had. After her last accident an insistent and charming social worker called Betty brought her into contact with another ‘survivor’, an older woman of Nigerian descent, with whom Miriam immediately bonded and who told Miriam what to expect. Betty also arranged for training to use a white stick. Miriam had to learn to walk the pathway from her flat to the tube station and how to feel distances, obstacles, the end of the side walk, downward or upward steps with the stick. She was paired up with a blind instructor who taught her how to do this step by step. The hardest part was to let go of using the remaining sight she still had. She could still recognize shades of grey, but needed to not make use of this in order to practice using non-visual technology. Otherwise, as she explained to me, she would be really disabled – meaning unable to do anything once her vision was totally gone. The same was true in learning new support software for her computer. During one of my visits she demonstrated to me the voice recognition programme, which allowed her to speak commands to the computer and have written texts read out to hear. While learning to use the new software, she became less skilled in the short term, as working with the software took much longer than trying to work with the shades of grey she could still see. In the process of becoming differently abled she was more disabled than before. But this was the requisite for becoming fluid in non-visual routines.

Learning new routes of capabilities through disability technologies was one of the ways in which Miriam incorporated into the local disability infrastructure. She engaged with her social workers, Betty, rehabilitation experts, attended lessons in Braille and experimented with computer software. All these activities made her relate in new ways to the neighbourhood in which she lived: learning to feel the sidewalk and tube entrance with the white stick, recognizing through sound the distance from one side of the street to the other. But it also transformed her migration project into a different one. Without her impairment, as Miriam told me, she would have returned to Ghana a long time ago and would be a successful professional woman in a computer-related business. As a highly skilled person, life in Ghana would be much more pleasant than in London, she argued. Now, as a woman with a recognized disability in Britain, she feels incorporated in a different way than before when she was just a student from Ghana. She has not only met new people, gained new friends, learned to know her neighbourhood in new ways, but enthusiastically embraces the so-called equal rights policy by saying, ‘Here I have rights, in Ghana I would be a burden’. This sentence was central in a letter Miriam wrote to her local member of parliament in which she articulated another subject position via her disability, that of being a disabled woman from Africa.
**Becoming a woman from Africa (again) and an activist in the medical realm**

When Miriam could not continue her work and studies due to her blindness, she was formally without legal status. She applied for leave to remain on compassionate grounds, citing her rare health condition in a letter to her local Member of Parliament (MP). Although rarely successful, a number of recognized ‘concessions’ have been established under which the Home Office of the UK can grant leave to remain outside the immigration rules. This is known as discretionary leave. If this leave is granted for health reasons, the applicant must provide evidence that her life would be in danger if she were deported to her home country due to insufficient health facilities there (Lawrance 2013).

Miriam’s arguments rested on two points. First, she argued that her damaged skin nerves did not allow her to live in a hot environment like that in Ghana, since exposure to temperatures above 21 degrees cause marks and severe itching on her skin. She could support this through a letter from her dermatologist. Second, she argued that the meaning of ‘life’ should be qualified in her case: although she would not physically die upon returning to Ghana, as a visually disabled person she would die socially. She would not be able to ‘live’ as in ‘living an independent life’. In Britain, in contrast, she could work and contribute to society, as she had demonstrated over the years she had lived here.

The letter to the local MP was not the deciding factor in legalizing her stay, because before she received a response from him, she was accepted to the Royal College of the Blind, regaining secure legal status as a student and regular access to health care. But the letter is an interesting moment of articulating different subject positions. Miriam did two things: she tuned into the discourse of the disability rights movement in the UK and she utilized colonial discourses that African countries are in need of development. In her letter, the UK appears to be more enlightened than the former British colony Ghana, empowering disabled people to live a fulfilled life. In Ghana, in contrast, disabled people have no rights and are social outcasts. She hereby picks up on the logic underpinning the illness clause legislation: if people can provide evidence (and this evidence will be checked through ‘experts’, (Lawrance 2013)), that they would die if they return to their country of origin due to lack of medical provision, they can be granted leave to remain. The combination of her sick and suffering body with the fact that she is African produces the possibility of a ‘right’. But there is no right for her as an unmarked human being as such.16 The person without right to stay becomes reduced to their sickness and being from a less ‘civilized’ country (in the sense of not having enough biomedical provision). In Ticktin’s terms, Miriam is here ‘evoking a historically located moral legitimacy’ that relies on colonial ‘circulating narratives, images, and histories’ (2011, 121). Within this positioning, Miriam’s body thus becomes not only ‘disabled’ but also racialized in colonial terms. Her body allows her to be classified as disabled, and as Black African, who belongs to a country that cannot take care of her needs sufficiently. So, she needs to declare one subject position in negative terms in order to allow her to qualify for the rights otherwise afforded to her, a compromise of which she was very aware. By pointing this out I am not de-legitimizing Miriam’s letter, but building on Ticktin (2011, 121), highlighting the colonial logic inherent in the illness clause.

Through her bodily condition Miriam did however also relate in new affective terms to her home country. Miriam herself probably survived the allergic reaction only because one nurse in Ghana identified the medication she was taking as the core of the problem. Thus, together with doctors and nurses in Ghana and London, she set up a knowledge exchange network in order to develop awareness campaigns among health professionals. She thereby positioned herself as an activist in the transnational medical space between Ghana and UK.17

**Becoming a chosen subject of god**

While Miriam recognized the education of health professionals about the rare allergic reaction as important, she understood the moment the nurse correctly interpreted her symptoms as an
intervention by God. In her Christian reading, the life threatening extreme allergic reaction, her miraculous recovery, and also all the resulting difficulties mark her as somebody chosen, like Job in the Bible, whom God loved so much that he allowed Satan to repeatedly test his faith. In this articulation of her impairment, her body is a battlefield for God and Satan. It is a point of contact with God, where Miriam can show her efforts to stay born again.

Born-again Christianity is an umbrella term for forms of Christianity which emphasize the need to constantly renew the relationship with God, often after a moment of rupture (the initial conversion), because the world is a ‘site of war between God and the devil’ (Meyer 2010, 115) in which every Christian must participate. It has been particularly successful in various forms in Ghana and West-Arica, and has been revived in European metropoles by migrants like Miriam. London is actually a hub for a great variety of churches and groups ranging from small scale prayer meetings held in private living rooms to mega churches. Miriam is a member of a small transnational Pentecostal church which is frequented by many student migrants, and that is where I met her for the first time.

While many groups within this strand of Christianity focus their energy on repeating moments of rupture by driving out evil spirits (Krause 2008b), others, like those in the group Miriam belongs to, concentrate on creating new points of contact with God in their daily practice. This includes living according to strict ethical rules and including prayers in the conduct of their daily lives (Fumanti 2010; Coleman and Maier 2011). Being-born-again in this religious practice is an ever unfinished business which needs to be achieved over and over again in practices of ‘hodological care’ (Krause and van Dijk 2016), the careful scrutinization of each connection and the securitization of potential harmful ones with the power of the Holy Spirit (Krause 2014, 2015). Similar to the unfinished project of staying born-again, the initial allergic reaction is unfolding and not yet fully known in its long-term effects to Miriam and her doctors. Her becoming disabled and staying born-again both require continuous work in adjusting, calibrating and finding out about her possible capacities and the dangers she faces. In her Christian motivational preaching, she articulated being disabled as something like a privilege which marked her as a chosen subject of God. The unpredictable nature of her chronic condition, her heat sensitive body, the irritability of her skin, her paining eyes became possible points of intervention by the Holy Spirit in her prayers for temporarily release from all the unease. The positioning of ‘becoming a chosen subject of God’ resembles what Mattia Fumanti (2010) has called ‘virtuous citizenship’, the making of a world through certain acts and behaviour beyond strategic legal definitions of citizenship. However, it also points to the never-finished projects of becoming and remaining a speaking subject in the sense of Stuart Hall’s idea of the suture outlined above.

Conclusion: speaking from the blind spot

Miriam’s story illustrates a double face of categorization: categories enable people, giving access to resources, but they also pin down articulations of being different. I took inspiration from feminist writers to take multiplicity as a starting point to think about how categories of difference can actually become the vehicle for incorporation and multiple ways of positioning. In looking at the different modes of becoming that articulated Miriam as survivor, expert, disabled, African, or Christian, I wanted to point to the manifold ways in which categories of difference enact different political subjectivities.

Describing multiplicity raises the questions of how these different articulations relate to each other and when one positioning is more powerful than the other. For instance, when, how and to whom was her uncertain legal status more important than her disability? In some moments, illegalization could become the all-determining factor. But ultimately it was not. When illegality was
undone, the disability stayed, and the impairments got even worse. However, the disability also became something different. This process was the result of a mixture of systemic and contingent developments: Miriam could stay incorporated in the care infrastructure because of the specific logics that were dominant within the NHS at that point in time and because of the rareness of her condition. Yet for the social scientist thinking with stories like Miriam’s the challenge remains to analytically capture the temporal, and situational, without losing sight of stabilization in power hierarchies. How do we speak about the ordering of disability and any sort of differences and rights without reproducing disabling and/or hurtful logics, those poisons of the past? Speaking with Ingunn Moser (2005, 668): how do we capture the articulation of an otherwise?

In her essay on ‘being allergic to onions’, Susan Leigh Star (1991) takes her own allergy against onions as a case to illustrate how not yet standardized diversions from recognized normalities (the ubiquitous presence of onions in a lot of food) become uninhabitable places. A lot of work and suffering can be involved in being not-yet recognized. Similarly, Miriam is in limbo when her blindness is not yet diagnosed. Star argues that the solution for creating inclusive environments lies not in providing potentially endless lists and standards of new categories of difference, but in acknowledging the fact of multiplicity in the first place. Multiplicity in Miriam’s case does not only refer to the fact that her story could be told in multiple ways, but to the multiple articulations of her impairment: her different bodily symptoms became part of a syndrome in her becoming a survivor. In being officially blind within the British disability infrastructure, she became disabled. In the Christian articulation she became somebody chosen by God. In addressing her local member of parliament, she became a woman from Africa, in need of British civilization in form of disability rights. The trajectories of these different forms of becoming disabled were bumpy and sometimes painful. It included two car accidents (because she did not see the vehicles), the loss of her student status (she could not keep up with the readings), loss of her job (because the job was linked to her student status), and loss of her legal status (because the status was also linked to her being a student). It also provided social workers who taught her how to apply for and then use a white stick. It included consultants from the dermatology and ophthalmology department. Furthermore, it involved learning to speak to her computer using special software designed for visually impaired people, as well as learning the braille alphabet. Miriam mobilized different publics and addressees, including social workers, medical specialists, a local member of parliament, religious groups, and transnationally operating NGOs, and with their responses they became part of socializing her disability via multiple encounters in various interfaces and scales.

Stuart Hall’s writing about identification in terms of a ‘suture’ points to the potential difficulties in articulating subject positions: multiple articulations do not necessarily sit comfortably with each other or complement each other easily. Miriam enacts a ‘less civilized Africa’ while articulating at the same time her social citizenship in a teaching hospital and her biological citizenship as ‘survivor’ in a transnational NGO. She is the chosen subject of God, whilst also the abject illegalized migrant and the special medical case who collaborates with doctors to make rare knowledge available. Judith Butler calls this inescapable complicity the ‘guilty embrace of the law’ (Butler 1997, 112). The multiple overlapping registers in which Miriam speaks from the ‘blind spot’ make her impairment not one thing, not one clear cut, but a suture with overlapping fringes. Different ‘laws’ or ways of ordering her bodily conditions are embraced by her. In ‘being African (again)’ via the illness clause, there is no claim-making possible without also describing Ghana as a place in which blind people have no rights. The colonial logic of the illness clause in this reading turns Miriam into a ‘savage’ who needs to be rescued from darkness by British disability infrastructure. The paradox in this example is that the subject is assumed to exist prior to its genesis. Butler argues that before the becoming of the subject there is the desire to be seen and to become, a ‘pursuit of recognition (...) which is indispensable from condemnation’ (Butler 1997,
Condemnation in Miriam’s case would entail deportation, indicating how risky it can be to address the state authority, because it means you become visible. By writing the letter, Miriam admits that she is staying in the UK with an uncertain legal status and knows about it.

Terms such as social, biological, medical or therapeutic citizenship seem to capture only some articulations of Miriam’s story. Instead, in Miriam’s story, being visually impaired is not only being disabled to different degrees, depending on the situation, but assuming that being blind becomes something different all together when being articulated via visual aids, a white stick, computer applications, or interactions with specialists, members of parliament and self-help groups. Having an oversensitive skin that reacts to heat and changes in temperature could be regarded merely as a sensitivity, or it can be seen as part of a rare syndrome around which affected people organize transnationally. Political subjectivities, then, are not fixed subject positions, but are a potentially articulated in multiple modes.

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Notes

1. ‘Miriam’ is a pseudonym. I met Miriam during fieldwork conducted in London and Ghana (2005–2011) on health practices and care in urban contexts. The following account is based on a written summary by Miriam, on two interviews conducted 13 March 2006 and 30 November 2008, a long conversation in June 2009, and several telephone conversations between 2008 and 2012. My last contact was via email in 2016. At that time Miriam was still living in London.
2. Doctors or administrative staff never asked Miriam for her passport or checked her legal status. Although health encounters can be the moment in which people become illegalized, this seems to not happen so frequently in the UK, due to the fact that many people reject the idea of ID-cards, and many doctors refuse to check passports (see ‘doctors should refuse to check patients immigration status’(BMJ 2015;350:h3468)). Another reason might be that the UK health system is funded through tax money and once somebody is registered in the system, it is quite easy to stay in there.
3. As former colony, Ghana has close links with UK. Several scholars have documented the intensification of transnational linkages between Ghana and London and different European destinations (van Dijk 1997; Manuh 1998; Van Hear 1998; Akyeampong 2000; Krause 2008a; Mazzucato 2008; Fumanti 2010; Nieswand 2011, among others). Ghanaian Londoners comprise of very diverse groups which can be roughly differentiated around educational background, migration routes, when they arrived (before and around independence, following the various coups, and the economic
hardships in the 1980s and 1990s. Thus we find low educated labour migrants next to highly skilled
migrants and elites, families who have lived in the city for several generations and new comers. One
outstanding pattern since the late 1990s is increasing back- and forth student mobility.
4. I use the term ‘incorporation’ deliberately, drawing on critical migration scholars who have highlighted
the normative baggage of terms such as integration or belonging (Glick-Schiller, Çaglar, and Guld-
brandsen 2008; Partridge 2008).
5. I am using here the understanding of a case study suggested by Annemarie Mol (2015): a story that
carries knowledge and condenses expertise in idiosyncratic ways, which need to be mobilized anew
when transferred to a different case.
6. His basic argument is that in order to have citizens who are educated and healthy enough to be electable
into offices (political citizenship), and to defend themselves in court (civic citizenship), social welfare
was needed. Understood in this sense, social citizenship encompasses all those projects that aim to
produce ‘reasonable’ citizens and conditions of legibility in Scott’s terms (Scott 1998; Trouillot
2001). The abilist and patriarchal undertones of this understanding has been noted by many commen-
tators since, see Lister (1997, 2008), Werbner and Yuval-Davis (1999), Turner (2009), Yalçın-Heck-
mann (2011).
7. Hall is drawing here on Heath who speaks of ‘suturing effects’ (quoted in Hall 2000, 19) in cinema
theory.
8. See Chimamanda Ngozi Adichie’s widely circulating Ted talk on ‘The danger of a single story’, https://
www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story.
9. In using ‘articulation’, I deliberately mix together Stuart Hall’s and Donna Haraway’s understandings
of the term. Both use it to denote the joining of disparate and unequal connections. Hall is interested in
how ways of speaking as a recognized subject can come about in the first place (Hall and Grossberg
1996, 141ff), while Haraway is more concerned with the relation between the knower and what is
known. She differentiates between ‘political semiotics of representation’ (all-knowing position) and
10. The objectification of suffering and the strategic use of the sick-role has been an object of study prior to
these writings. See in particular Young’s (1995) study on the benefits of the diagnosis posttraumatic
stress disorder.
11. The political question of course remains why companies can continue to make profits while taking the
risk of damaging bodies in such an extreme way.
12. However, as stressed by Röhl, looking comparatively, appeals on the grounds of health tend to be not
successful (Röhl 2005, 21–24).
14. I am drawing on Henriette Langstrup’s term ‘chronic care infrastructure’ (2013) to think of the health
system as infrastructure rather than as monolithic ‘system’. Looking at care in terms of infrastructure
brings to the fore the conglomerate of things which make up the ‘tracks on which care runs’ (2013,
1010), such as medication, nurses who come by the house, aids, and activities the impaired person
herself has to perform. In citizenship literature, infrastructure produces citizenship. In Langstrup’s
terms we can think about the tracks on which citizenship and belonging ‘run’.
15. See Kenneth Jernigan on the common misunderstanding around what ‘blindness’ is. He gives the fol-
lores definition in line with the social disability model:

One is blind to the extent that the individual must devise alternative techniques to do efficiently
those things which he would do if he had normal vision. An individual may properly be said to be
‘blind’ or a ‘blind person’ when he has to devise so many alternative techniques—that is, if he is to
function efficiently—that his pattern of daily living is substantially altered https://nfb.org/images/
nfb/publications/fr/fr19/fr05si03.htm.

16. This is a point discussed in the literature on humanitariansm, see above.
17. This initiative could be seen as an expression of ‘affective circuits’, as theorized by Cole and Groes
(2016, 6f).
18. The literature on born-again Christianity in Ghana and West Africa as well as on the transnational off-
shoots of these churches is too vast to review here. See Meyer (2004) and Peel (1968) for general over-
19. There is a rich body of literature on churches founded by African migrants in Europe. See van Dijk
20. These practices can be seen as technologies of the self which fit perfectly fine a neoliberal regime of self responsibilization. Yet, as I have argued above with Ingunn Moser, this framework kind of pre-assumes to know the outcome of the Christian practice: a disciplined self. If there would be more space in this article, we could trace the multiple enactments of being born-again. For the time being, staying born-again is made stable to show the multiplicity within being disabled.

21. She explains this in reference to the often quoted example of interpellation by Louis Althusser about the citizen who turns, when hailed at by a policemen. The hailed at subject turns towards the authority; without that turning there would be no interpellation, without submission no subject, without accepting to be categorized, and in that to be misrecognized, no care

This turning towards the voice of law is a sign of a certain desire to be beheld by and perhaps also to be behold the face of authority (...) that permits the misrecognition without which the sociality of the subject cannot be achieved. (Butler 1997, 112)

What Butler calls misrecognition is in my reading Stuart Hall’s idea of the suture.

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References


Isin, Engin. **2009.** “Citizenship in Flux: The Figure of the Activist Citizen.” *Subjectivity* 29: 367–388.


